2002

The social construction of an autistic child's "progression" and "regression"

Shannon D. Waltrip-Sequeira
San Jose State University

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

Recommended Citation

Waltrip-Sequeira, Shannon D., "The social construction of an autistic child's "progression" and "regression"" (2002). *Master's Theses*. 2340.
DOI: <https://doi.org/10.31979/etd.fg7c-kb7c>
https://scholarworks.sjsu.edu/etd_theses/2340

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.

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

ProQuest Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
800-521-0600

UMI[®]

**THE SOCIAL CONSTRUCTION OF AN AUTISTIC CHILD'S
"PROGRESSION" AND "REGRESSION"**

A Thesis

Presented to

The Faculty of the Department of Communication Studies

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

By

Shannon D. Waltrip-Sequeira

August 2002

UMI Number: 1410440

Copyright 2002 by
Waltrip-Sequeira, Shannon Deanne

All rights reserved.

UMI[®]

UMI Microform 1410440

Copyright 2002 by ProQuest Information and Learning Company.
All rights reserved. This microform edition is protected against
unauthorized copying under Title 17, United States Code.

ProQuest Information and Learning Company
300 North Zeeb Road
P.O. Box 1346
Ann Arbor, MI 48106-1346

©2002

Shannon D. Waltrip-Sequeira

ALL RIGHTS RESERVED

APPROVED FOR THE DEPARTMENT
OF COMMUNICATION STUDIES

A handwritten signature in cursive script, reading "Stephanie Coopman", written over a horizontal line.

Dr. Stephanie Coopman

A handwritten signature in cursive script, reading "Shawn Spano", written over a horizontal line.

Dr. Shawn Spano

A handwritten signature in cursive script, reading "Rona Halualani", written over a horizontal line.

Dr. Rona Halualani

APPROVED FOR THE UNIVERSITY

A handwritten signature in cursive script, appearing to read "Jent / Pol", written over a horizontal line.

ABSTRACT
THE SOCIAL CONSTRUCTION OF AN AUTISTIC CHILD'S
"PROGRESSION" AND "REGRESSION"

By Shannon D. Waltrip-Sequeira

This case study examines how the parent and teachers jointly negotiate definitions of progression and regression of an autistic child's social and communication skills. Although there are quantitative measures of progression and regression, this thesis explores how the parent and teachers who work with the autistic child socially construct these terms.

The researcher analyzed a diary the parent and teachers used to communicate about their observations of the child's behavioral and cognitive skills, identifying four themes associated with progression and regression in social and communication skills. The researcher then interviewed the parent and two teachers concerning their diary entries. The results underscore the importance of context in interpretations of progression and regression, as well as inequality in the distribution of power in the parent-teacher relationship. In addition, the study highlights the reflexive nature of the parent-teacher relationship and the social construction of the autistic child's progression and regression.

ACKNOWLEDGEMENTS

This thesis project came together after many stops and starts over the past few years. I want to first thank my husband, Dan Sequeira, for supporting me and encouraging me to do it, and to finally finish this! He knew that I *could* do it, and he patiently waited until I proved him right. Thank you, also, for the endless cups of tea.

I next want to thank my beautiful baby girl, Megan, and my sweet baby boy, Mitchell, for being my inspiration. I want to make them proud of their Mommy and I want to serve as their first teacher, their role model, and their guide as they navigate their paths through childhood, adolescence, and on into adulthood. I wish only the best for them and it is my hope that they achieve a worthy college education that will enrich their lives.

I especially want to thank the participants for their tremendous help. To “Howard,” I would not have been able to complete this project without your consent and helpful comments and suggestions during the data gathering process. I am so appreciative that you trusted me to learn more about your son’s condition. I want you to know that this entire thesis project merged my academic and personal interests. I chose to learn more about autism because I want to help you, and this in turn will help your son. I want you to know that *you are not alone* in understanding and dealing with “Matthew’s” autism. I am here to help you and to do what I can for you and for him.

I next want to thank “Nina” and “Waverly” for whom this project would not have been possible. I admire you both for your dedication, caring, and commitment as teachers of autistic children. Autistic children are like sailors lost at sea in the darkness

of night. You are the beacon of light that guides them toward the lighthouse. The compass you provide these children helps them to reach out to others and enables them to find their way to the outside world. Thank you for sharing your knowledge of autism and for your insights on furthering the potential of your students.

My mother-in-law and father-in-law, Mary and John Sequeira, helped me tremendously by evincing true regard for this project and for allowing me to vent my frustrations when I felt despair over the initial uncertainty and overall enormity of it. They also availed themselves to babysitting my daughter, Megan, my son, Mitchell, and Duke (my Boston Terrier) whenever I needed to work on the project without distractions and/or interruptions. I was grateful that they offered to take loving care of my children while I worked. Muito obrigado Pai e Mãe!

Thank you, as well, to the rest of my extended family including my brother, Todd Waltrip, his sons Jordan and Tyler Waltrip; my mother, Judy Waltrip; my father, Ted Waltrip and his wife, Debbie; my sister, Tracy Desjardin, her husband, James Desjardin, their son and daughter, Alex and Mackenzie Desjardin; my brother Derek Waltrip and his wife Michelle Waltrip. I know this project will help us all better understand autism as it answers many questions about this enigmatic condition. It will also assist us to empathize all the more with the dedication involved in caring for an autistic child.

To Gary and Tess Waltrip: You have always been my favorite uncle and aunt. I am grateful that I have you to look up to. I have enjoyed our talks over the years. You have always shown an interest in my college dreams and you enthusiastically supported

them. I admire you both for serving as my academic role models. Gary Jr., Sean, and Nick Waltrip—you sure are lucky to have them.

Thank you, Brooke Steckley, for being not only a close cousin, but also a good friend. You have also shown a real interest in my thesis and in my drive to go to graduate school. I'm so glad you and I can relate to each other because we both value a college education. Amber Steckley, the same can be said of you, too. I wish you the best of luck in working with autistic and other developmentally disabled children. You are also not only my cousin, but, my friend. Justin and Dick Steckley—we have to see each other more often. Thank you, also, for being supportive family members.

My late grandfather, Foy Waltrip, meant the world to me. I admired his wisdom and goodness and I watched how he taught his Adult Bible class on Sunday mornings with conviction, capability, and pride for his students. He inspired all he knew to learn more about the world around them. From him, I learned how to investigate topics I was interested in and really cared about. He is greatly loved and sorely missed. To his widow, my grandmother, Bertha Waltrip, I know your children and grandchildren mean everything to you, and know that we all love you, too. My late grandparents, Howard and Doris Steckley, I miss them so much it hurts. I would come over to their house on my lunch break from work or I'd stop by after work on my way to my evening classes and they would be so glad to see me, as I was glad to see them. We enjoyed our visits together. I remember how proud my grandma was of me getting my T.A. position a few years ago because she knew I was interested in teaching on the college level. I want you to know, Grandma, that I'm on my way! I love you both and think of you often.

Julie Ducato Marquez—thank you so very much for being a true friend when I needed one. I felt you and I were the only ones standing on an island of sanity amid a sea of insanity. Thanks to our God for the isolation! You have been my one and only college friend and I'm glad we endured the SJSU experiences together. I feel that along with a bachelor's degree and a master's degree, I got a wonderful lifelong friend from this university. When are we going to start that talk show?

This research project is really a merger between my personal and academic interests. What I learned about autism and communication will be shared with Matthew's teachers and his family so that they can learn more about how to help Matthew reach the world around him.

I thank those relatives and friends who provided support, interest, and encouragement, and I appreciate your genuine interest in this project. You know who you are.

I am indebted to my advisory committee: Stephanie Coopman, Shawn Spano, and Rona Halualani. I was never able to take a class with any of you, so it must have been strange for you to take me on since you didn't know me as one of your students. I know that you must have only known my writing style and capabilities through departmental word-of-mouth, and of course by working on this project with me. You gave helpful suggestions and comments, and I appreciate your participation.

Thanks to my committee chair, Stephanie Coopman, for stepping forward and throwing me a lifeline. I didn't know how I would form a committee until you helped me

to do so. Thank you, also, for the revisions and the excellent advice. You took me further than I could go.

Dennis Jaehne, Ken Salter, Judith Barnes, Hans Hohmann, and Tim Hegstrom—thank you for your teachings. I'm sorry you could not serve on my advisory committee, Professor Salter and Dr. Barnes, but I do understand the reasons. Dr. Jaehne, I admire your teaching style and I've learned from you what makes a great teacher by observing you teach and by learning the art of pedagogy from our T.A. seminar. Dr. Hohmann, I admire your passion for your area of expertise. Dr. Hegstrom, I admire your calm tranquility and unending patience in helping your students learn the material.

Dr. Barnes, I will never forget what you told us back in the spring of 1997 on the first day of our COMM 200, Introduction to Graduate Studies, seminar. You said we, as graduate students, are now entering our *field*, and not our major, as we had called it as undergraduates. I will never forget that and I feel that now I am ready to embark on a wonderful career in the field of communication studies.

TABLE OF CONTENTS

ABSTRACT.....	iv
ACKNOWLEDGMENTS.....	v
CHAPTER 1. INTRODUCTION.....	1
Personal Motivations for Researching Autism.....	5
Chapter Previews.....	6
CHAPTER 2. REVIEW OF THE THEORETICAL LITERATURE.....	8
Review of Autism Literature.....	8
Progression and Regression Defined.....	22
Autism's Limitations on Communication and Social Abilities.....	30
Review of Social Constructionism Literature.....	33
Metatheoretical Assumptions of Social Constructionism.....	34
Key Assumptions of Social Constructionism.....	36
Conceptual Definitions of Social Constructionism.....	39
Activity.....	39
Episode.....	41
Evaluative Statements.....	44
Language.....	45
Sense Making.....	47
Reflexivity.....	47
Summary and Research Question.....	51

CHAPTER 3. METHOD.....	53
The Methodology of Social Constructionism:	
Qualitative/Interpretive Methods.....	53
Case Study Method.....	54
Participants.....	57
Organization.....	59
Data-Gathering Strategies.....	59
The Diary.....	60
Interviews.....	61
Data Analysis Procedures.....	66
Summary.....	72
CHAPTER 4. FINDINGS AND INTERPRETATIONS.....	75
Themes Identified in the Diary Between Nina and Howard.....	76
Screaming.....	76
Providing Support for One Another.....	78
Alternative Forms of Communication.....	83
Themes Identified in the Diary Between Waverly and Howard.....	88
Verbal Communication.....	88
Providing Support for One Another.....	90
Social Skills.....	91
Summary of Diary Themes.....	93

Themes Identified in the Interviews.....	95
Answering the Research Question.....	108
Parents and Teachers Process Progression and Regression	
Similarly and Differently.....	115
Both Parents and Teachers Experience an Emotional Impact.....	126
Summary of Findings and Interpretations.....	128
CHAPTER 5. CONCLUSIONS.....	132
Theoretical Implications.....	132
Methodological Implications.....	135
Practical Implications.....	140
Parents and Teachers Approach Autism Differently-Parents' Continuous	
Vs. Teachers' Segmented Experiences.....	141
Parents and Teachers Learn from Each Other.....	142
Lack of Communication Between Parent and Teachers.....	145
Contributions to Autism Literature.....	145
Contributions to Communication Literature.....	149
Limitations.....	150
Suggestions for Future Research.....	152
Conclusions.....	153
Notes.....	156
References.....	158

Appendices.....	165
Appendix A: Interview Guide.....	166
Appendix B: Diary Interview Graph.....	168
Appendix C: IRB Approval Letter.....	203
Appendix D: Consent Form.....	205
Appendix E: Research Involving Children or Wards Form.....	207

CHAPTER 1

Introduction

Autism is a biological and neurological disability that severely affects the communicative and social development of those persons born with it. Organizations such as the Autism Society of America in Bethesda, MD; the Autism Research Institute in San Diego, CA; CAN (Cure Autism Now) in Los Angeles, CA; The National Autistic Society, in London, England, describe autism's manifestations as largely communicative in nature. A human mystery, autism intrigues and inspires people of different social scientific realms, including scholars in psychology, child development, health care, and interpersonal communication, to find some of the answers that lie within our reach.

Autism severely affects a child's ability to develop communication skills and social relationships. The child lives in a world of his or her own. Autism's rate of occurrence has increased to about 1 in 400 children. Autism appears around 18 months of age or older and it usually becomes evident before a child is three. It is more commonly found in boys than girls; however, girls who are afflicted with it typically possess more severe symptoms. No one knows what causes autism, and as yet there is no cure. It has a controversial past because it was formerly attributed to unresponsive parenting (cold or "refrigerator" parenting) or brain damage during labor and birth. Others blame environmental hazards or childhood vaccinations. A current view is that autism is a result of abnormal brain development particularly in the cerebellum (the structure of the brain responsible for voluntary muscle movement) and the limbic system (a group of deep brain structures in mammals associated with the primitive brain

functions).

Autism can also be described as a mental disorder, variously characterized by lack of emotion; failure to speak or to respond to speech; repetitive motions such as rocking back and forth; repeated hand clapping and spinning; intense fixations on objects such as rocks, strings, and the like; and unique memory disorders (photographic recall of some things, forgetfulness of others). Many autistic people are mentally disabled but others have normal intelligence, although they appear withdrawn or absorbed in daydreaming; at the very least, they exhibit social withdrawal. Autistic traits are presented in a wide range, from mild to moderate to severe. The disability includes impediments for developing community awareness, for relating to others, and even for demonstrating a sense of self.

Newsweek's July 31, 2000, cover story, "Understanding Autism" warned readers that this disorder is becoming more widespread. The story subsequently "drew more than 1,100 letters, primarily from readers thanking us [*Newsweek*] for focusing attention on what many consider an epidemic" (*Newsweek*, August 21, 2000, p. 14). Parents hailed the article for educating millions of people about autism and its common occurrence. One parent described autism as a "thief in the night" while another said, "One moment my child was there, the next he was gone" (*Newsweek*, August 21, 2000, p. 14). Readers stressed the need and importance for research. One parent wrote, "When we understand autism, we may well have the Rosetta stone for understanding the uniqueness of the human mind itself" (*Newsweek*, August 21, 2000, p. 14). That autism made the cover of *Newsweek* demonstrates its effect on many lives and its entrance into public discourse.

The need for research and education about this childhood disorder is great because, with proper education both at home and at school, these children can improve and lead much better lives than they did just 20 years ago.

This case study examines how parents and teachers socially construct progression and regression of communication and social skills in autistic children. It focuses on parent-teacher interactions and brings this new knowledge to our field. It strives to make a worthwhile contribution to this body of scholarly knowledge. Obviously, there is a need here to observe the relationship between parents and teachers of autistic children while simultaneously extending and improving past research. The present study explores an interesting and unique communication event because teachers with special education skills help autistic children, and at the same time, the teachers teach parents how to improve their child's communication and social abilities. Research such as this provides another way of helping the growing community of autistic children by informing people about the disorder and how to help educate these children. The research is also important because of the novel way it brings social constructionist theory to an in-depth examination of parent-teacher negotiations of "progression" and "regression" in one autistic child's social and communication skills.

This study integrates autism and communication research because both seek to explore ways in which we can make and/or share meaning with others. Scholars who study autism and communication strive to understand human interaction. The present study further expands and advances both autism and communication research by exploring the social construction of the autistic condition. This case study examines how

an autistic child's parent and teachers socially construct the child's "progression" and "regression"—key terms in the autism literature and treatment programs. Although "measures" of progression and regression exist, we know little of how these terms are constituted in the everyday lives of parents and teachers who work with autistic children.

Progression and regression variables as assessment measures have garnered much attention in traditional autism research, but have received no attention in communication research. The subject of autism has not appeared in the past three decades of *Communication Abstracts*. Although autism symptoms typically include inappropriate communicative behaviors, to date, there has been no bridge between autism and communication research. New research underscoring the importance to communication literature would acknowledge that communication enhancement plays a major part in autistic research and child development. Thus, communication theory and research can bring much to our understanding of autism. In turn, examining how autism is socially constructed illuminates the processual and complex nature of how we define phenomena. That is, we can identify multiple definitions of progression and regression in standard and medical dictionaries. Yet, how individuals negotiate definitions in caring for an autistic child reveals those terms in use or in action.

This thesis project is meant to uncover and expose the link between autism and communication and to call for scholars in each discipline to assist the other whenever possible. This is not meant to be an exhaustive study. However, one aspiration of this project is that it opens up the dialogue between professionals in autism and communication.

Personal Motivations for Researching Autism

Thesis topics often emerge from personal experiences. I first began thinking of conducting a case study about autism for two main reasons. The first reason is very personal because I know the child depicted in this thesis. When the child's parents were informed in 1994 that their son was autistic, they informed the rest of their family of his diagnosis. The family reacted with shock and understanding, since they knew there was something not quite right with the child, "Matthew" (a pseudonym). Of course they were stunned with the news, but at the same time, they knew that this was the answer to his odd social and communicative behaviors.

So, as I began to think about how I could help this child's father, "Howard," understand the complexities and the mysteries of autism, I thought that maybe researching and writing about it could add to the body of knowledge that he had already accumulated. I did not want Howard to have to handle it alone. I wanted him to know that I would be there to help by learning more about this pernicious disorder and sharing my knowledge with him.

The second reason I decided to write about Matthew was because I wanted to find ways through my thesis research to improve his education and his care, and more specifically, his social and communication abilities. Since Matthew has severe deficits in these areas, I thought that perhaps I would be able to develop ways to improve his education through the help of his parent and teachers.

This thesis project merges my personal and academic interests completely. I have been fortunate enough to study communication and use what I have learned to provide

support and insightful knowledge about autism, social constructionism, and helpful educational goals for Howard and his teachers in their efforts to improve Matthew's social and communicative functions. I have learned that parents and teachers construe progression and regression both similarly and differently, and that parents and teachers approach autism differently. Autism impacts parents and teachers in both similar and different ways. Its impact is affected by their relationship with the child and the different contexts in which this relationship is developed. The parents continuously experience the impact of autism because their child is always with them when he or she is not in school. The teacher experiences the impact of autism while the child is in class. The contexts of home and school are also factors because the child may or may not exhibit behaviors in each; for example, the child may use more nonverbal communication in the traditional setting of the classroom but not in the familiarity of home. Through this thesis project, I learned that *both* parents and teachers experience an emotional impact and that parents and teachers learn from each other.

Chapter Previews

Chapter 2 reviews literature in autism and social constructionism that forms the basis for the case study. This chapter gives an historical account of autism, explains past and present definitions of autism, and shows where the study and theory of autism have been and where they are today. The literature review also presents definitions of progression and regression, autism's limitations on communication and social abilities, an overview of social constructionism, metatheoretical assumptions of social constructionism, major assumptions of social constructionism, including conceptual

definitions of key terms dealing with social constructionism, and key concepts of social constructionism. The chapter ends with the research question posed for the study.

Chapter 3 presents the methodology of social constructionism, qualitative and interpretive methods, the participants, the organization, and data gathering strategies (diary and interviews). Logistical details for conducting the interviews are given. Data analysis procedures are discussed here. The chapter concludes with the summary of the methodology.

Chapter 4 includes the findings and interpretations. The chapter entails how these findings contribute to autism and to communication research. The themes identified in the diary and in the interviews are explored in the chapter. The chapter then answers the research question investigated for the thesis, and its denouement is the summary of the findings and discussion. Chapter 5 details the implications for this case study in relationship to social constructionism, limitations, conclusions, and puts forth recommendations for future research.

CHAPTER 2

Literature Review

This chapter begins with a review of the autism literature and definitions of progression and regression. The chapter then addresses social constructionism, reviewing definitions, metatheoretical assumptions (including the epistemology and ontology of social constructionism), major assumptions, and key terms and concepts, such as activity, episode, evaluative statements, language, sense making and reflexivity. The chapter includes a summary of the literature review and concludes with the research question.

Review of Autism Literature

Autism is becoming more and more prevalent everywhere, and its seriousness is obvious. Diagnoses of autism are increasing, and it is not known if it had either been misdiagnosed in the past or if it is simply occurring more frequently. Autism is the third most common developmental disability, and more common than Down syndrome (Autism Society of America, 2000). *Time* featured autism as the cover story for their May 6, 2002 issue. J. Madeleine Nash states that it is not known why autism diagnoses are on the rise, but it *is* known that the number of new cases is exploding and that these diagnoses occur in every socioeconomic class across the nation (Nash, 2002, p. 48). Nash gives the state of autism today:

Not long ago, autism was assumed to be comparatively rare, affecting as few as 1 in 10,000 people. The latest studies, however, suggest that as many as 1 in 50 kids age 10 and younger may be affected by autism or a related disorder—a total of nearly 300,000 children in the U.S. alone. If you include adults, according to

the Autism Society of America, more than a million people in the U.S. suffer from one of the autistic disorders (also known as pervasive developmental disorder or PDDs). The problem is five times as common as Down syndrome and three times as common as juvenile diabetes (p. 48).

Ruth C. Sullivan, Ph.D., executive director of the Autism Services Center in Huntington, West Virginia, is one of the country's premier experts in the field of autism. She explains, "The word autism comes from autos, a Greek word for self, representing the extreme aloneness seen in children with autism" (1994, p. 4). Sullivan goes on to note that, "the definition of autism has broadened significantly since Leo Kanner first wrote about it in 1943, but the basic characteristics of the syndrome are as valid today as then" (p. 4). Leo Kanner, a child psychiatrist at The Johns Hopkins University, published an article, *Autistic Disturbances of Affective Behavior*, after he had seen 11 children over a period of eight years who exhibited several distinctive characteristics. The most common characteristics were severe and unusual disturbances in social relationships and language and an intensive need for repetition and sameness. Based on what we now know about autism, Kanner was correct in his observations of common characteristics within autistic children and his belief the syndrome was organically based, or has as he stated, "inborn disturbances of affective contact" (Kanner, 1943, p. 250).

However, Kanner was incorrect when he concluded that most parents of autistic children are cold, unresponsive, and poor at providing love, affection, nurturing, and close physical contact with their children. He used the terms "refrigerator parenting" and "refrigerator babies" to describe this lack of parental affective contact. He wrote:

In the whole group, there are very few really warmhearted fathers and mothers.

For the most part they are strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people. Even some of the happiest marriages are rather cold and formal affairs (Kanner, 1943, p. 250).

Unfortunately, this theory, that deficient parenting causes autism, persevered and parents were blamed for causing autism until the mid 1970s, when new research began to support Leo Kanner's original belief that autism has a biophysical cause.

The CAN Scientific Advisory Board comments on autism's historical background:

First discovered by Leo Kanner in 1943, autism was mistakenly thought to be a rare emotional disorder caused by bad parenting. It was only after fifty years had passed that autism came to be recognized as a medical disorder for which medical treatments and a cure were possible, if properly funded (CAN, 1998, p. 1).

The psychiatrists who advanced the incorrect theory that autistic children were the result of "refrigerator mothers," proved a great detriment and impediment for understanding and helping those with autism break out of isolation. This tragic mistake ensured autism's neglect by the scientific and medical communities for over 40 years and an entire generation of children was lost.

Although Kanner's article was written nearly 60 years ago, his descriptions of autistic characteristics are still valid, followed, and helpful today. In discussing Kanner's work, Michael Rutter (1985) states:

The fact that he [Kanner] was the first person to recognize that this constellation

of behaviors constituted a condition that was different from the general run of problems grouped under “mental retardation” or “schizophrenia” was quite enough for the paper to receive an honored place in the history of psychiatry. It was indeed a reflection of Kanner’s remarkable clinical acumen that he was able to see so clearly that which had escaped the notice of his many distinguished contemporaries and predecessors... Kanner’s description of the syndrome of autism...is still read with profit by students today (p. 51).

Rutter applauds Kanner for his role as the pioneer of autism’s diagnosis and for giving highly useful definitions and observations of the condition back in 1943. Kanner believed that autism held an inborn or biophysical cause, and experts today concur with his original theory. He observed puzzling social and communicative behaviors found in autistic children. Sullivan (1994) has observed these same behaviors and includes them in her own present-day definition. According to Sullivan (1994), the essential features of autism are:

- Extreme aloneness and unresponsiveness to other people, especially in early childhood years.
- Profound inability to use language in a normal way. Half do not speak (although that will probably change with the advent of new teaching techniques), and those who do use only occasional words or language that is stilted, formal, and concrete.
- Compulsions and obsessions, which seriously interfere with learning and independent living. Kanner (1943) called this “maintenance of sameness” (p.

245). (p. 5)

Definitions of autism have changed over time, becoming more refined and concrete. Current definitions clearly underscore the link between autism and communicative behaviors.

The CAN Foundation urges work toward a cure for autism, highlighting the significant problem autism has become:

Autism is a severe developmental disability affecting communication, cognition, and social relatedness. It strikes sometime between 1 and 2 years of age and affects all national and ethnic groups similarly. Though some children make strides with early intervention, more than half of children with autism will never learn to talk. The vast majority will never go to college, marry or live independently. Once thought to be rare, autism is now known to be more common than multiple sclerosis, Down's syndrome, cystic fibrosis or childhood cancer. Autism occurs in one in 500 births today, and costs the country over \$13 billion a year (CAN, 1998, p. 2).

Autism experts seek to find the causes of the disability and ways in which to help autistic children function and interact with both autistic and non-autistic children. These experts agree that children afflicted with the condition experience deficits in their ability to communicate and/or socialize with others. According to The National Autistic Society (1998), "Autism is a disability that affects the way a person communicates and relates to people around them" (Autism – the invisible disability, ¶ 1). The Diagnostical and Statistical Manual, Part Three-Revised (DSM-III) states:

Autism is a severely incapacitating lifelong developmental disability which typically occurs during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its behavioral symptoms occur in approximately fifteen out of every 10,000 births. Autism is four times more common in boys than in girls (Online Psych Inc., 1997, ¶ 2).

The Autism Research Institute (ARI) describes the autistic condition:

Autism is a severely handicapping disorder that begins at birth or within the first 2-1/2 years of life. It affects about five children per 10,000. Most autistic children are perfectly normal in appearance, but spend their time engaging in puzzling and disturbing behaviors which are markedly different from those of normal children. They may stare into space for hours, throw uncontrollable tantrums, show no interest in people (including their parents) and pursue strange, repetitive activities for no apparent purpose. They have been described as living in a world of their own. Some have no speech; others have a limited ability to speak. Others are self-injurious. Some autistic individuals are remarkably gifted in certain areas such as music or mathematics, as depicted in the film *Rain Man*. All need help (What is Autism?, 1998, ¶ 1).

Although autism experts agree that those suffering from it experience deficits in communication and social ability, autism's origin is not certain. Some state that autism is a neurological disease, some say it's biological, and others feel it's a product of our diet and/or environment. The Autism Research Institute concedes that the causes of autism are not clear, "The causes of autism are poorly understood, although it is clear that autism

is a *biological* brain disorder. The Autism Research Institute is investigating various possible causal factors” (What is Autism?, 1998, ¶ 2). ARI also outlines the outlook for autism:

In recent years, there has been a marked increase in the percentage of autistic children who have been able to attend school with normal children, and to live more or less independently in community settings. However, the majority of autistic persons remain severely handicapped in their ability to communicate and socialize with other people (What is Autism?, 1998, ¶ 3).

The Autism Research Institute has released current information about the number of cases of autism diagnosed today, as well as possible causes for them:

For many years autism occurred in about 5 children per 10,000 live births.

However, since the early 1990's, the rate of autism has increased enormously throughout the world, so that figures as high as 60 per 10,000 are being reported.

The reasons for the increase are being debated, but the most likely cause appears to be the over vaccinations of infants (What is Autism?, 2002, ¶ 1).

This problem demonstrates an unmistakable need for further research.

Experts feel that the worst possible future for a person with this disability is to shield him or her from others. It is important not to isolate autistic individuals from the world, but to immerse them as much as possible into the community. Children with autism must explore beyond their homes and classrooms, experiencing life among people without the condition, observing non-autistic children behave, play, learn, and interact.

Another institution that is fighting to help autistic children is Cure Autism Now

(CAN), “A new organization founded by parents dedicated to finding effective biological treatments and a cure for autism” (CAN, 1998, p. 1). According to their mission statement:

The CAN Foundation is an organization of parents, clinicians and leading scientists dedicated to finding effective biological treatments, early detection, prevention and a cure for autism and related disorders. In addition to a primary focus of accelerating and funding critical biomedical research, CAN is committed to broadening awareness and understanding autism – a disease that has been virtually ignored for more than forty years (p. 1).

CAN explains that autism is worthy of our concern and has not been given the attention it deserves. The organization stresses that there is hope for a better life for autistic children. CAN also presents its definition of this disability and reinforces its commitment to helping those with autism:

Autism is a severe, lifelong neurological disorder that usually strikes some time in the first two years of life and can cause severe impairment in language, cognition, and communication. Though many children with autism make great strides through early intervention, even today, most people with autism will never marry, have a job, or live independently. Half of all autistic children will never learn to speak. Autism is a terrible disease that steals a child’s future and breaks a parent’s heart—a little more each day. But there is hope for a better life, and CAN is proud to be part of that effort... Today, autism is a national crisis affecting over 400,000 families and costing the nation over 13 billion dollars a

year. According to recent studies, as many as 2 in every 1000 children born today will be on the autistic spectrum. Autism is more common than Down syndrome, multiple sclerosis or cystic fibrosis and yet, autism research still receives less than 5% of the funding of these other diseases. CAN believes that we can't wait for someone else to decide that these children deserve help. The pace of scientific progress can and must be accelerated (p. 2).

CAN has given the absolute hard, cold facts regarding this severe problem, including the common trend or theme among experts that autism severely incapacitates the person's language, cognition, and communication. CAN demonstrates how autism affects a person from childhood to adulthood, stating that the autistic person "will never marry, have a job, or live independently" (1998 brochure). Most startling is that "half of all autistic children will never learn to speak" (1998 brochure). This very grim diagnosis explains just how severely autism affects a person's life and how this problem needs and deserves attention. Since communication and social interaction are the very foundation of human existence, it is easy to see that failing to understand and help those who do not have these communicative and social abilities will effectively hinder their lives, narrow their capabilities, and withhold potentially fulfilling futures.

Another definition of autism was put forth by the Emerson-Tufts Program in Health Communication at Emerson College on the "Campaign of the Month" Web site. Presenting January 1998, as the National Autism Awareness Month, the program states:

Autism is a developmental disability. Symptoms usually begin to appear during the first three years of life. It affects 15 out of every 10,000 individuals and is

more prevalent in boys. This disability interferes with the development of the brain and affects reasoning, social interaction, and communication skills. Autism usually manifests itself by the appearance of typical behavioral symptoms in the following areas:

1. Disturbances in the rate of physical, social and language skills.
2. Abnormal responses to sensations. Any one or a combination of senses or responses are affected, sight, hearing, touch, balance, reaction to pain or in the way the child holds his body.
3. Speech, language, and non-verbal communication.
4. Abnormal ways of relating to people, objects and to events in the environment
(Campaign of the Month-Emerson Tufts Program in Health Communication, 1998, ¶ 1-2).

The Emerson-Tufts program also shares the understanding that persons with autism undergo significant problems with communication and social skills. They have difficulty relating to people as well as to objects and events in their environment. The typical behavioral symptoms that children with autism exhibit are recognized by these various organizations and experts within these organizations seem to point to the same fact that autism stems from a neurological or brain disorder.

The Autism Society of America lists behavioral symptoms of autism:

Difficulty in mixing with other children; inappropriate laughing and giggling; little or no eye contact; apparent insensitivity to pain; prefers to be alone; aloof manner; spins objects; inappropriate attachment to objects; noticeable physical

overactivity or extreme underactivity; unresponsive to normal teaching methods; insistence on sameness; resists changes in routine; no real fear of dangers; sustained odd play; echolalia (repeating words or phrases in place of normal language); may not want cuddling or act cuddly; not responsive to verbal cues; acts as deaf; difficulty in expressing needs; uses gestures or pointing instead of words; tantrums—displays extreme distress for no apparent reason; uneven gross/fine motor skills, (may not want to kick a ball but can stack blocks.) (Autism Checklist, 1998).

Other descriptions of behavioral problems and the severity of these problems are discussed abroad. The general consensus remains the same: Children with autism are up against a significant social and communicative impairment. The National Autistic Society, located in London, England, states that autism “describes a condition with wide ranging degrees of severity, all those affected have a triad of impairments which will include all or some of the following: Difficulty with developing imagination...difficulty with verbal and non-verbal communication...difficulty with social relationships.” (Autism – the invisible disability, 1998, ¶ 1). A common theme found in these definitions and in this background is that autistic children are both socially and communicatively impaired. They need help, and it is up to parents and teachers to do all they can to bring them out as much as possible, to their own unique potential.

CAN’s comparison of autism to other diseases has shown that although autism is more widespread than other diseases, there simply is not adequate funding set aside for helping those with autism and for finding a cure. Since CAN sets itself apart from other

autism organizations by actively seeking to find a cure for autism, the organization holds fundraisers and has actively campaigned Congress for more funding.

On October 12, 1999, C-SPAN Today aired a congressional hearing on children's health, specifically on autism. The House Commerce Subcommittee listened to Jonathan Shestack, President of CAN, actress Rene Russo, member of the CAN Honorary Board, and Francine Young, the mother of an autistic child. This subcommittee panel on children's health appealed for more funding and stated that there are various theories regarding the cause of autism. Jonathan Shestack said:

We're seeing larger numbers within the past five years [of those persons born with autism]. This is a genetic epidemic that lies dormant. Something is bringing it out. Children with autism are severely emotionally disturbed or retarded. Autism today is where Alzheimer's, senile dementia, was fifteen years ago. There is a misdiagnosis of autism between parents and doctors, there are no real specialists, and there is no specific treatment.

He appealed to Congress by finishing with these statements:

Pediatricians need to be trained to identify and diagnose autism. We need to find the source of it. Don't lose years with misdiagnosis. We need to double the budget for autism to move towards a cure and to strive for early diagnosis and early intervention.

Francine Young tearfully narrated a story that clearly and undeniably persuaded Senators and Representatives to listen and empathize with her situation as a frustrated parent of an autistic son. She told of the time her young son pleaded through his eyes

with his mother to understand his plight. He stared at her and continually touched his throat because he could not *verbally tell* her that something was wrong. He could not tell her *what* was wrong with him. As Ms. Young tried to feed her son, he wouldn't eat and kept rubbing his throat. She thought he didn't like the food she was feeding him. The fact was, he was hungry and although he *wanted* to eat, he could not. She finally realized that his throat hurt, so she looked into his mouth and saw he had several sores covering the back of his throat. One can imagine her feelings at that point. Ms. Young stated to Congress that her son couldn't tell her that he had a sore throat. Because of the lack of communication between mother and son, Francine Young said her child could have died because his medical condition could have and would have most certainly worsened had she not guessed correctly about its existence.

