

2014

Listening and hearing the voices of parents with children with autism : a phenomenological study

Nicole Perez
California State University, Monterey Bay

Follow this and additional works at: https://digitalcommons.csumb.edu/caps_thes

Recommended Citation

Perez, Nicole, "Listening and hearing the voices of parents with children with autism : a phenomenological study" (2014). *Capstone Projects and Master's Theses*. 584.
https://digitalcommons.csumb.edu/caps_thes/584

This Master's Thesis is brought to you for free and open access by Digital Commons @ CSUMB. It has been accepted for inclusion in Capstone Projects and Master's Theses by an authorized administrator of Digital Commons @ CSUMB. Unless otherwise indicated, this project was conducted as practicum not subject to IRB review but conducted in keeping with applicable regulatory guidance for training purposes. For more information, please contact digitalcommons@csumb.edu.

2014

Listening and hearing the voices of parents with children with autism : a phenomenological study

Nicole Perez

California State University, Monterey Bay

Follow this and additional works at: http://digitalcommons.csumb.edu/caps_thes_restricted

Recommended Citation

Perez, Nicole, "Listening and hearing the voices of parents with children with autism : a phenomenological study" (2014). *Capstones and Theses (Restricted)*. Paper 495.

This Master's Thesis is brought to you for free and open access by the Capstones and Theses at Digital Commons @ CSUMB. It has been accepted for inclusion in Capstones and Theses (Restricted) by an authorized administrator of Digital Commons @ CSUMB. Unless otherwise indicated, this project was conducted as practicum not subject to IRB review but conducted in keeping with applicable regulatory guidance for training purposes. For more information, please contact digitalcommons@csumb.edu.

LISTENING AND HEARING THE VOICES OF PARENTS WITH CHILDREN WITH AUTISM: A
PHENOMENOLOGICAL STUDY

by

Nicole Perez

A thesis submitted in partial fulfillment of the requirements for the

Master of Arts in Education

Curriculum and Instruction

School of Education

California State University Monterey Bay

May 2014

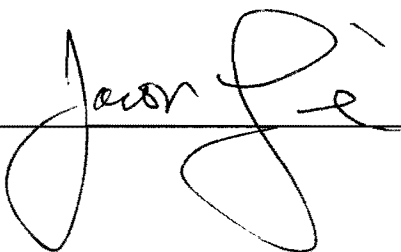
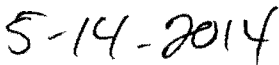
©2014 by Nicole Perez. All Rights Reserved.

LISTENING AND HEARING THE VOICES OF PARENTS WITH CHILDREN WITH AUTISM: A
PHENOMENOLOGICAL STUDY

by

Nicole Perez

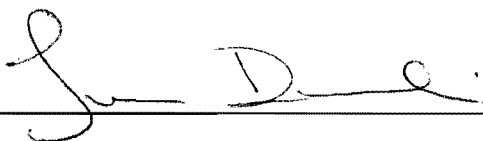
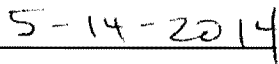
APPROVED BY THE GRADUATE ADVISORY COMMITTEE

DR. JASON LEVIN

DATE

GRADUATE ADVISOR

DR. LOUIS DENTI

DATE

CULMINATING PROJECT INSTRUCTOR

LISTENING AND HEARING THE VOICES OF PARENTS WITH CHILDREN WITH AUTISM: A
PHENOMENOLOGICAL STUDY

by

Nicole Perez

Abstract

This study describes the experiences of parents who have a child with autism. Four themes emerged from a thematic analysis of in depth interviews with eight parents. All the parents interviewed experienced a sense of isolation which often manifested itself in a reluctance to participate in social events. Also, the advent of having a child with autism impacted families in different ways, however variably all the parents described feeling overwhelmed due to the demands associated with services and care for their child. Lack of support from family, friends and school districts was noted. The study points out that it is necessary to provide continuous opportunities for parents to engage with others who have experienced the same phenomenon in order to share experiences and feel connected to one another.

Acknowledgements

I would like to personally thank my graduate advisor, Dr. Jason Levin and Dr. Lou Denti, program coordinator, for their guidance and patience with me these past two years. It was an honor to work with such talented, resourceful staff as yourselves. Dr. Terry Arambula-Greenfield, you are an amazing professor who goes above and beyond for your students. At first, you scared me to death but I quickly realized that you have high expectations for your students because you care so deeply. A special thanks to Jene Harris is long overdue. Thank you for keeping me on track with any necessary paperwork and deadlines.

To my husband Jason, your support and faith in me means more than you will ever know. It was difficult to balance our boys, work and school but somehow we managed. This long journey is ten years in the making and through it all, you are still the one. To my sons, Jacob and Nathaniel there is no greater honor than being your mom. Jacob, you have been grown to be a fine young man and encouraged me to finish my degree. I know it was tough for you when I had to leave to class in the evenings. I hope you have been inspired to never give up on your dreams, no matter the cost. Nathaniel, you are the reason I chose my thesis topic. You have taught me so much about patience, understanding and acceptance. I will never give up believing that children with autism are a gift. I would not want you any other way. You inspire me to do great things. I love you, Jason, Jacob and Nathaniel. To my parents, thank you for your prayers and believing I could accomplish this degree.

VOICES OF PARENTS

To my participants, I could not have done this without you. I have grown and learned so much from you all. Thank you for allowing me to record your stories. I am amazed at your strength and courage. You are a true inspiration and your resilience is unmatched.

Above all, I thank my Lord and Savior, Jesus Christ, for giving me the will to follow my dreams. There were times I wanted to give up and you carried me. I can do all things through Christ who gives me strength. Philippians 4:13

Table of Contents

Abstract.....	iii.
Acknowledgements.....	iv.
Chapter 1 Introduction 1	1.
Problem Statement 1	1.
Purpose.....	2
Theoretical Model	3
Research Questions.....	4
Researcher Background	5
Definition of Terms.....	5
Chapter 2 Literature Review	6
Introduction.....	6
History	7
Age of Diagnosis	7
Effects on Parents.....	9
Chapter 3 Methodology	12
Design	12
Setting	13
Research Participants	13
Data Collection	14
Instruments	16
Data Analysis	17
Limits/Threats to Internal Validity	18
Chapter 4 Results	19
Introduction.....	19
Isolation	20
Support.....	22
Grief.....	26
Resiliency.....	29

VOICES OF PARENTS

Summary	30
Chapter 5 Discussion/Action Plan.....	31
Introduction.....	31
Discussion.....	31
Limitations.....	34
Recommendations	35
Conclusion	35
References	35
Appendices	39
Appendix A	39
Appendix B	39
Appendix C	43
Appendix D	49
Appendix E.....	52
Appendix F.....	55
Appendix G	57
Appendix H	59
Appendix I.....	63
Appendix J	66

CHAPTER 1

Introduction

Autism Spectrum Disorder (ASD) is a complex disorder of brain development, characterized by difficulties in verbal and nonverbal communication, social interaction and repetitive behaviors.

The goal of my study is to improve the understanding of autism, specifically what it is like to be the parent of a child diagnosed with autism and how that can be impacted by the assessment process for students with autism in public schools, especially in terms of how students are labeled. The results of this study will be used to inform my practice as an educator. In addition, I will share my findings with parents, teachers and staff.

Problem Statement

Throughout the United States, the rates of autism appear to be increasing at an alarming rate. According to the Center for Disease Control (CDC), 1 in 150 children were diagnosed in 2002 (Center for Disease Control, 2002). Currently, 1 in 68 children are diagnosed with autism (Center for Disease Control, 2014).

Parents who have a child diagnosed with autism face many challenges and typically have a different quality of life compared to those who do not have children on the autism spectrum. This is associated with higher levels of stress and less time for parents to meet their own needs because they have to meet the many needs of their children.