The main goal of CAN is to find a cure. The organization is not alone in this quest. The National Autistic Society (1998) answers the question, 'Is there a cure?' by stating:

As yet there is no cure for autism, but specialized education and structured support can help maximize a child's skills and minimize any behavior problems. The right kind of education and care programs are essential. They make a real difference to the child's life enabling each individual, whatever their level of disability, to achieve as great a degree of independence as possible (Autism – the invisible disability, 1998, ¶ 7).

The Autism Society of America agrees, describing one of the most effective approaches to autism:

Experience has shown that individuals with autism respond well to a highly structured, specialized education and behavior modification program, tailored to the individual needs of the person. A well designed intervention approach will include some level of communication therapy, social skill development, sensory impairment therapy and behavior modification at a minimum, delivered by autism trained professionals in a consistent, comprehensive, and coordinated manner.

The severe challenges of some children with autism may be addressed by a structured education and behavior program which contains 1:1 teacher to student ratio or small group environment (What are the Most Effective Approaches to Autism?, 1998, ¶ 2).

Organizations such as the Autism Society of America in Bethesda, MD; the Autism Research Institute in San Diego, CA; CAN (Cure Autism Now) in Los Angeles, CA; and The National Autistic Society, in London, England, contribute to our knowledge of autism and assist those born with it. They recognize that this condition is characterized by developmental delays. They are devoted to conducting research and to disseminating the results of research on the causes of autism and on methods of preventing, diagnosing, and treating autism and other severe behavioral disorders of childhood. They provide information based on research to parents and professionals throughout the world.

Autism is just one of the developmental delay syndromes. No one knows as of yet how or why autism occurs, and there is no medical testing that can determine its presence. Diagnosis is made by observing behavioral symptoms including problems in social relatedness and communication, speech and language absence or delays, and abnormal

ways of relating to people, objects, and events. Temple Grandin, Ph.D., an assistant professor at Colorado State University in Fort Collins, Colorado, is autistic and has written extensively about what it is like to have autism and how early education and speech therapy pulled her out of the autistic world. She says that autism diagnoses are made by observation, "At the present time there are no medical tests for autism. Autism is diagnosed based on the child's behavior" (Grandin, 1998, p. 2). We are seeing increased diagnoses of autism and it is crucial that we investigate this disability further and work towards solving this human mystery.

Progression and Regression Defined

According to The National Autistic Society (1998), "progression" for an autistic child is defined as a moving forward or an improving, step-by-step, cumulative growth in learning and in developing communication and social skills and abilities. "Regression" is defined as the moving backward or return to a former, especially worse state, in learning and in developing communication social skills and abilities. For example, an autistic child may start to learn language, so she or he is progressing. But, the child may start to lose what language she or he has learned. When this happens, the child is regressing. If language skills are gradually building, the child is improving. If the child begins to lose what she or he has learned, the child is regressing. Progression in social interaction would be "reduced difficulty with social relationships," and regression of social interaction would be increased difficulty with social relationships. Progression of social communication would be "reduced difficulty with verbal and non-verbal communication," and regression of social communication would be increased difficulty

with verbal and non-verbal communication.

Dorland's Illustrated Medical Dictionary (1994) defines progression and regression. Progression is defined as, "1. the act of moving or walking forward. 2. the process of spreading or becoming more severe." Regression is defined as, "1. a return to a former or earlier state. 2. a subsidence of symptoms or of a disease process" (U.S. Department of Health and Human Services, 2000).

Clinical definitions of progression and regression are those defined by specialists in the field of autism. The CAN organization released an Autism Screening and Diagnostic Evaluation: CAN Consensus Statement (1998) that outlined clinical diagnoses of autism. According to CAN (1998):

Autism and related disorders occur in between one in 500 and one in 1,000 children. Many pediatricians are uncertain how to proceed with the work-up of the 1 to 2-year-old who looks normal, but in whom the parents complain of delayed language or social behavior relative to other children. Parents may even report subtle regression (p. 40).

Regression, then, is defined by autism experts as a delay in language or social behavior compared to the general development of non-autistic children.

Tuchman and Rapin (1997) explain that children with autism and other pervasive developmental disorders experience an early regression of unknown cause in their language, sociability, and play. These authors observe:

Pervasive developmental disorders (PDD) or autistic spectrum disorders (ASD) encompass a heterogeneous group of individuals with early childhood onset of

deficits in social interaction and language proficiency, a restricted repertoire of interests and activities, and a wide range of cognitive competence (Tuchman & Rapin, 1997, p. 560).

In discussing regression in autistic children, Tuchman and Rapin (1997) argue:

Deficits, including impaired language, are present from the start in the majority of young children on the autistic spectrum. A significant minority (20% to 40%) of parents report an early regression in their children's language, associated with a deterioration in nonverbal communication and play skills, a worsening of behavior, and, in a proportion of children, a cognitive decline. Some of these children are stated to have been entirely normal before the regression, others to have had some preexisting autistic traits that clearly worsened. Regression typically takes place between 1 and 3 years of age. It may be passed off at first, especially if insidious, in children who spoke only a few words and continued to acquire gross motor milestones (p. 560).

It is clear that autistic children demonstrate communication and social interaction early in their childhood, during the toddler years, and that these communication and social abilities decline between one and three years of age. Tuchman and Rabin caution parents that early diagnosis is critical. The authors argue that parents should have their children tested for autism once they suspect that their children are experiencing regression, (language loss, deterioration of nonverbal communication, play skills, worsening of behavior, and cognitive deficits). Tuchman and Rabin stress that time is of the essence for autistic children. If parents delay diagnosis or the pediatrician misdiagnoses the

condition, then the child loses precious time that could have been spent wisely. Early intervention is crucial because with it, the autistic child will be less likely to lose language and social skills.

McEachin, Smith, and Lovaas (1993) provide clinical definitions of progression in autistic children's communication and social skills. The authors describe how they developed a study on early intensive behavioral treatment for autistic children:

After a very intensive behavioral intervention, an experimental group of 19 preschool-age children with autism achieved less restrictive school placements and higher IQs than did a control group of 19 similar children by age 7 (Lovaas, 1987). The present study followed up this finding by assessing subjects at a mean age of 11.5 years. Results showed that the experimental group preserved its gains over the control group. The 9 experimental subjects who had achieved the best outcomes at age 7 received particularly extensive evaluations indicating that 8 of them were indistinguishable from average children on tests of intelligence and adaptive behavior. Thus, behavioral treatment may produce long-lasting and significant gains for many young children with autism (McEachin et al., 1993, p. 359).

It is important to understand how the study was conducted and to know the results of the study because there is a strong link between early intensive behavioral treatment and progression of communication and social skills in autistic children. McEachin et al. (1993) present their clinical definition of progression of communication and social skills in autistic children, maintaining that the correlation between intervention and enhanced

skills is clear: As early intensive behavioral treatment is applied, progression of communication and social skills increases. The researchers argue:

Professionals have attempted a wide variety of interventions in an effort to help children with autism. For many years, no scientific evidence showed that any of these interventions brightened the children's long-term prognosis... However, since the 1960s, one of these interventions, behavioral treatment, has appeared promising. Behavioral treatment has been found to increase adaptive behaviors such as language and social skills, while decreasing disruptive behaviors such as aggression... (McEachin et al., 1993, pp. 359-360).

According to McEachin et al., progression occurs when autistic children acquire more language and more social skills. The autistic children relate to others around them, while at the same time, they demonstrate fewer disruptive behaviors.

McEachin et al. (1993) examine regression as well as progression:

A test battery was constructed to assess a variety of possible deficits: for example, idiosyncratic thought patterns, mannerisms, and interests; lack of close relationships with family and friends; difficulty in getting along with people; relative weaknesses in certain areas of cognitive functioning, such as abstract reasoning; not working up to ability in school; flatness of affect; absence or peculiarity in sense of humor (p. 360).

In contrast, the researchers describe progression as, "normal intellectual functioning, good relationships with family members, ability to function independently, appropriate use of leisure time, and adequate socialization with peers" (McEachin et al., 1993, p.

360).

Based on their definitions of progression and regression for autistic children, McEachin et al. (1993) designed their study so that, "The treatment focused primarily on developing language, increasing social behavior, and promoting cooperative play with peers along with independent and appropriate toy play" (p. 361). When the children demonstrated these communicative and social behaviors, they demonstrated progression. To treat regressive behaviors, "substantial efforts were directed at decreasing excessive rituals, tantrums, and aggressive behavior" (McEachin et al., 1993, p. 361). Thus, the study sought to move children away from regression toward progression by using early intensive behavior treatment.

In Mesibov's (1993) response to McEachin et al.'s work, he agrees with the overall findings, yet adds a qualifier, "What is at issue is the magnitude of the changes and what they mean" (pp. 379-380). Mesibov explains that one must be careful in interpreting the successful results because readers might jump to the conclusion that the children have been cured. Although Mesibov believes the children in the study showed impressive results, they fell short of demonstrating normal functioning. So, although McEachin et al. (1993) documents *progression* with the early intensive behavior treatment because the communicative and social gains the children made were significant and important, this "progression" does not indicate normal or even near-normal functioning (Mesibov, 1993, p. 380).

Thus, Mesibov maintains that the children made gains, but warns that the children should not be thought of as "cured" and their condition should be realistically viewed.

The children made progress, but would not be considered within the normal ranges in communicative and social skills for their ages. Mesibov (1993) stresses this point:

There are many high-functioning people with autism with near-normal IQs and adaptive behavior participating in regular public school programs who remain severely handicapped. To think otherwise is to minimize the severity of the social, cognitive, and communicative aspects of autism (p. 380).

Mesibov (1993) further elaborates on his response to McEachin et al. (1993), arguing:

Many skills required for normal functioning have not been measured by McEachin et al. (1993). They did not report on the students' social interactions, friendships, conceptual abilities, and social communication, skills likely to differentiate children with autism from their peers without handicaps. These are important aspects of the autism syndrome and deserve more scrutiny in further studies (p. 380).

Freeman, Del'Homme, Guthrie, and Zhang (1999) provide additional insight into clinical definitions of progression and regression in autistic children in their examination of Vineland Adaptive Behavior Scale (VABS) scores. These researchers examine how VABS scores changed in individuals with the autistic disorder as a function of both age and initial IQ. Results reveal that subjects improved with age in all domains. The rate of growth in communication and daily living skills is related to initial IQ, while rate of growth in social skills is not (p. 379). The authors conclude that their results should provide hope for parents and further support for the importance of functional social-communication skills in the treatment of autism (p. 384).

Sullivan (1994) also describes the features of social debilitation or regression in autistic children:

A combination of some or all of these behaviors characterizes the individual with autism. These behaviors vary in severity and manner from person to person:

Extreme aloneness and impaired relatedness to other people. Infants and young children seem happiest when left alone, eerily occupied for hours on end by activities such as flipping a piece of string, playing with a dust ball, or spinning the wheels of a toy. They often stare into space or look through you rather than at you and appear to tune out their world, even their mothers. There is poor eye contact, as though only peripheral vision is used. Parents or caretakers typically report that these children do not reach out when someone picks them up (pp. 5-6).

In an insightful and moving description of autism, Cowley (2000) details the effects of autism on the individual, particularly on social ability:

What, ultimately, makes autistic people different? How do they experience the world? Twenty years ago no one had much of a clue. But a burgeoning body of research now suggests that the core of all autism is a syndrome known as mindblindness. For most of us, mind reading comes as naturally as walking or chewing. We readily deduce what other people know and what they don't, and we understand implicitly that thoughts and feelings are revealed in gestures, facial expressions and tone of voice. An autistic person may sense none of this... It's not hard to see how mindblindness would derail a person's social development. If you can't perceive mental states, you can't show empathy, practice deceit or

distinguish a joke from a threat—let alone make friends. Sharing becomes pointless when you can't see its effects on people, and conversation loses much of its meaning because you miss the unspoken intentions that hold it together (pp. 47-48).

The goal of parents and teachers of autistic children is to move these children, as much as possible, away from exhibiting signs of emotional disturbance and move them toward demonstrating adaptive and social skills. Parents and teachers work together by socially constructing and by negotiating progression and regression of the communicative and social skills in children. First teachers and parents must agree on how the terms, progression and regression, are defined. Then they must evaluate if the child is progressing and/or regressing in his or her communication and social skills. Finally, parents and teachers must work out a plan that they agree on to help the child reach her or his fullest potential.

Autism's Limitations on Communication and Social Abilities

It has been argued extensively thus far that autism severely affects the communication and social abilities of those born with it. Psychologist Dr. Lorna Wing of The National Autistic Society, formerly the British National Society for Autistic Children, explains how this occurs:

The disability is a problem of understanding messages from the senses, especially sight and hearing. Although the eyes and ears of autistic children seem normal, when messages from them reach the brain they are not linked into an understandable picture of the outside world, it is believed, leading to a lack of

understanding of speech and gesture and hence a lack of ability to communicate.

Because of this, autistic children appear to be withdrawn and seem to live in an isolated world of their own. Moreover, due to the frustration caused by the inability to communicate, there is often disturbed behavior (Wing, 1973, p. 1).

The National Institutes of Health (NIH) held an Autism State-of-the-Science conference on April 10 and 11, 1995, at the NIH in Bethesda, MD, in response to a congressional request. Scientists and parents assessed the state of the science in autism, identified gaps in knowledge, and made recommendations to the NIH regarding promising areas for future research (Alexander, Cowdry, Hall, and Snow, 1996, p. 117). Participants addressed the communication, social, and emotional development in children with autism. One question the group answered was, "What aspects of communicative, social, and/or emotional function/dysfunction are specific and perhaps universal to autism spectrum disorders (core deficits)?" Conference participants responded:

There is strong evidence that the capacity to share attention and emotion with others is specifically and universally impaired in autism. This is manifested in less joint attention and social referencing in young children with autism, less understanding of the feelings and thoughts of others in older children with autism, and less initiation of social behaviors and responsiveness to others' feelings at all ages. Simple recognition of facial expressions is intact in many individuals with autism. However, understanding that requires the person with autism to take the perspective of another, is generally limited. This deficit is also manifested in serious difficulties in the functional use (pragmatics) of language by those

individuals who acquire language skills. Understanding and assessment of these deficits raise particular problems in research with nonverbal children (Alexander et al., 1996, pp. 140-141).

It is not clear how or why autism limits communication and social abilities, but there are several theories and assumptions debated today. The National Institute of Mental Health explains, "It is generally accepted that autism is caused by abnormalities in brain structures or functions. Using a variety of new research tools to study human and animal brain growth, scientists are discovering more about normal development and how abnormalities occur" (NIMH, 1997, p. 22). It is assumed that there are several possible causes for autism. These range from heredity, (genetic errors), certain conditions like the mother's health during pregnancy, disruption of fetal brain growth during pregnancy, and other problems such as viral infections like rubella (German measles), lack of oxygen to the baby at delivery, problems during delivery, and other complications of delivery. Environmental factors and certain childhood vaccines, such as the MMR (measles, mumps, rubella) vaccine, have been discussed as possible causes, but there is no clear link between any of the above causes to autism.

Persons born with the autistic condition experience a lifetime of impaired thinking and social functioning, which are arguably our most human attributes. Autism adversely affects individuals' abilities to communicate, form relationships with others, develop a sense of self, develop awareness of others and their community, and to respond appropriately to the world around them.

Review of Social Constructionism Literature

Social constructionism is grounded in the assumption that our social world is created through social interaction and within context. Reality is socially constructed and created through human interaction. Social constructionists believe that physical reality (nature, rituals, cycles of life, etc.) exists beyond human interaction, but without human discourse, we cannot talk about reality. Gergen (1992) argues that reality becomes meaningful through interactants' conversations:

Constructionism makes no denials concerning explosions, poverty, death, or "the world out there" more generally. Neither does it make any affirmations... constructionism is ontologically mute. Whatever is, simply is. However, once we attempt to articulate *what* there is we enter the world of discourse. At that moment the process of construction commences, and this effort is inextricably woven into processes of social interchange (including conventions of discourse themselves)... There is no means of listing words on one side of the ledger, and "what there is" on the other, and then locating identities that transcend the conventions of a particular community. The adequacy of any word, or arrangement of words, to "capture reality as it is" is a matter of local convention (p. 171).

Pearce (1995) differentiates between constructivists and social constructionists, "Constructivists may be characterized by their interest in the *stories we make up* and then, of course, live in... Social constructionists, on the other hand, are characterized by their interest in the *stories we make real* in our actions" (p. 100). The philosophical roots and

distinctions of social constructionism are varied. According to Pearce (1995), social constructionism's "intellectual roots lie in the ecological epistemology of Gregory Bateson, American pragmatism, and the philosophical critiques of Ludwig Wittgenstein. In these approaches, the real world of social action, not the cognitive world of knowing, is the realm of interest" (p.100). Thus, social constructionist approaches focus on creating social reality through language and human interaction in specific contexts.

Metatheoretical Assumptions of Social Constructionism

Epistemology is the branch of philosophy that investigates the origin, nature, methods, and limits of human knowledge. As Dance (1982) states, "Epistemology is the study of the ways in which we come to 'discover' or 'create' knowledge" (p. 246).

Social constructionism is a communication theory, a progressive perspective, and a social approach within the field of communication studies that maintains that communication is produced in and reproduces our community, our human social world, and that knowledge and meaning are created, co-created, maintained, and altered through social interaction and within context (Shotter, 1993; Cronen, Pearce, & Harris 1982). Leeds-Hurwitz (1995) argues, "Social approaches are first and foremost *social*. That is, they describe events occurring between people in the process of interacting rather than reporting how events are perceived through a single person's understanding" (p. 6). So, social approaches such as social constructionism, are concerned with what occur between people and not within separate individuals. Therefore, the epistemology of social constructionism is that knowledge is the product of social interaction, and that communicators create reality through language and through activities such as verbal and

non-verbal communication. Leeds-Hurwitz (1995) states, "In this view, social reality is not a fact or set of facts existing prior to human activity; it is created through human interaction. We create our social world through our words and other symbols and through our behavior" (p. 7).

By accepting the above definitions, we recognize the epistemology of social constructionism. We can also understand that knowledge and meaning are created through our social interactions with one another and within the contexts we participate in. Dance (1982) reminds us, "Behind every theory lies a set of normally tacit assumptions about knowledge" (p. 246). We shall see that these "tacit" or unspoken assumptions can be understood without being openly expressed or implied when we accept that our speech acts, along with the contexts we communicate in, create knowledge and meaning. Meaning arises out of interpersonal negotiation (Gergen & Gergen, 1982).

Ontology, the branch of metaphysics that studies the nature of existence or being as such, is intimately connected with epistemology. As earlier stated, Gergen (1992) argues that "constructionism is ontologically mute" and that "whatever is, simply is." Social constructionism does not say what does or does not exist and that these entities do not depend on one another. In other words, we do not need to prove reality exists by pointing to it and saying, "There is reality." We do not necessary require our five senses to know reality exists. We *discuss* reality and therefore, *create* it as we discuss it. We talk reality into being (Shotter, 1993).

The ontology of social constructionism can also be explained in another way by saying what it is *not*. The thrust of this thesis is to examine *how* progression and

regression of an autistic child's communication and social skills are socially constructed in parent-teacher interactions. Social constructionism is the theoretical perspective, the tool which will *not* show us *if* progression and regression are created; it will show us *how* interactions create the meanings and actions of progression and regression.

Key Assumptions of Social Constructionism

Without communication, we would have no social reality. An argument, for example, is an episode, an exchange, and an interaction between two or more people.

Central to social constructionism is the notion of speech acts. Pearce (1994a) argues:

Social theorists have two ways of thinking about speech acts. One may be characterized as the *basic building blocks approach*; the other as the *unfinished creative process approach*... Speech acts are the component parts of larger communication patterns... Speech acts are not things; they are configurations in the logic of meaning and action of conversations, and these configurations are co-constructed (pp. 105-107).

So, a speech act is a comment, question, insult, etc., and there must be two or more people to complete the speech act. The speech acts that are co-created between the parent and the teachers of the autistic child will be analyzed in this thesis.

John Shotter (1993) reiterates this with his term, "joint-action," or speakers "making connections" with their audiences. He also asserts:

Rather than with language considered in terms of previously existing patterns or systems formed from 'already spoken words', the version of social constructionism explored here focuses upon the formative uses to which 'words in

their speaking' are put, and upon the nature of the relational 'situations' thus created between those in communicative contact with each other in their speakings (Shotter, 1993, p. 6).

Shotter (1993) further explains, "in social constructionism, we attend to events within the contingent flow of continuous communicative interaction between human beings" (p. 7).

Therefore, parents and teachers "make connections" in their interactions, and in doing so, develop their relationships. The parents and teachers cannot create reality about the autistic child unless they engage in social talk about her or him. When they jointly discuss and engage in conversation about the child with autism, they are interested in discovering how they can determine if that child is progressing or regressing in his communication and social skills.

We create our social world through communication, and we create reality through *talk*. The world is created through the process of people talking with each other. We also create reality nonverbally. Reality emerges from the continual process of our communicative episodes. Pearce (1994a) emphasizes this point:

There is no such ambiguity about the social world. Clearly, the social world is in a process of continual creation. The actions that you perform in this moment add to the sum total of human experience; the future of the human race is not fixed, it is still being developed through our actions (p. 75).

Rorty (1980) makes a similar argument:

If we see knowing as not having an essence, to be described by scientists or philosophers, but rather as a right, by current standards to believe, then we are

well on the way to seeing *conversation* as the ultimate context within which knowledge is to be understood (p. 3).

Thus, it is through conversation that we gain knowledge about our world.

Pearce (1994b) argues that it is important to illuminate conversation and to recognize that ontology, the nature of being, has its place in the social constructionist paradigm. However, ontology undergoes a change in this paradigm because objects in reality are not separate from conversation. Reality, as said previously, arises out of our talk or discourse:

Rather, ontology is a method for discerning local, temporary, contingent configurations or conversations. That is, it is not just that epistemology or reality has attributes *like* those of conversation. Rather, the events and objects of the human world comprise particular configurations of conversations. The most immediate implication of this notion is that there is no “gap” between ontology and activity, no “distance” between the events/objects of the human world and the conversations in which we participate. The human world is in a condition of continual creation; our next act inevitably and unavoidably adds something to reality... The work communication does is to make things, not talk about them. Conversations are the ontological “stuff” of the human world, not just a place where this stuff is shaped (Pearce, 1994b, p. 39).

The parent and the teachers of the autistic child record episodes within a diary they share. These documented episodes serve to show how they talk about and negotiate progression and/or regression of the child’s communication and social skills. So, as Pearce (1994b)

states above, these documented episodes or interactions between the parent and teachers of the autistic child are the conversations, the ontological “stuff” of this particular aspect of the human world. As the parent and teachers communicate with each other in the diary, they constitute and construct the autistic child’s progression and/or regression of his communication and social skills.

Conceptual Definitions of Social Constructionism

To understand social constructionism is to understand the nomenclature essential to it. The following section illuminates the most salient terms applicable to the present study.

Activity. Pearce (1995) addresses the commonalities among social constructionists, noting the important key concept of activity within the realm of social constructionism. Shotter (1989) observes that social constructionists share:

a certain vision of the world and of our knowledge of it, that both consist of *activities* of various kinds...and also a certain stance towards the conduct of research into such activity—that of investigating its nature from a position of active involvement in it, rather than contemplative withdrawal from it (p. 132).

So, then, the researcher becomes a part of the research and cannot extricate herself or himself from it. The researcher has a reflexive position inside the research itself.

From a social constructionist perspective, “the activities performed by persons in conversations are themselves real. Persons are not only cognizing entities, we are embodied; our activities are real” (Pearce, 1995, p. 95). Social worlds are continually created and re-created through communication. Conversations are not tangible objects,

but they are as real as any tangible object. As Pearce (1994a) argues, conversations “are a form of action and they are, in themselves, the real substance of our social worlds” (p. 74). Human talk and human action are the same phenomenon because talk *is* action. Similarly, human interaction through human discourse and action is as real, tangible, genuine, authentic, actual and veritable as nature’s elements that consist of the material world and its phenomena such as air, water, fire and earth.

Our actions, talk, conversation, and interactions all create and re-create the social world continuously and impact, develop, and change the future of the social world. Depending on what we say to one another, courses of action literally change due to those conversations. Pearce (1994a) observes:

When we communicate, we are not just talking *about* the social world, we are literally participating in the creation of the social universe. What will be will grow out of what was, but it will take on the form of the actions that you and I perform in this particular moment (p. 75).

A central tenet of social constructionism is that every form of communication we engage in, both verbal and nonverbal, changes the course of the future.

People do not just think; they act. Human actions are as real as anything we can point to in the real world. Our activities are our realities. Our stories are put into motion by our actions. As Pearce (1995) reiterates, “Social constructionists...are characterized by their interest in the *stories we make real* in our actions” (p. 100). Pearce (1995) demonstrates this by showing the dichotomous position between the constructivists who are characterized by their stance that we tell *stories we make up* (storytelling for

example), and then we live within those stories. Constructionists tell stories through their actions. It is paramount to understand the differences between the two philosophical roots of constructivism and constructionism. Since the former believes that communication is a cognitive process of knowing the world and the latter believes that communication is a social process of creating the world, we can see that the constructivists eschew the notion that we must *act in order to create*. The creation of social worlds is not possible without our actively being involved in it, and this means we create through our actions.

Realism, according to social constructionists, can be seen in our actions. We construct or participate in the construction of our social worlds. Actions are also related to contexts. We act into our contexts; this means that our actions will become a part of continuing patterns. We give meaning to these unfolding patterns and we act into contexts because our actions make the contexts real and the contexts are made real by our actions. There is reflexivity here: contexts becoming meaningful through our actions and actions become meaningful through our contexts. Another far-reaching relationship between communication and context is that communication occurs in contexts *and* communication creates contexts.

Episode. Episodes are the events that occur among and between humans. As Vernon Cronen (1995) argues:

The terms “episode” and “forms of life” indicate that human life is made up of multiple, varied patterns. Episodes are not little monads of practice, but, rather, have multiple relationships to each other. Together, they produce what

Wittgenstein (1953) called forms of life. I choose these terms to call attention to the need to see human action in larger terms than the single episode or single relationship (p. 232).

Episodes, then, are interlocking. They depend on each other and do not exist independently from one another.

Episodes and speech acts are forms of context. It is important to differentiate episodes from speech acts, "Formal definitions of the term *episode* can be misleading because episodes themselves are made and are constantly in the process of being made" (Pearce, 1994a, p. 154). Cronen et al. (1982) define episodes as, "Communication routines that persons view as wholes. Episodes are comprised of reciprocal speech acts and are characterized by their constitutive and regulative rules" (p. 71). What then, are speech acts? Pearce (1994a) defines them as:

made when the actions of two or more people combine in certain ways. It would be hard to exaggerate the importance of your ability to affect what speech acts are made in your conversations. Literally, the quality of your life consists of the speech acts in which you participate (p. 146).

Similarly, Cronen et al. (1982) define speech acts as, "The things that people do to each other with words and gestures. Speech acts refer to the relational level of meaning (e.g., compliments, threats, promises, etc.)" (p. 71). For example, during a ritual such as a wedding ceremony, the bride and groom say "I do" when asked if they each take their spouse and will honor the vows they have just spoken to each other. As soon as they have committed to each other by saying "I do," as soon as these words are spoken, the

level of meaning is understood to be that the legalities of the marriage have just commenced and that these two people are bound to each other by religious and societal laws. The words, "I do," mean, in this context, that the individuals will honor each other by honoring their marriage vows. If one were to say "I do I do I do I do I do" as one walked down the street with apparent abandon and without any relational level of meaning, then it would be a non-sequitur because it is a statement which does not logically follow from events that preceded it. The bride and groom who say, "I do" to each other in the ritual of the wedding ceremony, do so with the implicit cultural knowledge that this speech act contains the constitutive and regulative rules that show the inherent, essential meanings of the words, "I do." As Shotter (1993) states:

Hence, in becoming an autonomous adult within a group, one learns a grasp of what might be called the "ethical logistics" involved in the management of personal transactions within that group, the means to coordinate the different responsibilities involved in negotiating the social construction of meanings (p. 47).

We know what we know about the words and the promise of the words, "I do," because we have an understanding about the nature of the wedding ceremony and what is expected of two people who engage in this ceremony.

Our social worlds are so intricate that it is best to begin understanding them by looking at them as episodes. Pearce (1994a) quotes Gumperz's (1972, p. 17) definition of episodes, "[Episodes are] communicative routines which [communicators] view as distinct wholes, separate from other types of discourse, characterized by special rules of

speech and nonverbal behavior and often distinguished by clearly recognizable opening or closing sequences” (p. 152). An example of an episode, then, would be a classroom period, a conference call at work, a telephone call, etc. Pearce (1994a) argues:

The best way of defining them [episodes] is as a category of events and objects in our social worlds. They function as *frames* that define some things as “inside and during” the episode and others as “outside and before or after” the episode.

Episodes have an internal structure. Whether rigid or flexible, they are perceived as a pattern (p. 154).

Evaluative Statements. The term “evaluative statements” has an unconventional meaning in social constructionism. Here, it is specific to social constructionism and it is meant to show that we create reality through our interactions with one another. In social constructionism, we construct our reality through our conversations. Conversations contain verbal and nonverbal elements. Shotter (1993) explains that human realities:

must be sustained in existence by being continually remade in people’s everyday social activities, and that in such processes, people mutually judge and correct both each other and themselves as to the “fittingness” of their actions to what they take their reality to be. He points to Wittgenstein, ‘if language is to be a means of communication there must be agreement not only in definitions but also (queer as this may sound) in judgments’. Utterances are judged, then, not solely or primarily in terms of their grammatical form, but are evaluated in terms of the ‘countless’ uses they can have in relation to the social reality in which they occur. And conversation is the ultimate sphere in which all such judging and evaluating

takes place, and in which such assessments are negotiated and shared agreements are reached (p. 40).

Our evaluative statements are utterances (units of dialogue), which are made in response to other utterances.

Language. Social constructionism addresses the process of creating realities through *language* in specific contexts. It is most important to note that in social constructionism, language is reflexive and possesses circularity because the language we use creates our world, and this in turn creates the language we use. Pearce (1994a) puts forth his views on the importance of language to human activity, stating:

Language is the single most powerful tool that humans have ever invented for the creation of social worlds. In fact, it is so powerful a tool that some thoughtful analysts have suggested that language created us! Do we speak language or does language speak us? Which came first, the thought or the word? (p. 71).

Because of language, we are able to create our social worlds. Wittgenstein (1972) asserted that words do not have *meanings*; rather, they have *uses*.

Wittgenstein's (1972) work helped establish social constructionism. His philosophy and beliefs changed the social constructionist perspective by focusing on language in use. Wittgenstein posited three rules that have their place in the formation of the social constructionism theory. The first rule is the language game. A language game is basically a communication event in which interaction between participants occurs. In this interaction, there are rules that shape the language we employ. We make these rules ourselves, we make these rules with one another (co-creating them), and we agree on

these language rules. Schulte (1992) explains, “in one respect, the concept of language games simply serves to emphasize the importance of taking context into account when trying to understand or explain the meaning of linguistic expressions” (p. 103). So, we must know that context plays an important role in language games. Context points to language participants’ meanings.

Wittgenstein (1972) uses the terms “tools” and “games” to describe language within the language game. Tools are words; games are achieved by using the tools. Participants must not only recognize the word, but also recognize how the word works in the situation in which it is used. Words (or tools) are used to create and co-create realities, or our social world. Tools create reality; we use them within our language games. A language game uses rules we have agreed upon and uses these rules within a context. These rules are not permanently set; they can and do change over time because we negotiate these rules through our language use.

The second rule of language is the idea of rules. The third rule of language is the idea of grammar. We have rules for our language in use that belong to the episodes or communicative events we engage in. These rules for language in use create the grammar of these episodes or communicative events. Rules are rules when they are used in episodes. When we share these rules, we create an episode. When a person plays the language game, the person uses the rules (grammar). The rules and grammar for language use depend on the situation or game. These rules change when the situations change. Again, we see that as communication changes, context changes.

However, we must realize that we live in a world in which rules are set in place,

and we must adapt to those rules. In any society or culture, rules exist which tell people how to engage in communication. Cronen (1995) asserts, "We are born into a pre-existing social world and we learn our rule-using abilities by acting into the practices of others in that world" (p. 233).

Sense Making. We communicate and socially interact when we agree on our communication, when we engage in sense making. We produce and reproduce the events and objects of our social worlds by engaging in a process of making and doing and agreeing on shared meaning. We use words such as "I do" in a wedding service because we understand that there is meaning tied to this phrase. These words do not define or point to any tangible object; they are used in the matrimonial ritual and we understand their meaning.

Pearce (1995) explains that knowledge is gained as a participant, rather than as a spectator. We make sense of our world by creating it through our talk and in our interactions with one another. Pearce notes the difference between the constructivists and social constructionists and through this, clarifies how we make sense of our world, of our social reality. He says, "Although it is an oversimplification, it is useful to say that constructivists see communication as a *cognitive* process of *knowing* the world and social constructionists see it as a *social* process of *creating* the world" (p. 98). Thus, we know what we know about ourselves through creating and not in cognition alone.

Reflexivity. Reflexivity is another important term in social constructionism; it implies circularity. From the social constructionist perspective, speech is action. Pearce (1994a) argues that we coordinate with others to create meaning in specific contexts.

Meaning or negotiation of the terms of progression and regression is constructed between people in the communication process known as reflexivity. It is not ostensive nor does it exist in the minds of people. Reflexivity is the relationship (interconnectedness) between speech acts and context. Pearce (1994a) observes:

Relationships are a part of our social worlds; they are embedded in the logics of meaning and action that govern the way we think and act. Well-established contexts function as reasons for our actions; we say that we *had* to act as we did because of our relationship (p. 209).

Speech acts create contexts and contexts determine which speech acts may be performed, how speech acts are to be interpreted, and what speech acts mean (Pearce, 1994a). So, speech acts and contexts exist hand-in-hand. With these, people create meaning.

This thesis is a research project in which the participants are engaged in a reflexive loop (Pearce, 1994a) because they are a part of the process of social action. The research project, the case study, is about socially constructed events and at the same time, it is an example of the social construction of events.

Stewart (1995) refers to Leeds-Hurwitz's explanation of reflexivity "as a process of 'questioning,' 'accepting a multiplicity of meanings in events,' and the potential 'discovery of the frequently hidden 'I,' the self of the researcher, no longer absent from the final reporting of results'" (p. 34). The researcher is just as involved as the subjects, and the researcher's results are questioned along with the subject's responses. Leeds-Hurwitz (1995) asserts that the researcher is a part of the research and co-creates reality; that is, the researcher cannot be removed from the research. She gives a detailed

description of reflexivity:

Reflexivity implies accepting a multiplicity of meanings in events, and of participants' viewpoints, acknowledging that any study is but a partial accounting, heavily dependent on the particular researcher's training, questions, and assumptions. Reflexivity requires understanding research as a process involving the researcher as much as the "subjects," questioning the researcher's results no less than the subjects' responses. It accepts research as a complex process, with understanding emerging throughout rather than imposed once, securely, at the onset (Leeds-Hurwitz, 1995, p. 10).

Stewart (1995) provides further insight into reflexivity:

The point is not to "add" reflexivity but to acknowledge explicitly that reflexivity is inescapable and pervasive. Because humans are inherently self-interpreting, all human projects—including research—both affect and are affected by these self-interpretations (Steier, 1991). So reflexivity is not an option; as Leeds-Hurwitz notes, "Those who accept a reflexive approach feel it does no more than what is *necessary*" (p. 10, emphasis added)" (p. 34).

Reflexivity can be seen as a circular pattern that describes how conversations between communicative participants affect the relationship, and in turn, the relationship affects the conversations. Indeed, Pearce (1994a) suggests we think in spirals and circles, and not straight lines. He goes on to say, "Reflexivity describes a pattern in which one thing affects another which then, in turn, affects the first. In this definition, conversations are forms of action that affect relationships, and those relationships in turn affect

conversation” (Pearce, 1994a, p. 203). Reflexive loops, circles, or spirals are terms that also describe this pattern. Steier (1995) makes clear that this is “a pattern that is embedded in a relationship” and reflexivity really means “a bending back onto a self” (p. 63). His comments on reflexivity show how important this concept is:

What is critical here is that reflexivity is a property of a relationship and not of the individuals. Further, reflexivity, as a relationship, is tied to a particular context and not a property of that relationship apart from that context. Reflexivity is thus relational-in-a-context (Steier, 1995, p. 64).

Steier argues that the researcher must include him or herself in the research process (self-interpret), while we make our interpersonal communication claims. Both the researcher, as an active observer and interpreter, and the subjects participate in the circular pattern of reflexivity. As Steier (1995) notes, “Reflexive approaches thus move us to develop an awareness of the multiple conversations, contexts, and relationships in which we and our reciprocators interactively participate...they move us to develop a clinical sensitivity as interpersonal researchers” (p. 82). So, researchers must not forget to include themselves in their projects; they must look back on themselves as they conduct their work and realize their place within the research. Steier (1995) reiterates that his writing “is, after all, about affording recognition to a self-reflexiveness and ‘inter-personal’-autobiographical character of our interpersonal communication research... My own research is constituted by these very same multiple and reflexive conversations of which I claim we must develop an awareness” (p. 83).

Steier (1995) shows us that reflexivity offers us several communication

possibilities. He concludes:

A concern for reflexivity thus moves us simultaneously in several directions. It forces us to develop an awareness of how we recursively and interactively construct our claims of interpersonal communication processes of others and thus encourages us to point to ourselves as the active observers and interpreters that we are. However, rather than solely “closing the circle,” it allows us to open outward toward other forms of this self-expression, and toward an awareness of the multiple conversations in which we and our reciprocators participate (Steier, 1995, p. 84).

Summary and Research Question

In summary, the literature on autism points to the overwhelming problem autism poses for communication and social functions. The literature on social constructionism shows that it deals with the process of creating realities through language or talk in contexts. The literature review reveals that the autism and communication research share an important principle, and that is the desire to enhance communication. Parents and teachers work together to achieve the goal of enhancing the autistic child’s communication and social skills, and while they do this, they work together to socially construct the child’s progression and/or regression.

This thesis project looks at how parents and teachers socially construct progression and regression of the autistic child’s communication and social abilities. I used the theoretical tool of social constructionism, identifying and examining the themes found in the participants’ diary and interviews. Based on the literature review, I asked the

following research question:

How do parents and teachers socially construct progression and regression of communication and social skills in children with autism?

My objective was to find out how the parents and teachers of autistic children jointly negotiate definitions of progression and regression of the autistic child's language and social skills as they develop a working relationship together. I examined how progression and regression were contested and negotiated in parent-teacher interactions. In the following chapter, I discuss the methods I used in investigating the research question.

CHAPTER 3

Method

This chapter outlines the methods used to investigate a parent and teachers' social construction of the progression and regression of an autistic child's communicative and social skills. Participants in the study were the parent and teachers of the autistic child. The chapter discusses the method of social constructionism, qualitative methods, participants, the organization, data gathering strategies, (diary and interviews), and data analysis procedures.

The Methodology of Social Constructionism:

Qualitative/Interpretive Methods

In order to learn how our social world is created, our words, behaviors, and interactions are research topics to be studied. In her discussion of the methods associated with social constructionist research, Leeds-Hurwitz (1995) explains, "Most basically, a social constructionist view of the world implies that we question the validity of traditional 'scientific' experiments" (p. 7). The methodology, also known as the researcher's "approach to data collection" (Lindlof, 1995, p. 4), utilized for this thesis project is innovative and exciting in that I used both a diary and interview method, which has not been done often in past theses. This method, also known as the diary/diary-interview method, was chosen because the goal of this study is to describe *how* parent-teacher interactions are constructed. Therefore, since this is descriptive, not prescriptive research, qualitative research methods were used.

Since I am the researcher, I had to situate myself, or include myself, in the project.

Lindlof (1995) states, "Qualitative inquiry is personal, involved inquiry" (p. 5). This project was not about just obtaining facts; it was also about my undergoing the feelings and experiences along with the participants. I sought to understand the in-depth story behind the parent-teacher relationship and their negotiations regarding the autistic child's communication and social skills. As the researcher, I was directly involved in the research situation. Since social knowledge is created between people in interaction, then the researcher is a part of the co-creation of social meaning that arises from the research project (Steier, 1995).

Case Study Method

The case study method is used to locate meaning and purposes within the real, social world of communicative actions. The criteria for interpreting and evaluating case studies are discussed in this section. Chen and Pearce (1995) remind us that:

In the communication science paradigm, the well-known criteria for interpreting and evaluating research assume that the object of study stands still external to the investigator's perspective. Social constructionists believe that human conversation is in principle unfinished and imperfect, that the researcher stands in a participant's perspective, both changing it and being changed by the conversation as part of the process of inquiry. Good research then consists of engaging with (instead of remaining distant from), and thus affecting, that which is studied (p. 148).

The researcher stands alongside the subject of the case study. The researcher and the subject of the case study have equally important roles in the research process. They are

very much like two parts that complete a whole; each relies on the other. Chen and Pearce explain this:

Richness of a case study involves the polyphonic and polysemous quality of the stories told. "A good interpretation of anything...takes us into the heart of that of which it is the interpretation" (Geertz, 1973, p. 18). To illuminate the reader, "An interpretation must bring alive what is being studied" (Denzin, 1989, p. 63). A comprehensive case study certainly does not mean that it identifies all the possible variables pertinent to the case. Rather, it takes the historicity of the case into account, pays attention to the nuances of the observed phenomenon, calls attention to the multiple perspectives of the interpretation, and accounts for the recursive features of the case that the process of communication generates (p. 149).

Case studies are beneficial in that they thread the entire project together, yet they illuminate each aspect of the research:

Various pieces of the stories told in a case study should also be interconnected; however, this does not mean that they should (or can) be totally consistent with one another. One way to strive for comprehensiveness and interconnectedness in a case study is to realize that what we call social facts are historically situated and culturally created (Gergen, 1978). Often communication can be paradoxical, and it is far more significant to discern structural similarities (the patterns that connect) that are developed over time than to argue for the internal consistency across situations (Chen and Pearce, 1995, p. 149).

One of the strengths of the case study method is that it allows the conversation to

continue:

Finally, open-endedness is an essential criterion for a case study. The pragmatist tradition sees meaning as a social product that is always unfinished and incomplete. Even the most carefully conducted case study that satisfies all (and more than) the above criteria still does not have the “final say” of what the event means. Rather, it provokes readers to think beyond what the text provides and invites them to offer a different interpretation (Chen and Pearce, 1995, pp. 149-150).

Chen and Pearce offer their final thoughts about case studies and how they contribute to the richness of interpersonal communication:

As scholars and researchers in interpersonal communication, we are often made to apologize for what we do best: the illumination of specific communication practices in specific social relationships. The appeal of doing case studies in social constructionism derives from the resonance among its goals, interests, criteria, and that which our case studies reveal about the nature of communication per se. Conducting case studies also suggests an other-oriented (instead of researcher-centered) approach to study communication. Although the researcher may eventually authorize the final presentation of the study, the authority of the discourse no longer rests fully in the researcher’s hand. The process of reconstructing the informant’s own stories and narratives is a dialogical one, and this fits well with our metaphor of conversation in studying communication (pp. 150-151).

Participants

Three individuals participated in this study: Howard (child's parent), Nina (child's teacher 1998-1999) and Waverly (child's teacher 1997-1998, 1999-2000, 2000-2001, 2001-2002).¹ Howard is a divorced father with two sons. The elder son is non-autistic, and the younger son, Matthew, is autistic. The boys are 19 months apart in age. The parent works fulltime, and at the time of the study, was the primary parental figure in the children's lives. The parent shares custody with the mother of the boys. During the study, the parent's father and stepmother cared for the children after they returned home from school and before the parent returned home from work.

Waverly was Matthew's teacher 1997-1998; she and Howard used the diary to communicate about their observations of Matthew. Nina, Matthew's teacher in the 1998-1999 school year, teaches younger autistic children from about 4 to 5 years of age. She and Howard wrote conversations or episodes back and forth in the diary about the autistic child's educational progress. Waverly was again Matthew's teacher during the 1999-2000 and 2000-2001 school years, and continued in the 2001-2002 school year. She also wrote conversations or episodes back and forth with Howard about the child's educational progress.

The autistic child, Matthew, is now nine years old; when this project commenced he was five years old. His school file reports a primary medical diagnosis of autism; there is no record of hearing or vision problems or indications of significant health problems. Matthew lived with his father, paternal grandfather, paternal step-grandmother, and brother and he stayed with his mother on alternate weekends and one

day per week until November 2001. He now lives with his brother, his mother, and her husband and visits his father, paternal grandfather, and paternal step-grandmother on alternate weekends and one day per week. Both parents appear to be involved in and supportive of their son's educational program. Matthew has been enrolled in the Autism Project since December 1996.

Matthew has been tested extensively to evaluate his psychological, social, physical, and communication abilities.² Results from an October 1996 testing identified Matthew's physical age as 30 months, his self-help age as 22 months, his social age as 14 months, his academic age as 22 months, and his communication age as 8 months. In September 1999, Matthew was tested in the areas of imitation, perception, fine motor, gross motor, eye-hand integration, cognitive performance, and cognitive verbal. He was evaluated as performing significantly below his chronological age.

Matthew's developmental, physical, self-help, social, academic, and communication skills were tested and changes were recorded over the time period from October 1996 to September 1999. Although some skills, such as self-help, greatly improved, Matthew's most severe developmental problems continued to lie in the areas of social and communication skills, the focus of this thesis. For example, in the social area, Matthew has displayed some feelings of jealousy toward his classmates and has shown interest in their activities. This suggests an increased awareness of his social environment. It is crucial that he becomes even more aware of his community and the world around him and that he work towards these goals. He says a few short words, but he could improve in this area. His language skills need to be strengthened. Further

development of his communication skills needs to be met. Recent state-mandated testing found that although Matthew has exhibited gains in some areas; he still clearly meets the state's definition of autistic. Matthew is thus eligible for enrollment in the Autism Project at the School.

Organization

The school depicted in this thesis is located in a large metropolitan city on the West Coast. It is a public school and its student body is comprised of autistic and non-autistic students. The school has an Autism Preschool program as well as an Autism Project program and offers an educational curriculum to fit the needs of autistic children.

The classrooms for the autistic children were exceptionally well-organized and offered individual workstations for each child. Each student had his or her own desk and cubbyhole to place personal items such as shoes and backpacks. The teacher has one or two aides to help assist her whenever they are needed. The autistic and non-autistic children eat together in the cafeteria at lunchtime and play together on the playground at recess. Although there are separate classrooms for autistic and non-autistic children, the two groups of children socially interact outside of the classrooms.

Data-Gathering Strategies

The autistic child's parent and teachers wrote in a diary to record his day-to-day behaviors. The diary contains entries from the 1997-1998, 1998-1999, and 1999-2000 academic school years. The participants sent it back and forth each school day and wrote comments in it that pertained to Matthew's learning methods, educational goals, etc. Howard, Nina, and Waverly engaged in dialogue, asked questions, and made requests

through the diary. It was an ongoing communicative tool that they utilized. It shows how they negotiated what constituted Matthew's progression or regression of his communication and social skills.

The Diary

The diary method was essential to this project because the autistic child's progression and/or regression of his communication and social skills needed to be tracked over time to observe how the parent and teachers constructed his improvement and/or deterioration in these areas. Also, direct observation was not realistic because much of the parent-teacher communication occurred through the diary. In addition, I could not practically observe the possible face-to-face contacts between the parent and teachers as those contacts were not regular or planned. The diary allowed me to observe how the parent and teachers jointly constructed the child's progression/regression in social and communication skills. Then, I asked questions regarding these diary entries through interviews with the participants. Lindlof (1995) discusses the reasons for data collection from a diary:

Some activities occur only intermittently over long stretches of time, or so spontaneously that direct observation would be inefficient. Still other activities are not easily observable because of the secretive or solitary manner in which they are usually carried out. One procedure designed to document such activities is the diary, or "diary-interview" method (Zimmerman & Wieder, 1977). A diary is a chronological log of events and/or perceptions recorded by a participant (p. 120). The working relationship between the participants, the parent and teachers, was

partly observed through a diary. Only one diary was used between the parent and the teachers to record Matthew's day-to-day behaviors. Therefore, it is a continuous document with recordings made during subsequent academic school years. Howard and Waverly wrote in the diary during the 1997-1998 academic school year. Howard recorded 3 entries, Waverly recorded 9 entries, and Matthew's step-grandmother (on Howard's behalf) recorded 2 entries. Howard and Nina wrote in the diary during the 1998-1999 academic school year. Howard recorded 10 entries, Nina recorded 31 entries, and Matthew's step-grandmother (on Howard's behalf) recorded 2 entries. Howard and Waverly wrote in the diary during the 1999-2000 academic school year. Howard recorded 3 entries and Waverly recorded 6 entries. Parent and teachers sent the diary back and forth each school day and wrote comments in it that pertained to Matthew's food, dress, learning methods, and other behaviors. This data collection strategy revealed how Howard, Nina, and Waverly constructed the diary together and engaged in dialogue through it. The diary presented how they talked about progression and regression. It also demonstrates how they negotiated what constituted Matthew's progress or regression in communication and social skills. They had written in the diary for three years. I studied the diary and chose instances or episodes about which to question the participants in the interviews. I read the diary in its entirety, separated topically related areas, highlighted areas where the participants documented communication and social skills, and then developed my interview guide (Appendix A).

Interviews

Lindlof (1995) explains the importance and the value of the interview method:

In qualitative research, one interviews people to understand their perspectives on a scene, to retrieve experiences from the past, to gain expert insight or information, to obtain descriptions of events or scenes that are normally unavailable for observation, to foster trust, to understand a sensitive or intimate relationship, or to analyze certain kinds of discourse (p. 5).

I interviewed the parent and the teachers in order to achieve the goals outlined by Lindlof (1995) above. I had read the diary from the previous two years' time (before the interviews were conducted), so I needed the participants' perspectives on their interactions with one another, and their recollections about their experiences from the past. I also needed to understand the parent's experiences with the autistic child at home, in the personal context, as well as to understand the teachers' experiences with the child at school, in the public context. So, in doing this, I gained their expert insight and information while at the same time getting an insider's view (obtaining descriptions of events or scenes) into these two contexts since they are unavailable for my direct observation.

These interviews allowed me to further foster trust between myself and the parent and two teachers since they got to know my background and reasons for conducting the thesis project, and I got to know their feelings and motivations as parent and teachers. With the interview, I walked away with an enriched understanding of the parent-teacher relationship, and learned things I did not know before, and that I could not have learned just by reading the diary alone. I also was able to analyze certain types of discourse because I learned that the parent and the teachers use their own jargon or terms when they

discuss Matthew's educational goals.

The interview is crucial for the method to work because through participants' answers, it is possible to delve more deeply into how they socially construct progress and regression. They were asked the same questions in each of their interviews (See Appendix A). Their answers attest to how they negotiate what constitutes progression and regression. The interview questions focused on how the parent and teachers identify Matthew's progress and regression, what each of those terms "means" to them, disagreements about those meanings, and how they think those meanings have changed over time. Participants were interviewed based on what they documented in the diary. The similar trends and themes identified in the diary were the basis for the interview questions. Zimmerman and Wieder (1977) argue, "The diary interview converts the diary—a source of data in its own right—into a question-generating and, hence, data-generating device" (p. 489). I held the three interviews separately and audiotaped them, later transcribing the tapes for analysis.

I called Howard, Matthew's father, Nina, Matthew's former teacher, and Waverly, Matthew's current teacher, and arranged to interview them. Nina and Waverly's interviews were held on February 10, 2000, and Howard's was held on February 11, 2000. I went to the school and interviewed each teacher in her respective classroom. I interviewed Howard at my home.

On the day of Nina's scheduled interview, I went to her classroom and introduced myself, set up the tape recorder, and sat down to interview her. I tape recorded the interview in its entirety and took notes throughout it. The interview lasted approximately

one hour and fifteen minutes. As I sat down for the interview, I was immediately impressed with the structure and order in her classroom. Each child had his or her own work area, complete with desk and cubbyholes for their supplies. It was a warm, bright, and colorful room. There was a play area at the back of the classroom, which doubled as a story time circle. The children gather in a circle when Nina reads them a story. I also noticed that only a few children were curious about my presence. Most ignored me. This is typical because as Nina stated, "Autistic children need balance and order. They want to be comfortable and are resistant to change in their environment." One little boy did approach me and sat on my lap. He looked at me, pointed to his shoe, and said, "Tie shoe," so I did. I was quite taken with him and amused because he was not shy at all. He was an exception because many autistic children prefer to be on their own more or less. However, Nina also pointed out of course that each child is different and has his or her own uniqueness.

I interviewed Waverly in her classroom, introduced myself, set up the tape recorder, and taped the entire interview, which was approximately one hour in length. When I entered Waverly's classroom to conduct the interview, I was struck by how loud it was in there. I had come in as the school day was coming to an end, and the students were bouncing around the room. Waverly had two aides with her to help keep the children under control. The children are physically strong and active, and it would be overwhelming for just one adult to keep them in some sort of order. The aides round them up and get them where they need to be, whether it's time for a story, or to work at their own work stations, or if it's time to head to the cafeteria to eat or outside to play in

the yard at recess. School let out and the children left for home, and we sat down after getting the tape recorder ready to record the interview. I had to draw the responses and answers out of Waverly, whereas they were more forthcoming from Nina.

On the day of Howard's interview, he met me at my home. The interview environment with Howard was completely different from the previous interviews because it was outside of a classroom, without the competing noise of students. It was quiet and we were able to take our time to complete the interview and to learn a lot from each other about our knowledge of autism. As with the teachers' interviews, I audiotaped my meeting with Howard, which lasted about one hour and thirty minutes. I had to elicit responses from Howard during the earlier stages of the interview, but found that as it went on, he spoke more and more freely.

I also recorded a few pages of unstructured notes in the interviews. These observations helped me to further understand the challenges parents and teachers of autistic children undergo. I was able to observe the personal, very real side of the parenting and teaching of autistic children. I wrote my notes as we talked and noted salient comments or interesting observations. I recorded the activities going on in each interview context, nonverbal communication and behaviors of the parent, of the teachers, and of the autistic students. I also wrote my impressions of the learning environments in the classrooms. These interview notes were extremely important as they reinforced and strengthened the most distinctive and significant points in the interviews to learn from and remember.

Data Analysis Procedures

The diary and the transcription of the diary interviews were thematically analyzed. According to Peterson et al. (1994), thematic data analysis is conducted in the following steps:

1. Search for individual themes in each transcript;
2. Develop each of the themes identified in step one;
3. Determine relative significance of themes;
4. Search for oppositions among themes, and thematic hierarchies;
5. Compare thematic hierarchies and oppositions across transcripts (p. 206).

I found these steps to be very useful when comparing three separate viewpoints in the diary and in the diary interview transcripts. Peterson et al.'s (1994) system allows the researcher to identify and examine themes, to weigh their importance, to search for oppositions among them, and to see which themes are more important or relevant to the research project and which will answer the research question posed within it. I was also able to compare thematic hierarchies and oppositions across transcripts. That is, I could compare themes found in the diary between Howard and Nina and between Howard and Waverly because I was able to look for similar trends and themes between diaries.

In order to achieve these steps with the interview transcripts, I transcribed the tapes resulting in 64 double-spaced pages. I then organized the transcribed interview responses on a diary interview graph (See Appendix B). The diary interview graph made it easier to visually compare and contrast the participants' answers to the questions and to

more easily and clearly follow Peterson et al.'s (1994) five steps. The diary interview graph contains the three interview transcripts. These transcripts were analyzed just as the diary itself was analyzed. Topically-related questions and answers in both the diary and diary interview graph were clustered. By using Peterson et al.'s (1994) thematic data analysis system, I was able to take specific diary entries and interview answers given by the participants and make broader observations regarding the joint negotiation of progression and regression by the parent and the teachers of the autistic child's communication and social skills.

The diaries were analyzed well in advance of the diary interviews. I carefully examined each of the 66 diary entries. Following Peterson et al. (1994), I first clustered topically-related diary entries. These clusters were, diet, toilet training, receptive communication, expressive communication (language), social skills, negotiation and support between parent/teachers, and Matthew's instances of progression and regression (noted in the diary by the parent or teachers). In the second step, important aspects of the diary entries were identified—aspects that would help to answer the thesis question. For example, the areas of communicative and social skills were specifically highlighted. My attention and interest were drawn when I saw one of the participants bring up either of these domains. For example, Waverly wrote in her diary entry of April 29, 1998, "He only makes a few sounds at school, but one day he said clearly, 'More popcorn.' D. [Matthew's paternal step-grandmother] said that he says about 10 words at home." I immediately highlighted this comment because it caught my attention as it was a lucid example of communicative competence and/or an instance of progression of Matthew's

communication skills. Another example illustrating how I identified the important aspects of the diary entries that would answer the thesis question is the diary entry of April 6, 1998, in which Nina wrote to Howard, "Matthew seemed to be feeling fine and was cooperative." Her documentation here pointed to his social skills and signified her opinion of his progression in his social abilities.

In the third step, diary entries that were most relevant to the thesis project were identified. These entries focused on receptive and expressive communication, social skills, negotiation and support between parent/teachers, and Matthew's instances of progression and regression. In the fourth step, relationships between diary entries were identified. For example, "asking what OT [Occupation Therapist] stands for" and "requesting that the parent call the teacher if there are other questions" were identified in entries exchanged between Howard and Waverly; these constituted negotiation and support between participants. This step involved showing the relationship between these two diary entries because the parent asked the teacher what OT stands for and this resulted in the teacher answering the question and then telling the parent to call her if he needed any additional information.

In the fifth step of the Peterson et al. (1994) system of thematic data analysis, thematic similarities between the diaries were identified. It is important to note that the diary is one continuous diary; however, it is sectioned into different "diaries" when it is used between the parent and the two separate teachers during each school year. Examples of the thematic similarities between the diaries are teachers' notations made about Matthew's cooperation ability. On January 26, 1999, Nina wrote, "Matthew's really

doing fine in class,” and this corresponds with Waverly’s April 20, 1998, observation that, “He had a pretty good day today.” Having a good day and doing fine in class, according to Nina and Waverly, mean that the child is settling in to the routine of the class and is exhibiting a normal comfort level. This is a large step for autistic children because it is harder for them to adjust to different environments. The classroom context, for non-autistic children, can be intimidating and difficult to adapt to, but for children with autism, they can be terrified if their workstations, supplies, or classmates change in the slightest way. A familiar autistic trait, as coined by Leo Kanner (1943), is their need for this “maintenance of sameness.”

The interview transcripts were analyzed in the same way that the diary was analyzed; each followed the same steps. First, topically related individual answers were clustered. The questions and answers appear in three columns for each of the three respective participants. This is the diary interview graph (Appendix B). Several statements about certain topics such as Matthew’s screaming were made during the interviews; the topic of screaming can be interpreted in several ways and will be addressed in detail in the findings and interpretations section. Second, important topically-related answers were identified. Screaming was an important topic and was discussed at length by all three participants. An answer such as, “For him, he’s getting what he wants,” was identified as one important topically-related answer within the cluster of statements pertaining to Matthew’s screaming. Third, clusters necessary to the joint negotiation of the participants’ social construction of Matthew’s communication and social skills were identified. Fourth, relationships between statements (answers) were

examined. For example, a relationship between “progression and regression of Matthew’s communication skills” and “progression and regression of Matthew’s social skills” was identified in that Nina explained that Matthew’s language deficit affects his social behavior. She said, “Maybe he doesn’t have the language, so we have to work with that. Whoever is at home, they need to be firm. Tell him no means no. He has nonverbal, communicative behavior. Because he is communicating with his behavior.” These two categories indeed have a relationship between them. Matthew’s inability or refusal to communicate verbally was replaced with his ability to nonverbally communicate to others through his behavior. The fifth step involved comparing thematic hierarchies and oppositions across transcripts.

One example of the thematic similarities between transcripts can be observed in Howard’s answer to the question, “How do the teachers let you know that you are working together as a team?” This can also be found in Nina and Waverly’s answers to the question, “How does the parent let you know you are working together as a team?” The thematic similarity here is that there seemed to be something lacking in the communication between the parent and the teachers. Howard’s answer, “They are pretty available, yeah, I would think so,” points to his brevity in feedback. He seemed to provide very concise information at times, and this is reflected in the teachers’ answers. Nina said:

I don’t know because Howard, we really didn’t do much except the IEP report.

We talked about Matthew, but we never really had time to sit... I just said this

works, try this at home. If anything works at home, please let me know. He will

nod and then he walks and I said so much and he didn't say much. But then, I just had the feeling that well, if he didn't say much, either he agreed with me or he's gonna try. So we really haven't had that many, I think I met him once or twice. Nina provided an extensive answer; Howard's was quite short. The thematic hierarchy here is that Nina's need to sit down more often with Howard for meetings regarding Matthew's educational development coincides with her need for him to provide more answers and responses. Comparing their answers highlights their relationship: Nina gives more information than Howard does. She suggests she needs help from Howard. One way he can help her is to confirm what she's said and/or give his thoughts.

In contrast, Waverly said:

I think it's just the ongoing communication with the diary and talking on the phone, I would have to say. Also, I try to send a general letter home once a month. I don't always get it out. Just tell them what we're doing this month, how often we're going to McDonald's or everywhere. That's just a general one that goes home to every parent. So, it gives Howard an idea just what's going on in the classroom. The letter is once a month, phone calls work out to about once a week. I feel support from Howard.

This demonstrates that specific details regarding *how* she feels supported by Howard are absent. Waverly did not seem to interpret Howard's lack of communication as lack of support, however. Although she didn't verbally communicate with him frequently, she knew he was there to help if and when he was needed, and this constituted support for her.

Summary

To summarize, I employed two primary methods in this study: the diary and the diary-interviews. These methods allowed me to investigate and answer my research question in an innovative, challenging, and insightful way. The diary allowed me to observe how the parent and teachers wrote back and forth to each other, sharing information about the autistic child's educational progress. These "conversations" revealed much to me in that I got to know how the parent and teachers socially constructed Matthew's progression and regression.

The interviews allowed me to learn about and understand autism even more because I witnessed it in action, versus simply reading about it in the diary. I learned things I didn't know before, and by talking to the participants, I gained more knowledge and would have missed this opportunity without the interviews. To further illustrate this, I will give an example. Nina explained that an autistic child's neurological wiring harms communication. Nina asks others to understand the frustration the child feels by imagining their desire to talk but that they can't because having autism is like having a tied up mouth. It's not that they do not want to communicate verbally, but that they are prevented from communicating. Nina told me that autistic children experience communication and social deficits, and that their place in society is not an easy place to be in because there is "No society without communication." She did go on to say that communication doesn't have to be verbal, that it of course can be nonverbal. Pearls of wisdom such as these enriched the interview experience and allowed me to ask pertinent questions that furthered my research.

The interviews helped to answer the research question because I specifically asked the three participants questions that would reveal the answers I needed to know. In the diary, I had a great wealth of information to start with. The diary contained areas of diet, toilet training, and an array of other topics, but I needed to know specifically about communication and social abilities. So, I searched for and found these areas to work with in the diary entries. Then, I wrote questions about these instances for the interviews. I wanted to draw answers from the participants based on the knowledge I had gained from their diary chronicles. The questions that proved to be the most beneficial in answering the research question were asking the participants how they each helped each other understand Matthew's development, how they defined progression, and how they defined regression. Other questions that also greatly helped were asking the participants how they determine progression and regression of Matthew's communication and social skills and to give examples for each of these areas. Since screaming was a common theme in the diary, an essential question was, "When Matthew is screaming, how does that fit in with his progression or regression?" and to give an example of this. I also found it helpful to ask them what they each needed from the other participants to help them improve Matthew's communication and social skills, as well as to ask if there was anything else they thought I should know. These two broad, far-reaching and wide-ranging questions allowed the participants to expand on their answers, and to provide information they thought was helpful and pertinent. The answers to these questions unveil how parents and teachers socially construct progression and regression of communication and social skills in children with autism.

My interview notes took me back to the days I conducted these interviews. I was able to remember more clearly the observations I made. The notes enabled me to focus on the *relationship* between the parent and his child and the relationship between each teacher and the child. Because the interviews were tape recorded, I could record other aspects of the interaction such as nonverbal communication, behaviors, my impressions, and other observations I found particularly noteworthy. My notes allowed me to enjoy the interviews more because I could establish a rapport between my participants and myself while the real work of recording the answers to my interview questions was being done by the tape recorder, ready for me to transcribe later.

CHAPTER 4

Findings and Interpretations

The research question in this thesis—How do parents and teachers socially construct progression and regression of communication and social skills in children with autism?—is answered by a thematic analysis of the diary exchanged between the parent and teachers and by a thematic analysis of the transcribed interviews found on the diary interview graph (Appendix B). The objective was to find out how the parents and teachers of autistic children jointly negotiate definitions of progression and regression of the autistic child's language and social skills as they develop a working relationship, and this objective was met. Through this diary/interview method, I examined how progression and regression are contested and negotiated in parent-teacher interactions.

The themes I identified in the diary and in the interviews are the foundations for this chapter. First, I discuss the episodes documented in the diary and the themes identified within them to answer the research question. Second, I present the information from the interviews (on the diary interview graph) and identify themes to answer the research question. Third, I use these themes from the diary and from the interviews to show how a parent and teachers socially construct progression and regression of communication and social skills in a child with autism. Thus, this chapter answers the research question. It also includes interpretations of how parents and teachers process progression similarly and differently and how both parents and teachers experience an emotional impact. The chapter concludes with a summary of the findings and interpretations.

Themes Identified in the Diary Between Nina and Howard

This section examines the social construction of progression and regression of Matthew's communication and social skills through the parent-teacher negotiations and interactions found in the diary between Nina and Howard during the 1998-1999 academic school year. The chronological history of the diary is as follows: Matthew was a student in Waverly's class during the 1997-1998 school year, then he was a student in Nina's class during the 1998-1999 school year, and he was again a student in Waverly's class during the 1999-2000 school year. Each teacher, along with Matthew's father, used the diary during the school year in which Matthew was her student.

Nina regularly recorded diary entries that addressed Matthew's communication (language) and social skills. The diary entries that mention communication skills will be discussed first and the diary entries that note social skills will be then be discussed. Three themes were identified, "Screaming," "Providing Support for One Another," and "Alternative Forms of Communication."

Screaming

The first entry Nina made about Matthew's communication skills appeared on September 1, 1998, in Nina's welcome to school message and in her introduction of herself to Matthew and his family. She stated, "We will be working on finding ways to help him communicate or verbalize, instead of screaming or yelling. I'll keep you informed about our progress." The issue of Matthew's screaming or yelling was immediately apparent, and this first entry was a harbinger of her recurrent concern about this area. Howard responded to Nina's first entry in his September 2, 1998 diary entry,

“Thank you for the message on the preceding page...I have noticed that he will point to things he wants with more frequency than yelling. Especially if you ask him, ‘Matthew, show me what you want.’ Please let me know if you need any other information.” Here, Nina and Howard are socially constructing what Matthew’s screaming means and how to deal with it. Harré’s (1983) claim is that the primary human reality is conversation. Nina and Howard’s conversations, carried out in the diary, contain negotiations of definitions and meanings. As Pearce (1995) argues, we negotiate definitions and meanings with others in our conversations, or in this case, the written diary. Nina presents her definition of screaming as a problem and Howard affirms that definition. The actions that Nina and Howard take toward Matthew are grounded in defining screaming as a problem. That is, they act on their reality as they have constructed it. Teacher and parent work together as a team to negotiate and define the meaning of Matthew’s screaming.

Shotter (1993) observes that individuals take on responsibilities when they socially construct definitions and meanings. Applied to the present study, when Nina and Howard socially constructed the definition and meaning of Matthew’s screaming, they each assumed roles or positions within their parent-teacher relationship that revealed the power they each held. Here, Shotter suggests that part of constructing meaning is constructing roles as well, or who is responsible for what in a relationship. Nina defined the problem, and Howard accepted Nina’s definition. This was the beginning of Nina’s role as the expert on autism and the beginning of Howard’s role as the expert on Matthew. As Matthew’s parent, Howard knew of Matthew’s at-home behaviors and kept Nina apprised of them.

Nina's diary entry of September 1, 1998 includes her definition of screaming. She stressed that she and Howard would work on ways to help Matthew verbalize or communicate, *instead of* screaming or yelling. This means that she wanted to replace his screaming with more acceptable forms of communication. She said she would keep Howard informed of their progress, which meant she would be going ahead with the plan to reduce his screaming. These comments point to the power she held in this relationship, that as Matthew's teacher, she would be working with Matthew on his communication skills. The importance of Nina's diary entry also shows that she provided the definition of screaming and that it worked against communication. Howard accepted her definition and affirmed it by thanking her for her message and by noting Matthew's pointing and yelling. In this exchange, they began to define their roles in that Howard supported Nina's definition of screaming; this points to a beginning hint of how power was distributed between them.