(Bouma and Schweitzer 1990; Donenberg and Baker 1993; Escobar et al. 2005; Fombonne et al. 2001; Klassen et al. 2004; Seltzer et al. 2004).

There are a number of standardized diagnostic instruments that are used to diagnose autism in public schools and there has been some debate as to which ones are the most accurate in making a diagnosis. It has been noted by some professionals (Stone et al., 1999) that as children evolve in age and maturity they should be re-assessed for autism after their primary diagnosis. When children are diagnosed with autism at a young age, it is probable that there could be a change in symptomology and behavior as they age. There is also the potential for error on behalf of the clinician, inaccurate parental reporting, and atypical behavior of the child. Therefore, it is necessary to periodically reassess and diagnose students after their initial diagnosis to ensure the stability of the diagnosis (Matson, Wilkins & Gonzalez, 2008; Stone et al., 1999; Woolfenden, Sarkozy, Ridley & Williams, 2012). In doing so, there could potentially be a decrease in the amount of students on the autism spectrum (Matson, 2007).

There is limited research that includes the parents' voice in terms of what they think is important regarding autism and assessments associated with autism, therefore there is a need to interview parents about their experiences to gain a deeper understanding of this issue.

Purpose

The purpose of this phenomenological study is to describe the lived experience of parents with children with autism and learn how to better serve those parents, their families and of course the children diagnosed with the disorder. Parents who have children diagnosed with autism face many challenges. When a child is diagnosed with autism, there are many questions

VOICES OF PARENTS

parents typically have, questions such as the permanence and accuracy of the diagnosis. It is necessary to find out the types of services and support children and their parents have been offered by school districts. As a parent of a child with autism, it is pivotal that every child on the spectrum be properly and thoroughly assessed. However, standardized assessments can be taxing on parents and do not clearly define the child as a whole person. Such tests only look at problematic behaviors and do not offer a sense of a child's personhood and potential. I will never forget the day my child was diagnosed with autism. The psychologist made recommendations in terms of possible medications and stated that my son would never develop the same as a neuro typical child. For example, he would not be able to fully develop fine and gross motor skills. My child was assessed and his future was predetermined based on the results of the assessments.

There is limited research that includes what parents think is important for others to know regarding what it is like to have a child with autism. Findings from this study will contribute to the body of knowledge regarding autism spectrum disorder. Specifically, the findings will focus on, what it is like to be the parent of a child diagnosed with ASD, especially with respect to how their lives have been impacted by the assessment process of an autism diagnosis. Due to the lack of information about parents' perspectives, my findings will fill in the gaps of literature.

Theoretical Model

The theoretical model which forms the basis of this study is Grounded Theory, specifically, systematic design. Glaser and Strauss (1967) were the first proponents of particular

this theoretical approach. Grounded theory is a systematic generation of theory from orderly and methodological research, rooted in data collection that a researcher carefully analyzes.

Grounded theory encompasses four stages of analysis. The first stage is called open coding. It is a process where the researcher forms preliminary categories from data such as interviews, observations, and researcher's memos or notes (Creswell, 2005). In this phase, there are also subcategories that are formed secondary to the initial categories. The second stage is axial coding. The researcher identifies an open ended category as the focal point of the phenomenon that is being reviewed and relates other categories to it. The final stage is selective coding, a process where Interrelationships of the categories are found and used to create a theory.

I chose grounded theory because it represented the steps I took to create themes based on initial coding. I followed the steps in sequence. That is, I collected data, analyzed the data, used preliminary and secondary codes and found themes based on the codes I assigned. Following a grounded theory approach enabled me to answer my research questions to the best of my ability.

Research Questions

Within the context of my phenomenological study I propose the following research questions.

What does it mean to be the parent of a child diagnosed with autism spectrum disorder? That is:

- 1) What are the structural meanings of life as a parent of a child diagnosed with autism?
- 2) What are the underlying themes and contexts that account for this view of life?

Researcher Background

I am a mother of a child with autism. I have worked with students for eight years, including two years as a preschool teacher and six years as a behavioral technician in special education programs. I have witnessed the difficulty parents' face in terms of guilt and fear when their child is given a diagnosis of autism. Many parents feel devastated when their child is given a label that will be used to judge him/her for the rest of his or her life. Through this study I aim to allow parents to speak and let their voices be heard so that others may learn from their experiences.

Definition of Terms

Asperger's Syndrome: is an autism spectrum disorder (ASD) that is characterized by significant difficulties in social interaction, alongside restricted and repetitive patterns of behavior and interests.

Autism: is a disorder of neural development characterized by impaired social interaction and communication, and by restricted and repetitive behavior.

Center for Disease Control (CDC): is a national public health institution for the United States that educates and protects citizens through control and prevention of diseases.

Diagnosis: is the identification of a disease or disorder.

Individuals with Disabilities Education Act (IDEA): is a United States federal law that governs how states and public agencies provide early intervention, special education, and related services to children with disabilities.

VOICES OF PARENTS

Leo Kanner: was a Jewish American psychiatrist and physician known for his work related to autism.

Pervasive Development Disorder Not Otherwise Specified: is a diagnosis that is used for "severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive development disorder or for several other disorders.

Phenomenology: is the study of the structure of experience.

Rett Syndrome: is a neurodevelopmental disorder of the grey matter of the brain that almost exclusively affects females but has also been found in male patients.

CHAPTER 2

Literature Review

Introduction

This is an overview of what autism is and how it affects parents and caretakers. The purpose of this paper is to determine whether the literature findings coincide with the findings from my phenomenological study. First, I examined the studies on what autism is, briefly including its history to provide a context in understanding the disorder more specifically. Second, I looked at studies that discuss the age of diagnosis and diagnostic measures used to make a diagnosis. Third, I analyzed studies about the effects an autism diagnosis has on parents.

History

In this section, I examine studies that provide a brief history of autism and basic characteristics of the disorder.

The research indicated that autism was first learned about in 1943 by a psychiatrist named Kanner. According to Wing (1993), he investigated children who visited his clinic and took an interest in those who appeared to have abnormal behavior. Kanner was one of the first in creating criteria for diagnosing autism.

Autism Spectrum Disorder (ASD) is a complex disorder of brain development. For example, some characteristics may be difficulties in verbal and nonverbal communication, social interaction, and repetitive behaviors. Autistic disorder, Rett Syndrome, Childhood Disintegrative Disorder, Asperger Syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) are all classified under the umbrella of autism and vary in degree (Posserud, Lundervold & Gilberg 2010; Worley, Matson, Sipes & Kozlowski 2010; Wing, 1993). Since autism is a spectrum disorder, every person differs in terms of symptomology and severity.

Age of Diagnosis

In this section, I review general studies that discuss the age of diagnosis and the factors that attribute to an inaccurate diagnosis.

The rates of autism may be increasing due to children being diagnosed at an earlier age than in the past. In the late eighties, the age of diagnosis was six, and today it is at age three.

However, there has been a shift to diagnose as early as 1.5 years old. This may be due to hypersensitivity in symptomology. An early diagnosis should not be the end of evaluation for children with ASD because children, especially in the early ages, are constantly changing and maturing over time, so there is the potential for a diagnosis to change over time. Specifically, it is vital to have an ongoing review of a diagnosis in all children diagnosed with ASD to ensure the stability of a diagnosis (Matson, Wilkins, & Gonzalez, 2008; Stone, et. al, 1999; Woolfenden, Sarkozy, Ridley, & Williams, 2012).

Inaccuracy of Diagnosis

Rates may also be on the rise due to inaccurate diagnoses. There has been a great deal of research debating whether diagnoses are accurate and remain stable over time. Some studies suggested that diagnoses vary depending on the testing instruments that are used (Kleinman, et. al, 2008; Simek & Wahlberg, 2011). That is, some tests used can be administered by teachers, school psychologists, and those with specific training for a given test. For example, the Gilliam Autism Rating Scale (GARS) is a standardized autism diagnostic instrument that relies on teacher or parent report. This rating scale is appealing because it requires limited training and time to administer.

Recent studies have shown that GARS may miss up to 58% of children on the autism spectrum (Lecavalier, 2005; South et al., 2002). Klose, et al. (2012) argued that to accurately assess ASD, professionals must have knowledge of diagnostic characteristics, differential diagnosis and implications for interventions. Another example is the Childhood Autism Rating Scale (CARS) which was created to meet the administrative and research needs of the

Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) program in North Carolina. The CARS instrument is widely used and according to Saemundsen et al. (2003), higher numbers of autism occurred when using the test.

The debate is over whether or not the diagnoses are accurate because the tests are not as thorough. There are more sophisticated tests that can only be administered by clinicians and autism experts who have had extensive training within the field of autism. For example, the Autism Diagnostic Observation Schedule (ADOS) is one of the few standardized diagnostic instruments that involve scoring direct observations of children's interactions and account for the developmental level and age of the child (Akshoomoff, Corsello & Schmidt, 2006).

It has been reported that those who administered ADOS considered themselves to be autism experts, where those who administered the CARS required less training to administer such tests compared to the ADOS administrators. Such tests are used less frequently because they are more expensive to administer and analyze. They also yield fewer diagnoses (Allen, Robins & Decker, 2008). The federal government does not mandate any particular tests in public schools to be administered to students who are suspected of being on the spectrum. Therefore, the results can vary depending on the selection of assessments.

Effects on Parents

In this section, I review studies that describe ways that an autism diagnosis may affect parents and caretakers.

Isolation

The research generally indicates that parents with children with autism feel isolated which manifests itself in different ways. Isolation for parents of children with autism can be described as lack of understanding from society, lower levels of engagement in social events and being disconnected from family and friends (Bekhet, Johnson & Zauszniewski, 2012; Boushley, 2001; Brobst, Clopton & Hendrick, 2008; Gill & Liamputtong, 2011; Lee et al., 2008; Woodgate, Ateah & Secco, 2008).

Some parents feel like no one understands what it feels like to have a child with autism. According to Boushley (2001), a mother stated, “No one could understand what I was going through except another mom of a child with a disability.” This study also found that parents felt society did not understand their children’s behavior and therefore judged them based on how they acted. Similarly, Woodgate, Ateah and Secco (2008), expressed that the parents in their study felt that society placed less value on their children’s lives and their children were stigmatized based on having an autism diagnosis.

Parents of children with autism often have lower levels of social engagement. According to Lee, Harrington and Newschaffer (2008), those lower levels may be a result of the child not wanting to leave their home environment to go other places that are unfamiliar or overcrowded. Other studies mentioned that parents were less involved in events because of their children’s behavior i.e. tantrums, outbursts or social stigma (Bekhet, Johnson and Zauszniewski, 2012).

Finally, parents can become disconnected from their families and friends. Some parents felt that even the people closest to them did not understand their lives or their children’s lives.

VOICES OF PARENTS

On the other hand, some parents found most support from their family and friends (Woodgate, Ateah and Secco, 2008). However, parents suggested that the withdrawal from events was often easier and less stressful.

Stress

Studies have indicated that having a child with autism is associated with higher levels of stress in terms of finances (Brobst, Clopton & Hendrick, 2009; ; Gill and Liamputtong, 2013; Lee, Harrington & Newschaffer, 2008). For some families, medical costs that were not fully covered by their insurance company for various types of therapy resulted in a financial burden. Other parents expressed that they had to miss days of work to take for their children to appointments, which resulted in some losing their jobs or giving up their careers to care for their children.

Other studies have found that parents of children with autism often neglect their own needs. In some cases, such neglect has led to negative health outcomes. For example, some mothers delayed health checkups or personal care because they were too consumed in caring for their children with autism (Brobst, Clopton & Hendrick, 2009). Finally, other studies have demonstrated that marital stress and in some cases, divorce are more prominent compared to couples without children with special needs (Brobst, Clopton & Hendrick, 2009). These studies mentioned that although the couples experienced lower levels of relationship satisfaction, such dissatisfaction did not hinder their commitment to their children.

Guilt

A study emphasized that parents of children with autism feel a sense of guilt. That is, mothers often feel responsible and think that they must have done something during their pregnancy that caused autism (Boushey, 2001). The study also mentioned that for some parents no matter how hard they try to not blame themselves they have a difficult time letting their guilt go.

Other studies indicated that mothers felt that they were not doing enough for their children and they should do more to help them become more successful. According to Gill and Liamputtong (2011), mothers interviewed in their study felt inadequate and as though they had failed their children.

In this chapter, I reviewed the literature about the history and characteristics of autism, age of diagnosis and the effects a diagnosis has on parents and caretakers. Overall, I found that the age of diagnosis is happening at a younger age than in the past. I also learned that parents experience varying levels of isolation, stress and guilt due to having a child on the autism spectrum. In the next chapter, I discuss the methods I used to collect and analyze data to investigate my research questions.

CHAPTER 3

Methodology

Design

The methodology I used is qualitative research because, per McMillan and Schumacher (2006), it is the ideal research plan to collect data in face-to-face situations by interacting with selected participants. I also used qualitative research to describe and analyze people's perceptions.

The type of qualitative research I used is a phenomenological study because it is designed to describe the meaning of a lived experience for several individuals regarding a specific phenomenon. As the focus of my research was on how parents experience the phenomenon of having children with autism, this approach was best to answer my research questions.

The essence of phenomenology is to paint a portrait of the richness and diversity of all of the participants' points of view. In addition, a phenomenological approach allows investigation of the perception of a particular phenomenon from the perspectives of those who experienced that phenomenon; through phenomenology the researcher can gain insight into the participants' world and describe their perceptions and reactions to the phenomenon in question.

Setting

There was no particular setting for my study because I conducted interviews in various places according to what worked best for my participants. This took place in the homes of participants, at a local coffee shop or wherever was most practical for the participants.

Research Participants

VOICES OF PARENTS

The following eight persons participated in my study. Each is described using a pseudonym.

- Adam is Mexican-American, 32 years old, and married. He is a biologist and has a ten year old son with autism.
- Brenda is Mexican-American, 60 years old, and single. She is a psychologist and has an adult son with autism.
- Jesse is Mexican-American, 33 years old, and married. He is a general contractor and has a nine year old son with autism.
- Jodi is Caucasian, 50 years old, and single. She is a Speech and Language Pathologist and has an adult son with autism.
- Kelly is Caucasian, 36 years old, and married. She is a stay at home mom and has a 6 year old son with autism.
- Mary is Caucasian, 50 years old, and married. She is a homemaker and has a fifteen year old son with autism.
- Molly is Mexican-American, 43 years old, and married. She is a special education teacher and has a 9 year old son with autism.
- Sue is Caucasian, 35 years old, and married. She is stay at home mom and has a 3 year old son with autism.

As is customary to qualitative research, I also will describe myself as the researcher-participant with respect to my own cultural “lenses”. I am Mexican-American, 33 years old, and married. I am a graduate student and have an 11 year old son with autism.

Data Collection

To address the problem identified, I conducted a phenomenological study of parents who have children diagnosed with autism spectrum disorder (ASD). I created and implemented an interview protocol for a group of parents who are “living the phenomenon,” and interviewed each participant at length on a one-on-one basis. The interview protocol consisted of 11 open ended questions, targeting participants’ perceptions of what it is like to live the phenomenon of being the parent of a child with autism. Questions were broad enough for participants to express their feelings and opinions fully and freely, but also focused enough to provide information to answer my research questions in depth. Major topics include what it is like to be the parent of a child with autism, types of support given by school district, family, and friends, and the experience of the assessment process. The responses given to these questions adequately described what it is like to experience the phenomenon of being the parent of a child with autism.