Providing Support for One Another

The first theme, Matthew's screaming, is related to the second theme, providing support. That is, addressing Matthew's behavioral problems were framed within an attitude of working together as a team towards solving the problems. Nina presented a problem, that Matthew's screaming needed to be substituted with another form of communication, and Howard provided an observation of Matthew's at-home behavior—Matthew pointing to what he wanted—so Howard told Nina to look for a repetition of that at school. He also provided a solution, advising her to use the phrase, "Matthew, show me what you want," because this had worked at home. These diary entries show

that they are working together in improving Matthew's communication by suggesting other options beyond screaming.

For Nina, Matthew showed regression in his communication skills (screaming), so she advocated alternative forms of communication (verbalizing) other than screaming or yelling. For Howard, Matthew showed progression because he used pointing instead of screaming to nonverbally express what he wanted. Howard then emphasized this by writing that Matthew would probably be more likely to point if directed with the phrase, "Matthew, show me what you want." The themes, working together to solve the screaming issue and providing help for one another, underscore how the parent and the teacher socially constructed Matthew's progression and/or regression. Interestingly, the screaming is seen as progression *and* regression and the meaning of the screaming is negotiated in these parent-teacher interactions. Through the diary, the parent and teacher negotiate what his screaming means and how to work with it.

The parent-teacher negotiation can further be seen in Nina's response to Howard's September 2, 1998 diary entry. In her September 3, 1998 diary entry, she stated, "Yes, I've noticed the pointing and try to give him choices of 2 or 3 things and will give him what he points to, to help reinforce his effort." Nina and Howard are making sense out of the pointing and are working with it together to assist Matthew's communication efforts. Nina goes on to say, in this same diary entry, "I'll seek your help if I need any other information. You, too, can ask me about classroom information that you need. You have a nice day. Matthew's day went well. He's getting adjusted to his new class and friends." Here, Nina has commented on the support or teamwork evolving between them,

as well as on Matthew's social skills and her observation of his emerging sense of comfort in his new class.

On October 6, 1998, Nina mentioned that, "Matthew has cut down a lot on his screaming." She then drew a smile next to this comment. For her, she saw this as progression. She felt that reducing the amount of screaming was progress and an improvement. However, Nina's entry functioned to comment on her relationship with Howard as well. Nina routinely used the phrases, "Nice day" or "Have a nice day" and also drew smiles in her diary entries. She went beyond simply recording her observations of Matthew's behaviors, to provide support to Howard. Later in our interview, Howard told me that the cheerful phrases and drawings made him smile. For him, this further supported their sense of being a team. In Howard's October 7, 1998 diary entry, he said, "Thank you for the very frequent updates/notes on Matthew...Please let me know if I can provide any other information or anything else for Matthew or the class' needs...Thank you for everything." This diary entry made evident that their collaboration was helpful and highly meaningful to him. Again, the theme here is that the teamwork between the parent and the teacher is instrumental in how they socially construct progression and regression. The way they set up their relationship allowed for this to happen. As Duck (1994) argues, we create our relationships through language and nonverbal cues, using messages to define or construct the boundaries that constitute the relationship. For Nina and Howard, the definition seems to be "we're a team in caring for Matthew." This definition then influences their behaviors with Matthew, and their interactions with each other.

We socially construct relationships and in doing so, we construct meaning. Meaning is negotiated between individuals and emerges in dialogue. From the social constructionist perspective, meaning is in use. Gergen and Gergen (1982) declare that since meaning arises out of interpersonal negotiation, multiple behaviors may be interpreted as one kind of act. Thus, Matthew's screaming can be interpreted as one kind of act representing several kinds of social and communicative behaviors.

We socially construct relationships as we strive to understand each other. "From the constructionist position the process of understanding is not automatically driven by the forces of nature, but is the result of the active, cooperative enterprise of persons in relationship" (Gergen, 1985, p. 267). Meaning is constructed between individuals and is reflected in their talk. For meaning to take place, the relationship between communicators must be established. One cannot take place without the other. The way in which the participants talk to and negotiate with one another contributes to their relationship with one another. It also shapes and forms the way they behave with each other. The speech acts they engage in create a context within which Nina and Howard socially construct Matthew's social and communicative abilities. Progression and regression of his abilities are created and re-created in interpersonal discourse. During this process, they socially construct their relationship as well. Participants act as they do in relationships because of the relationship itself.

Reflexivity exists between the relationship and the way we act or talk in it; the conversation affects the relationship and the relationship affects the conversation. Pearce (1994a) observes, "The meaning of a particular relationship is determined by just those

conversations that occur in it" (p. 208). In the present study, the parent and teacher know their common mission is to assist the child in achieving his goals, so they strategize between themselves on how best to do this. They behave towards each other in ways that reflect their common mission. This relationship influences their conversations, which in turn influence their relationship.

Nina again brought Matthew's screaming up in her November 25, 1998 diary entry, "Matthew had a very good day. Is he screaming a lot at home when he's upset? He's cut down a lot in class lately, but does make up for it when he gets upset." Here, Nina requested information from the parent about the screaming taking place at home and said that Matthew has reduced this in class (he stopped screaming intermittently) but screamed when upset. This can be seen as progression and regression, progression for the former and regression for the latter. There were no comments from Howard in response to this diary entry. This was not contested. Howard's silence will be addressed in the analysis of the diary transcripts, for in her interview, Nina discussed his silence and how she responded to it.

The most important aspect identified from these diary entries about communication skills is Matthew's screaming. This is a monumentally important issue for Nina because his screaming can be construed as either positive or negative, depending on the context and on Matthew's emotions during the screaming. He screams if he is happy, sad, frustrated, excited, mad, etc. He screams when he's experiencing a wide range of emotions, and the difficulty is figuring out if he's being constructive with this communicative behavior or not. Nina and Howard's "team effort" centered on

determining when to encourage or discourage his screaming, depending on what he is using it for at the time.

Alternative Forms of Communication

The third theme identified to answer the research question is negotiating alternative forms of communication (besides screaming) for Matthew to use. Matthew started to use more forms of communication other than screaming. He followed verbal instruction and gestures, he traded pictures (icons) out of his communication book to show what he wanted or needed,³ and he imitated sounds (by identifying letters, numbers, and animals). Nina and Matthew's paternal step-grandmother (who substituted for Howard when he was unavailable) defined the alternate forms of communication that Matthew used as progression.

Nina made a request in her February 18, 1999 diary entry asking Howard for help, "Please give me a list of what you see as Matthew's strengths (healthy, good eater, affectionate and so on) and areas of needing some improvements (potty training, communication, etc)." In this request for help, she mentioned where Matthew could use improvement, and one of these is communication. It is here where she demonstrated her belief that Matthew could work on this skill and she asked Howard to consider this.

The first time Nina talked about Matthew's social skills was in her first diary entry of the 1998-1999 school year, in her welcome salutation. She wrote:

Please call me if you have any questions, concerns, or need clarification. You know Matthew better than me...Matthew is a nice little guy. He has adjusted to the class and his classmates very well so quickly; he also responds very well to

praises and affection...I'll keep you informed about our progress. Any information, help, or input you can assist me with, concerning Matthew, will be greatly appreciated. Matthew appears to have a lot of potential. He also smiles beautifully when I tickle him gently. I even notice that he has dimples in his cheeks when he's laughing.

In this diary entry, Nina commented about Matthew's social skills and in them, she noticed his ability to adapt and adjust to his new classroom environment. Her comments note his progression in this area.

Nina let Howard know that they would help each other out. She said that he should contact her for help if he needed it and likewise, she would contact him if she needed help. The themes identified here are of the desire to work together as a team, to each become actively involved in Matthew's educational progress, and to get to know the child personally. Nina has shown in this diary entry her ability to give the child praise and affection as learning tools. It is immediately apparent that she noticed individualistic characteristics about the child, how he smiled when she tickled him and that he had dimples in his cheeks when laughing. This compassionate care is one of the many educational tools Nina used to reach out to and teach the autistic child.

Howard's response in his September 2, 1998 diary entry to Nina's request that they contact each other for help when needed is, "You can call me at...home or pager...if you need to contact me," and included the numbers. This response indicated his wish to be contacted, per Nina's request, if needed in the future. They mutually communicated the fact that they wanted to work together as a team and become actively involved in

Matthew's educational progress. The teamwork they created helped them socially construct progression and regression of Matthew's communication and social skills.

Another diary entry that embodies Matthew's social skills behavior is the November 4, 1998 entry. In it, Nina said:

Matthew had a good day. He's fine in the new classroom, as you already know, he does not like any change in his routine, so we had to make everything as close to his regular classroom as possible...He's adjusted very well to the new site, and loves the motor room on site—where you go and do a lot of gross/fine motor stuff with a lot of freedom (supervised of course), and choices.

These observations are important in several ways. First, Matthew exhibited a familiar autistic trait, that children with autism don't like change. Second, it reiterated that Nina felt Matthew had progressed in his social skills because he was fine in the new classroom and in the new site where the students work on their motor skills. Again, Howard did not comment on Nina's observations. When one reads the diary, it is noteworthy to see that Matthew's teachers do most of the writing. It is also plain to see that the diary is not written in every single school day, but intermittently. Also, the parent did not always respond to the teacher's comments, but the teacher always responded when the parent wrote in the diary. (I discuss Howard's silence in later sections of the thesis. For example, Nina commented on Howard's brief responses and silence in her interview.)

In her diary entry for November 20, 1998, Nina similarly wrote, "Matthew is being a bit more interactive with his classmates, but still will not share what he likes. You have a nice day and a great weekend. Matthew is also being more cooperative

during work sessions.” So, on the one hand, he was more interactive and engaged with his classmates, but on the other hand, he didn’t want to share. For Nina, he had shown progression socially because he’s more interactive with his classmates. This was a goal that they set and this instance demonstrates it was met. He was also more cooperative while working at his desk, further demonstrating progression. Howard’s December 1, 1998 response does not mention Matthew’s behavior at school, but he did say, “Thank you for the updates on Matthew.” So, Howard does not indicate whether he sees this as progression or regression of Matthew’s social skills, but this may have been silent agreement. In the diary entry of February 3, 1999, Nina recounted this episode:

Matthew had a good day. He has some 2-3 red marks on the right side of his face, under his right ear. He was struggling with a friend about the dinosaurs. He hit the friend, who in turn grabbed his face. He didn’t cry or anything. I checked and cleaned it—he helped me to clean it too.

In this example, Matthew had shown regression, according to Nina, because he was uncooperative with another student. Again, there is no response from the parent on this incident. Howard’s silence may be interpreted as a communicative practice and/or strategy. Carbaugh and Hastings (1995) discuss the use of silence, “(1) Silence is used and interpreted as a communicative act; (2) silence is typically directed at a focal participant; and (3) when used, silence is associated with relationships among focal participants that are uncertain, ambiguous, or unpredictable” (p. 178). These three conditions describe the parent-teacher relationship between Nina and Howard in that Howard may have used his silence to say what he thought or how he felt, and he directed

his silence at a focal participant (Nina). The relationship between parent and teacher certainly fits the description of uncertainty, ambiguity, and unpredictability. Carbaugh and Hastings (1995) go on to discuss a community on the basis of several problematic episodes, "that among males, silence was associated with asymmetrical role relationships, whereas speaking was associated with symmetrical role relationships" (p. 178). So, a balanced and harmonious relationship epitomizes a speaking relationship, conversely, a hierarchical relationship embodies a silent relationship. The way the relationship is viewed through the eyes of the participant(s) influences the type of communication involved, and can affect the speaking or silence of one of the participants.

Meaning can be socially constructed when one person is silent. Howard's lack of communication may yield greater power in negotiating Matthew's progression and regression to Nina because silence can suggest agreement or acquiescence. Howard's silence may serve other functions as well. His silence may reflect a reluctance to change the status quo; Matthew's progress may have been sufficient for him so there may have not been a need or desire to change or alter Matthew's behavior at that time. Howard's silence may also have been a signal of how he dealt with the situation at hand or it may have been typical of his communication style. Howard may have been using the communicative act of silence to represent his emotions about Matthew's progress. Carbaugh and Hastings (1995) theorize that silence, as a feature of communication, constructs contexts, communities, and relationships. Thus, Howard's silence can be construed as a communicative activity that functioned to comment on Matthew's progression/regression and his relationship with Matthew's teacher.

Themes Identified in the Diary Between Waverly and Howard

This section examines the social construction of progression and regression of Matthew's communication and social skills through the parent-teacher negotiations and interactions identified in the diary between Waverly and Howard during the 1999-2000 academic school year. Waverly did not utilize the diary as often as Nina did. She used it only occasionally throughout the year. Matthew's communication skills were not discussed during the 1999-2000 school year, but they were briefly discussed in the 1997-1998 school year, the first year that Matthew was Waverly's student. The recorded diary entries address Matthew's communication and social skills and these will be presented.

Waverly and Howard's social construction of Matthew's progression and regression of communication and social skills began in her few diary entries at the close of the 1997-1998 academic school year. These diary entries will be given at the beginning of this section. To reiterate, Matthew was a student in Waverly's class during the 1997-1998 school year, then he was a student in Nina's class during the 1998-1999 school year, and he was again a student in Waverly's class during the 1999-2000 school year. Three themes were identified in Waverly and Howard's entries, "Verbal Communication," "Providing Support for One Another," and "Social Skills." These themes are discussed in the following sections.

Verbal Communication

Progression in Matthew's verbal skills was evident during the 1997-1998 academic school year. Matthew made attempts at verbal communication during this time and he showed improvement in his language skills by learning to say numbers and letters

of the alphabet. According to Waverly's May 1, 1998, diary entry, Matthew was expanding his vocabulary. Whereas *he used to* utter a few sounds such as "noo" for "noodle," he started to say words such as "out" for "going outside." In the diary entry for April 29, 1998, Waverly mentioned that Matthew one day clearly said, "More popcorn." The teacher had recalled this incident for Matthew's father so that he would know that Matthew had made this verbal request instead of just using the few sounds that he normally used at school up until then. The exact date of the "More popcorn" request was not given, but the teacher mentioned it and asked for a list of words Matthew commonly uses at home.

Matthew's paternal step-grandmother made a few diary entries for Howard, the parent, and responded in her April 29, 1998 diary entry to this by saying:

These are the words Matthew says at home. You might not recognize some of them at school because when he's learning a word he leaves out the sound of the 1st letter or last letter in the word (usually the last letter).

1. Mama
2. Dada or Daddy (occasionally)
3. Debbie
4. Howie (his favorite dog)
5. bad
6. mad (new word)
7. out
8. more (new word)

9. no

10. dog or doggie

Makes the sounds Yaaah!!! when excited. Animal sounds also.

Matthew's paternal step-grandmother also mentioned his burgeoning verbal skills in her May 19, 1998 entry, "After Matthew and I played Reader Rabbit Toddler, he grabbed the Aristocats and started making 'meow' sounds." Waverly's response to this in her diary entry of May 20, 1998, was a description of a communication episode (event), "Matthew makes several animal sounds here. Today he was playing with his toy snake and said 'ssss.'" Matthew's paternal step-grandmother and Waverly concurred that Matthew had made progression here because he was recognizing that animals make distinctive sounds and imitating these sounds. The identified revelation here is that both at school and at home, Matthew had begun to transition from making sounds to making words. This obviously points to progression of his verbal communication skills. This was the nascent stage. His emerging verbal skills would be evident later during the 1998-1999 school year, while a student in Nina's class.

Providing Support for One Another

Howard wrote a long greeting to Waverly on August 30, 1999, "Welcome back to being Matthew's teacher again. He has gotten very big over the summer. He may take a few days getting used to school again." This diary entry manifested Howard's desire to continue the helpful parent-teacher relationship, which again identifies with and builds on the second theme in the diaries, that the parent and teacher provided support for one another and demonstrated a willingness to come together as a team. He also warned

Matthew might have trouble adjusting to school for the first few days. This could be construed as regression of his social skills or it may be that Howard mentioned what most parents and teachers know: a child's reluctance to give up his or her summer vacation for the routines of school. Howard next discussed potty training and diet, and then went on to say, "Please let me know if you need any additional information." This is another example of Howard's willingness to continue the teamwork the parent and teachers had with the mutual goal of assisting Matthew and providing for his needs.

Social Skills

Waverly replied to Howard in her September 7, 1999 diary entry, "Matthew's been doing well and seems to have matured some." Here, Waverly documented her assessment of Matthew's progression in the social skills area. For her, she viewed his maturity as progression in his social ability. Since she had known Matthew in prior years (she was his teacher for the 1997-1998 school year), she knew by experience how he had behaved and performed in the past. She was familiar with his communicative and social history and she gave her opinion in the September 7 diary entry that he had improved.

In this same diary entry, Waverly commented on Matthew's toilet training and diet and then said:

Our occupational therapist...wants to do an OT assessment on Matthew to see if he can benefit from OT, which would be given at school. ...[The OT] will be here at school tomorrow, so if you have any questions, you can call one of us. If you consent to having the assessment done, please sign the enclosed form...thank you.

Howard's answer:

I have signed and returned the enclosed form. What does OT stand for? ... Please call me if you need any additional information. My phone #'s on the inside flap of the journal. Can you please write the classroom or school phone # if I need to ever contact you. Thank you.

Again, the theme documented in the diary between Waverly and Howard is one of a desire to become a team, to help each other out.

Waverly responded, "Thanks for returning the doctor's permission and the consent to the assessment plan." This also documents her part of the team they created.

In her September 29, 1999 diary entry, she said:

Matthew's IEP [Individualized Education Program] is all set for Wednesday, Oct. 20, at 2:30 p.m. You'll be getting a form to sign verifying this. OT stands for Occupational Therapy and deals with both fine and gross motor movement. It's been very helpful with my students because it helps with things such as sensory processing, postural stability, muscle tone, etc., which help the students concentrate and not feel so overwhelmed.

In this entry, she told Howard that she saw OT as a way to help Matthew. She answered Howard's question about occupational therapy and explained what it is and why it is so beneficial to autistic children. Again, the theme of teamwork arising out of the parent-teacher interaction and the supportive relationship between Waverly and Howard as they both worked to help Matthew, is evident. Again we see that the teacher defined the problem and strategies for addressing it. This is similar to what I observed in the diary

entries between Nina and Howard. They work together as a team; however, the teacher is in charge based on the diary entries.

In her October 27, 1999 diary entry, Waverly told Howard, “Matthew did well on picture day, but looked a little worried when it was his turn to have his picture taken.” Waverly identified Matthew’s social skills as progressing in her account of his behavior on picture day. It is also a description of her interpretation of Matthew’s feelings, and this means that she wants to let Howard know how Matthew is doing at school behaviorally, so that Howard is apprised of his son’s progress. This points to her commitment to work as a team.

Summary of Diary Themes

Comparing and contrasting the identified themes in the diary between Nina and Howard and in the diary between Waverly and Howard demonstrates the differences and similarities between them. The contrast is that Nina and Howard focused more on communication, whereas Waverly and Howard focused more on social skills. Nina and Howard primarily discussed Matthew’s screaming and each suggested alternative forms of communication (besides screaming) for him to use. Waverly and Howard primarily discussed Matthew’s social skills and behaviors. The commonality is that providing support for one another (teamwork) was evidenced within each parent-teacher relationship.

Thematic analysis was conducted on the diaries. Individual themes were identified and developed. The four significant themes identified in the thematic data analysis of the diaries are actions in which the participants involved themselves:

1. They worked together to solve the screaming issue (Nina and Howard).
2. They provided support (teamwork) for one another (Nina and Howard; Waverly and Howard).
3. They negotiated alternative forms of communication (besides screaming) for Matthew to use (Nina and Howard).
4. They worked together to improve Matthew's social skills (Waverly and Howard).

These identified diary themes indicate the participants' social construction of progression and regression. For Nina and Howard, progression and regression centered on screaming and alternative forms of communication. For Waverly and Howard, progression and regression were defined in terms of broader social skills. Teamwork was seen as an important, integral part of each relationship, Nina and Howard's and Waverly and Howard's. However, although each parent-teacher pairing functioned as a team, the teachers guided the diary topics and frequency of entries. They were much more proactive whereas the parent was more reactive. Thus, based on the diary entries, the teachers exercised greater power in defining progression and regression.

The ability to change and/or affect the course of the future can be seen in the diary recordings. The documented episodes are conversations between the participants. Conversations initiate social interaction. Therefore, the diary became a powerful tool to get the conversation started. When one of the participants recorded an entry in the diary, he or she created a speech act to be continued by another conversant. Speech acts, or conversations, contribute to a pattern that will be played out into a future that has no end.

In other words, the speech acts that happen today will grow and evolve tomorrow and ultimately go on and on indefinitely. The person who initiates the speech act and who works to continue the conversation becomes a powerful person. Pearce (1994a) maintains that conversations "...do not stand alone; they are a part of 'clusters' of conversations...they are a moment in a historical process in which what comes before and after affect what happens in the moving moment of 'now'" (p. 33).

Pearce's atomic model of conversation provides a visual guide to understanding this process. He explains the model in this way:

Each action we perform is simultaneously a part of many conversations. In this model, four clusters of conversations are depicted: those comprising the conversant's sense of self, those comprising his or her relationships to others, those comprising the enactment of particular episodes, and those comprising his or her culture (Pearce, 1994a, p. 34).

Anything that a person says is part of several different conversations in the person's life, and these conversations are those held in these domains: self, episode, culture, and relationships. When people hold conversations, such as those between the teachers and parent in this thesis, then the conversations between them affect the conversations in each respective participant's life. So, each conversation in the diary affects conversations *to be*. The power in that is inherent in that what is said affects the future of what will be said and the relationship between conversants is impacted as well.

Themes Identified in the Interviews

Similar trends and themes of the results or findings are presented in this section.

The interview questions I asked of the participants, Howard, Nina, and Waverly, are given in the interview guide (Appendix A). Their answers to these interview questions are given in the diary interview graph (Appendix B). These answers demonstrate how the themes or trends in the interviews of Howard, Nina, and Waverly indicate the social construction of “progression” or “regression” of the autistic child’s social and communication skills.

The interviews enabled me to hear participants’ stories about Matthew at home and at school and to hear how the participants defined progression and regression. The three interviews were transcribed and, as mentioned earlier, formatted on a diary interview graph so that it is easier to identify the intersections among responses. As with the diary, I thematically analyzed the diary interview transcriptions. I examined the transcripts for oppositions among themes and for thematic hierarchies. The diary/interview method proved to be the complete companion to answering the research question.

The interviews gave me insight into what life is like as Matthew’s parent and as his teacher. I was grateful to hear about the participant’s in-depth stories about Matthew and without the interviews, this would not have been possible. There were episodes recorded in the diary, but I heard rich stories in the interviews that gave me an even deeper understanding of what interacting with a child with autism is like and how rewarding it can be.

The participants jointly negotiated the definitions of progress and regression when they wrote, in their own words, specific instances of these in the diary. I learned from

their evaluative statements and the language that they used. The interview responses allowed me to move from the specific instances or episodes towards general observations. The participants were also asked in their interviews how they define progression and regression, and these definitions are given here.

When Howard was asked, "How do you define progression?" he answered that progression, for him, is when Matthew wants something, he will go and get it instead of screaming for it as he had done before. It used to be a guessing game. Howard had no idea and he had to try to figure out what Matthew wanted when he would just scream. Before, Matthew would just scream; now Matthew will help himself. Howard sees progression as an increase in nonverbal communication, in Matthew's using actions instead of screaming. Howard used specific examples to further explain this, such as:

But now he, he can communicate where when he doesn't like something like, he'll give you the remote to turn the t.v. on, so you know he wants to watch t.v. But he'll turn it on himself but he can't get it to the right channel and he'll show his displeasure. You know, or you're flicking the channels and he'll grab the remote from you. That means that's the one (the channel) he wants. Stop there, he doesn't want you to turn it anymore. So, he'll take the remote and he'll put it down on the dresser and he'll go "Bye!", you're done, I'm done with you, you can go now. That's what I wanted, he's all bye, leave me alone 'cause I don't want you changing the channel anymore. So, his nonverbal communication has gone up and gestures. His screaming has decreased.

Howard then went on to say that of course Matthew still does scream, but it is for

emotional reasons. He does not scream at home unless he is playing, being loud and making his noises and he's happy. He also may scream when he's running with his brother, and he may scream at his brother when he's mad. So, progression is more nonverbal communication, more gestures, and less screaming. Decreased screaming and being able to convey what he wants in other ways is progression, but screaming for emotional reasons is reasonable for Howard. Screaming to communicate is not progression; screaming mainly to express emotion is progression.

When I asked Nina what progression meant for her, she said affection is part of it.

When Matthew showed affection, he showed progression:

Reduction of screaming; going to the bathroom, (successful potty training).

Making progress or part of progress is not so much compliance but following routine, because when they follow routine he can build his own personal routine.

When they come here, it's not time to go to the play area. When they come off the bus, first of all take off your jacket, hang it up, take off your backpack.

Matthew will open his lunch, take out his lunch, put it in the refrigerator. These are all little steps, and he follows the steps. So in the area of self-help skills, he's improving. Social skills—eating and keeping your hands to yourself. If somebody takes your food, you don't slap them across the face. He makes some sign (his face in his hands), that's the way I know someone is bugging him. But when he gets excited, he does the same thing. You really, it's a fine line. I have to look at his face or his eyes to know. So, in my dilemma, he was using the screaming to express pleasure which I didn't want to extinguish, but at the same

time he was using it to express frustration which I did want to extinguish.

Nina then said this was a very difficult time for her. Her quandary was deciphering his screaming, so she determined what his screaming was used for when she considered the context in which it was used. We can apply the tool of social constructionism for this in that speech acts within which screaming occurs may be constructed as pleasure or as frustration. Therefore, screaming may be perceived positively or negatively (progression or regression) depending on the context in which the behavior is embedded.

Nina then went on to say that, “For me, my thing I’m seeing is that progress for kids sometimes is different than progress for us.” Again, social realities are created differently, as we know from the social constructionist viewpoint. Nina gave her strategies for dealing with the screaming and for working that problem out. She said that she reinforced Matthew’s quiet behavior and gave him a reward for that and let him know that screaming does not have a reward:

Now, with the screaming, we have to let him know that at this time the screaming is not appropriate. If you want something, if you’re quiet, I will give it to you.

So, he’ll know that being quiet has a reward. Screaming doesn’t have a reward.

Progress is meeting little goals. We have a lot of regression, progression, regression, so, you have to know what is it you really want?

Autistic children typically regress, progress, regress, progress—regression and progression fluctuate. They take one step forward, one step back, and so on. The smallest developmental steps are huge leaps for them.

From the social constructionist perspective, people construct different realities.

For Waverly, screaming was recognized differently. She talked about Matthew's progression through episodes, and how she defined progression:

Well, one thing he does, he yells when he wants something rather than asking. I am working with the speech therapist; she's giving him more icons. Because sometimes, like he loves potato chips and salty things. He'll go to all the trouble of going over there and get his book. He usually doesn't use the communication book for meals, but he'll go through the pages, he'll find the chips icon.

Although, sometimes he'll say it, too. But, he'll show me, communicate in different ways. Now, he does scream more than I like. We're trying to get him different ways to communicate and to ask quietly. Or sometimes it's just impatience, like, he's done his job and he knows that he gets to pick a toy from the toy cabinets. So, he's standing in front of the toy cabinets screaming. Or we're trying to show him, we'll tell him we'll be there or you wait and that he needs to learn the waiting, you know, control the screaming.

Nina considered that Matthew used screaming partly for emotional reasons, whereas Waverly viewed the screaming as impatience; he used screaming as a request. Waverly sought to reduce the screaming and Nina wanted to differentiate it. Waverly further explained how she interpreted Matthew's screaming as a request:

One thing he might think that we're not hearing him and that's why he reverts to the screaming. Or I've seen it with other autistic children, sometimes you'll tell them no and they think you don't get it so they're screaming, "Chips, chips, chips!" and you say, "No, we're all out of chips," or "You've had enough chips,"

and they just think you don't get it. So, pretty soon they're in your face, "Aaahhh! Aaahhh!" and they think *you* don't get it, you know, so that's an autistic characteristic, yeah.

This account highlights the frustration autistic children likely feel because they are trying to communicate what they want, but they think others do not understand them. So, Matthew, like other autistic children, does not know how else to ask for something besides screaming. Teachers like Nina and Waverly encourage autistic children to use other ways to communicate, such as the icon book Waverly mentioned previously.

Waverly also defined progression as cognitive improvement. She said:

I see progress with the cognitive although he might be a little noisier, too.

Although, we're trying not to reinforce it, [the screaming]. But, ...he's very good when we've been in the community. I guess the family has had some problems bringing him out in the community. But he's pretty good... So socially, with that, he's doing well.

She has defined progression as higher cognitive ability. She also defined it as improved social ability in the community, so this serves as an example of progression in his social skills.

I also asked study participants about their definitions of regression. When Howard was asked, "How do you define regression?" he responded:

Well, it seems like sometimes his speech goes up and then it goes down. You may hear a word one time but then he'll stop saying it. I guess he had said,

"popcorn" at school. You know, I've never really heard him say popcorn. Um, I

was told by the teachers that he said “popcorn,” yeah, “more popcorn.” I don’t, I don’t know if he’s not using it or if he just forgot it or you know, there’s new words he learns. Or he’ll say, “this,” he says “this,” you want this? And I go “this” point, “this.” But he doesn’t like anything, instead of sometimes saying no, like you offer him a certain drink or food and he doesn’t like it, he’ll go, “Aahh.” You know, instead of saying no, he’ll just, he’ll just make that face like that disgusts me. He’ll put his tongue out and turn his head. That means, “I don’t want it.”

Howard has defined regression as a reduction in spoken words, verbal language and intermittent use of learned vocabulary. Matthew would sometimes use a word, and then he wouldn’t say it again.

For Nina, regression was defined as:

Old behavior that we dealt with that they started off with, because when they get stressed, they go back to their old behavior, like screaming. He’s stressed or if that behavior produces the results he wants, he’ll go back to it. For him, he’s getting what he wants. For us, it’s regression. He thinks he’s getting what he wants. His scream is so piercing that you want to give him what he wants just to keep him quiet.

Nina said regression was reverting back to old behavior that had been corrected. When old behavior reappeared, it was regression. She gave strategies for dealing with this. She then stated, however, that when Matthew screamed, she would find that he was screaming because someone was bothering him. She repeated her position that sometimes Matthew

would scream for appropriate emotional reasons instead of communicative ones. Nina constructed screaming as being either of the two, and she would always look for the reason behind the screaming in this way. She provided additional insights on this topic:

So I don't talk about the screaming; I just talk about what happened. He has so much inbred screaming to the point that, he will always have a little bit, maybe not permanently, but he will kind of always revert back to that because if something works for you, why change it?

Nina had gotten to know the child's history and personal characteristics. She also commented:

We have to give him something new. And hopefully when he starts to use verbal language, then we can extinguish a lot of that screaming. Screaming is a way of communication, but at the same time, it's a very distracting way for him, and everybody else, and for the kids. Socially, it draws attention to him, and one of our reasons is to draw as little attention as possible to our kids for them to be acceptable in the community.

Regression is defined as drawing too much attention to one's self, and for Matthew, he had done this every time he used screaming as an inappropriate way to communicate.

Nina described her strategies for handling this regressive behavior:

You have to provide a replacement or alternative to a regressive behavior. If Matthew is humming, I say, "Oh! You're singing!" so that he will continue this positive behavior. If he is screaming, I just sit there with no expression. When he stops, I say, "Matthew wants this?" And give it to him after he stopped the

screaming. Using the icon book, or using gestures, is better. If you do anything else (communicate other than screaming), you'll get what you want.

So, again, an increase in other forms of communication is progression whereas an increase in screaming is regression.

Waverly defined regression in episodes such as these:

With the screaming, it's a good point, too, there's an indoor voice and an outdoor voice. And he has screamed on the playground, but it's almost been appropriate, almost for a reason, like, we have three tricycles and he likes the red one, and sometimes and then we'll be getting them [the tricycles] out of the closet.

Somebody else will grab the red one when he's been expecting it. Now, that to me, is you know, is an appropriate reason. Now, he shouldn't be screaming, so that would be a little more inappropriate and also, um, there's a little kindergarten bathroom right off the playground and it's very cute, it's got two stalls and he kind of likes to use that. But, like the other day, he really had to go a lot, and he said, "Aaahhh! Aaahh!" so I let him in to use the kindergarten bathroom and actually it's rewarding it, like I need to get the icon to say, "What do you want? Ok, let's go," and have him ask for it quietly first, to ask quietly, and then he can get it.

Because I realize we're inadvertently rewarding it, you know, he screams, he gets results. And we are, you know, working on that.

She felt it was inappropriate to scream, but more appropriate when the context changed.

So when Matthew was outdoors playing on the playground and screamed, it was more appropriate. But then, she said regression occurred if he resorted to screaming when he

wanted the red tricycle or had to use the bathroom. She felt the same way as Nina did when she said that Matthew would scream if he knew he could get what he wanted from it. She knew that she had to force him to use other ways to communicate, like getting the communication book, picking the icon for “bathroom,” instead of screaming. But then again, if an issue is pressing, like having to use the bathroom, of course time may be limited. She then went on to say, “Unless we kind of get things coordinated with the speech therapist, you know, with one another, I’m hoping he’ll quickly come back up to where he was.” She saw that Matthew had regressed in his communication skills because he used fewer words and screamed more often.

Waverly then went on to talk about regression in social skills. She said that autistic children don’t really know how to socialize, so they may show inappropriate social skills and that can be regression. They may want to become friends with another child, but don’t know how to go about doing it, so they will pull hair or mess up a puzzle the other child is working on. She said, “...sometimes, kids, they want to socialize, the autistic kids especially, but they don’t know how to do it.” A typical symptom of autism that she referred to is that children with autism simply do not know social rules that people normally know and follow. So, autistic children will work out how to socialize with each other on their own. If there is increased interaction among classmates, she felt that was a progression. If that interaction included pulling hair and similar behaviors, then that was not regression because they don’t really know how to behave and they have to be guided. Waverly judged regression in the social skills area as a lack of participation and unwillingness to interact with others.

Autism experts define regression in many ways. Due to the ambiguous nature of definitions of regression, it is difficult to operationally define or conceptualize the term. There is consensus, however, in that autism experts agree that children with autism exhibit peculiar social behaviors and have great difficulty interacting with others. For example, Sullivan (1994) described the features of social debilitation or regression as an inability to relate with others, a preference for being left alone, lack of eye contact, and a disinterest in physical contact. Sullivan concluded, "Their [autistic children's] expression is one of complete self-satisfaction, impenetrable, and unshared" (p. 6). Cowley (2000) describes the autistic condition as "mindblindness," or the complete inability to interpret others' intention, emotions, and thoughts based on social and interpersonal cues. Matthew's incapacity in relating to others socially is manifested as regression in his social ability. For Waverly, Matthew showed progression and regression in the social skills area because although he would intermittently interact with one or two classmates, for the most part, he preferred to be alone.

At the end of each interview, I asked the participants, "Are there any other things that you think I should know?" These suggestions, of course, are meant for me and for the other participants in this study to know and learn from as well. Howard said:

Regarding Matthew's education? The only thing I think, I've heard different people say that autistic children, they're only gonna learn at the pace given them and that they do need to be more surrounded or involved with other children who don't have disabilities. So that they *know* what's normal, so that they know what's normal behavior. Maybe they may not be able to learn at that curve...

They'll never be the same because of their learning disabilities, but, how are they ever gonna know unless, you know, unless they're in that environment? You know what I mean? I understand that they take the kids on certain trips like lunch trips or field trips and things like that but it's always with, also within the group of the class, you know. How would it be to take the kids into the lunchroom with all the other kids, you know? They're not even, or, or play with, with the other kids and not in their, just their specific playground. I don't know if it's just assigned to them or what have you, you know. How are they going to develop their social skills (if they're not around non-autistic children)?

Nina stated that with regards to Matthew's education:

Well, wherever he's at, affection should be included. He responds well to that. But also include, let him know when it's time to play and when it's time to be serious. He responds very well to facial expressions and tone of voice. But also he, he needs some structure, structurally at home. Structure in the sense that, somehow the parents need a schedule.

Another piece of advice Nina gave was, "Whoever is at home, they need to be firm. Tell him no means no." She said communicating with Matthew and other autistic children is essential because, "They'll pick up something eventually. They gotta pick up something. There's just something about human nature. Communication is so *powerful*, that people have got to, no matter how, they gotta pick up something." She said it is important to teach autistic children that language is power and that when the children use language, they get rewards. She also suggested extending Matthew's vocabulary by increasing the

use of the icons in the communication book.

Waverly offered her advice as, “I would like him to join the group a little better. If he [Howard] has any ideas of why he feels overwhelmed at circle. Just, like, give him the same activities there [at home].” She said that Matthew was curious about circle time and watched the other students in the circle while a story was being read to them. But, he would never join the circle himself. It was something that was overwhelming for him, and Waverly didn’t know why. He did his writing, he completed his workstation tasks, he went to play at recess, and engaged in other activities. However, she wanted to work him into the whole routine of the class, to participate in it fully, and she wanted advice on how to get him to join the circle. Like Howard, Waverly also wanted to make sure that the same behaviors were taught and reinforced at home and at school. She wanted to have a plan to make sure that the strategies were the same and that issues (like screaming and compliance for circle time) were being handled in the same way.

Answering the Research Question

The diary and interview themes demonstrate how progression and regression of the autistic child’s communication and social skills are defined and contested in parent-teacher interactions. The progression and regression of Matthew’s communication and social skills were socially constructed and contested in the diary between his parent and his teachers in a reflexive communication process. The parent-teacher interactions in the diary affect their relationship, and the relationship, in turn, affects their interactions. So what they communicate and how they communicate directly affects the relationship they have. The interviews also allowed me to hear how they defined and contested these

constructs.

The diary's importance as a communicative tool between the participants was discussed in the interviews. The diary between Nina and Howard is much lengthier than the diary between Waverly and Howard. When I asked Waverly and Howard why they chose not to use it as often as it had been used in the past, they each gave their reasons. Howard said that he responded when asked for input. When asked, "How does the diary help you?" he answered:

It helps me, in a way, to communicate with his teacher, what he's doing, mainly if there's any problems or new things that she doesn't understand that he may be, you know, yelling for this or trying to make a sound for that. Basically, it's a communication tool between us, while he's in school. It goes to school with him every day; it comes back every day. It's not used daily by me or by Waverly. It was more by Nina when he was in her class, just basically to state, you know, what he's doing in class, and how he's doing in any, like new things she may be teaching him. She may need some information on what he likes or dislikes and things like that.

Waverly explained that she did not rely on the diary as much as other forms of communication, such as phoning or through the Individualized Education Program (IEP) Report Card. The IEP report lists goals for the student to achieve. So, basically Waverly substituted the IEP for the diary. She gave detailed reasons for this during my interview with her when I asked how the diary helped her:

Well, it gives an ongoing, day-to-day communication with the parents. We can

check things. Also, they can tell us if there's some variable factor going on that day like maybe he didn't sleep the night before or maybe he has a cold. Um, there might be some variable factor, but like as I explained to you before, I do most of the communication on the phone both with the grandparents and the parents. So, there's not as much day-to-day communication as there was last year when he was in Nina's class. But it does help 'cause it's a means of ongoing communication. Keeps the lines of communication open. It reinforces what we say in our conversations, too. Like I can say, "Here are the forms you requested" or "Let me know if there's anything else," so it also reinforces the phone conversations. So, it's not one or the other; it's several tools used.

For Nina, the diary was used more often and this helped the ongoing communication between the parent and teacher. She explained why she used it:

It's the only way to keep constant communication between home and school; also I can know what's happening at home. It tells the parent what's happening here. I use it to ask for things that the child needs-diapers, extra clothing. Sends notices home. I ask the parents questions in it, they respond and they ask me questions in it and I respond. Daily or weekly thing. Tells the parents what we are going to do. Gives me more time to say more on a form rather than on the phone-I really don't have much time for the phone so I write after the kids have gone. Helps to keep a log in case something happens; parents say I wrote you and asked for this, etc. Helps for compliance. Protective for both of us. I need to know what's happening at home, whatever the parents want me to know.

Because the interactions between Waverly and Howard were infrequent, this affected the nature of their relationship and underscores how the reflexive communication process works. Waverly felt that Howard did not respond as much or as often as he could have, and Howard felt that he needed more weekly, written updates via the diary. This reflexive loop (Pearce 1994a) can be observed in how the lack of communication affected their relationship, and their more distant relationship affected their communication. The parent-teacher relationship may have been closer if they had each known of the other's needs. They each did not know of the other's needs because they did not express these to each other and this created a more distant relationship. They did work together as a team, but they did not share their ideas to help Matthew as often as Howard would have liked.

The importance of parents and teachers working together and of parent-teacher communication cannot be overstated. Bower (1981) stresses this:

The causes of autism remain in question and no cures are in sight. Early psychological theories stressed parental effects and led to "parentectomy" therapy, typified by Bettelheim's approach of separating the child from its parents and substituting warm, accepting parent surrogates. The strength of biological evidence has steered modern treatment back toward parents. A good example is Division TEACCH, a statewide outpatient program in North Carolina run by Eric Schopler and his colleagues at the University of North Carolina at Chapel Hill. The program pulls together elements of developmental assessment, problem-oriented goal setting, behavior modification, consumer advocacy and community support. Parents can participate in the clinical setting and in special educational

classrooms set up in conjunction with local school systems (p. 155).

Bower offers his view that the autistic child benefits when his or her parents and teachers work together as a team. The child's treatment is hinged on the "home-teaching program," which is a list of activities and techniques based on a developmental assessment of the child. Parents learn the home program, and are counseled on behavior management techniques, through demonstration and coaching by TEACCH trainers. Everyone benefits from this program. The teachers and the parents work together as a team, the teachers provide the parents with the techniques and knowledge they need to assist the child, and the parents learn about their child's assessment and participate more in their child's education. Ultimately, the child's education is balanced between home and school because the same techniques are used in each of these contexts. The child's comfort level is increased because the preservation of sameness is maintained through this parent-teacher teamwork.

More communication probably would have led to increased teamwork between Waverly and Howard. This may have improved the effectiveness of their communication. The lack of communication between them affected their relationship, and this, in turn, affected their communication. This reflexive loop, an example of a communication system, shows how these parts do not simply affect one another, but come together as a whole. It is an intricate and complex system that shows the dependence that communication has on relationships, and that relationships have on communication. Pearce (1994a) explains that, "Communication systems are structured by reflexive loops rather than linear causal sequences; they evolve as wholes rather than

just one part affecting the other” (p. 238).

Nina and Howard’s communication was much more frequent. They documented episodes and the evaluative statements, the sense making, and the language they used, all contributed to their closer working relationship. Their continual interaction through the diary supported and sustained their relationship, and conversely, their relationship supported and sustained their communication. Frequency of communication, and more importantly, quality of communication, are essential components of a strong relationship. As Pearce (1994a) suggested, “Relationships are an important part of our social worlds, and like all other events and objects in our social worlds, are made in conversations” (p. 204). The social constructionist perspective holds that in order to understand a relationship, such as the parent-teacher relationship depicted in this thesis, one must look at how it is made in conversations.

The participants jointly negotiated progression and regression in the diary. Joint negotiation was not meant to be a sense of agreement on defining these terms between the parent and teachers, but to identify what it is they needed from each other in order to understand the child better and to investigate how his progress could be enhanced. Their support for each other and the teamwork that evolved out of this negotiation constitute another relevant and pivotal theme as well. Waverly reiterated this point when she responded to the question, “How does the parent let you know you are working together as a team?” by stating:

I think it’s just the ongoing communication with the diary and the phone, I would have to say. Also, I try to send a general letter home once a month. I don’t

always get it out... That's just a general one that goes out to every parent. So, it gives Howard an idea just what's going on in the classroom. The letter is once a month; phone calls work out to about once a week. I feel support from Howard. Teamwork includes communicating in the diary, on the phone, and in letters. The parent and teachers in this study agreed that these communicative tools were beneficial to them all.

Nina's answer to this question emphasized the importance of dialogue:

I don't know because Howard, we really didn't do much except the IEP report.

We talked about Matthew, but we never really had time to sit... I just said this works, try it at home. If anything works at home, please let me know. He will nod and then he walks and I said so much and he didn't say much. But then, I just had the feeling that well, if he didn't say much, either he agreed with me or he's gonna try. So we really haven't had that many, I think I met him once or twice.

These statements attest to the fact that teamwork is crucial to their mutual goal of meeting Matthew's educational goals and improving his social and communicative abilities. Nina also implied that she needed more feedback from Howard. Although his silence could be interpreted as agreement, Nina could not be certain of this interpretation. It is important to discuss the notion of dialogic communication here. From a dialogic perspective, a person's voice arises in conversation or is suppressed in conversation, as Pearce (1994a) argues:

Not every conversation is a dialogue, of course. In dialogue, the conversation is constructed in such a manner as to allow the individual participants to speak in

their own voices, and these voices are woven together into a tapestry in which each has its place (p. 329).

Thus, at times, the Nina-Howard diary entries seemed more of a monologue than a dialogue, with Nina carrying the majority of the conversation. Yet, there seemed to be sufficient dialogic communication to create this tapestry of teamwork.

Parents and Teachers Process Progression and Regression Similarly and Differently

It is clear from these research findings that participants constructed different realities. In one question, both teachers were asked, “When Matthew is screaming, how does that fit in with his progression or regression?” and then were asked to give an example. Each teacher responded differently, with screaming constructed as progression, regression, and/or both. Nina said:

The more he screams, that’s a regression—the more he screams—the frequency, the pitch, because when you don’t respond to him, he opens his mouth wider and screams louder. The pitch’s intensity. Frequency, pitch, and intensity lets me know he’s regressing. Progress, that comes with that, too. The pitch is different, the duration is kind of shut, because if you’re doing that, when you’re calling, he can turn around, but when he’s really in a regressive mood, he would just scream and scream. You literally have to take his hand and say, “You need to be quiet.” But, otherwise, when he’s just you know, doing the funny calling, he’ll turn around, smile, and then go back. So that lets me know, that he, he’s not into it so much that he cannot attend to something else. But when he’s regressive, in a regressive stage, he’ll just go on and on. You really have to go there physically to

help him. Hold his hand or do something, (keep eye contact), look at me.

Because if he looks at me, he has to stop, and my thing is trying to get him to stop, because if he's screaming and you're talking, the more you talk, he just continues.

Matthew needs to look at me, to get his attention.

Nina defined Matthew's screaming as progression *and* regression, depending on *how* he screamed—the frequency, intensity, duration and pitch of the screaming—as well as his non-verbal facial expressions during the screaming (when he smiles, or doing “the funny calling,” he's not in a “regressive mood”). So he is progressing when he's screaming in a less intense way and when he's using it to communicate. He's regressing when he's using it to show displeasure. For Nina, the context is also a deciding factor between progression and regression. Thus, the *context* affects the speech act, and the speech act affects the context. It is reflexive; it shows circularity between the two (Pearce, 1994a).

This example also elucidates the fact that people construct different realities; social construction theorists posit that people do this when they live in social systems (Pearce 1994). We create our social worlds. Waverly's answer to this very same question produced a different reality. Waverly's reality differs from Nina's reality. She gave her interpretation:

Well, it's both really. Like it's inappropriate communication, certainly, especially. And he hasn't really done it in public. It if was happening in public, it would be very inappropriate. Even on the playground, it's inappropriate because all the people see our classes, all the wild kids out there or something. And so, um, it's kind of regression and progression both because he is communicating,

he's trying to let us know what he wants but he's doing it in an inappropriate way. He learns; he knows it works, you know, and we have to work that out, too. In fact, I'm working on a behavior plan and I thought, I thought maybe I'd see if Howard would sign it off, too, and just, just to say exactly how we're gonna handle the screaming because Matthew, he's a big boy and he's what, seven years old already and, and the idea is to give him more ways to communicate, not to, not to reinforce the screaming.

Waverly interprets screaming differently from Nina in that Waverly does not differentiate screaming based on the pitch, the frequency, and the intensity. Waverly simply views the behavior as one unit of screaming. She evaluates screaming as inappropriate communication—communication that should be replaced by other appropriate forms of communication, which she would like to put into action through a behavior plan. She wants to move away from screaming, not to reinforce it, and to give other ideas of communicating. For her, screaming is seen in the same way as Nina in that it is inappropriate behavior. They both want Matthew to avoid using it. They would like him to communicate in different ways. The subtle difference between their views is that Nina differentiates *types of* screaming. If Matthew's nonverbal behavior suggests that he is angry, frustrated or upset, then the screaming is inappropriate. However, if the screaming seems to reflect happy emotions, then Nina defines the behavior as appropriate. The other difference between Nina and Waverly's interpretation of Matthew's screaming is that Waverly identifies *where* the screaming is taking place as having an affect on progression or regression. If the screaming is happening on the playground or in any

other public place, the behavior is inappropriate and regressive, communicative or otherwise.

Nina and Waverly defined screaming as *both* progression *and* regression, but in different ways. Nina saw it as progression when Matthew used screaming to communicate but he could “attend to something else.” If he screamed on and on and did not stop and could not attend to something else, then it was purely regressive, as he showed he was in a “regressive mood or stage.” So, the fine line between progression and regression is the mood Matthew is in when he’s using screaming to communicate. For Nina, screaming is both progression and regression. Waverly constructed screaming similarly in that screaming was revealed as both progression and regression. When she said, “He’s trying to let us know what he wants but he’s doing it in an inappropriate way. He learns; he knows it works, you know, and we have to work that out, too,” she expressed her thoughts that he is trying to communicate, but that he should not do it in that way. Waverly believed that screaming is progression because it is, in itself, communication. The child is trying to tell others what he wants through screaming. However, it is regression because it is inappropriate communication. She also explained here that Matthew demonstrated he could cognitively understand and learn what worked for him because he knew how to get what he wanted—screaming would produce the desired effect. When he screamed, he got what he wanted, and that needed to change in the future.

Howard also suggested that speech acts create a context in which screaming may be construed as progression, regression, and/or both. He illustrated this point when asked

how screaming fit in with Matthew's progression or regression:

It depends on the circumstance. Sometimes, he, he screams when he's yelled at, for doing something he shouldn't be doing. And he, he'll, he may cry and what he tries to do is, he tries to make it up to you by coming over to hug you and pat you on your belly. And I think, I think, my, what I think he's thinking is, he feels that you're mad at him and that you don't love him anymore. And he doesn't comprehend that you're telling him no for a reason and it's not that because you don't love him, it's because you want him to stop what he's doing wrong or it could hurt him or whatever. So he tries to come up to you and he tries to hug you and love you by patting you on the belly and going, saying, "Doo Doo Doo Doo" and he's crying and he, he puts his arms around you and then he will, you know, he will take your arms if you don't do it yourself, he will take *your* arms and put them around him.

For Howard, there is a reflexive relationship between speech acts and contexts. The speech act (screaming) is provoked by the context (being yelled at). Howard's answer is additional evidence that screaming for Matthew is to show emotion. So, like Nina, Howard views Matthew's screaming as showing feelings. Nina may have helped to influence Howard's understanding of Matthew's screaming because she conveyed her thoughts on this subject. For her, it was an important topic, one to be investigated. She knew that Matthew needed help in this area, and she looked for strategies to reduce the screaming and to replace it with other, more viable forms of communication. Howard and Nina socially constructed the meaning of screaming in that they both wanted to help

Matthew move away from it as much as possible. They each defined screaming as a problem if Matthew used it as a request. They also agreed that it was acceptable for Matthew to use screaming as a way to express emotion.

Waverly offered a different definition of screaming, suggesting that Matthew would scream to get what he wanted. Howard said that Matthew would scream to get what he wanted in the past, but that this behavior had since stopped. He said when Matthew would scream, Howard did not know what Matthew wanted, and so it was like a guessing game. Now, Matthew uses nonverbal behavior to indicate what he wants. This difference of opinion between Howard and Waverly signaled their disagreement on the screaming issue, and/or of their possible need to recognize and/or accept their differing perspectives. The issue of power is again a factor in that the participants' negotiation of the progression and regression of Matthew's communication and social skills is surely impressed upon by power dynamics between the parent and teachers. The relationship, while appearing as an egalitarian one, may not be. Power seemed to shift slightly more toward the teachers in that they had a greater say in the negotiation process. They would make requests from Howard, while Howard would essentially answer these requests and yet would not ask for help, input, or feedback from the teachers.

Parents and teachers approach progression and regression both similarly and differently. Nina gave other examples of what progression meant for her. She said that Matthew communicated with his behavior. So although his language ability was low, he did communicate nonverbally. In her class, he demonstrated good cognitive ability and showed a sense of shame when he covered his face with his hands when he'd done

something wrong. He also remembered when someone had done something against him, such as hitting him or taking a toy from him. He was also very protective of his things. These behaviors all indicated good cognitive ability, communication skills, social skills, and a less-than-severe autistic condition in Matthew. She said:

He understands. Language takes awhile but a lot of time verbal is considered communication but communication is, as you already know, beyond verbal. It takes a lot of cognitive skills to retaliate, especially something that happened way back when, and he's very possessive about his space, you know you don't bother his things, and the thing about this is, if somebody comes in the class, autistic or not, they stay away from Matthew. Because they know he'll get them back. And that's good for me because I know those kids, they're not severe. Not severe, kind of mild to moderate to know that. Now a child who's severe doesn't care; he'll keep going.

These comments show how Nina determined progression and regression. Waverly defined progression as Matthew following directions more. He regressed when he screamed more, and the amount of screaming would increase and decrease, so it was difficult to decide that it was one or the other; for her it was both progression and regression. For Howard, determining progression and regression was one and the same. He said, "...about the words. You hear new words, but then sometimes he doesn't say the old words. Um, but it's definitely that he has learned more words than he has ever lost, stopped speaking, you know." So although he progressed by learning new words, he regressed by not saying them. But then again, Howard said that Matthew understood

words, even if he didn't vocalize them, "I think he, he understands, he understands certain words. He may not be able to say the words, but he understands, you know, what some, you know like, especially the word 'no'. Oh, he knows what that means." Howard gave other words that Matthew knew but didn't always say: "Spank, bath, bye-bye, kiss, night-night," and phrases such as, "Give me love," "Go to bed," and "Give it to Bubba" (his brother). He also complied when asked, "Can Bubba see?" This was when his brother wanted to see what Matthew had at the time. These examples show how Howard determined progression and regression.

Negotiating and defining terms like progression and regression are a complex process. Participants depend on each other for meaning. If one person makes a statement (a speech act), it does not have meaning until another person responds to it. Social constructionists argue that speech acts are indeterminate and serve to create reality:

From the Wittgensteinian approach, speech acts are never completed. Rather, they are part of an ongoing process in which they both fit into contexts and create the contexts in which they fit, and in which they are a part of a continuing sequence of actions, each of which has the potential to reinterpret those that came before them. Among other things, the "incompleteness" of speech acts implies that the meanings of our social worlds are not fully determined. A certain openness in the meanings of what we say and do is not just the result of our lack of precision but because of the nature of speech acts themselves (Pearce, 1994a, p. 115).

Speech acts are never finished and continue on indefinitely. Reflexivity exists between

speech acts and context; their symbiotic relationship binds them together. The continual creation and re-creation of the speech act is the continual creation and re-creation of our social world.

Dr. Bernard Rimland, a psychologist with nearly 40 years of experience in research in the field of autism and one of the country's leading authorities on the treatment of autistic children, founded the Autism Society of America in 1965, and in 1967, founded the Autism Research Institute. He concedes that with regard to diagnosing autism, "Experts, even high-priced experts, tend to disagree with each other. Parents should not be surprised at the diversity of opinions," (Rimland, 1996, p. 1). Rimland's (1994) definitions of progression and regression stem from his definition of recovery. He writes extensively of the possibility for recovery, or for degrees of recovery:

Autism. The word seems synonymous with controversy. There is hardly a statement that can be made about autism that has not been challenged. The most recent controversy concerns the concept of recovery. Conventional wisdom has held, from the very beginning, that autism is a life-long disability and that, while some individuals may improve, autism is always there. Conventional wisdom notwithstanding, we are beginning to hear increasingly about recovery. The matter deserves our close attention. Reports of recovery, partial recovery, or near-recovery come from several sources (p. 3).

In the field of autism, it is nearly impossible to find agreement among experts for the definitions of the terms progression and regression, but many, like Rimland, believe that progression is achieved when the autistic individual moves away from autistic behaviors

and moves toward normality. When a person leaves autism behind, he or she has come a long way from his or her autism. When he or she learns what behaviors need to be abandoned, that person has progressed. Dr. Sidney M. Baker (1996) gives his definition of regression:

I was such a physician, twenty-five years ago when a child psychiatrist sent me Martin Z. for evaluation of his seasonal behavioral deterioration. Martin was on the verge of being thrown out of his school program where he was in a group of other school-aged children with severe developmental and behavioral problems, mostly in the autistic spectrum. Martin was aggressive, hyperactive, and destructive (p. 3).

Displaying aggression, hyperactivity, and destructiveness are all indicators of regression for Dr. Baker. Negotiation of the terms progression and regression is a complicated process and experts in the field of autism such as Dr. Bernard Rimland and Dr. Sidney M. Baker define these terms in their own words through speech acts. Their viewpoints further extend on and create autism research. Dr. Rimland and Dr. Baker offer clinical definitions, (with Dr. Rimland focusing on recovery and Dr. Baker focusing on regressive behaviors), that differ from Howard's, Nina's, and Waverly's more experiential definitions. However, on a spectrum of experiential definitions offered by the participants, Howard's definitions were the most experiential. Waverly's definitions were less experiential and more clinical, and Nina's definitions were a combination of clinical and experiential. Thus, autism experts offer concrete, clinical definitions of regression and progression in autism. For the parent and teachers, experience with the

child, and their communication with each other, mediated clinical definitions of regression and progression. That is, Howard, Nina, and Waverly have negotiated definitions of regression and progression as they reflect on and jointly construct their experiences with Matthew.

Pearce's (1994a) notion of reflexivity between speech acts and context is especially relevant, as speech acts affect context and vice versa. There is a reflexive relationship between contexts and the speech acts that occur in them. So, the context impacts the speech acts and the speech acts impact the context. It is a continual reflexive loop.

Pearce's (1994a) idea "that the meaning of any act depends on the context in which it occurs" (p. 114), makes clear that the different contexts that the teachers and parent work in affects their speech acts. Therefore, context is extremely important. Pearce makes this clear, "Contexts are made by specific actions. At the same time, specific actions derive their meaning from the contexts in which they occur" (p. 114). This is important to understand because we have the power to create our social worlds in this way. We make changes in our social world because contexts are affected by our actions. Our actions affect our contexts so therefore, contexts are ever changing. We can change our contexts through our actions.

"People's lives are fabricated in and by their relationships with other people. Our greatest moments of joy and sorrow are found in relationships" (Duck, 1985, p. 655). The relationship each participant has with the child (the parent-child relationship and the teacher-student relationship) frames the context surrounding them and obviously, these

are separate contexts. These contexts do come into play when the participants construct progression and regression of the autistic child's communicative and social abilities.

However, it is how the teacher and parent come together and discuss and contest these constructs that will be developed in the next sections.

Both Parents and Teachers Experience an Emotional Impact

When I started working on this thesis in the spring of 1998, I had no idea how much I would learn and how deeply layered and rich this research project would become. A crucial learning point for me was that parents are not the only ones emotionally affected by the struggle for the autistic child to communicate and socially engage with others. I knew and witnessed firsthand the emotional impact it has had for Matthew's parent. Since Matthew displays significant autistic symptoms and the nature of his autism is substantial, Howard has had to change patterns in his life to fit the needs and abilities of his child. For example, he is now hesitant to bring Matthew out into the community or into social situations because Matthew's behavior is unpredictable. This cannot be easy for Howard. Howard has withdrawn from others in the years following Matthew's diagnosis. Thus, his child's autism has affected not only Matthew himself, but Howard and his other child as well.

The teachers' lives also are affected, personally and emotionally. For example, Nina's own affective feelings for Matthew and the rest of her students was made clear in the diary, in her interview, and in my observation of her enthusiastic interactions with her students. She truly cares for them. Autistic children also care for their teacher, and in this way they are no different than their non-autistic peers, the other students at school.

I have also learned that the emotional impact plays a significant part in social construction because it influences the way people interpret reality; it affects how they communicate about their social world and what they observe in the world around them. One of the first occasions in which the emotional impact of autism affects the way parents perceive the social world is when their child is first diagnosed with the disorder. The parents of an autistic child have probably already detected their child's "odd" behaviors before the diagnosis was made. But when they get a word for these strange and often bizarre behaviors, they experience sharp emotional feelings that affect how they view reality. Sullivan (1997) explicates the emotional reactions to the diagnosis of autism:

If you know what autism is before you receive a diagnosis, you are likely to have thought of it long before you presented your child for a label. Quite possibly, you'll even be relieved that someone else has corroborated what you already suspected, even though it confirms your worst fears. Professionals are sometimes surprised at this relief, and may even mistake it in a parent as insensitivity—or refer to you as "aloof" in their notes (p. 1009).

The diagnosis triggers emotional feelings that affect the parent's perceptions of the world. Parents who feel that someone else has finally seen what they have seen in their child's bewildering behavior see the world differently than they had before the diagnosis was made.

Emotions constitute conversations and are embedded in conversations. Cronen (1995) declares that communication is not all talk and that it has affective qualities that are rarely considered, even in the social approaches. He affirms, "that feelings matter in

communication” (p. 227) and explains:

These aspects of experience are not proofs of the truth or our experience but aspects of experience (Dewey, 1934a). However, without these experiences we are not talking about a human life worth living. Such experiences must be included in our ideas about reflexivity as well. As Dewey observed, the ability to have a profound esthetic experience impacts upon our ability to have further experiences and reflects upon our stories about ourselves, our relationships to others, and even our relationships to the cosmos (Dewey, 1934b). Thus, we may inquire into the grammar of emotions and other feelings (p. 228).

The research project stresses that feelings impact communication and that this impacts the way interlocutors view the world around them. The affective qualities of communication surely affect the social construction of reality.

Summary of Findings and Interpretations

The research question, “How do parents and teachers socially construct progression and regression of communication and social skills in children with autism?” was answered by the participants’ diary and their interviews. The diary provided a record of the parent and teachers’ everyday negotiation of the autistic child’s progression and regression. Interviewing the participants provided a deeper understanding of the diary entries, the relationships between the participants, and the process of defining the child’s progression and regression. The diary and the interview transcripts were thematically analyzed to identify how participants negotiated definitions of the autistic child’s progression and regression in communication and social skills. The definitions were

contested and socially constructed in parent-teacher interactions. The four identified themes that arose out of this methodological process centered on defining and socially constructing progression and regression:

1. They worked together to solve the screaming issue, (Nina and Howard).
2. They provided support (teamwork) for one another, (Nina and Howard; Waverly and Howard).
3. They negotiated alternative forms of communication (besides screaming) for Matthew to use, (Nina and Howard).
4. They worked together to improve Matthew's social skills, (Waverly and Howard).

One of the most important findings is that the same behavior, screaming, counted as both progression and regression. This provides theoretical support for social constructionism. Nina explained that she defined screaming as both progression and regression, depending on how Matthew used it. She said her dilemma was to decipher how he was using it because he used screaming to express pleasure, which she did not want to extinguish, but at the same time he used it to express frustration, which she did want to extinguish. She constructed screaming as progression and regression.

Howard said screaming was used to show emotion and to make a request. To him, when Matthew used screaming more often to express his anger or frustration, it was regression. When Matthew used screaming more often to make a request, it was progression. Again, screaming is seen as progression and regression, depending on how Matthew used it.

Waverly also defined screaming as progression and regression in that Matthew would use it for emotional reasons and to ask for something. He would scream when he wanted something, rather than asking for it (again it was used as a request). She said he would scream to express emotions such as impatience when he couldn't have what he wanted. Waverly wanted to control the screaming when it was used to express impatience because she felt Matthew needed to learn to wait for whatever he wanted at the time. She said she wanted to try to get him to communicate in different ways (other than screaming) and to ask quietly.

All three participants socially constructed the definitions of progression and regression of screaming. For them, screaming is both progression and regression, depending on its use. They all agreed that Matthew utilized screaming for emotional reasons and to make requests. The teachers discussed the need to teach Matthew better ways to communicate his needs other than reverting to screaming. While the parent was interested in finding other ways to help him communicate with his child, (such as using more hand gestures), he did not take an active role in this area. The teachers would suggest alternative forms of communication, and the parent would willingly listen to and was supportive of their ideas.

In addition, the importance of the teachers' role is a factor in the process of constructing definitions of regression and progression. To a large extent, it seems that Howard followed the teachers' lead. Thus, power is an issue in how regression and progression are defined. While Howard is the expert on Matthew, the teachers are experts on autism. Those who display more power (the teachers), define progression and

regression more often than the parent, who tended to wait for the teachers' direction.

Screaming was the major focus of Matthew's communicative and social behaviors because it permeated his interactions with others. Howard said that Matthew's screaming was becoming more *emotional* (such as anger) rather than to ask or request something. Before, Matthew would scream to achieve either emotion *or* request. Now, it is used more often to express emotion such as anger, displeasure, or frustration. Matthew's screaming behavior constitutes a more specific speech act, to display emotion, rather than two possible speech acts—expressing emotion and request. Still, Howard looks at Matthew's face to see if Matthew is expressing emotion or is actually asking for something. He is improving and not screaming as often as before. The goal has always been, for Howard, to move Matthew from screaming for everything to using other forms of communication to ask for what he wants or needs. Progression is thus associated with a greater repertoire of communication behaviors.

CHAPTER 5

Conclusions

This study asked, “How do parents and teachers socially construct progression and regression of communication and social skills in children with autism?” This chapter addresses theoretical, methodological, and practical implications of the study’s findings. It includes discussion of how parents and teachers approach autism differently and of how parents and teachers learn from each other. In addition, the chapter identifies the study’s contributions to autism literature and communication literature, as well as the study’s limitations and suggestions for further research.

Theoretical Implications

This case study has theoretical implications for examining the definition and construction of progression and regression of the autistic child’s communication and social skills. The tool of social constructionism allows us to understand that parents and teachers of autistic children discuss and negotiate the child’s progress and regression and these negotiations and constructions create reality. The social constructionist perspective enables us to realize that although we know autistic children can be “measured” in terms of their progress and regression, we do not know how these terms are discussed and agreed upon in the everyday lives of parents and teachers who work with children with autism.

The theory of social constructionism allows us to understand that parents and teachers negotiate meanings of progression and regression of communication and social skills in interaction. Meaning is not tied to a literal viewing, an ostensive understanding

of these terms, but is constructed in talk. The social constructionist perspective is a unique one because with it, we can observe how parents and teachers construct their notions of progression and regression. No other theory can do this, or claims to be able to do this. Social science scholars in communication, psychology, child development, health communication, interpersonal communication, and autism research can benefit from the tool of social constructionism by understanding how it applies to helping parents and teachers negotiate how autistic children progress or regress in their communication and social skills.

Reflexivity is a crucial point of social constructionism, and one must understand reflexivity in order to understand this theory. The term “reflexivity” implies the process itself, that speech acts and contexts are inextricably intertwined. Speech acts create contexts and contexts determine what speech acts may be performed and how speech acts are to be interpreted (Pearce, 1994a). These research findings demonstrate that the joint negotiation by parents and teachers of progression and regression of an autistic child’s communication and social skills is constructed in parent-teacher interactions in a reflexive communication process. The social constructionist perspective enables us to understand that these negotiations are created by reflexive communication; in other words, negotiations are constructed in a reflexive communication process.

The social constructionist perspective reveals much about the relationship between the parent and the teachers in that issues such as power are crucial to the communication between them, and to the relationship itself. The teachers were not in power simply because of their role—simply because they are “teachers.” Likewise, the

parent was not in power just because of his role as the child's parent. Each brings power resources to the relationship, yet the implementation of that power occurs in the interactions between the participants. Although in this study the teachers exercised greater power in defining the child's social and communicative progression and regression, social constructionism reminds us that the participants could have negotiated an alternative power structure.

This research project sheds light on the validity of the social constructionist framework. The main tenet of social constructionism holds that meaning is not tied to messages and to words themselves but that meaning is in use. If we understand this, we can understand that speech is action. Pearce (1994a) illuminates this point and declares that we coordinate with others to create meaning in specific contexts. Meaning arises in episodes between and among people.

This research is an important starting point for merging the study of communication and the study of autism. The social constructionist tool shows how we construct meaning through talk, and how people's interactions create social reality. Leeds-Hurwitz (1995) underscores these points when she states:

As with all theoretical statements, there are important implications for research. Most basically, a social constructionist view of the world implies that we question the validity of traditional "scientific" experiments. As Anderson (1990) tells us, "For the interpretive social scientist (who is necessarily a constructionist), the business of inquiry is not to reveal the world to us but to create some part of the world for us. Inquiry is the professional practice of the social creation of reality"

(p. 14). The implication of social constructionism for the study of interaction is to put forth a view of interaction as a social accomplishment, a human creation, and, thus, emphasize the element of creativity in interaction, the interplay between new and old, the ways in which innovation mixes with tradition. Researchers look to determine how people manage their interactions, how they invent and display their various social identities and roles, and how they respond to the inventions and displays of others (p. 7).