The implementation of my data collection is as follows. Before my study began, I created the interview to include a series of open ended questions aimed to elicit and probe the participants’ views of the phenomenon. I tested my interview protocol using a volunteer from among my friends who also has experienced the phenomenon of having a child diagnosed with ASD. After testing the interview protocol, I refined the questions as needed and contacted each participant to secure their cooperation as well as to set a date, time, and place for the interview. I conducted and audio-recorded the interviews. The interviews took place in a location most comfortable to my participants, such as in their homes or in a convenient coffee

shop, etc., and each was at least 30 minutes in duration. As I asked each question, I encouraged participants to express themselves fully and freely. For example, if participants provided a brief response initially, I gently probed them for greater depth, more examples, etc. I never pressed them for information, but let them know that all information they provided to me is completely confidential and that they were free to be honest in all responses. Throughout the interviews, it was imperative that I took extreme caution not to give participants the impression that I was expecting a specific response, or disapproved of their responses, etc., as that could have biased their responses and also threaten the internal validity of the study. This is one of the reasons I engaged in at least one practice interview prior to conducting the actual interviews. At the end of each interview I thanked my participants and gave them the opportunity to ask any questions about the study, or about my own experiences as the parent of a child with autism.

Instruments

My personal phenomenon interview protocol is as follows:

1. How did you feel when you first learned your child was diagnosed with autism?
2. How did your family and friends react to an autism diagnosis?
3. In what ways would you say life for you changed when you learned of the diagnosis?
4. What support options were offered to your child by the school/district?
5. How satisfied have you been with those options?
6. What support options were offered to you personally (law, academic, peer, etc.)?

VOICES OF PARENTS

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?
8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?
9. Could you share one or two of the best experiences you have had as a parent with a child with autism?
10. What advice would you offer to others who have just learned they have a child diagnosed with autism?
11. If you could change anything about the whole experience of the assessment process what would it be-and why?

Data Analysis

I first transcribed the interviews to prepare them for analysis. I read all documents and coded them, initially using codes derived from my research questions, but remained alert for emergent codes suggested by the data. As documents were coded, I continually reviewed and revised my list of codes to combine redundant codes and add new codes as necessary. During the coding process, I searched for patterns in the coded data across all data sources. That is, groups of codes that focused on closely-related issues were categorized together under a broader heading; each new category was compared to others and related categories were subsumed under an even broader heading. When all remaining categories were broad and mutually exclusive, they served as patterns, or themes to answer the research questions. I triangulated the results of the qualitative data analyses to answer my research questions.

Limits/Threats to Internal Validity

Although efforts were made to minimize threats to internal validity, there were many potential threats that could limit the overall validity, or credibility, and usefulness of the findings. The major methods I used to enhance the credibility of my findings are detailed below.

In the case of implementation fidelity, I interviewed each participant once, so there is a possibility that I did not implement as adequate or fully as designed. To minimize this threat, I conducted a practice interview with a volunteer outside of the study. Descriptive validity refers to the factual accuracy of data collected and described. To address this, I ensured the following. I provided “thick” descriptions in terms of describing both the phenomenon being observed and the context in which it is occurring with sufficient detail to give the reader a sense of being there. As mentioned earlier, I used member checking, a process in which I sent each participant a copy of their transcribed interview to allow for accuracy of what was said. Another threat was interpretive validity. This refers to the degree to which participants’ viewpoints, thoughts, intentions, and experiences are accurately understood and reported by the researcher. To address this, I used “low-inference descriptors” which means recording very precise, and often literal, descriptions of my participants’ views and relying heavily on their own words instead of on my interpretations of them. I will cross-checked information and conclusions through the use of multiple informants via triangulation. I actively had to seek out, reported, and analyzed negative or discrepant data that seemed to suggest an exception to any patterns I identified to ensure that all views were included. To address confirmability, the ability of other researchers to examine the data to confirm the results and interpretations contained

in it, I kept an audit trail, I saved all my interviews, transcriptions, codes and themes so other researchers wanting to duplicate my study could do so and reach comparable instead of contrary conclusions. Lastly, reflexivity was a threat to internal validity, therefore, I engaged in critical self-reflection regarding any potential biases and predispositions, as they may have affected the research process and conclusions.

CHAPTER 4

Results

Introduction

In this chapter, I will analyze my participants' responses to the interview questions to identify their perceptions of what it is like to have a child with autism. The goal of this research is to improve my understanding of autism; specifically what it is like to be a parent with a child with autism and what themes emerged regarding this view of life. The purpose is to use my findings to help better serve students with autism and their families.

My questions were aimed at determining what everyday life is like for parents with children with autism. Through data analysis of the in depth interviews, I identified four major themes: isolation, support, grief and resiliency. These are discussed below in order of influence from greatest to least.

The table below lists the different themes and sub-themes that emerged from the data analysis.

VOICES OF PARENTS

	Theme: Isolation		Theme: Support			Theme: Grief			Theme: Resiliency	
	Sub-theme		Sub-theme			Sub-theme			Sub-theme	
Parent	Preoccupied with Caring for Children	Judgment	Support Offered to Participants' Children	Lack of Support	Support from Family and Friends	Emotions	Blame	Grief for Children	Hope	Children's Victories
P1	x	x	x		x	x			x	x
P2	x	x	x	x	x	x			x	x
P3	x		x	x	x	x		x	x	x
P4	x	x	x	x	x	x			x	x
P5	x		x	x	x	x			x	x
P6	x	x	x	x	x	x			x	x
P7	x	x	x		x	x	x	x	x	x
P8	x	x	x	x	x	x	x	x	x	x

Isolation

Isolation was the theme with the greatest influence. Six out of eight participants expressed varying degrees of isolation. The causes of isolation that emerged from the data were preoccupation with caring for the children with autism and judgment from others. This caused a decline in parents attending social events.

Preoccupied with Caring for Children. The first type of isolation was caused by being consumed with caring for the children. That is, taking them to appointments and continuously caring for basic everyday needs. All of the participants interviewed indicated that they felt this way on some level.

All eight participants stated that once their child diagnosed, their lives consisted of scheduling and taking their children to appointments and therapy sessions. A parent interviewed stated:

Life simply changed into a regimen. The therapies, sessions and meetings took all my time so I decided to give up on the idea of working in a couple of years and instead have stayed home with her until now when she is almost about to turn 11. [Parent of a child with autism, March 26, 2014]

One of the parents stated that she spends any extra time working with her son on the techniques he has learned from his speech therapist. She also expressed that even though her son gets easily frustrated and does not want to do it, she pushes him to work hard.

Another parent expressed the depth of caring for her child's needs in this way:

Raising Aidan had become a daily struggle, along with this struggle came complete isolation, people that I talked with or had any social interaction, had become nonexistent. [Parent of a child with autism, March 30, 2014]

For this particular parent her son had a limited choice of foods in his diet. She tracked her son's calorie intake daily and stated that some days at one or two in the afternoon, it would be at zero. The mother described how she shopped at three different grocery stores in hopes of finding things her son would eat. This caused her to become stressed and eventually isolated from others.