Leeds-Hurwitz observes that social constructionist researchers question conventional modalities of inquiry such as surveys. Through their inquiry, they help to create the social world along with the participants they study. In other words, the researcher studies the interactions among and between participants and in doing so, becomes part of the research itself.

Methodological Implications

This study also has methodological implications for the study of communication and autism. The method used is not an innovative one, but using the diary/interview method to identify the social construction of progression and regression of an autistic child's communication and social skills is unprecedented. Communication scholars may see this as the beginning for further research between the two fields of communication and autism.

This method was the best method to use for this type of research because the parent and the teachers use the diary to interact between one another, so this was an excellent starting point. But it was also the best method for this type of research because

I was able to question the participants based on their diary episodes, and then I added the diary interview graph to provide a map to compare the participants' responses. After I did this, I was able to observe how their answers, when juxtaposed against one another, highlighted how they negotiated progression and regression of the child's communication and social abilities.

The case study method was valuable in that case studies are central to social constructionism and in that there is so much to be learned through them. This can be seen in Chen and Pearce's admiration for the beauty of case studies:

Doing case studies within social constructionism is our scholarly commitment to a particular style of intellectual pursuit. We take Geertz's (1973) position to heart when he said, "Interpretive anthropology is a science whose progress is marked less by a perfection of consensus than by a refinement of debate. What gets better is the precision with which we vex each other" (p. 29). If Geertz is right, the most beautiful case studies are those that enrich our conversation the most. They embody eternal joy, and yet rather than a timeless "joy forever," they are enjoyed because they enable the conversation to move beyond them (p. 151).

Case studies help to get the conversation started, and then the conversation continues on after the case study is completed.

My methods are different from traditional autism research because researchers in autism have not utilized the combination of the diary and interview methods. Autism research methods have been grounded in different "treatments of choice" (Watson, 1996). These include an early and intensive intervention behavior modification program created

by O. Ivar Lovass (1987), and normal classroom placement based on a high level of functioning and achievement of normal intelligence test scores. The treatment of choice for children with autism may be the Lovaas program. But the best approach can be decided by considering several issues: “(1) the age of the child; (2) the treatment strategy; (3) individual differences among children with autism; and (4) intensity of intervention” (Watson, 1996, p. 1). These issues contribute to the type of method used to study autism and therefore, assist the autistic child to better communicate. Watson (1996) gives other research strategies:

Another important issue in communication intervention is the use of augmentative communication. The emphasis in the Lovaas program is on verbal imitation and production, but there is evidence for benefits of the early introduction of augmentative strategies to children with autism. For instance, Bondy and Frost (1995) have formalized steps for teaching young children with autism to use a Picture Exchange Communication System (PECS) and implemented this approach with 66 preschool children with autism who entered their program without functional speech. All of the children were able to learn to use the PECS at some level, and 73% of the children went on to develop verbal skills. Although there was no comparison group included in the study, Bondy and Frost pointed out that this percentage is higher than figures cited in the literature that only around 50% of children with autism develop useful verbal skills (p. 2).

The methods employed by autism researchers assist children with autism to communicate with others, in verbal and nonverbal ways. The PECS strategy is similar to

the icon books that Nina and Waverly use in that pictures help these children ask for items they want or need. Others have investigated the use of different communication treatments with children with autism, including speech-only, sign-only, total communication, and alternating sign and speech training (Layton, 1988). The most-used method in studying autism is diagnosis made by observing behavioral symptoms. Bachevalier and Loveland (1996), two of the country's leading authorities on autism, recognize autism as an incapacitating, lifelong, pervasive developmental disability characterized by problems with social interaction and communication and odd patterns of activities (p. 1). They observe: "problems in social relatedness and communication; abnormal responses to one or a combination of senses such as sight, hearing, touch, balance, smell, taste, reaction to pain; speech and language absence or delays; abnormal ways of relating to people, objects, and events" (p. 2). Observing behavioral symptoms such as these has been critical to research methods in the field of autism. Loveland (1996) explains that autism affects thought, perception, and attention, stating, "We believe that autism is a broad spectrum of disorders that ranges from mild to severe; therefore, we refer to 'autistic spectrum disorders'" (p. 1). Loveland, an expert in language pragmatics, (the use of language in relation to social context), also stresses that these behavioral observations include language pragmatics. So what is observed in autistic children is their inability to know how or when to *use* language. Loveland (1996) argues:

An aspect of language that tends to be disturbed in autistic people has to do with knowing how to use language appropriately and in context. That includes

knowing how to hold a conversation, thinking about what the other person in a conversation understands and believes, and tuning in to the meta-linguistic signals of the other person, such as facial expression, tone of voice and body language. It is important to remember that communication is as much nonverbal as it is verbal, and autistic people have great difficulty 'reading' nonverbal language (p. 2).

Autism research focuses on strategies that parents, teachers, and clinicians use to help autistic children communicate with and socially relate to others.

My research methods, using the diary and the interviews together, helped me to learn how the parents and teachers of autistic children define and negotiate progression and regression. Their social construction of progression and regression of the autistic child's communication and social abilities was identified by examining the diary episodes and by analyzing their answers to interview questions based on their diary recordings. By combining the diary and interview methods, I was able to investigate how the parent and teachers negotiate definitions of regression and progression, and the implications of that process.

The case study is useful in that it is a detailed analysis of how the parent and teachers *talk about* and *construct* the autistic child's behaviors. That is, the diary and diary/interview provided a glimpse into how the parent and teachers construct meanings *together* of the autistic child's progression and regression in communication and social skills. Traditionally, the individual is the unit of analysis from a medical approach to autism. By studying communication processes, I was able to examine the "betweenness" or joint construction of the parent-teacher relationship, rather than simply focusing on

participants as individual, isolated units.

Practical Implications

Parents and teachers of autistic children approach autism differently in that their roles are grounded in different experiences. Depending on their role, parents and teachers clinically and experientially define the behaviors and symptoms of autistic children. Parents tend to experientially define their child's behaviors, whereas teachers tend to clinically define their students' behaviors. A parent or a teacher may define autistic behavior clinically, experientially, or both. Parents are their children's first teachers and typically view their children as extensions of themselves. Parents have the permanent responsibility of raising the child and working with the child's disability. Teachers have the temporary responsibility of pedagogically guiding the child while the child is under their care.

Reflexivity also has practical implications for parents and teachers of autistic children. The negotiated definitions of progression and regression influence how the parent and the teachers interact with the autistic child. The parent's and the teachers' interactions with the child influence the definitions they negotiate. For example, Waverly found screaming to be progression and regression. She viewed screaming as communication, so that is progression, but she also said screaming is drawing too much attention to one's self, and that constitutes regression. Waverly will interact differently with the child, depending on if the child is progressing or regressing. She will work with the child to move toward progression and will work with the child to move away from regression. Her definitions of his progression and regression help to determine how she

interacts with him.

Parents and Teachers Approach Autism Differently-Parents' Continuous Vs. Teachers' Segmented Experiences

This study highlights the differences in parents' and teachers' experiences with autistic children. Parents and teachers of autistic children approach autism differently because parents have a continuous, never-ending experience with the child, whereas teachers have segmented experiences. Parents of autistic children have an overwhelming responsibility because they never "get a break from autism." It pervades their environment. Raising a non-autistic child, a "normally developing" child, is exhausting enough, but it doesn't even come close to raising an autistic child. The demands of the non-autistic child pale in comparison to the demands of the autistic child. This important point must not be forgotten and that is why it deserves special attention and consideration. It is also very relevant to context. Teachers and parents experience autism differently because the contexts they are operating in are so distinct and disparate.

The autistic child's teacher interacts with and observes the student in a more formal, traditional, fixed-time setting, whereas the autistic child's parent witnesses the ongoing progression and regression day-to-day. The teacher cannot observe how the child behaves or what the child is like outside of school. Parents generally do not observe their children while they are in school.

Howard told me that he didn't know what Matthew was doing in school. If the teacher does not say what Matthew likes or dislikes in school, then Howard won't know. When I interviewed Howard, he asked me, "What does Matthew do during recess?" He

wanted to know about Matthew's activities and interests, too. He's interested in knowing what Matthew is achieving academically, of course, but he wants to know specifically what he does when he's with other children. These are important things for him to know. They are things the teacher may not know about or may not have thought about. He would like to be kept informed of Matthew's behavior outside of the classroom, during recess, field trips, etc. Behaviors the teacher may think are mundane may be of vital importance to the parent. Because Howard cannot be there himself, he would like more frequent comments and updates on what Matthew is doing at school since Matthew cannot tell his father himself. So, the episodes and speech acts that are parts of the context need to be relayed to Howard.

Howard also conveyed the fact that Matthew shares more with his brother than he does with children in his class. So, the teacher cannot observe that in the context of home since Matthew has a different side to him at home than he does at school. The same can be said that Matthew is different at school than he is at home. If the teachers and the parent do not regularly compare notes, how will they ever know about this discrepancy? They each do not always know of the different episodes happening in these two very separate contexts. More two-way communication between the parent and teachers is needed. They would each benefit greatly from hearing of the at-home and at-school behaviors that Matthew displays for each.

Parents and Teachers Learn from Each Other

One important principle that each participant divulged to me was that whatever Matthew is being taught at school should be enforced at home, and conversely, whatever

is being taught at home should be enforced at school. In this way, Matthew won't receive conflicting information and whatever he is being taught would transfer to the other environment. Participants in this research project learn from each other because they freely gave of their time, attention, effort, and consideration. Their ultimate concern was to advance Matthew's educational progress and to improve his communication and social abilities. However, Howard indicated that he would like to know what his son is doing at school such as playing in the yard at recess or eating in the cafeteria at lunch. The most mundane behaviors that parents of non-autistic children take for granted are the interactions of their children at work and at play. They are able to directly communicate with their children in ways that parents of autistic children (as well as parents of children whose disabilities impact parent-teacher communication) cannot do.

Parents of autistic children can communicate directly with their children, of course, but their communication is more limited and they often have to resort to observations of their child. Parents rely on the teacher's observations to tell them what they cannot observe themselves while the child is at school. When an autistic child communicates or momentarily and briefly reaches out to us, that window of opportunity is rare and must be seized by the teacher and then passed on to the parent. This means so much to the parent, to be able to learn about and know their child as much as they possibly can.

The main request from Howard to improve Matthew's educational program is to complete a *quarterly*, a *monthly*, or even a *weekly* progress report on a standard school form. This form should detail what the child has done in school with the teacher's

comments on it about Matthew's behaviors or any behaviors that come to mind or stand out. It should also state if Matthew has or has not reached IEP goals. Howard would like to see broad goals mutually defined, between the teacher and him. He would also like to have more feedback from the teacher, what she would want Howard to teach Matthew at home, so Howard can better help the teacher (reinforce what Matthew is learning and keep it consistent at home and at school). Then he can communicate with the teacher and know what Matthew is learning and when he does or does not use language, gestures, or other nonverbal forms of communication.

The need for this standard school form can be shown in the following example. Howard was unaware of Matthew's desire to ride the red bike at school. Howard did not know about this or even that his son enjoys riding bikes. Howard would like to have known that Matthew tries to get the red bike every day at school during recess. Howard asked, "Is it the color he likes or the type of bike [over the other tricycles]?" The point is, Howard does not know his child's behaviors or desires at school. Matthew exhibits two different sets of behaviors at home and at school because the contexts are so different from one another. Generally, parents of non-autistic children take for granted that they can simply ask their child what they have done in school each day and the child can respond to their parent's inquiries. Autistic children do not have this traditional form of communication. Howard asks that the teachers write out progress reports explaining these types of incidents so that he can get to know his son even better. If the teachers do not inform the parent of these events, how will the parent ever know?

Lack of Communication Between Parent and Teachers

There was a significant lack of communication between the participants, especially in the third year of the diary, from 1999-2000. The diary for the 1999-2000 school year under Waverly's tutelage contained entries from August 1999 to November 1999, and very few were recorded during that time. The November entries were the last to be documented before my February 2000 interviews with the participants. Taking advantage of the diary more often would surely have augmented their communication, which would have increased their opportunities to socially construct Matthew's progression and regression of communication and social abilities. If they had regularly put this powerful communicative tool to use, they would have experienced a heightened sense of teamwork. The few diary entries between Waverly and Howard strengthen and further show the centrality of regular communication in the social construction of the parent-teacher relationship and definitions of the child's progression and regression.

Contributions to Autism Literature

This thesis extends on autism research because it illuminates the close bond that can form between teacher and student. It also shows that because of the intensity of the symptoms of autism (that each child needs more attention), as well as the much smaller class size, the teacher gets to know the child much more than a teacher would in a typical, non-autistic class. Nina gave me insight into Matthew because as his second teacher, she was able to learn about his particular likes/dislikes and communication and social behaviors. She gave some information about him without my requesting it, thoughts that came to mind without prodding at all. It was amazing that she could identify him and that

she knew so much about him, as she does with each of her students. I realized that she forms a strong bond with them and they with her.

The relevant information regarding Matthew's communication and social abilities was that he appears to be ego-centric, self-centered, and that he grabs something (like a toy) when he wants it instead of using the icon book or requesting it in any other way. He cannot process too many stimuli or too many things all at once. When he is overwhelmed with excessive stimuli, he will cover up his ears and this lets the teacher know he is distressed with it all. He eats the same things over and over for lunch and at snack time and must eat on the same place mat every day. It was a major accomplishment when Nina gradually switched from a green place mat to a white one to introduce change for him. He put up quite a fuss about it but eventually allowed it. He is very ritualistic and this is typical of autistic children.

Another area Nina discussed was Matthews's inability to engage in sharing and turn taking and his socially inappropriate behavior, also very typical in children with autism. For example, the class takes integrated trips to locations outside of the school, such as the nearby McDonald's. They learn to walk together as a group and to follow directions. Once there, Matthew had a habit of taking and eating french fries from strangers' tables before Nina could stop him. Usually the stranger was mildly taken aback but then understood when the teacher apologized and explained his disability. However, the teacher used these as learning points and told Matthew that he could not do this and that they were not his to eat. The reason that these students with autism took these trips was to integrate them into society and to learn to be a cohesive group, a class.

If autistic students are kept isolated from non-autistic children and from the rest of society, then they do not learn how to follow implicit and explicit social rules.

This concurs with the autism literature because as Dr. Ruth Sullivan (1994) states, "Among more disabled individuals, there is a severe deficit in social skills. Even higher functioning individuals have significant difficulty understanding the nuances of normal social behavior, with its myriad and changing social rules" (p. 6).

This thesis project further adds to the body of knowledge in autism literature. My interview with Waverly illustrates this. I found that Waverly is a soothing, pleasant person, and I could see the high level of patience and the desire to help others within her. Waverly prefers to use the telephone to writing in the diary. She likes to call her students' parents when she needs something instead of writing in the diary. So, there is not as much in the diary from her as there was from Nina. She says because of this, there is not as much day-to-day written communication as there was in Nina's class. But, she does say that the diary provides a means of ongoing communication and that it keeps the lines of communication open. She uses the diary as a backup and says it reinforces what the parent and teacher say in their phone conversations. She explains it is not one or the other, but several communication tools that are used.

Waverly also pointed out that the IEP (Individualized Education Program) Report Card is used heavily by her because everybody (the teacher, the parent, the school psychologist, the school nurse) gets together to discuss the student's goals. It is sort of a meeting place for everyone to make sure they are all on the same page and are describing the same child. This is because they often find that the child is a different person in

different contexts. An autistic child (as in any other child, autistic or not) may act very differently than he or she does at home than at school, or vice versa. The IEP Report Card allows everyone involved to understand the child more fully. I found that Waverly relies on the IEP Report Card and that she places great importance on it, and with good reason. It is here that goals are set for each child and it calls for the teachers to be accountable for working toward these goals. The IEP Report Card adds to autism literature because it is another way for parents and teachers to meet the educational goals of autistic children.

The present study suggests that parents and teachers of autistic children must *continuously* engage in two-way, open communication. This two-way communication is required and the absence of it truly affects the parent-teacher interaction, influencing how they socially construct progression and regression of the autistic child's communication and social skills. For example, the parent's brief or non-existent responses had a deleterious effect on the social construction of these terms. Although the parent and teachers in this study communicated with each other, they expressed a need for increased interaction. This would provide greater opportunities for defining the autistic child's progression and regression. Defining and socially constructing these terms will help parents and teachers strategize and develop more comprehensive educational plans by identifying areas the child could work on and improve in.

In order to better define and socially construct the progression and regression of the child's communication and social skills, parents and teachers should provide support for each other and to work together as a team. In the present study, the parent and

teachers expressed the desire to talk with each other more and gain more from each other. For example, Howard wanted to know what the teachers were teaching Matthew in school. He said that the teachers had taught Matthew hand gestures, as in sign language. Matthew had learned the hand gesture for “water,” but Howard did not know this was what Matthew was learning in school. So, at home, when Matthew gestured for water, Howard did not know the gesture’s meaning. Howard said he needs to understand Matthew and he needs to know what he is learning so that they can together use these hand gestures, or sign language, at home. Howard felt bad when he did not know what his son was trying to convey to him.

Contributions to Communication Literature

This thesis project is unique in the field of communication studies in that it demonstrates that working with autistic children is a distinctly different communication event and is unlike other communication events because parents and teachers try to help autistic children break out of communicative and social isolation. Therefore, the *lack or reduction* of communication and social ability in autistic children can be improved by a merging of the autism and communication fields and by turning to this work to witness how this can take place.

My findings fit with previous communication research in that they demonstrate how social constructionism emphasizes the view that social knowledge is created through human interaction. Interlocutors, like the participants in this study, create and re-create the social world in which they live through communicative action, and in reflexive communication processes. The thesis also evidences social constructionism’s roots and

distinctions by again unveiling the mystical, undetermined and ever-changing nature of life.

This thesis project sets a precedent in that social scientific scholars in communication and autism research can benefit from the tool of social constructionism by seeing how it applies to helping parents and teachers negotiate how autistic children progress or regress in their communication and social skills. This is something that has not been done before. This thesis also departs from the more common methodologies used in social scientific research because it advances and utilizes the diary/interview method. This dual method has rarely been used before, so the methodology extends on past communication research. The diary interview graph, another new facet of the methodology, is novel. The thesis provides an introduction of new methods that will provide another avenue for social constructionist theorists to conduct their methodologies and it will build upon the body of knowledge in communication research.

Limitations

There are limitations to this thesis project. The limitations relate to the methodology used and to some objections about social constructionism. Since this is a case study, it is just *one* set of experiences regarding a single autistic child. It cannot represent all autistic children, or even the majority of autistic children. Future research should include several case studies in order to obtain data from different children in other educational contexts. In this way, a researcher could gather the experiences of parents and teachers of autistic children who fall within varying degrees of the autistic spectrum, as these interactions may vary according to the severity of the child's autism. If a child

has a more severe condition, then the interactions would change between the parent and the teacher because the child would need more intensive help such as a 1:1 teacher-student ratio. Also, more help from the parent would be required. Thus, we would expect increased interaction between the parent and teacher of a child with a more severe diagnosis of autism on topics not relevant to children with milder cases of autism.

Different degrees in the severity of the autistic condition require different educational and parental interventions.

A second limitation of the research stems from problems associated with the diary method, such as, “uncertainty about how typical the diary week was, uncertainty about how conscientious the diary keepers were, and a noticeable ‘fatigue’ with the task near the end of the week” (Lindlof, 1995, p. 121). The parent and the teachers recorded episodes in the diary, but these recordings were done sporadically, and not always on a daily or regular basis. This can be alleviated if they do not have to make entries in a rigid fashion. If they have flexibility, then it should not be a problem. The participants in this study did indeed have flexibility because there were no set “rules” for writing in the diary. They had a mutual understanding that they would write in the diary only when they had something to say to one another. The parent and teachers knew they were not forced to make comments when they did not perceive a need. On the other hand, this flexibility led to Nina and Howard exchanging many more entries than Waverly and Howard.

A third limitation of the present study stems from the nature of theory framing the research. Social constructionism, as a micro-level theory, does not address larger issues of power based on institutional structures. For example, Matthew’s teachers brought

power to their relationships with Howard based on their positions in the school and their roles in society as experts on instructing autistic children. Social constructionism, with its emphasis on interpersonal communication, neglects outside forces that may impinge on the participants' relationships and interactions.

A fourth limitation of this research is that the theory of social constructionism has its detractors. Willmott (1994) declares that, "Constructionism is based upon the understanding that all knowledge, including scientific knowledge, is socially organized and lacks absolute foundations" (p. 43). Still, this argument could be applied to the entire field of communication, as there are few absolute foundations about anything with which we cannot experience with our five senses of smell, sound, sight, touch and taste. This theory does not have absolute foundations, yet this lack of absoluteness recognizes that our social world is forever changing.

Suggestions for Further Research

Communication and autism scholars could improve and enhance the usefulness of the diary/interview method used in this project by conducting the participant interviews together. In this way, the researcher would be able to observe the joint negotiations of terms such as progression and regression of communication and social skills in parent-teacher or participant interactions themselves in action.

It would benefit both communication and autism scholars to share their research and to work together to help autistic children battle the neurological storm raging within them and the effects this storm has for them. If communication scholars understood how and why autism robs children of their sense of selves and their social relatedness, and if

autism scholars developed a deeper awareness of the pervasiveness of communication, then they can appreciate how their separate and distinct, yet inter-linking fields contribute to each other's body of knowledge.

The combination and duality of communication and autism research would be very valuable in lessening the deficit in communication and social skills in autistic children because shared knowledge would only help to solve the puzzling riddle, the enigmatic mystery of autism. This partnership would improve the chances for autistic children to live in a world where they better understand us and we more fully understand them.

Alternative theoretical approaches, such as critical theory, would highlight different aspects of the communication, and ultimately, the relationships, between parents and teachers of autistic children. More can be learned about the relationships and communication between parents and teachers by researching them through other theoretical approaches. The varied ways to view the communication and relationship aspects of the participants can be achieved through these approaches and can only add to the research.

Conclusions

After completing the research for this thesis project, I realized that Matthew's communication and social skills may or may not improve. They may continue to progress or regress in the future; it is not certain what will happen. Although Matthew speaks more than he used to, he demonstrates little speech at this time; it is unclear if he will speak more at a later time. However, Sullivan (1994) declares:

For the overwhelming majority of individuals who do not make it to college, it is best to assume, even if there is little or no speech, that they know more than you see or they can tell you. In my agency, Autism Services Center, we tell staff to expect that they understand most, if not all, of what is going on in their environment (p. 7).

Those close to Matthew have known for several years now that he knows what is going on around him. In fact, even though he experiences and suffers from impaired communication abilities, he acts and reacts to others in each communicative event, situation, and episode in which he is a participant. He may not be able to communicate as we do or to engage in the same social skills we use, but he is able to convey his feelings, wants, and needs in his own way. Those who know him are able to understand him and are willing to work with him to ensure that he receives further training to improve his communication and social skills.

Before I undertook this study, I thought that only the parent of the autistic child experienced an emotional impact. After completing the study, I realize that teachers experience this emotional impact, too. As the researcher, I, too, experienced an emotional impact. Both parents and teachers strive to improve the child's education and care. Both parents and teachers immerse themselves into this goal. They can also self-reflect and see how they have worked toward this goal. This research project has allowed me to help the parent and teachers achieve this. In regard to the autistic child's behavior, parents obviously want the child to move away from negative behaviors and move towards positive ones. Reflexivity takes parents and teachers in a different direction.

They recognize their own roles in the social construction of the parent-teacher relationship. As the researcher, I intervened and worked toward the goal to improve Matthew's education and care, and because of this, I became a part of the construction process as well.

This thesis project used social constructionism as a tool for the analysis of the discourse of parent-teacher negotiation of progression and regression of an autistic child's social and communication skills. It is innovative because this project is the first of its kind to use the social constructionist theory and the diary/interview method to investigate how parents and teachers negotiate, contest, and socially construct these abilities for the child depicted in the case study.

Notes

¹ Administrative clearance for the use of human subjects was gained from San Jose State University's Human Subjects-Institutional Review Board. Dr. Nabil Ibrahim of Graduate Studies sent a letter to the author approving this project (See Appendix C). This approval was contingent upon the subjects participating in the research project being appropriately protected from risk, which includes keeping the identity of the subjects confidential and keeping any and all data collected confidential-the diary and the interview transcripts. Thus, all names used in the thesis are pseudonyms; the child's school and city of residence are not specifically identified. As Lindlof (1995) maintains, "human subjects protections seem to work to the mutual interests of researchers, institutions, participants, and society as a whole" (p. 105).

Signed consent forms on SJSU Communication Studies Department letterhead (Appendix D) were obtained from the participants, (Howard, Nina, and Waverly). A second consent form was also obtained from the parent (Howard) of the autistic child for Research Involving Children or Wards (Appendix E). The principal of the School, who is also the head of the Autism Project of the County Office of Education, also signed a consent form on County Office of Education letterhead. IRB requested this form because the County Autism Project at the School is part of the County Office of Education.

² Although the School provided the research with more specific information concerning Matthew's testing, confidentiality requirements do not allow that information to be included in this thesis.

³ Icon or communication books have received little, if any, attention in autism and communication studies literature. Icon books shed light on how to communicate with an autistic child. Instead of trying to guess what the child wants or needs by attempting to decipher his or her communicative oddities, icon books may be used. As Nina explained in her interview, the students use icons in each of their icon books to tell her what they want/need. These icon books are crucial to the teacher/student communication. I could immediately see that icons are extremely important to Nina, and students must first use them when they approach her to convey their needs. There are two reasons for this. First, without icon books, the classroom would be chaotic. If each child were to attempt to communicate verbally and/or nonverbally simultaneously, there would be disorder; it would be impossible for the teacher to address their requests individually or otherwise. The second reason icon books are used is to encourage the child to communicate instead of to grunt, for example. If a child points and grunts at something she or he wants, then she or he relies on that form of communication alone. If it works and the child's request is met by simply pointing and grunting, then the child doesn't learn how to use other forms of communication.

The icon books are plastic and have several pages. These pages contain tiny plastic pictures or images with Velcro attached to the back of each. The child takes the icons and places them on the pages to show the teacher what he or she wants. For

example, if a child is thirsty, he or she will take the icon with a glass or cup and place it on a page in the book. The teacher can then ask the child to show what type of drink he or she wants. The child then can take either the apple, orange, or grape icon, for example, place that icon next to the glass or cup icon, and thus show the teacher that he or she has chosen either apple, orange, or grape juice. Or the milk icon is used to show he or she wants milk. The point here is that the icon book encourages the child to communicate what he or she wants by *showing through pictures*. If the child cannot verbally or nonverbally explain what he or she wants to drink, then the icon book shows clearly what he or she wants to drink. The icon book offers variety and allows the child to communicate for him or herself clearly while reducing his or her level of frustration because the child cannot say what he or she wants without it.

References

- Alexander, D., Cowdry, R. W., Hall, Z. W., Snow, J. B. (1996). The state of the science in autism: A view from the national institutes of health. *Journal of Autism and Developmental Disorders*, 26(2), 117-154.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: American Psychiatric Association Press.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed.-r). Washington, DC: American Psychiatric Association Press.
- Autism Research Institute, 4182 Adams Ave., San Diego, CA 92116 Tel: (619) 657-2881 or (619) 281-7165 Fax: (619) 563-6840 Web site: <http://www.autism.com/ari>
<http://www.autismresearchinstitute.com> or <http://www.autism.tv>
- Autism Research Institute. (1996, May). *ARI standard form letter reply* (ARI Publication No. 13). San Diego, CA: Dr. Bernard Rimland.
- Autism Research Institute. (n.d.). *Information about the autism research institute*. Retrieved March 14, 1998, from <http://www.autism.com/ari/icbr.html>
- Autism Research Institute. (n.d.). *What is autism?* Retrieved March 14, 1998, from <http://autism.com/ari/autism.html>
- Autism Research Institute. (n.d.). *What is autism?* Retrieved May 8, 2002, from <http://www.autism.com/ari/autism.html>
- Autism Services Center (National Autism Hotline), The Pritchard Building, 605 Ninth St. or P.O. Box 507 Huntington, WV 25710-0507 Tel: (304) 525-8014 Fax: (304) 525-8026.
- Autism Society of America, 7910 Woodmont Ave., Suite 300, Bethesda, MD 20814-3067 Tel: (301) 657-0881 or (800)-3AUTISM Fax: (301)-657-0869 Web site: <http://www.autism-society.org>
- Autism Society of America. (n.d.). *Autism checklist*. Retrieved March 14, 1998, from <http://www.autism-society.org/whatisautism/checklist.html>
- Autism Society of America. (n.d.). *Mission statement*. Retrieved March 14, 1998, from http://www.autism-society.org/asa_home.html

- Autism Society of America. (n.d.). *What are the most effective approaches to autism?* Retrieved March 14, 1998, from <http://www.autism-society.org/whatisautism/autism.html#approach>
- Bachevalier, J. & Loveland, K. (1996, March). Autism research. The University of Texas-Houston Health Science Center. Retrieved March 14, 1998, from http://www.uth.tmc.edu/uth_orgs/pub_affairs/uthouston/mar_96/aut.html
- Baker, S. M. (1996). Food allergies and autism spectrum problems in children. *Autism Research Review International*, 10(4), 3.
- Bondy, A. S. & Frost, L. A. (1995). Educational approaches in preschool. In E. Schopler & G. Mesibov (Eds.), *Learning and cognition in autism* (pp. 311-333). New York: Plenum.
- Bower, B. (1981). Autism: A world apart. *Science News*, 119, 154-155.
- Brown, J., & Prelock, P. A. (1995). Brief report: The impact of regression on language development in autism. *Journal of Autism and Developmental Disorders*, 25(3), 305-309.
- CAN (The Cure Autism Now Foundation), 5225 Wilshire Blvd., Suite 226, Los Angeles, CA 90036 Tel: (213) 549-0500 or (323) 540-0500 or (888) 8-AUTISM Fax: (213) 549-0547 E-mail: CAN@primenet.com or info@cureautism.now.org Web site: <http://www.canfoundation.org>
- CAN (Cure Autism Now). (1998). *A new organization founded by parents dedicated to finding effective biological treatments and a cure for autism* [Brochure]. Los Angeles, CA: Author.
- CAN Consensus Group. (1998). Autism screening and diagnostic evaluation: CAN consensus statement. *CNS Spectrums*, 3(3), 40-49.
- Carbaugh, D. & Hastings, S. O. (1995). A role for communication theory in ethnographic studies of interpersonal communication. In W. L. Hurwitz (Ed.), *Social approaches to communication* (pp. 171-187). New York: The Guilford Press.
- Chen, V. & Pearce, W. B. (1995). Even if a thing of beauty, can a case study be a joy forever? A social constructionist approach to theory and research. In W. Leeds-Hurwitz (Ed.), *Social approaches to communication* (pp. 135-154). New York: The Guilford Press.

- Cowley, G. (2000, July 31). Understanding autism: More kids than ever are facing the challenge of 'mindblindness.' *Newsweek*, 46-50.
- Cronen, V. E., Pearce, B. W., & Harris, L. M. (1982). The coordinated management of meaning. In F. E. X. Dance (Ed.), *Human communication theory* (pp. 61-89). New York: Harper & Row Publishers.
- Cronen, V. E. (1995). Practical theory and the tasks ahead for social approaches to communication. In W. L. Hurwitz (Ed.), *Social approaches to communication* (pp. 217-242). New York: The Guilford Press.
- C-SPAN Today. (1999, October 12). *Congressional hearing on children's health: CAN (cure autism now) addressing the house commerce subcommittee* [Television broadcast]. Washington, DC: C-SPAN.
- Dance, F. E. X. (1982). *Human communication theory*. New York: Harper & Row Publishers.
- Deetz, S. A. (1994). Future of the discipline: The challenges, the research, and the social contribution. In S. A. Deetz (Ed.), *Communication yearbook 17* (pp. 565-600). New Brunswick, NJ: Transaction.
- Dorland's Illustrated Medical Dictionary* (28th ed.). (1994). Philadelphia: W. B. Saunders Company.
- Duck, S. (1985). Social and personal relationships. In M. L. Knapp, & G. R. Miller (Eds.), *Handbook of interpersonal communication* (pp. 655-686). Beverly Hills: Sage.
- Duck, S. (1991). Diaries and logs. In B. M. Montgomery, & S. Duck (Eds.), *Studying interpersonal interaction* (pp. 141-161). New York: The Guilford Press.
- Duck, S. (1994). *Meaningful relationships: Talking, sense, and relating*. Thousand Oaks: Sage Publications, Inc.
- Emerson College, Emerson-Tufts Program in Health Communication. (1998, January). *Campaign of the month. National autism awareness month*. Retrieved March 14, 1998, from <http://www.emerson.edu/acadepts/cs/healthcom/Resources/autism.html>
- Freeman, B. J., Del'Homme, M., Guthrie, D., & Zhang, F. (1999). Vineland adaptive behavior scale scores as a function of age and initial IQ in 210 autistic children. *Autism Developmental Disorders*, 5, 379-384. Department of Psychiatry and Biobehavioral Sciences, UCLA School of Medicine/NPI 90024 USA.

- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40, 266-275.
- Gergen, K. J. (1992). Social construction in question. *Human Systems*, 3, 163-182.
- Gergen, K. J., & Gergen, M. M. (1982). The social construction of helping relationships. In J. D. Fisher, A. Nadler, & B. DePaulo (Eds.), *New directions in helping relationships*, 1, 144-163. New York: Academic Press.
- Grandin, T. (1998, January). *Frequently asked questions about autism*. Retrieved March 14, 1998, from <http://www.autism.org/temple/faq.html> from The Center for the Study of Autism Web site: <http://www.autism.org/contents.html>
- Greenspan, S. I. (1992). Reconsidering the diagnosis and treatment of very young children with autism spectrum or pervasive developmental disorder. *Zero to Three*, 13(2), 1-9.
- Harré, R. (1983). *Personal being: A theory for individual psychology*. Oxford: Basil Blackwell.
- Kanner, L. (1943). Autistic disturbances of affective behavior. *Nervous Child*, 2, 217-250.
- Layton, T. L. (1988). Language training with autistic children using four different modes of presentation. *Journal of Communication Disorders*, 21, 333-350.
- Leeds-Hurwitz, W. (1995). Introducing social approaches. In W. Leeds-Hurwitz (Ed.), *Social approaches to communication*. New York: The Guilford Press.
- Lindlof, T. R. (1995). *Qualitative communication research methods*. Thousand Oaks, CA: Sage Publications, Inc.
- Lovaas, O. I. (1987). Behavior treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavior treatment. *American Journal on Mental Retardation*, 97(4), 359-373.
- Mesibov, G. B. (1993). Treatment outcome is encouraging. *American Journal on Mental Retardation*, 97(4), 379-380.