Judgment. The second type of isolation is caused by being judged by others. This subtheme correlates with the literature findings in terms of parents feeling like society places less value on their children's lives, due in part because of the social stigma of autism. Six out of

VOICES OF PARENTS

eight participants felt like they were being judged because of their child's autism. Three of the eight participants indicated that they would withdraw from social situations because they felt they were being judged by others. Two parents expressed that people look at their children differently now that they have autism. An example stated in our interview is:

I feel like when people find out A has autism they look at him differently. I am not sure if people are just uneducated about autism and are curious or if they are waiting to see how he acts or reacts to things. [Parent of a child with autism, April 17, 2014]

This response was echoed by another participant:

They began to stare at J every time he would walk into the room. It's like they were waiting to see how he would behave or what he would do. This really bothered me and I began to stay away and avoid phone calls. [Parent of a child with autism, April 10, 2014]

One parent said that she experienced depression after finding out her son has autism but kept it a secret because she did not want to be judged. In our interview she expressed:

I was depressed for weeks but I had to hide my feelings from others because I did not want to be further judged. That is, I already received stares from others whenever I took my son out in public. His tantrums or disruptive behavior caused whispers and disgusted looks from others. [Parent of a child with autism, March 28, 2014]

To avoid the scrutiny of others and the judgment faced, the participants mentioned above chose to refrain from attending social events.

Support

The next theme is support. There were three sub-themes of support: 1) support offered to participants' children, 2) lack of personal support and 3) support from family and friends. The subthemes are explained in order from the greatest to the least influence.

Support Offered to Participants' Children. The participants all stated that their children received many supportive services from their school districts. The services included speech and language, occupational therapy and in some instances applied behavior analysis (ABA) therapy.

Seven of the eight participants stated that their child received speech and language therapy on a weekly basis. This is a common service provided to children on the spectrum because speech is typically affected in some way. Three parents stated that their child received occupational therapy each week and five participants stated that their child was placed in a specialized program. That is, a program that tailors to the specific needs of the child i.e. an autism program.

One of the participants explained how she was worried how her nonverbal son would do at his new school without her because she was his translator, however, her son made tremendous progress over time. Another parent stated that the program her daughter attended allowed her to actively participate in the classroom. The teacher allowed the parent to provide input in terms of how long the therapy sessions would be and who would work directly with her daughter. This was comforting to the parent because she was able to track her daughter's progress daily and felt like part of the support team. Each of the participants agreed that they were satisfied with the support options their child was offered.

Lack of Personal Support. As opposed to the positive feelings related by parents regarding professional support for their children, six of the eight parents interviewed stated

VOICES OF PARENTS

that they were not offered any personal support from their child's school district. That is, they were not guided to any support groups that would help them cope with the challenges of having a child with autism. Two parents stated that they were offered in home respite care for their children but declined services. This is a service where someone comes into the home to care for a child with a disability giving the parent's time for themselves. As stated in our interview:

As an example we could have in home service even on Saturdays from regional center for ABA but we wanted to keep Saturdays as family days so we can enjoy weekends as a family together. We were offered respite care services but never used those either as I never ever left my kids with anyone. [Parent of a child with autism, March 26, 2014]

This was echoed by another respondent:

I was offered support from the regional center but I declined. I did not feel comfortable with someone coming in my home and watching my son. [Parent of a child with autism, March 28, 2014]

On the other hand, one of the participants stated that she received personal support from her child's speech therapist. She was able to talk to her about any concerns or ask questions about her daughter's progress. She was so satisfied with the support that when asked what advice she would offer to someone who just learned they have a child diagnosed with autism she stated:

Find someone you can connect with, a life line, like Ms. Michelle. [Parent of a child with autism, April 7, 2014]

This is echoed by another respondent that expressed that she had an understanding

with her daughter's teacher that she could be closely involved in the classroom when she needed to be to further support her daughter.

Support from family and friends. The final subtheme is support from family and friends. All of my participants experienced support from their family and friends in different ways. Some received phone calls, visits or the understanding that there was help available if needed.

On the other hand, three of my participants stated that their family offered extensive support. One parent expressed that her family was available for anything she needed. This was echoed by another participant that stated her parents were there for her through the most difficult times and challenges. She stated:

Aidan's grandparents were the only ones who would see the daily ins and outs of our struggles mainly because I would show up at their doorstep a few times a week sobbing, just sobbing. [Parent of a child with autism, March 30, 2014]

Two parents responded that their families were neutral and did not say much because they did not live nearby. Three of the participants expressed that their families were in denial of the diagnosis and made judgmental comments:

He will grow out of it, give him time. He is just too spoiled. [Parent of a child with autism, March 28, 2014]

This was followed by another response:

They told us we were wrong, she just needed to grow up a little more since she was only two when diagnosed. [Parent of a child with autism, March 26, 2014]

The same respondent above stated that the topic of her daughter's autism was not discussed after the initial comments were made. Although there was support offered, a

majority of the participants felt that those closest to them did not truly understand what it is like to have a child with autism.

Grief

Varying levels of grief played a role in how participants felt when first learning their child was diagnosed with autism. It was especially difficult in deciding how to title this subsection because describing grief is complex and takes many forms. The subthemes that emerged were emotions, blame and grief for the children.

Emotions. When parents learn that their child has autism it is an emotional experience. Many times during our interviews, parents explained how they spent time crying when first learning of their child's diagnosis. This was the first step in the grieving process for parents. For example:

When we left, I cried in the parking lot and had to pull over on the way home to throw up. [Parent of a child with autism, March 30, 2014]

Another respondent said:

I think I cried hard every third day but then got up and did what was needed to be done. [Parent of a child with autism, March 26, 2014]

This was echoed by another parent that stated:

I remember crying a lot. It almost felt as if someone died. [Parent of a child with autism, March 28, 2014]

One participant stated that when he first learned his son has autism he felt complete devastation, anger and wanted answers as to what caused his son's autism. He stated that he felt like his entire world turned upside down and did not have a clue how to fix it:

Being a man I just wanted to fix it. You know if something is broken, you just fix it. But there was no fixing in this case. [Parent of a child with autism, April 12, 2014]

Two of the participants stated that they felt confused about the diagnosis because they knew very little about autism in general. They both said that they read every article they could get their hands on to learn more about the mysterious disorder and better assist their children.

Blame. It is common for parent to blame themselves or the environment for their child's autism. Because there is no known cause of autism, it is typical for parents to question the cause of their child's disorder.

One parent stated that when her child was initially diagnosed, she blamed herself and felt like a bad parent. As stated in our interview:

I blamed myself and wondered what I did to cause the disorder. Did I not take proper care of myself when I was pregnant? Or do I carry a gene that triggered autism?[Parent of a child with autism, March 28, 2014]

Another example of blame is provided by a participant's response:

I feel guilty, like I caused my son's autism because I have Asperger's or what if I exposed him to environmental triggers that caused it. I live with this guilt every day and it kills me. [Parent of a child with autism, April 12, 2014]

The parent also stated that the guilt he felt also put a strain on his marriage because in the initial stages of his son's autism diagnosis his wife blamed him.

On the other hand, one of my participants expressed that having a child with autism is extremely challenging and some days are harder than others; however parents need to be on the same page with one another and not blame each other for their child's diagnosis.

Grief for Children. Other participants indicated that they felt grief for their children. They wondered what kind of lives their children would live in the future and if they would be able to live independently.

One of the participants expressed that her son already had bipolar disorder and then was diagnosed with autism. She was overwhelmed and did not think she could handle anything else. She explained how she feared for her child's future because having a double diagnosis was a lot for anyone to handle. For example, as stated in our interview:

I felt really afraid of my son's future. Would he be able to grow up and be on his own or would he require my care for the rest of his life? I grieved for my son because I knew the road ahead would be long and uncertain. [A parent of a child with autism, April 5, 2014]

This was echoed by another respondent that stated:

Once it was confirmed, it felt like someone died. It was like the son I knew was gone. I wanted to wake up from the nightmare and have my baby back. [A parent of a child with autism, April 7, 2014]

A parent interviewed said that her son was developing normally, meeting all the milestones children typically meet in the first year. However there was a shift when he turned two and he lost most of his language. The child had a difficult time communicating his needs and his mother was heartbroken for her son. For example:

In my case, from going from having a very verbal son to minimum speech is hard to believe. It is like I was given a different child. He is easily agitated when he cannot communicate his needs or I do not understand fast enough. [Parent of a child with autism, April 7, 2014]

The theme of grief coincides with the findings in the literature review.