- Nash, J. M. (2002, May 6). The secrets of autism: The number of children diagnosed with autism and asperger's in the u.s. is exploding: Why? *Time*, 159(18), 46-56.
- National Institute of Mental Health, Office of Communications and Public Liaison, 6001 Executive Blvd., Room 8184, MSC 9663, Bethesda, MD 20892-9663 Information Resources and Inquiries Branch, 5600 Fishers Lane, Room 7C-02, MSC 8030, Bethesda, MD 20892-8030 Tel: (301) 443-4513 TTY: (301) 443-8431 Fax: (301) 443-4279 E-mail: nimhinfo@nih.gov Web site: www.nimh.nih.gov
- National Institute of Mental Health. (1997). *Decade of the Brain: Autism* (NIH Publication No. 97-4023). Bethesda, MD: Author.
- Online Psych Inc. (1997). *So...what IS autism?* Retrieved March 14, 1998, from <http://www.onlinepsych.com.html>
- Pearce, W. B. (1989). *Communication and the human condition*. Carbondale, IL: Southern Illinois University Press.
- Pearce, W. B. (1994a). *Interpersonal communication: Making social worlds*. New York: Harper Collins.
- Pearce, W. B. (1994b). Recovering agency. In S. A. Deetz (Ed.), *Communication yearbook 17* (pp. 34-41). New Brunswick, NJ: Transaction.
- Pearce, W. B. (1995). A sailing guide for social constructionists. In W. Leeds-Hurwitz (Ed.), *Social approaches to communication* (pp. 88-113). New York: The Guilford Press.
- Pearce, W. B. & Cronen, V. E. (1980). *Communication, action, and meaning: The creation of social realities*. New York: Praeger.
- Peterson, T. R., Witte, K., Enkerlin-Hoeflich, E., Espericueta, L., Flora, J. T., Florey, N., et al. (1994). Using informant directed interviews to discover risk orientation: How formative evaluations based in interpretive analysis can improve persuasive safety campaigns. *Journal of Applied Communication*, 22, 199-215.
- Rimland, B. (1994). Recovery from autism is possible. *Autism Research Review International*, 8(2), 3.
- Rorty, R. (1980). *Philosophy and the mirror of nature*. Oxford: Basil Blackwell.

- Rutter, M. (1985). Commentary on Leo Kanner's 1943 article "autistic disturbances of affective contact." In A. Donnellan (Ed.), *Classic readings in autism* (pp. 51-60). New York: Teachers College Press.
- Santa Clara County Office of Education, Individualized Education Program Report Card (2001, March).
- Santa Clara County Office of Education, PsychoEducational Assessment Report (1999, September).
- Santa Clara County Office of Education, Speech and Language Evaluation – Triennial Report (1999, October).
- Schulte, J. (1992). *Wittgenstein: An introduction*. Albany, NY: State University of New York Press.
- Shotter, J. (1989). Social accountability and the construction of "you." In J. Shotter & K. J. Gergen (Eds.), *Texts of identity* (pp. 133-151). London: Sage.
- Shotter, J. (1993). *Conversational realities: Constructing life through language*. London: Sage Publications, Inc.
- Shotter, J., & Gergen, K. J. (1994). Social construction: Knowledge, self, others, and continuing the conversation. In S. A. Deetz (Ed.), *Communication yearbook 17* (pp. 3-33). New Brunswick, NJ: Transaction.
- Steier, F. (1995). Reflexivity, interpersonal communication, and interpersonal communication research. In W. Leeds-Hurwitz (Ed.), *Social approaches to communication* (pp. 63-87). New York: The Guilford Press.
- Stewart, J. (1995). Philosophical features of social approaches to interpersonal communication. In W. Leeds-Hurwitz (Ed.), *Social approaches to communication* (pp. 23-45). New York: The Guilford Press.
- Strock, M. National Institute of Mental Health, 5600 Fishers Lane, Room 7C-02, Rockville, MD 20857 Tel: (301) 443-4513. Mstrock@mail.nih.gov
- Sullivan, R. C. (1988). *Definitions of autism*. Huntington, WV: Butterworth-Heinemann.
- Sullivan, R. C. (1994). Autism: Definitions past and present. *J Vocal Rehabil*, 4(1), 4-9.

- Sullivan, R. C. (1997). Diagnosis autism: You can handle it! In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 1007-1020). New York: John Wiley & Sons.
- The enigma of autism, (2000, August 21). *Newsweek*, 14.
- The National Autistic Society, 393 City Road, London, EC1V 1NG, United Kingdom
Tel: +44 (0)20 7833 2299; Fax: +44 (0)20 7833 9666
Web site: <http://www.nas.org.uk>
- The National Autistic Society. (n.d). *Autism – the invisible disability*. Retrieved March 14, 1998, from http://www.oneworld.org/autism_uk/autism.html
- Tuchman, R. F., & Rapin, I. (1997). Regression in pervasive developmental disorders: Seizures and epileptiform electroencephalogram correlates. *Pediatrics*, 99(4), 560-566.
- U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, National Institute of Neurological Disorders & Stroke (NINDS), Office of Communications and Public Liaison, Bldg. 31, Room 8A-06, 31 Center Dr. MSC 2540, Bethesda, MD 20892-2540 or P.O. Box 5801, Bethesda, MD 20824 Tel: (301) 496-5751 (800) 352-9424 Fax: (301) 402-2186
Web site: <http://www.ninds.nih.gov>
- Watson, L. R. (1996). Communication intervention for children with autism: An update. *California Speech-Language-Hearing Association*, 25(4), 1-5.
- Willmott, H. (1994). Social constructionism and communication studies: Hearing the conversation but losing the dialogue. In S. A. Deetz (Ed.), *Communication yearbook 17* (pp. 42-54). New Brunswick, NJ: Transaction.
- Wing, L. (1973). Autism. *British National Society for Autistic Children*. The National Autistic Society, 1-2.
- Wittgenstein, L. (1972). *Philosophical investigations* (3rd ed.). Oxford, England: Basil Blackwell & Mott, Ltd.
- Zimmerman, D. H., & Wieder, D. L. (1977). The diary: Diary-interview method. *Urban Life*, 5, 479-498.

APPENDICES

Appendix A: Interview Guide

The following questions were based on the diary recordings made between the parent and the teachers of the autistic child during the 1997-1998, 1998-1999, and 1999-2000 academic school years. Aliases were used for the participants in this study. An alias (Matthew) was used for the child. An alias (Howard) was used for the parent. An alias (Nina) was used for the teacher during the 1998-1999 school year, and an alias (Waverly) was used for the teacher during the 1997-1998, 1999-2000 school years.

1. How does the diary help you? {To Howard, Nina, and Waverly}
2. How has it helped you with Matthew? {To Howard, Nina, and Waverly}
3. How does the parent help you understand Matthew's development? {To Nina and Waverly}
4. How do the teachers help you understand Matthew's development? {To Howard}
5. How do you define progression? {To Howard, Nina, and Waverly}
6. How do you define regression? {To Howard, Nina, and Waverly}
7. How is it that the teachers inform you of Matthew's communication and social skills? {To Howard}
8. How do you (as the parent) feel about the school's plan for developing Matthew's communication skills, for helping him to communicate or verbalize? {To Howard}
9. How does the parent respond to questions about Matthew's communication skills? {To Nina and Waverly}
10. How does the parent respond to questions about Matthew's social skills? {To Nina and Waverly}
11. How do you determine progression and regression of Matthew's communication skills? Please give 2-3 examples. {To Howard, Nina, and Waverly}
12. How do you determine progression and regression of Matthew's social skills? Please give 2-3 examples. {To Howard, Nina, and Waverly}

13. How do the teachers let you know that you are working together as a team? {To Howard}
14. How does the parent let you know that you are working together as a team? {To Nina and Waverly}
15. When Matthew is screaming, how does that fit in with his progression or regression? Please give me an example. {To Howard, Nina, and Waverly}
16. Has the screaming increased or decreased since you began writing in the diary? {To Howard, Nina, and Waverly}
17. What do you need from the other participants to help you improve Matthew's communication and social skills? {To Howard, Nina, and Waverly}
18. Are there any other things that you think I should know? {To Howard, Nina, and Waverly}

Appendix B: Diary Interview Graph

Diary Interview Graph
Graph of Participants' Interview Questions and Answers
Based on the Diary Entries: Methodological Results

Questions	Answers-Parent (Howard)	Answers-Teacher (Nina)	Answers-Teacher (Waverly)
1. How does the diary help you?	<p>ANSWER TO QUESTION #1</p> <p>It helps me, in a way, to communicate with his teacher, what he's doing, mainly if there's any problems or new things that she doesn't understand that he may be, you know, yelling for this or trying to make a sound for that. Basically, it's a communication tool between us, while he's in school. It goes to school with him every day; it comes back every day. It's not used daily by me or by Waverly. It was more by Nina when he was in her class, just basically to state, you know, what he's doing in class, and how he's doing in any, like new things she may be teaching him. She may need some information on what he likes or dislikes</p>	<p>ANSWER TO QUESTION #1</p> <p>It's the only way to keep constant communication between home and school; also I can know what's happening at home. It tells the parents what's happening here. I use it to ask for things that the child needs-diapers, extra clothing. Sends notices home. I ask the parents questions in it, they respond and they ask me questions in it and I respond. Daily or weekly thing. Tells the parents what we are going to do. Gives me more time to say more on a form rather than on the phone-I really don't have much time for the phone so I write after the kids have gone. Helps to keep a log in case something happens; parents say I wrote you and asked for</p>	<p>ANSWER TO QUESTION #1</p> <p>Well, it gives an ongoing, day-to-day communication with the parents. We can check things. Also, they can tell us if there's some variable factor going on that day like maybe he didn't sleep the night before or maybe he has a cold. Um, there might be some variable factor, but like as I explained to you before, I do most of the communication on the phone both with the grandparents and the parents. So, there's not as much day-to-day communication as there was last year when he was in Nina's class. But it does help 'cause it's a means of ongoing communication. Keeps the lines of communication open. It reinforces what we say in our</p>

2. How has it helped you with Matthew?

and things like that.

ANSWER TO QUESTION #2

I don't really think so. It's just more of a way to communicate with the teacher. Without the diary, it would be more difficult to communicate with the teacher. It's easier to write in a diary than calling Waverly or you know, when he was with Nina, to find out, you know, what was going on. But, I did want more feedback on certain issues regarding, I felt I wasn't getting enough back from Waverly, about what's his program, you know, what are you teaching him in class and how is he doing compared to you know, the other students in the class and things like that. I would actually prefer something more um, like, uh, a

this, etc. Helps for compliance. Protective for both of us. I need to know what's happening at home, whatever the parents want me to know.

ANSWER TO QUESTION #2

For example, Matthew was screaming in class, very possessive. I found out that there was another baby in his home sharing his space. For me that helped me and that made it easier for us to deal with him. Whenever there is a new behavior, you have to really take care of that behavior because the kid tends to stay, (self-stand). If they have a behavior that works, they continue and it just progresses and progresses and it makes it uncomfortable for everybody, for the kids, too. I need to know what's going on at home. If there's a change in the environment at home, if he's fighting for the toys,

conversations, too. Like I can say, "Here are the forms you requested" or "Let me know if there's anything else," so it also reinforces the phone conversations. So, it's not one or the other; it's several tools used.

ANSWER TO QUESTION #2

Well, the IEP, [Individualized Education Program for Special Education Report Card] yeah, that has that's where, course, everybody gets together and you sit down and you discuss the goals. Like the teacher writes something in the description but we ask the parents if that sounds like him because sometimes the teacher will write up a description and it's a different boy. He might be one person at home and another person at school. So, it gets everybody on the same wavelength. Then, I don't know how familiar you

standard school form, you know, that says, you know, what we're teaching him here, in, you know, for communication skills, or what we're teaching him here for math skills or reading skills or all the way down the line instead of a diary. An actual something that's you know, addresses each area. And I think that's done in his IEP but that's done every one or three years, you know. Weekly would be fine. Or, you know, you know, how is he doing with eating his lunch, is he trying new things, is he eating the snacks I give him. Would it be possible for them to have the kids more around the other kids in the school in the lunch room, or at least going to the lunch room and see if they would even want anything from there because, you know, he takes his lunch all the time. And because of his

I can know why. Then I can work more that he has to share. Since he has difficulty with sharing I can say, "Look what I do in class is I tried with him. You give me the horse and I give you the dinosaur." So then the parent can also do it at home so Matthew doesn't have that control. Understand his birthday, blowing out candles, ask parent to bring cupcakes to blow out candles. Parent said well he came from school today and he had red eyes, and they asked me if anything was wrong. So I told the parent what happened, that he cried just before the bus came. The parent cannot be here all the time but they have an idea what's happening all the time in this environment. I like the parent input because my philosophy is that the parent is the child's first teacher in the child's life. The parent may not

are with IEPs. Every three years we have the Triennial where all the assessments are done. The OT (Occupational Therapist), speech therapy, the psychologist comes and usually someone from the school district. But, we also have the yearly updates. And so it just keeps you current and forces us to get together, you know, at least once a year and talk it over and then, um, there's, they also have to be updated every three months you have to, and of course it forces you to look at the goals and to write up a little progress report on each of the goals and where you are. You should have had the speech therapist come. I think it's three, two or three times a week. Let me see in his IEP report. She'd be another one to interview if you would want to try and set up a time. She's fairly new to Matthew,

limited appetite for certain types of food, you know, I would think he gets tired of peanut butter and jelly sandwiches every day but that's what I know, he will eat it. That's why my concern is, you know, is he getting tired of it but he has such a limited range of foods that he likes, I want them to make sure he eats something, you know. For the standard school form, I'd like to see diet, behaviors, math, what type of program is he doing every week or month. Like, be specific in that we're trying to get him to say the vowel sounds, you know, how are they teaching him math skills, things like that. Even though he's probably very limited, you know, is his curriculum changing every week, every month so he's constantly trying to learn something new. Yeah, maybe, you know, an update,

be professionally trained like we are, to have the professional terminology, but the parent says, "Ah, that cry-I think he wants this." The parents just know their child, they have the instinct to know what they want/need. They might not have the label for it but if they know it, it helps me a lot. So I can professionally polish it but it was the parent's idea. Both of us learn by communicating to each other. What happened was, today we went for a walk he did not want to go on, so that's why he's miserable and screaming today when he's coming home from school on the bus. The diary helps in so many ways. It also helps when I'm working with something in class that is positive, I say, "Look this is working in class, why don't you try it at home?" I try not to tell the parents to

she's new to our school this year. Let me see. Ok, he gets speech therapy two times a week. He gets individual therapy two times a week for twenty minutes. Now one time a week he gets classroom group therapy where the speech therapist does something with the whole group. The diary is day-to-day and the phone conversations are day-to-day. This (the IEP) would be more, like something I may check once a week or once a month. It's not as much day-to-day. But then, since this new form is so detailed. At first I didn't like it, but I really like it now. For one thing, it's on the computer and I can just type things out, I don't have to write everything, I type it. But also, it's so broken down that you, like we have, for each goal, there's at least two or three benchmarks and then those have to be reported on

3. How does the parent help you understand Matthew's development?

like has he achieved this goal in the IEP, you know. I have no idea until the next IEP. The triennial is three years and the other one's one year. There's nothing to say that he has or has not (reached the goals in the IEP). Because I know what he does at home, but nothing what he does at school, in regards to learning. And if he's actually doing very well in a certain area by learning something by, I don't know, repetition or by constantly being reinforced, then it would be helpful to know that so we can do the same things with him at home.

Well, like, they now turn in, I guess he does his work at school, a paper, or I don't know, writing numbers, or tracing, I don't know if he's writing them on his own, if he's, if he's being helped by tracing the numbers, or the letter, or what have you, and there's no.... I get

do something, but parents really want to help their kids. Professionals, we have to really be careful, we're not supposed to dictate to parents. I know we get carried away. Sometimes in our professionalism, I try to define a word for a parent. We have professional jargon that we have to explain. In communication, there is jargon that the parents don't understand so we have to explain what the jargon means.

ANSWER TO QUESTION #3

Using the communication book (diary) with some consistency, 3-4 times a week. Responding to my questions. Howard told me that he worked at night, so I could leave a message, leave a note, etc. It was

once every, at least every three months. And he does have three communication goals, three pages of that, that he's working on. So, I like the form now, once I learned, you know, figured out how to use it. Which isn't really too hard, it just took a lot longer. It calls for accountability of the teachers, I think and it's good. With the IEP, you can see what you're working on. What the broad goal is, too, sometimes in the day-to-day thing, you're worried about, you know, changing a diaper and keeping them quiet and you know, but you forget the overall goals. And also, you can just look at the top ones, they kind of remind you of the broad goals you're working towards, too.

ANSWER TO QUESTION #3

Well, usually I ask him if I have a question, like

the sheet and it has his name on it, and let's say one through ten, and you can tell that somebody wrote over the numbers, now there's no note on it stating did he do this by himself, was he helped by somebody, did he do half of it with somebody and then he was left to do it, you know. I don't know if he did it on his own, or if they just did it with him. They should comment on them.

4. How do the teachers help you understand Matthew's development?

ANSWER TO QUESTION #4
In what way, with his education?
[Yes] Well, Waverly may write a note every once in awhile saying that, you know, Matthew's screaming has, you know, regressed but he still may be out, you know, scream once or twice during the day, and usually I think he screams, is when Matthew doesn't have any patience for anything and if he wants something, he

understood that he would get back to me. So we didn't really talk much but somewhere through the book (diary) we established that when you ask me a question, it's ok if it takes a day or two to get back to me. I ask permission from Howard through notes in the book (diary). I need to get permission from the primary caregiver [Howard] to speak with Matthew's mother. I would ask why Howard didn't bring something and I'd find out that he'd been staying with his mother and so then I let an aide know that if it looks like after the weekend he had spent time with his mother, we would know why he didn't bring his food. If the food isn't there, he would scream.

ANSWER TO QUESTION #5
Affection: he's very affectionate. When Matthew is running away, I hold out my arms to him and say,

sometimes it's like, "Oh, Matthew said Howard," you know, it's the dog at home, and he'll say, "Oh yes, he's been saying that for three years." You know, I think he said something brand new, and so it keeps it, you know, sometimes they'll do things at school they won't do at home, and they'll do things at home they won't do at school. But, Howard's pretty good, he'll call and tell me, you know if there's any change if um, you know Matthew suddenly doesn't like to eat something, he's pretty good about keeping us informed. Any changes. Usually he calls, sometimes he writes in the book (diary), too. He always returns my calls. Sometimes I can never find him. I'll call his home number, but he always returns the calls within the day, yeah. He's very good about that.

5. How do you define progression?

doesn't understand why he can't have it now when he wants it. And when he doesn't get it, his behavior is to either scream or throw a little temper tantrum or cry. You know, to say, "I want this; why can't I have it?" He doesn't understand why he can't have it, you know, at that time. I think he uses it (the screaming), so he shows, he, that's the way he communicates how he wants something and his displeasure when he can't get it. And he knows that when he screams, that he's communicating the fact that I want this and you're not letting me have it and I'm upset. So, because I can't explain to him, you know, you know, like for example, driving down the road, he points to McDonald's but he goes, "Doo Doo Doo Doo," and we stop off at Blockbuster and we come back out, we come, you know,

"Come on, come on!" and he comes running for the hug. I can't run after him because he'll run even farther. I got him to come. Reduction of screaming, going to the bathroom, (successful potty training). Making progress or part of progress is not so much compliance but following routine, because when they follow routine he can build his own personal routine. When they come here, it's not time to go to the play area. When they come off the bus, first of all take off your jacket, hang it up, take off your backpack. Matthew will open his lunch, take out his lunch, put it in the refrigerator. These are all little steps, and he follows the steps. So in the area of self-help skills, he's improving. Social skills-eating and keeping your hands to yourself. If somebody takes your food, you don't

ANSWER TO QUESTION #5

Ok, so the gist of this is on communication and social skills. Well, one thing he does, he yells when he wants something rather than asking. I am working with the speech therapist; she's giving him more icons. Because sometimes, like he loves potato chips and salty things. He'll go to all the trouble of going over there and get his book. He usually doesn't use the communication book for meals, but he'll go through the pages, he'll find the chips icon. Although, sometimes he'll say it, too. But, he'll show me, communicate in different ways. Now, he does scream more than I like. We're trying to get him different ways to communicate and to ask quietly. Or sometimes it's just impatience, like, he's done his job and he knows that

out the driveway, and well, I gotta go do some other (errands), I gotta go to the bank and the post office first, then we're gonna go to McDonald's and have lunch. But, by him seeing it [McDonald's], and passing it, he figures, we need to go there *now*, and there's no way for me to communicate to him that we will be coming back to there. And he just feels that once we leave, he's not gonna get it. And by him screaming, showing his displeasure, he's like, pissed off. I mean, he doesn't understand why. Well, he's like any child, he doesn't like to be told no, you know, he's mischievous. And he knows when he's doing something wrong and when he's not supposed to do something, and when he gets caught, because he laughs. Like, when he does the VCR and he, for whatever reason and I still

slap them across the face. He makes some sign, (his face in his hands), that's the way I know someone is bugging him. But then when he gets excited, he does the same thing. You really, it's a fine line. I have to look at his face and see the smile on his face or his eyes to know. So, in my dilemma, he was using the screaming to express pleasure which I didn't want to extinguish, but at the same time he was using it to express frustration which I did want to extinguish. So it was really a very difficult time for me. So what I had to do was, when he started screaming I would say, "Shhh [with finger at lips], Matthew, Matthew we have to be quiet..." Or if you listen to the radio or watching TV (and he's screaming) I turn it down so that he has to stop to hear what's going on. When he wants to hear it, I turn the volume down so he

he gets to pick a toy from the toy cabinets. So, he's standing in front of the toy cabinets screaming. Or we're trying to show him, you know, we'll tell him we'll be there or you wait and that he needs to learn the waiting, you know, control the screaming. [With the screaming] He seems to be a little bit worse now, but it's um, just a lot of things going on, like a lot of celebrations and stuff. We were in the Chinese New Year parade. It's like he progressed and he might have slipped back a little. One thing he might think that we're not hearing him and that's why he reverts to the screaming. Or I've seen it with other autistic children, sometimes you'll tell them no and they think you don't get it so they're screaming, "Chips! Chips! Chips!" and you say, "No, we're all out of chips," or "You've had

don't know why, he likes to fast, watch movies fast forward, and it's either because he doesn't like a certain part or he just likes the way it looks, or whatever. And I've told him, you know, to stop because it ruins the tape and the VCR and everything, so, when I walk out the room, after, he knows after I walk out the room, he'll say, "Bye!" And I shut the door and I'll sneak over and I'm looking through the door and I can see him push the button and I'll he'll see me and I'll walk in real fast and I'll say, "Matthew, I said no!" and it's like even if he hears me coming, I've seen him walk over there, push the button real quick so it'll stop, and then he'll kind of like walk back over towards the bed and look at me like, (he's caught), and smile. 'Cause he knows he's doing wrong and he knows he's not supposed to

has to stop everything to listen. Or I turn the lights off or something. He likes deep pressure on the head (with the permission of the O.T.-Occupational Therapist) to help Matthew calm down. He likes to put things in his mouth so you have to find something really safe for him to chew on. So for me, my thing I'm seeing is that progress for the kids sometimes is different than progress for us. When he became potty trained, he made progress. Now, with the screaming, we have to let him know that at this time the screaming is not appropriate. If you want something, if you're quiet, I will give it to you. So, he'll know that being quiet has a reward. Screaming doesn't have a reward. Progress is meeting little goals. We have a lot of regression, progression,

enough chips," and they just think you don't get it. So, pretty soon they're in your face. "Aaahhh! Aaahhh!" and they think *you* don't get it, you know, and so that's an autistic characteristic, yeah. And I am working with the speech therapist on giving ways for Matthew to communicate. Also, the ways to tell him, "No, you can't have it" or "Wait." I see progress with the cognitive although he might be a little noisier, too. Also, we're trying not to reinforce it, [the screaming]. But thing, like, he's very good when we've been in the community. I guess the family has had some problems bringing him out in the community. But he's pretty good. We usually go to McDonald's. He knows, like, where we're going, what to expect, how long it's gonna take, when he's gonna be finished. So, he pretty much knows

6. How do you define regression?

do it but he'll do it anyway. And it's like a game to him. (about the teachers using sign language to communicate with Matthew). That would help, too, if I knew, you know, because I think at one time they taught him how to say "drink" by using his, you know, by gesture, or "more," but you know, I had no idea what that meant, and if I had, if I had seen him do it at home, I'm like, I don't know, I thought he was playing with his hands or doing something, you know. Instead of, because it's better for him to do a hand gesture like that than walk to the refrigerator and get me a cup. I know then obviously what he wants, but if he used the hand, you know, because it's like, let's say if I have a glass on the dresser or something, I said, "Matthew, can you go get me the water," you know,

regression, so, you have to know, what is it you really want? Like going to the bathroom, that was a big one. Sitting there feeding himself, helping to get himself dressed, waiting, turn taking, now he's riding a bike on the playground, only the red bike-no other bike.

ANSWER TO QUESTION #6
Old behavior that we dealt with that they started off with, because when they get stressed, they go back to their old behavior, like screaming. He's stressed or if that behavior produces the results he wants, he'll go back to it. For him, he's getting what he wants. For us, it's regression. He thinks he's getting what he wants. His scream is so piercing that you want to give him what he wants just to keep him quiet

how to do it, plus he loves french fries, so it's a rewarding thing 'cause I have a couple of the other kids, like McDonald's is always giving this toy or that toy, and they'll practically break into the little displays and Matthew doesn't do any of that. We do insist we hold his hand because we're going on busy streets, Blossom Hill and Snell, you know, there's just no other way we can do it. He's accepted that. So socially, with that, he's doing well.

ANSWER TO QUESTION #6
With the screaming, it's a good point, too, there's an outdoor voice and an indoor voice. And he has screamed on the playground, but it's almost been appropriate, almost for a reason, like, we have three tricycles and he likes the red one, and sometimes and then we'll be getting

7. How is it that the teachers inform you of Matthew's communication and social skills?

he doesn't *understand* what that means. He'll go to the dresser, if I point, he'll go to the dresser and he'll pick something up, but it may not be the glass. It may be the comb, the brush, my watch, my wallet, whatever. But if I go like this, (uses the hand gesture for water), with the hand gesture, then he more realizes what that means. You know, than just by the verbal, speaking it. I need to know what the teachers have taught him for hand gestures or any, you know, whatever. Matthew wonders, "Why don't you understand?" him when he uses the hand gestures he learned at school.

ANSWER TO QUESTION #5
Potty training.
He's, I don't know, he's, he's lazy, but he relies, he can, if he really wants to, he can put his own clothes on. You know, with some difficulty. Um, he's

to keep him quiet. And that's a normal thing for everyone but what you're reinforcing is the screaming behavior but what I do sometime is I'll say, "Ok, I'll tell you why you're not gonna have this." All we need is for him to stop screaming for his shoes so we'll sit there 30 minutes, 20 minutes, and then eventually he'll stop and then we say, "Oh, you can get your shoes back." And if he continues and continues to want his shoes, next time he'll get his shoes and give them to you. But, there's a time when he's screaming and I know someone is bothering him and I go find him; they took his toy, and I take it and give it back. At that time I don't comment on the screaming, I just get his stuff (toy), then he knows that I asked for help and I got it. So, it was kind of appropriate (for him to scream). So I don't talk about

them [the tricycles] out of the closet. Somebody else will grab the red one when he's been expecting it. Now, that to me, is you know, is an appropriate reason. Now, he shouldn't be screaming, so that would be a little more appropriate and also, um, there's a little kindergarten bathroom right off the playground and it's very cute, it's got two stalls and he kind of likes to use that. But, like the other day, he really had to go a lot, and he said, "Aaahhh! Aaahhh!" so I let him in to use the kindergarten bathroom and actually it's rewarding it, like I need to get the icon to say, "What do you want? Ok, let's go," and have him ask for it quietly first, to ask quietly, and then he can get it. Because I realize we're inadvertently rewarding it, you know, he screams, he gets results. And we are, you know, working on that.

8. How do you (as the parent) feel about the school's plan for developing Matthew's communication skills, for helping him to communicate or verbalize?

better off now to go help himself if he wants something, if he can reach it. He wants water, he wants food, he'll go get it instead of before, he would just scream. And we didn't know if he was hungry or you know, when he was in diapers, if he was wet or what have you, we didn't know. We didn't know what his need was. Now it's easier to understand because of his actions of just helping himself, you know, if he wants to go somewhere, he'll go get his clothes and his shoes. That means he wants to go somewhere. Where before, he just screamed, you had no idea, you said, ok, well, let's see if he wants, if he's thirsty, if he's hungry. You're kind of like playing a guessing game. But now he's more, he can help himself. It's like, if he wants to watch t.v., he'll watch t.v. Um, if he wants to play a video, he'll play a

the screaming; I just talk about what happened. He has so much inbred screaming to the point that, he will always have a little bit, maybe not permanently, but he will kind of always revert back to that because if something works for you, why change it? We have to give him something new. And hopefully when he starts to use verbal language, then we can extinguish a lot of that screaming. Screaming is a way of communication, but at the same time, it's a very distracting way for him, and everybody else, and for the other kids. Socially, it draws attention to him, and one of our reasons is to draw as little attention as possible to our kids for them to be acceptable in the community. So, and we say, "shhh"; he knows what "shhh" means. If you want to blow a bubble you can't scream. So, he has to stop to

Sometimes it's in a busy, hectic time like when we're cleaning up right after lunch, and he wants something, I can imagine how he'd be at home, too. They're fixing dinner or getting ready for bed, you know, and he starts screaming about something, you know, it's just easier to even like have him ask a little bit appropriately than give him what he wants or even, like if he screams, and then you have him ask quietly, well, at least he's gotten our attention by screaming and then, so we have to kind of work backwards, get him to, you know, ask appropriately with the screaming and then without the screaming, hopefully. Just come over and ask for it or give me an icon. He's screaming a little more, but also, communicating more in other ways. He's saying a few more words. Well,

9. How does the parent respond to questions about Matthew's communication skills?

video, he'll do it himself, he understands that. Where before, you know, he would just, you wouldn't know what he wanted. But now he, he can communicate where when he doesn't like something like, he'll give you the remote to turn the t.v. on, so you know he wants to watch t.v. But he'll turn it on himself but he can't get it to the right channel where it's not playing the picture. Or, he'll go and you change the channel and he'll show his displeasure. You know, or you're flicking the channels and he'll grab the remote from you. That means that's the one (the channel) he wants. Stop there, he doesn't want you to turn it anymore. So, he'll take the remote and he'll put in down on the dresser and he'll go. "Bye!", you're done, I'm done with you, you can go now. That's what I

form his lips to blow a bubble. So there's no way he can scream and blow a bubble together. You have to provide a replacement or alternative to a regressive behavior. If Matthew is humming, I say, "Oh! You're singing!" so that he will continue this positive behavior. If he is screaming, I just sit there with no expression. When he stops, I say, "Matthew wants this?" And give it to him after he stopped the screaming. Using the icon book, or using gestures, is better. If you do anything else (communicate other than screaming), you'll get what you want.

ANSWER TO QUESTION #9
Howard has come here. Howard will write me back or when we have a phone call, he will give me the answer. So, I think it was positive. Most of

he said, "Pop" for popcorn, although he has said that in the past. He was in my class for a short time until there was room in Nina's class. And he was saying a few words at that time but he hadn't, this is the first time he said it since September (1999) in here. He makes little sounds for chips, he loves chips, he likes salty things, in fact. He makes the "I" sound in the word "chip." But, also, just the way he's using his communication book. He'll go get it and show you what he wants. He has improved in that, so, although he is screaming a little more now, I think he's also improving in other ways. Unless we kind of get things coordinated with the speech therapist, you know, with one another, I'm hoping he'll quickly come back up to where he was. [With social skills] I'd say, there's one boy, they kind of like the

10. How does the parent respond to questions about Matthew's social skills?

wanted, he's all bye, leave me alone 'cause I don't want you changing the channel anymore. So, his nonverbal communication has gone up and gestures. His screaming has decreased. He doesn't really scream at home, it's just, you know, there's sometimes when he's playing where he's loud and you know, making his noises and he's happy or he's running or whatever or he fights with his brother and you know, he screams at his brother because he's *mad* at him and that's how he's, he doesn't, like normal kids when they get mad, really mad where they start hitting each other, he won't hit his brother unless his brother hits him first. But he may yell at his brother by going you know, "AAAHHH!" like that. And the louder he says it; that means he's really mad at him.

the time, I did most of the writing but somehow I will get my answer, (phone, visit, diary). He will tell me, "Oh I did this or I read some books to him." He lets me know that the things we talk about he's doing at home. He said, oh I did this, or I read at home. I said, "Oh he likes books, are you reading at home? And he says yeah." I said, "Since he likes animals, get him an animal book, and he said, yeah."

ANSWER TO QUESTION #10
Howard doesn't do much communicating, but he answers the questions to the best of his ability. If I talk to him he tells me, you know, I don't want to be sexist here, but men are pretty direct and answer questions differently than women. Men say he's sick or he's not sick. A response from a father and a response from a

same toys, they'll grab them from each other but they seem to work it out and they aren't hurting each other, so we leave them alone. And then there's another one who I think is jealous of Matthew. Matthew is working a puzzle, he'll come and mess the whole thing up, and we're just trying to keep them a little bit separate 'cause they would, I think they have, you know, kid's sock each other and so, mostly we're trying to keep them apart but also trying to teach them the appropriate skills. It's kind of cute, sometimes he'll do, like, just little vocalizations, I guess you'd call it. I had one workstation task where he was separating happy pictures and sad pictures, and he was doing. "Oh! Oh! Oh!" (sad, whimpering sounds). What was the other? Oh, he'll get animals too, and go "Grrrr!" and

11. How do you determine progression or regression of Matthew's communication skills? Please give 2-3 examples.

ANSWER TO QUESTION #6
Well, it seems like sometimes his speech goes up and then it goes down. You may hear a word one time but then he'll stop saying it. I guess he had said "popcorn" at school. You know, I've never really heard him say popcorn. Um, I was told by the teachers that he said "popcorn," yeah, "more popcorn." I don't, I don't know if he's not using it or if he just forgot it or you know, there's new words he learns. Or he'll say, "this," he says "this," you want this? And I go "this" point, "this." But he doesn't like anything, instead of sometimes saying no, like you offer him a certain drink or food and he doesn't like it, he'll go, "Aahh." You know, instead of saying no, he'll just, he'll just make that face like that disgusts me. He'll put his tongue out

mother are quite different, but from those, I can determine the answer that I want.