Resiliency

The final theme is resiliency. This theme manifested itself in terms of hope and children's victories.

Hope. All of the participants stated that despite the challenges they are faced with in terms of raising their children with autism they will never lose hope. For example, a parent explained in our interview that she was not sure if her son would ever be able to say I love you, however she never let go of her desire to hear those words from her son. She stated that her best experience of having a child with autism so far is when her son expressed his love for her. She said that it was having her nonverbal ASD son call her mommy for the first time. [Parent of a child with autism, March 30, 2014] Another parent expressed:

By far one of my best experiences was when my son was able to ride a bike. When he was diagnosed with autism the psychologist said he would never be able to ride a bike on his own. I knew at that moment when he rode the bike without training wheels it was a special moment, he could do anything he wanted to do if he worked hard and wanted it enough.[Parent of a child with autism, March 28, 2014]

This event also caused the parent to realize that despite what the experts say, there is room for human error and his son could do all the things he wanted to do. He was given hope for the first time and embraced his son. All of the participants stated to some degree that having a child with autism gets easier over time.

Children's Victories. The parents I interviewed celebrated in the small victories of their children. They did explain that others may not understand why they celebrate such things. That is, trying a new food or reading a novel as these things marked success.

A parent stated that her child had a difficult time engaging with other students and making friends. This is common for children on the autism spectrum. She stated in our interview:

Another memorable experience was when my son was invited to a classmate's birthday party. To others this would be a minimal thing but to me it meant my son was accepted and noticed. [Parent of a child with autism, March 28, 2014]

As she explained this story, she stopped several times and was filled with emotion. This was echoed by another respondent that stated that for the first time, her son made friends in high school and they all spend time together at her house. She said it is a joy to see her son interacting with others and looks forward to the days his friends visit.

Another parent celebrated when her daughter was able to sleep through the night without wetting the bed. She stated her best experiences so far have been when, she realized she did not have a single pee or potty accident at night and when she makes stick figures and all her hugs. [Parent of a child with autism, March 26, 2014]

Two participants stated that their child made tremendous progress and others have been surprised to learn that they have autism. This is the hope of every parent that has a child with autism.

Summary

The participants' responses to the interview questions were analyzed through the lens of the research questions regarding what it means to be a parent of a child with autism and what themes account for that view of life. There was variability in the responses of each participant concerning isolation, grief and support. The parents were grateful for the services provided to their children; however 75% of parents expressed the need for school districts to provide support groups. All of the participants expressed their feelings of hope regarding their child with autism and celebrated their child's accomplishments no matter how large or small.

CHAPTER 5

DISCUSSION, ACTION PLAN

Introduction

In order to provide further information about the impact an autism diagnosis has on parents, this study investigated what it is like to be the parent of a child diagnosed with autism. The participants were eight parents that have a child with autism. The goal of my study was to improve the understanding of autism, specifically, what it is like to be the parent of a child diagnosed with autism. That is, what it was like from the initial diagnosis and the experiences thus far. The research indicated that parents have varying degrees of isolation, stress and guilt when having a child with autism. In relation to the research, my participants experienced isolation, grief, support and resiliency. After each interview, I wrote down my thoughts and compared them to each transcription. As I compared the responses to my own experience, I realized how similar our experiences were.

Discussion

Before I started the interviews I did not think the process would be so difficult emotionally, since I have been on this journey for 10 years with my son who has autism. The first time I asked the question: How did you feel when you first learned your child has autism? I was overwhelmed with emotion. The look in my participant's eyes and expression on her face took me back to that exact day, November 18, 2004, the day my son was diagnosed. I struggled to keep my composure because I knew the same pain and heartache my participant described very well. When I received the news of my son's diagnosis, I felt like the world I knew was turned upside down. With each interview, I was reminded of that day. I realized that kind of devastation and fear cannot be erased. The participants expressed that having a child with autism was difficult in terms of isolation, grief, support and lack of support and through it all remained resilient. The responses my participants gave allowed me to answer my research question: What does it mean to be the parent of a child diagnosed with autism spectrum disorder?

When I asked the participants how their family and friends reacted to the news of their child's diagnosis, I was stunned. I expected all the responses to be similar. That is, their family and friends were supportive. After I reviewed the responses from three of the participants and realized that not everyone was supportive, my first reaction was anger. I did not understand how family members could say things such as, "He is spoiled" or "He will grow out of it" when learning of the diagnosis. I read through those three interviews multiple times to determine if I misinterpreted what the participants stated. I came to the conclusion that the comments were a defense mechanism to mask the grief that was felt because the grandparents that made the comments were grieving too. For the first time I realized that an autism diagnosis does not only

affect the child and parents, it affects each person connected to the child in different ways. The responses to this question were two fold; I learned from the participants' experiences and was able to understand the similar comments that some of my family members made about my son's diagnosis. It was a healing process for me that I had not anticipated. The responses also provided context to what it means to have a child with autism.

In the beginning of my study, I thought the problem was the lack of an ongoing assessment after a primary diagnosis was made to determine if the child was still on the spectrum. In my opinion, this was an issue that was not addressed and children were not being reassessed as they aged and matured. I anticipated asking questions about which assessments parents thought were the best and how satisfied they were with the assessment used for their child. Once I began interviewing my participants, I found that they did not have this concern. In fact, parents did not have much to say about the assessment process. Some stated it was too lengthy for their children and emotionally draining for them, while others stated that they felt the tests proctored were rushed and there was not enough time to ask questions. The real problem my participants identified was the lack of personal support from their child's school district.

After I concluded all the interviews and analyzed each one, I could not stop thinking about why parents seemed to not be concerned with assessments for autism. I realized that for some parents they were grateful that their child was assessed and for others they just trusted the experts that make the diagnosis and never questioned it. To see if there were any discrepancies in cost, I compared the cost of three widely used diagnostic tools: Autism Diagnostic Observation Schedule (ADOS), Gilliam Autism Rating Scale (GARS) and Childhood

Autism Rating Scale (CARS). There was indeed a massive difference in the cost of one of the assessments. ADOS is administered by clinicians and autism experts who have had extensive training within the field of autism and costs about \$1995.00 for a set of 50 protocols (wpspublish.com), almost ten times as expensive as the other two assessments, GARS and CARS. GARS relies on teacher or parent report. It costs about \$163.00 for a set of 50 protocols (proedinc.com) and CARS is about \$175.00 for a set of 25 protocols (ecom.mhs.com). Both GARS and CARS require less training and time to administer than ADOS. I do not know the protocols that were used for my participants' children; however, I question if cost is a factor in terms of parents not knowing there are assessment options. In my opinion parents, should be made aware of the different types of assessments that are used in diagnosing autism and be allowed to choose the one that best suits their child. However, if school districts pay for the assessments, they will likely choose the most cost effective tool. I plan to further investigate this issue until I get a more thorough answer and share my findings with parents to educate them regarding this issue.

Limitations

There were limitations in my study. It was challenging to arrange interviews with my parents as they were preoccupied with caring for their children and living their everyday lives. Some of my participants explained to me upfront that they only had an allotted amount of time which made me anxious to get through all the questions in time because I did not want to over impose. Also, it may have been beneficial to limit the number of interview questions so parents did not feel overwhelmed by the amount of time the interview took to conduct.