ANSWER TO QUESTION #11
He says "no," sometimes shakes head. He shook his head to accompany that so I know he knew no. He said, "apple" and sometimes he stopped and I know that there have been words that I've heard and he stopped saying them, so I noticed a regression-work on it. Words that I haven't heard, I don't push it because maybe he hasn't started it yet. He blows bubbles, hums "hmmmm," and sings, "la la la la la la la," "ma ma ma ma ma."

ANSWER TO QUESTION #12
He plays with the kids but he kind of parallel plays, and he's pretty strong and if you take his stuff, he'll beat you up. So, I have to tell the other kids

"Rraah!" and so he's doing other vocalizations, too. That's not using a lot of words so he does come out with these things which are appropriate. He's done (vocalizations) since he's been here in September [1999], I'd say, about the same, yeah. So, you know, it's all part of speech. [With interaction with classmates] I just want to say one more about this one boy who comes in and messes up his [Matthew's] puzzles, he's also pulled Matthew's hair. At first I thought he was just jealous of Matthew, but now I think he might be trying to make friends with Matthew. 'Cause sometimes, kids, they want to socialize, the autistic kids especially, but they don't know how to do it. There was another class I was in, it wasn't autistic, it was just severely handicapped. There was this cutest little

13. How do the teachers let you know that you are working together as a team?

and turn his head. That means, "I don't want it."

ANSWER TO QUESTION #7

Just during whenever we meet with them or during his IEP, you know. Not all the time, not really with the diary, just when we meet with the IEP and we go over his social skills and his sharing skills. He still does not like to share with the other kids or really play with the other kids. He just, kind of like, he doesn't, unless it's they're during their circle time or whatever, but when it's play time, he's fine just playing by himself. And he kind of like tolerates everyone around him. As long as you don't, it's like, leave me alone and I'll leave you alone. You know, he has no problem playing by himself. The teachers inform me of his communication skills in the same way and also in the diary.

not to bother him but play. There will be one or two other kids that he'll allow, he allows to take his stuff. He has a favored peer that is the only person. Any other person he'll hit them and the thing about it is he never forgets who bothered him if it takes until the end of the day. So, that it also shows that he has some good cognitive ability to remember that you are the one who bothered him before this day is out or somewhere when nobody is looking, I'm gonna hit you back. I think that, in some ways he's been allowed to get away with a lot of stuff. Sometimes when I'm upset, I'm talking to him, he looks at me, and I know something is happening in there. He's getting something; that this is not ok. I say, "I'm mad at you. You made me sad. I don't like it." And, he'll just sit there and look, you know? And

boy, he used to sit down next to someone he'd want to be friends with. Pretty soon, he'd be pinching him and doing all these inappropriate things. He just, he didn't know how to be friends, he didn't know how to make it. So I think that's what might be going on with Ben and Matthew. At first I thought Ben was just jealous of him, but now I think there might be a little more 'cause lately when Ben's come in and messed up something Matthew's done, Matthew's taking it well and then we have Ben help him pick up the things or put it together.

ANSWER TO QUESTION #9

Well, usually we're just asking him specific questions like what words does Matthew say, how does he communicate, and when he's hungry, tired, um, so they're pretty, almost cut and dried questions

ANSWER TO
QUESTION #8

I think it's fine. My main concern in which I think is a big problem is that he's *constantly* getting new speech therapists. And I don't know the reason. I think it's either they're quitting or whatever reason and it's not because he's changing classes so frequently, he's not changing classes so frequently. He's in Waverly's for one or two years, prior to that another teacher at the other school and it's like, it seems every IEP that I've gone to in the last two, three years, it's a new speech therapist.

ANSWER TO
QUESTION #11

Answered above, about the words. You hear new words, but then sometimes he doesn't say the old words. Um, but it's definitely that he has learned more words than he has ever lost, stopped

sometimes he'll cover his eyes, like go away. That's a sense of shame. That was not what I was doing, but when he expresses that, that tells me he knows when something is not right. Maybe he doesn't have the language, so we have to work with that. Whoever is at home, they need to be firm. Tell him no means no. He has non-verbal, communicative behavior. Because he is

communicating with his behavior. One thing he doesn't like-academic tabletop activity. He doesn't. He likes to pull things apart. Give him something that writes with a different shine or glow, something that will give him a reward. When he was in my class, I told him, "It's not appropriate to scream." If he hits, he has to sit in a chair, we're not supposed to isolate, but we have a little

so, like sometimes when we meet with the IEP team, we're just sitting around the table talking too, so it's a little bit informal. So, we're going over formal goals and everything but then just a little info, or anecdotes, and what he's doing at home, and what he likes to do, his preferences. Howard's been pretty much open, straightforward and then we just ask him what we need to know.

ANSWER TO
QUESTION #10

He has mentioned, like the problems going to McDonald's, say, that that he is hard to take out in public. Hopefully, just going out with the class, maybe that'll help just have a familiarity that that'll be easier for Matthew and again it's just working with him. Like maybe he knows he can scream with Howard when he's out in public or he can scream with the

speaking, you know. I think he, he understands, he understands certain words. He may not be able to say the words, but he understands, you know, what some, you know like, especially the word "no." Oh, he knows what that means. He understands the word "no," he understands the word, "spank," he understands the word, "bath," you know. He understands um, "bye-bye," he knows bye-bye means let's go. Yeah we're going away. He knows what the word "kiss" means, he knows what the words, "Give me love" means. "Kiss" he knows means kiss somebody. "Love" he knows means I'm hugging somebody. He knows what "night-night" means. Let's go, time to go to bed. Usually I just say, "Night" or you know, "Go to bed." I don't know if he

chair, and they sit down. If he gets up, I say, "Matthew!" He stops. He understands. Language takes awhile but a lot of time verbal is considered communication but communication is, as you already know, beyond verbal. It takes a lot of cognitive skills to retaliate, especially something that happened way back when, and he's very possessive about his space, you know you don't bother his things, and the thing about is, if somebody comes in the class, autistic or not, they stay away from Matthew. Because they know he'll get them back. And that's good for me because I know those kids, they're not severe. Not severe, kind of mild to moderate to know that. Now a child who's severe doesn't care; he'll keep going. So for me, even though he's interactive, and he sits in the chair, he likes the music,

teacher when he's in the classroom. Maybe he's, he's working out his system, too. Sometimes when he gets excited or tired he really can throw up his hands and walk around in circles and we try and re-direct him to something, but yeah for the most part we try and keep him busy. The only thing I guess he doesn't really do, he doesn't like to come to circle and I don't know if it's too overwhelming or what, and Benoit is the one who, you know bothers him, he was exactly like that, it took a whole year before we could get him into the circle. And so, we went, the rule is, Matthew has to be either in the play area, he can't be wandering around the room, he likes to go over there and get a book. He has to be either there or he has to be in circle. And also the speech therapist, one of the things she's been doing

14. How does the parent let you know you are working together as a team?

knows his brother's name. We don't really say his brother's name, we say, "Bubba" or "Give it to Bubba." Or, "Give it to your brother." He shares more with his brother than the kids in his class, but there's still times when he won't share with his brother. But if his brother asks him, he may say, Matthew may have something that he just got at the store, and his brother will say, "Matthew, can Bubba see?" And, most times, Matthew, Matthew will just give it to him. He knows what that means, "Can Bubba see?" And he'll give it to him to look at, you know.

ANSWER TO QUESTION #12
I don't think they've really changed. I don't see, his social skills with are fine with me, his brother, and probably his mom, but, you know, his family. Um, he's, he's

but he will like the kids around him. Just don't take his stuff; just don't bother him, except just one or two kids that he likes.

ANSWER TO QUESTION #14
I don't know because Howard, we really didn't do much except the IEP report. We talked about Matthew, but we never really had time to sit... I just said this works, try it at home. If anything works at home, please let me know. He will nod and then he walks and I said so much and he didn't say much. But then, I just had the feeling that well, if he didn't say much, either he agreed with me or he's gonna try. So we really haven't had that many, I think I met him once or twice.

ANSWER TO QUESTION #15
The more he screams, that's a regression—the more he screams—

with him is just getting a chair and having Matthew face her so they'll be doing the same things in the play area just one-to-one that we're doing here in circle, and we're trying to gradually work Matthew into the circle. 'Cause he um, he just refuses to come to circle, you know, he's so big and strong, an immovable object. We've let that go because he's done the other classroom routines pretty well. He goes, he does his writing with help from the staff, he likes doing his five or six workstation tasks by himself, he usually does that independently. In fact, I have to update them. I tend to, you know, let them go too long before. We're supposed to be changing two every week, or as they meet the goal. I think he's [Howard's] been pretty, you know, much open and straightforward.

15. When Matthew is screaming, how does that fit in with his progression or regression? Please give me an example.

content with playing, you know, with him, by himself. Or, I mean, it comes, depending on what he wants to do at that time, you know. When he's playing a game with like, D [Matthew's step-grandmother] he takes turns. With the games, like there's a new phonics game he's playing.

ANSWER TO QUESTION #13
They are pretty available; yeah, I would think so.

ANSWER TO QUESTION #15
It depends on the circumstance. Sometimes, he, he screams when he's yelled at, for doing something he shouldn't be doing. And he, he'll, he may cry and what he tries to do is, he tries to make it up to you by coming over to hug you and pat you on your belly. And I think, I think, my, what I think he's thinking is, he feels that you're

the frequency, the pitch, because when you don't respond to him, he opens his mouth wider and screams louder.

The pitch's intensity.

Frequency, pitch, and intensity lets me know he's regressing.

Progress, that comes with that, too. The pitch is different, the duration is kind of shut, because if you're doing that, when you're calling, he can turn around, but when he's really in a regressive mood, he would just scream and scream.

You literally have to take his hand and say, "You need to be quiet." But otherwise, when he's just you know, doing the funny calling, he'll turn around, smile, and then go back. So that lets me know, that he, he's not into it so much that he cannot attend to something else. But when he's regressive, in a regressive stage, he'll just go on and on. You really have

Both Howard and G [Matthew's mother] and D [Matthew's step-grandmother] too, I talk to her sometimes. It's more on the day-to-day things like, did he bring his lunch; the lunch got lost on the bus a couple times. As far as the day-to-day things, did you send his jacket. But, but other things, too. She [D] tells me like, she's working on the phonics game with him. She spends a lot of time (with him), she's there.

ANSWER TO QUESTION #11
Ok, well, the obvious one he's regressed is that's he's screaming more. But, the way that he's improved is, well for one thing is that he's following directions better. Like, when I had him just for, it was about three months he was in this class, we could barely get him to come with the class, we'd be dancing for him and everything

16. Has the screaming increased or decreased since you began writing in the diary?

mad at him and that you don't love him anymore. And he doesn't comprehend that you're telling him no for a reason and it's not that because you don't love him, it's because you want him to stop what he's doing wrong or it could hurt him or whatever. So he tries to come up to you and he tries to hug you and love you by patting you on the belly and going, saying, "Doo Doo Doo Doo" and he's crying and he, he puts his arms around you and then he will, you know, he will take your arms if you don't do it yourself, he will take *your* arms and put them around him.

ANSWER TO QUESTION #16
Answered in a previous question (#5). The screaming has decreased at home, but he will scream when he's expressing an emotion such as anger.

to go there physically to help him. Hold his hand or do something, (keep eye contact), look at me. Because if he looks at me, he has to stop, and my thing is trying to get him to stop, because if he's screaming and you're talking, the more you talk, he just continues. Matthew needs to look at me, to get his attention.

ANSWER TO QUESTION #16
There were times it decreased, and I told them about it because we were trying to find other ways for him to communicate, but there were other times he would come from the bus screaming. So we would stop, and we'd go back (to the bus stop), he'd start screaming, we would stop and we would go back, and I tell him when he's quiet we will walk. When he started screaming we would go back. Somehow he got it that if I start, screaming,

else just to get him from here to there and from here to outside, so he's made just a tremendous improvement in that. And so he's following directions better, although he has, like in circle, and I think, sometimes it's just too overwhelming for some of the students 'cause Ben wouldn't come to circle for a whole year or he'd come just for a short time and dash away as soon as he could. And so it's just, to have the whole group here, like usually they're just working either individually or in very small groups. Hopefully the screaming will go down again but he is communicating where he's following directions better.

ANSWER TO QUESTION #12
With (social skills) sometimes he'll grab something. Sometimes at the end of the day, not

17. What do you need from the other participants to help you improve Matthew's communication and social skills?

ANSWER TO QUESTION #17
A standard weekly school form. Specifically, what is he learning? Comments on his homework that he returns home. What type of um, what type of uh, learning exercises would be helpful and um, enforce what he's learning at school. So I know what he's learning at school, you know, in regards to talking,

we'll go back. So, it's not magic. Sometimes I try everything he will still scream. There were times it subsided drastically and I told Howard about that. One other time it started so I learned he went to his mom's over the weekend. It's the changes, because also if you say don't scream, don't scream five days a week Monday through Friday, and I go home, I get to scream, I come Monday morning, I get to scream. So it started again, so then I say what's happening. So, it varies. Or, he will stop screaming at home and then go somewhere else and then, you know, (scream). It's kind of hard to predict, it depends on what's happening. I've been hearing him a lot more recently, even from my classroom, and I think he's been doing a lot more recently, I don't know why...yeah,

every day, but a couple times a week, we do a little game where it's turn taking like um, Mr. Mouth, where they, or sometimes they're just playing it together, they'll, they'll all be putting flies in Mr. Mouth. And I got this one little game, it was penguins and you balanced them on the iceberg, and the iceberg goes around and you balance it. But the kids, they just love those little penguins and that was just, it didn't quite get to be the same turn taking, a cooperative thing, and they just left the penguins there and I'm still finding penguins in my pockets because I had to take them away from three other students, and so that game was a little too cute. It didn't, it didn't do what I wanted, so like he'll get something, where he likes a toy or he likes a figure and he'll just grab on to it and it's his. But, he has other ones

gestures, you know, what have you. That's what I would, I would prefer. I would like to know what the speech therapist is teaching him. He has no problem with his motor skills, (so not the occupational therapist, but the speech therapist). You know, and it would be nice to know, what does he like to during recess time? You said he likes to ride a bike. I don't, I didn't know that, you know. Because you know, we've tried to get him to ride a bike at home. It wasn't a tricycle, it was like a bike, you know. But it had training wheels on it. So, I mean maybe he would like something like a Big Wheel, you know. So that he can go outside, instead of just running around, he could, you know, pedal something, you know. I need a weekly, or even a monthly, progress report. Like a monthly, I can see, I

and that's (not good).

ANSWER TO QUESTION #17

When Matthew is wrestling with the kids, because he's strong, he will hurt someone and I found out that he and Dad wrestle. I tried to tiptoe around it. Because the kids are young I try to remove words like aggressive, defiant; I just think they're too big for little boys and I say he's very energetic, he's highly active. So he'll go to somebody and it might be maybe he was trying to wrestle with them because he does, and he, you know, you have to look at his face and see his face to know if he's angry. Whatever we're doing in class, that it be carried over at home. And one other thing, ask the parents to visit, to observe. Use the icon book, also, at home, if he wants something, he has to use the icon (communication)

where he is doing the cooperating, a little turn taking. Actually, he likes games and I think he's gotten some of that home with D [Matthew's step-grandmother] and maybe with his brother where he's done a little board games, turn taking, uh-huh, and that's improved. With certain objects and certain toys he will not take a turn, you know, or he'll find it the next day in his backpack, like the little pelican he wanted. In fact, I didn't know what happened to it, I mentioned it to Howard and he said, "I think we have that at home." I described it, it's really just like a mini Beanie Baby. They were giving them at McDonald's and it's called Spook the Pelican. And Howard said, "Oh I think we have that at home," and he [Matthew] held on to it all day, so there, he hasn't completely let go of it but I say he's

can see, send home a uh, I don't know, a monthly progress report and a quarterly report of what they've done and what they're, you know, improving or whatever. I'd like to see this type of monthly or quarterly progress report along with a weekly report on a standard school form showing what he's learned every day that school week.

book. So the child doesn't think he can get away (with not asking) because he's pretty smart. So to know that, oh you want orange juice, get your book. Or you take those things away. Because at home, I know they think, why bother to talk? Hide them, lock them up so that they have to make some attempt at communicating to get those things. Reinforce what we're doing at school at home but also, school can never be like home. They're two different...the kids also have to have a breather. You have to feel comfortable in your home. Your kids can go home and kick back go watch TV or get some popcorn, sit on the floor, but at the same time, give me the icon for TV, give me the icon for popcorn. And when it's done, it's done. All done, let's go do something else. So, the reinforcement is not just carried

doing better in that type of thing but there are certain things that you know, he hangs on to, he doesn't share. (Favored peers). With one boy, they grab toys back and forth. Unless he's sitting at the table, he really prefers to play alone. Um, now with Ben, he likes to pull Matthew's hair. They're kind of working something out but we just pull Ben back because we don't want him to hurt Matthew although Matthew would probably just sock him back. Well, also, I've had him share the red bike out on the playground and tell him it's somebody else's turn, he'll throw the bike over, he's done that a couple times. That's his private property. But like I say, he's doing better. One time, he wouldn't do it at all, now he's, he's sharing a few things. Although there's still some that are his own; he

18. Are there any other things that you think I should know?

ANSWER TO QUESTION #18
Regarding Matthew's education? [Yes]. The only thing I think, I've heard different people say that autistic children, they're only gonna learn at the pace given them and that they do need to be more surrounded or involved with other children who don't have disabilities. So that they *know* what's normal, so that they know what's normal behavior. Maybe they may not be able to learn at that

always in the classroom; whatever you're doing in your home, apply the same principle like this child has to learn no is no. Some kids don't. For success or for progress, you just look for the little, because if you're gonna set your goal up high, you feel so disappointed, you'll feel so inadequate. The first year I was just like, I felt like, I was just "Oh my God, I don't even know what I'm doing, you know." And it was not because of that, you know my principal had a talk with me, it was because I had set goals. Then I come here and I said, "Oh," (to the kid) could you do this and really develop mental stages...it doesn't work. It doesn't cut it with these kids. And then when they go over that (the small goals), that's good for everybody. Then we build on that and we build on that, because these kinds of kids, they

probably thinks of them as part of him, you know. They're his own personal private things. He's starting to share the school toys. Like we share the playground equipment with the kindergartners. Throwing a ball, if you throw it to him, he'll throw it off to the side, um, sometimes he'll try to make a basket, he kind of likes the plastic basketball hoop. He'll try and do that but then he'll, other times he'll just throw it away or sometimes he'll throw it out on the playground.

ANSWER TO QUESTION #14
I think it's just the ongoing communication with the diary and talking on the phone, I would have to say. Also, I try to send a general letter home once a month. I don't always get it out. Just tell them what we're doing this month, how often we're going to McDonald's or

curve, but they, they know that, um, so that they may be possible one day, you know, so they can, maybe. They'll never be the same because of their learning disabilities, but, how are they ever gonna know unless, you know, unless they're in that environment? You know what I mean? I understand that they take the kids on certain trips like lunch trips or field trips and things like that but it's always with, also within the group of the class, you know. How would it be to take the kids into the lunchroom with all the other kids, you know? They're not even, or, or play with, with the other kids and not in their, just their specific playground. I don't know if it's just assigned to them or what have you, you know. How are they going to develop their social skills (if they're not around non-autistic children)? Probably feedback from the

don't pick up on that like other kids in the sense that, "I missed this, I can get it up there." You know, if you miss that step, you have to regress, and for some of us as teachers, professionals, we feel like our profession is on the line when I have to, you know, modify my goals downward. But, it's better to modify downward so the kids can meet the goals. When you work with kids, you expect some progress. When you work with these kids, sometimes *nothing* happens.

ANSWER TO QUESTION #18
Well, wherever he's [Matthew's] at, affection should be included [in his education]. He responds well to that. But also include, let him know when it's time to play and when it's time to be serious. He responds very well to facial expressions

everywhere. That's just a general one that goes home to every parent. So, it gives Howard an idea just what's going on in the classroom. The letter is once a month; phone calls work out to about once a week. I feel support from Howard.

ANSWER TO QUESTION #15
Well, it's both really. Like it's inappropriate communication, certainly, especially. And he hasn't really done it in public. If it was happening in public, it would be very inappropriate. Even on the playground, it's inappropriate because all the people see our classes, all the wild kids out there or something. And so, um, it's kind of regression and progression both because he is communicating, he's trying to let us know what he wants but he's doing it in an inappropriate

teachers, what they would want me or his parents to teach him at home, so we can better help them at school. So that it helps them with their work at school. And then, so that we're communicating between each other, so that we know what he's learning and when he does not use speech (verbal), and when he's using gestures, or what have you, prompts, we both know what it means.

and tone of voice. But also he, he needs some structure, structurally at home. Structure in the sense that, somehow the parents need a schedule. He was on a schedule—that was my goal. He was in Waverly's class. He was supposed to be here but my class was filled, so he went to Waverly. When I got space, he came back, which is difficult for him because he'd go in to play but he doesn't know who to go back to and we have to work with that. So he had to go back, so even though he's in Waverly's class, every day I go at 12:30 (to Matthew) I shake his hand, I do things. Let him know that people can be out of your life but they're still around. I go in there and I say, "How are you doing, Matthew?" He shakes my hand like (he's saying) "How are you today?" Every

way. He learns; he knows it works, you know, and we have to work that out, too. In fact, I'm working on a behavior plan and I thought, I thought maybe I'd see if Howard would sign it off, too, and just, just to say exactly how we're gonna handle the screaming because Matthew, he's a big boy and he's what, seven years old already and, and the idea is to give him more ways to communicate, not to, not to reinforce the screaming. With the screaming at home, it sounds like, like the one thing he's doing at home that he's not doing here, well it's not really home but when Howard takes him out in the community, he might scream. And for us, he's been pretty good in the community because he likes going there. He'd rather do that than be here working. So that may be the one thing that's a little

morning I'd say (singing), "Hello, hello, hello to Matthew." I put out my hand and he'll come and shake my hand. Because one of the things the kids don't understand is, you were here in my life and you're not here anymore, you're with somebody else. But you still have to show him, to let him know there's a continuation. Even though I'm not your teacher anymore, but we still can do the things, we can play, we can jump. And with his teacher's permission, you know, we go around, I like to swing him around, something like that. And also, he's the kind of kid that, this is me personally, he might, he might not develop language. But, If I were doing the parenting, I would not-verbal language, ok. He has some oral structure. He was trying to say, "noodle." He was *really* trying; he was

out of sync but I don't know how much he's actually screaming in the home for what he wants. If he does it to get what he wants here, but sometimes the things he's asking for are very appropriate like when he does his workstation tasks, he gets to go to the toy cabinet, pick out a toy, and show the picture of the toy. So what he's asking for is very appropriate, it's just the way he's asking is not good. But he learns, he knows it gets results. He's using it to get what he wants, quicker too. He is also using the communication book. He'll like, kind of dig it out, too. Some of them I send home every day, but Matthew's is here, yeah. Some of the children use them at home. I don't know if Matthew brought his home last year or not.

really trying. So, we can pair it (oral communication) with whatever we want, with some sort of communicative object or something or picture or something to represent the thing. Because there are some kids who can look at the word and know what you want. So, not just to leave it and say, "Oh, we'll wait until he talks." No, we've got to use whatever we can and *add* the language to that, and add the language to that because to a nicer way we're saying, "Matthew's gonna do this (speak)," if language comes, fine. Language comes, but not when we want it. Even if language comes, it may not always be as intelligible as we want it to (be). The thing I've heard him say that I can say, "That's what he's saying" (understand him) because I've spent so much time with him. With

ANSWER TO QUESTION #16
Well, I've always used the diary and IEP report, so I wouldn't have any comparison. I've never been without it. So I really don't have that information.

ANSWER TO QUESTION #17
Well, he's doing pretty much, keep us informed of what's going on or successful things, too. Not just problems, but things-I would like to know the new words that Matthew's saying at home, the new things he's doing. The positive things as well as the bad behaviors he's picking up. Matthew hasn't tried to wrestle, but some of the other kids have, though. Like, they're used to wrestling with their dads. The kids will come in and knock you over or something. Matthew hasn't done that, though.

him, the word may change from one day to the next. What happens when he goes into the community, that's a big problem. But when you say red light is stop, he sees a red light, he stops. Unintelligible talk is not failure because he has some (verbal) communication. If it's not intelligible, you respond to him as if it was intelligible. But whatever he's saying, say it back but say it in a way that you know if he says, "Wa wa," say, "Oh, you want water. You want to drink water." So you're not disrespecting what he said. You're just refining it for him. And continue it and continue it and he may get to the point (thinking), "Oh it's not wa wa, it's water." If you make him feel bad, you shut him down. He's autistic, but he's like anybody else, we're like that. If you wrote a nice paper and the teacher put terrible

No, so I guess he's figured out not to do that. Matthew hasn't been a problem. He's been able to keep that context.

ANSWER TO QUESTION #18

I would just like to get him to join the group a little better. If he [Howard] has any ideas of why he feels overwhelmed at circle. Just, like give him the same activities there, [at home]. Because sometimes he'll be standing back there just watching us or we'll be reading a book and he's kind of looking at us. So, he's curious. He's interested but he hasn't, he hasn't joined the circle. He never has joined the circle. A couple time, a couple time he was over here. We could keep him here, you know, practically by holding him down but he'd cry and carry on the whole time. And it's just something I think, is overwhelming for him. Whether it's

things on it, you won't want to try. The teacher should say, "You know what, this is what you need to work on, but this is good." Watch him when he walks. We went walking. We looked at the flowers, the birds, we talk about things that are around. He'll pick a flower and he'll smell it. You gotta just input, input, input. They'll pick up something eventually. They gotta pick up something. There's just something about human nature. Communication is so *powerful*, that people have got to, no matter how, they gotta pick up something. Whenever they're making an attempt, you kind of emphasize it. "You gave me a napkin, oh I'm gonna blow my nose! Or wipe my face!" Let him know that this napkin has so many purposes. Teach kids also that language is power, that language-you

too much noise, too much although they sit him, you know, fairly well, certainly not perfectly. Um, it's a pretty organized activity. Um, you know, more than if they're [the students] all walking around the room. He might just rather be doing his own thing rather than do (the circle). Because he's doing these other things, he's doing his writing, he's doing his workstation tasks, he comes out with us to recess, um, yeah, we have let this go for awhile, but I want to work him into the whole routine of the class, yeah. He's always kind of peeked over to see what we're doing, so I'd say he's about the same (as before). The only thing is the speech therapist, a couple times a week, does work with him on the circle activities, one-to-one. With the IEP report, it makes it very manageable, step-by-step, and if it's

get rewards from language. Also, every attempt at communication, like the picture I show, he knows grapes, now we have red grapes, purple grapes, and green grapes. So, extending his vocabulary so he can know (the options). There are juices, not just juice, water, but also orange juice, apple juice, grape juice and all of these juices. Now we go on to punch, we go on to lemonade, sodas. Not just a drink, build up their vocabulary so they can know, so when they look in their (icon) book, so when they think well, I want a soda, or orange juice, they can look in their book and get the right icons for it. And that tells you a lot of stuff, a lot of communication is happening in there. We've gotta work with Matthew more. Matthew needs, he needs to know, I think his Grandpa is doing a good thing,

not working, then we can just hold a meeting. One thing, parents, or teachers too, the IEPs are for a year at a time, but any time during the year, if they want to question something or add or delete it, if they say, "Wait a minute, that's not him," you know, then they can do that, they can change it. Matthew prefers to play alone. Although he kind of watches, he is curious, he needs to see what's going on, what we're doing. Actually, that's a strength, the curiosity. I think what's good about this program is the very good team approach. Children are all in occupational therapy, as well as speech therapy. We have a psychologist. He doesn't come to my class quite so often. He used to come here all the time. So we have a lot of people to consult. The principal is consulted. So, it's a good team

(making him say noodles when he wants noodles, etc.), I mean it might seem a little bit too firm, but I think actually it's a good think in the sense that you gotta balance, try. But also sometimes we can frustrate him or force him to say words when he's not getting the words, so you have to pair it with something (say noodles but show him the picture of the noodles). Howard needs to find out Matthew's routine, ask the speech therapist to create icons so he can use them at home. If he says, "Matthew, it's time to go to the store, go get your jacket, we're gonna buy this and this and this." Show him the pictures (choices). He has to pick what he wants (from them). And then he learns this is what you can get from the store. If he throws a tantrum, so what. A lot of times I tell the kids, after walking, we gotta go back to

approach. And Howard and G [Matthew's mother], come to the annual meetings. She brings him in once in awhile when he stays at her house, she'll bring him directly here, so I get to say hello to her. Matthew screams when someone grabs a toy from him, but he will try another means sometimes to communicate. But, if nobody's paying any attention to him, then he starts screaming and gets his results. He needs improvement in circle time, just for that one thing. Like, at first we couldn't get him to a workstation, and then we kind of coaxed him over and rewarded him and he saw everybody else doing it. So, he's doing that fine; it's not even a problem. Matthew has all these people (in his family) concerned and that's why I want to get together and talk about the screaming and

class. It's over, it's over, I'm gone. Sometimes they'll be there (with me), but then I turn my back, but I'm not really leaving. They'll come running back, but I say, "Ok, we're walking, we're walking," and I exaggerate the walk so they know I'm walking, [to show them].

maybe sign off a plan because Matthew certainly has all these people concerned about him, so we need to get together. At first it was for non-compliance, then screaming, and we might put the non-compliance in, too, but right now it would be the screaming just so we're all handling it the same way, [at home and school].

Appendix C: IRB Approval Letter

San José State
UNIVERSITY

**Office of the Academic
Vice President**

**Associate Vice President
Graduate Studies and Research**

One Washington Square
San Jose, CA 95192-0025
Voice: 408-924-2480
Fax: 408-924-2477
E-mail: gstudies@whoo.sjsu.edu
<http://www.sjsu.edu>

TO: Shannon D. Waltrip-Sequeira
1764 Albert Ave.
San Jose, CA 95124

FROM: Nabil Ibrahim,
AVP, Graduate Studies & Research

DATE: October 22, 1999

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"Parent-Teacher Social Construction of 'Progression' and 'Regression' of an Autistic Child's Social and Communication Skills: A Case Study"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Nabil Ibrahim, Ph.D., immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that all subjects need to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate, or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact me at (408) 924-2480.

The California State University:
Chancellor's Office
Bakersfield, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Muncipal
Long Beach, Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
Sacramento, San Bernardino, San Diego,
San Francisco, San Jose, San Luis Obispo,
San Marcos, Sonoma, Stanislaus

Appendix D: Consent Form

San José State
UNIVERSITY

College of Social Sciences
Department of Communication
Studies

One Washington Square
San Jose, CA 95192-0112
Voice: 408-924-5360
Fax: 408-924-5396
E-mail: commstud@email.sjsu.edu
www.sjsu.edu/depts/commstudies

**Parent-Teacher Social Construction of "Progression"
and "Regression" of an Autistic Child's Social and
Communication Skills: A Case Study**
CONSENT FORM

Name of Investigator: Shannon Waltrip-Sequeira

Name of Participant: _____
(please print)

Purpose of Study

The purpose of this study is to examine how progression and regression are socially constructed in parent-teacher interactions. I would like to observe the interactions via the diary method and in interviews to find out how they define and construct progression and regression of social and communication skills within the autistic child. The results of this study will benefit parents and teachers of autistic children, schools autistic children attend, organizations interested in the autistic condition, autism scholars and communication scholars.

Confidentiality/Anonymity

All the information gathered in this study will remain anonymous and will be held strictly confidential. The information gathered may be published; however, you will not be personally identified in any way.

Procedures

I will examine the diary in which both the parent and teacher write, to identify how they discuss the child's progress and regression. I will then conduct interviews, based on the diary, with 2 adult individuals. These two individuals are the parent and the teacher of the autistic child who is the subject of this case study. In these interviews, you will be asked questions about your experiences communicating with each other via the diary you have been using. These interviews will be audiotaped and transcribed for analysis.

Researcher's Address

If you have any questions, you may contact the researcher, Shannon Waltrip-Sequeira, at 1764 Albert Avenue, San Jose, CA 95124 or by calling (408) 978-9779. Complaints about the research may be directed to Professor Stephanie Coopman, Department of Communication Studies, San Jose State University, (408) 924-5366. If you have questions or complaints about research subjects' rights, or you experience a research-related injury, please contact Dr. Nabil Ibrahim, Associate Academic Vice President for Graduate Studies and Research at San Jose State University, at (408) 924-2480.

Voluntary Participation

Participation in this study is voluntary; refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled.

Please read the following before signing:

"I have read this form and it is clear to me what it means. I am signing to show that I wish to be a part of this study. I am signing of my own free will. I have been given a copy of this form."

Signature of Participant/Date

Signature of Investigator/Date

The California State University
Chancellor's Office
Bakersfield, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Humboldt,
Long Beach, Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
Sacramento, San Bernardino, San Diego,
San Francisco, San Jose, San Luis Obispo,
San Marcos, Sonoma, Stanislaus

Appendix E: Research Involving Children or Wards Form

San José State
UNIVERSITY

College of Social Sciences
Department of Communication
Studies

One Washington Square
San José, CA 95192-0112
Voice: 408-924-5360
Fax: 408-924-5386
E-mail: commstud@email.sjsu.edu
www.sjsu.edu/depts/commstudies

Research Involving Children or Wards

The signature of a parent or guardian on this document indicates approval for the child or ward to be a passive participant in this study. That is, the child will not be interviewed, observed, or otherwise have any contact with the investigator for any sort of research purposes.

However, the investigator will have access to the diary completed by the child's parent and teacher and will interview the child's parent and teacher about their interpretations of the child's behaviors. The child in this study will be fully protected.

Name of Child or Ward Parent or Guardian's Signature Date

Relation to Child or Ward Date

Full Mailing Address

Investigator's Signature Date

The California State University
Chancellor's Office
Bakersfield, Chico, Dominguez Hills,
Fresno, Fullerton, Hayward, Humboldt,
Long Beach, Los Angeles, Maritime Academy,
Monterey Bay, Northridge, Pomona,
Sacramento, San Bernardino, San Diego,
San Francisco, San Jose, San Luis Obispo,
San Marcos, Sonoma, Stanislaus