Recommendations

Due to the lack of support my participants received from their child's school district, there appears to be a need for districts to provide support groups for parents. I would like to form a local group for parents like myself and others who have children with autism. All of the conversations will be confidential as I know that is highly important for parents because of the in depth conversation topics that may occur. I have taken the initial steps at my school site by speaking with the school psychologist. I have a list of families who potentially may be interested in joining. I will be contacting the families to set up a time to meet and I will also give them each a copy of this thesis in hopes of sparking further interest. While I am happy to do this in my community, it seems clear that a more concerted, cohesive effort from districts would be beneficial to parents.

Conclusion

This purpose of this study was to interview parents to determine what it means to be a parent with a child with autism and what themes account for this view of life. The participants were relatively explicit about their experiences and were forthcoming about their feelings. Each parent had something unique to share. The findings of this study made it clear that more personal support is necessary for parents. Based on the responses from the participants, there is a lack of understanding in terms of how they feel and what their lives entail with having a child on the spectrum. There is also a need to ascertain what the current diagnostic practices are in public schools and decide if cost is a factor in assessment selection.

References

- Akshoomoff, N., Corsello, C. & Schmidt, H. (2006). The role of the autism diagnostic schedule observation in the assessment of autism spectrum disorders in school and community settings. *The California School Psychologist*, 11, 7-19.
- Allen, R., Robins, D., & Decker, S. (2008). Autism spectrum disorders: Neurobiology and current assessment practices. *Psychology in the Schools*, 45, (10) 905-917.
- Bekhet, A., Johnson, N., & Zauszniewski, J. (2012). Effects on resilience of caregivers of persons with autism spectrum disorder: The role of positive cognitions. *Journal of the American Psychiatric Nurses Association*, 1-8.
- Bolt, D., et al. (2010). The relative risk and timing of divorce in families of children with an Autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449-457.
- Bouma, R. & Schweitzer, R. (1991). The impact of chronic childhood illness of the family: A comparison of autism and cystic fibrosis. *Journal of Clinical Psychology*, (46)6, 722-730.
- Boushley, A. (2001). The grief cycle-one parent's trip around. *Focus on Autism and Other Developmental Disabilities*, 16(1), 27-30.
- Brobst, J., Clopton, J., & Hendrick, S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, 24(1), 38-49.
- Center for Disease Control. (2012). Autism Spectrum Disorders: Data and statistics. Retrieved from <http://www.cdc.gov/ncbddd/autism/data.html>
- Creswell, J. (2005). Educational research planning: Planning, conducting, and evaluating quantitative and qualitative research. New Jersey: Pearson Prentice Hall.
- Donenberg, G. & Baker, B.L. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology*, 21(2), 179-198.
- Escobar, R. et al. (2005). Worse quality of life for children with newly diagnosed attention-deficit/hyper activity disorder. Compared with asthmatic and healthy children. *Pediatrics*, 116(3), 364-369.
- Fombonne, E. (2005). Epidemiology of autistic disorder and other pervasive developmental

- disorders. *Journal of Clinical Psychiatry*, 66, 3-8.
- Gill, J & Liamputtong, P. (2013). Walk a mile in my shoes: Life as a mother of a child with Asperger's Syndrome. *Qualitative Social Work* , 12(1), 41-56.
- Glaser, B. & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative Research. New York: Aldine de Gruyter.
- Klassen, A.F., Miller, A. & Fine, S. (2004). Health-related quality of life in children and adolescents who have a diagnosis of attention-deficit/hyperactivity disorder. *Pediatrics*, 114(5), 541-547.
- Kleinman, J. et al. (2008). Diagnostic stability in very young children with autism spectrum disorders. *Journal Autism Development Disorder*, 38, 606-615.
- Klose, L., Plotts, C., Kozeneski, N. & Skinner-Foster, J. (2012). A review of assessment tools for Diagnosis of autism spectrum disorders: Implications for School Practice. *Assessment for Effective Intervention*, 37(4), 236-242.
- Lecavalier, L. (2005). An evaluation of the Gilliam Autism Rating Scale. *Journal of Autism and Developmental Disorders*, 35, 795-805.
- Lee, L., Harrington, R., Louie, B. & Newschaffer, C. (2008). Children with autism: Quality of life and parental concerns. *Journal of Developmental Disorders*, 38, 1147-1160.
- Matson, J. (2007). Current status of differential diagnosis for children with autism spectrum Disorders. *Research in Developmental Studies*, 28, 109-118.
- Matson, J., & Kozlowski A. (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 418-425.
- Matson, J., Wilkins, J. & Gonzalez, M. (2008). Early identification and diagnosis in autism spectrum disorders in young children and infants: How early is too early? *Research in Autism Spectrum Disorders*, 2, 75-84.
- Posserud, M., Lundervold, A., Lie, S. & Gillberg, C. (2010). The prevalence of autism spectrum impact of diagnostic instrument and non-response bias. *Society Psychiatric Epidemiology*, 45, 319-327.

- Rojahn, J. & Matson, J. (2010). Assessment and diagnosis of autism spectrum disorders in children. *Journal Developmental Physical Disabilities*, 22, 313-315.
- Saemundsen, E., Magnusson, P., Smari, J & Sigurdardottir, S. (2003). Autism Diagnostic Interview-Revised and the Childhood Rating Scale: Convergence and discrepancy in diagnosing autism. *Journal of Autism and Developmental Disorders*, 33(3), 319-328.
- Seltzer, M.M., Shattuck, P., Abbeduto, L. & Greenberg, J.S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 10(4), 234-247.
- Simek, A. & Wahlberg, A. (2011). Test review: autism spectrum rating scales. *Journal of Psychoeducational Assessment*, 29(2), 191-195.
- South, M. et al. (2002). Utility of the Gilliam Autism Rating Scale in research and clinical populations. *Journal of Autism and Developmental Disorders*, 32(6), 593-599.
- Stone, W. et al. (1999). Can autism be diagnosed accurately in children under 3 years? *Journal Child Psychology Psychiatry*, 40(2), 219-226.
- Wing, L. (1993). The definition and prevalence of autism: A review. *European Child and Adolescent Psychiatry*, 2(2), 61-74.
- Woodgate, R., Ateah, C. & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075-1083.
- Woolfenden, S., Sarkozy, V., Ridley, G., & Williams, K. (2012). A systematic review of the diagnostic stability of autism spectrum disorder. *Research in Autism Spectrum Disorders*, 6, 345-354.
- Worley, J., Matson, J., Sipes, M., & Kozłowski, A. (2011). Prevalence of autism spectrum Disorders in toddlers receiving early intervention services. *Research in Autism Spectrum Disorders*, 5, 920-925.

Appendices

Appendix A

1. How did you feel when you first learned your child was diagnosed with autism?
2. How did your family and friends react to an autism diagnosis?
3. In what ways would you say life for you changed when you learned of the diagnosis?
4. What support options were offered to your child by the school/district?
5. How satisfied have you been with those options?
6. What support options were offered to you personally (law, academic, peer, etc.)?
7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?
8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?
9. Could you share one or two of the best experiences you have had as a parent with a child with autism?
10. What advice would you offer to others who have just learned they have a child diagnosed with autism?
11. If you could change anything about the whole experience of the assessment process what would it be-and why?

Appendix B

1. How did you feel when you first learned your child was diagnosed with autism?

I was uneducated in terms of what autism was. I quickly became a mini expert and tried to learn as much as I could so that I could begin to understand my child's diagnosis. I

was scared and began to isolate myself from the outside world. I remember crying a lot. It almost felt as if someone had died. I didn't know what to expect or what to even think at the time. I blamed myself and wondered what I did to cause the disorder. Did I not take proper care of myself when I was pregnant? Or do I carry a gene that triggered autism? So many thoughts and emotions filled my mind. I was depressed for weeks but I had to hide my feelings from others because I did not want to be further judged. That is, I already received stares from others whenever I took my son out in public. His tantrums or disruptive behavior caused whispers and disgusted looks from others.

2. How did your family and friends react to an autism diagnosis?

My family made comments such as, "He will grow out of it, give him time." Or my favorite response was, "He is just too spoiled!" Really? Comments as such made me fall into a deeper depression. At times I felt like I was crazy, meaning, am I looking too much into this whole autism thing? Were the others right? My son's diagnosis put a strain on my marriage because my husband was in denial. I know he was silently grieving for our son. He became distant. Being a stay at home mom, I dealt with all the appointments and therapy sessions. As far as reactions from friends, I received numerous apologies. I'm so sorry for what you are going through or I am here if you need to talk.

3. In what ways would you say life for you changed when you learned of the diagnosis?

I immediately knew that my needs were on the back burner. Life was about what my son needed. His needs were priority and everything else was secondary. Looking back, I feel as though my older son was cheated. What I mean is we stopped doing things we had done in the past because it was so difficult to take my son with autism places. I felt

VOICES OF PARENTS

as if my energy was sucked out of me. From speech and occupational therapy, constant tantrums, excessive crying from not being able to communicate effectively, life was tough.

4. What support options were offered to your child by the school/district?

Speech and occupational therapy were provided.

5. How satisfied have you been with those options?

At the time I was satisfied with the services provided but I wish there could have been more of a social aspect.

Please explain?

My son has difficulty with social, peer relationships. It is hard to teach such skills because he is older now.

6. What support options were offered to you personally (law, academic, peer, etc.)?

I was offered support from the regional center but declined. I did not feel comfortable with someone coming into my home and watching my son.

Can you explain what you mean?

The regional center provided a service where someone would come to my home and watch my son for an hour per week so I could have time for myself. I did not want to leave my son because I would just worry about him and wonder if his needs were being met.

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?

VOICES OF PARENTS

I did not take advantage of the service and sometimes wonder if my son would have benefitted from others coming in and working with him.

8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?

Being a parent of a child with autism is an emotional roller coaster. My child has days where he is extremely sad and will cry for hours. It is heart breaking because I have to stand back and watch. I feel helpless because I cannot change what he is feeling because he does not know why he feels so sad. It is also difficult because my son wants to play sports but lacks the large gross motor skills to do so. Whereas, my older son is naturally gifted in this area and plays with ease. One of the most challenging times in my life was when my son asked me why he is different from others. I was taken back. My response was, "How would life be if everyone looked and acted the same?" life would be boring and unexciting. I told him that he looks at the world through a different lens as others but is smart and exceptional at everything he does.

9. Could you share one or two of the best experiences you have had as a parent with a child with autism?

By far my one of my best experiences was when my son was able to ride a bike. I knew at that moment when he rode the bike without training wheels, he could do anything he wanted to do if he worked hard and wanted it enough. Another memorable experience was when my son was invited to a classmate's birthday party. To others this would be a minimal thing but to me it meant my son was accepted and noticed.

VOICES OF PARENTS

10. What advice would you offer to others who have just learned they have a child diagnosed with autism?

Be an advocate and fight for whatever your child needs! You know your child inside and out and do not ever let a label define who your child is. Speak up! When one door closes another will open. I would also suggest to someone learning they have a child with autism to be surrounded by people who have lived the same experience.

11. If you could change anything about the whole experience of the assessment process what would it be-and why?

I would ask for alternative testing that would represent what my child can do well. It seemed like the focus was on what he could not do. I think it would be helpful for children to be assessed in a natural environment rather than in a place that is foreign to them.

Appendix C

Background Information:

I married at 22 and had my first daughter at 24. Second daughter followed quickly a year later. She is a classic late onset case at least that is what we think. She seemed to be doing great for the first year of her life. I do not remember much as there were two kids growing up together but I do remember her exchanging some words with her dad when we would drive to places and my husband would reply and she would giggle. However, by age 15 months something seemed to be off. She lost all vocabulary and would not make eye contact. She was run further

VOICES OF PARENTS

away when called out. We almost lost her twice but had to be extremely vigilant keeping an eye on her until she was 7 years old.

When she was a year and a half, I was about to travel to another country so made some appointments at three different places and by the time I returned we were asked to come in. All these places diagnosed her with autism. One was Oakland Children Hospital and another was Kaiser Permanente Autism center in San Jose.

Then began our arduous but very fulfilling journey towards understanding autism and how we could better support my daughter and help her become the best version of what she can be. Today, proudly, she is full inclusion 80% to 100% in academic scores at school with zero modifications. I always make sure she gets accommodations as they can benefit any student. Socially she is doing much better but still finds it challenging to make friends. By the time she was age 7, we were able to explain to her about her diagnosis and help her understand some of the challenges she faces.

She has influenced her, our family in incredible ways from where we choose to live to our professions and our whole approach towards life. It improved for the better!

1. How did you feel when you first learned your child was diagnosed with autism?

It was confusing, since I did not completely understand the diagnosis. In my head I was confusing Down Syndrome with autism. However, the experts in the field did help us a lot and we got initial guidance from them. Then we read up a lot on our own and found every source

VOICES OF PARENTS

we could to learn more. It was emotionally very hard. I think I cried hard every third day but then got up and did what was needed to be done.

2. How did your family and friends react to an autism diagnosis?

I have always been forthcoming about the diagnosis. They told us that we were wrong; she just needed to grow up a little more since she was only 2 when diagnosed. But since we put up a strong front, they respected it. Generally it was not discussed. We do not have family in the area where we live.

3. In what ways would you say life for you changed when you learned of the diagnosis?

Life simply changed into a regimen. The therapies, sessions and meetings took all my time so I decided to give up on idea of working in a couple of years and instead have stayed home with her until now when she is almost about to turn eleven. I would visit her every day at her pre-school. Sessions, school and my other daughter took all my time. My husband worked full time and so we could make ends meet easily. We did not visit many people as my daughter could throw tantrums.

4. What support options were offered to your child by the school/district?

In Pre-k she had special day class from 8 to 12 followed by DTT after school 2 hour session in a close by class. She walked there with her aide. She was hardly 3 and a half. At my request, the supervisor included me in planning for her DTT sessions and services. I was able to provide a lot of input, even to the extent of where I wanted her to sit and how long her sessions should be and with whom.

VOICES OF PARENTS

Then we changed counties and got the best Pre-k services which were amazingly supplemented by regional center services. I was able to be on campus every day and work with her when I wanted. Teachers respected my input and I was able to transfer her into full inclusion at age 5 with full time aide.

We only recently ended ABA services at home last year. We did not think she needed them anymore.

5. How satisfied have you been with those options?

Very satisfied. I wish there was more social provided when she between 4 and 6. I independently of school and Regional center was able to put her in a program sort of Play Gym, which forced her to be with age appropriate peers. I was able to combine this with her ABA once a week. She also got three hours of speech and more per week between school and regional center.

6. What support options were offered to you personally (law, academic, peer, etc.)?

All possible supports but what I counted on most was that we were able to develop relationships with our providers, SLPs, teachers, aides and ABA people who would then guide us and suggest what other options we had. At that time insurance and medical did absolutely nothing once the diagnosis had been provided.

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?

VOICES OF PARENTS

I am very satisfied with whatever services we got, since we did get a lot of services. We got so much that I told them I did not want that much. As an example we could have in home service even on Saturdays from regional center for ABA (Behavior) but we wanted to keep Saturdays as family days so we can enjoy weekends as a family together. We were offered respite care services but never used those either as I never ever left my kids with anyone. Everything else we used. I loved that all the school I have had my daughter in let me participate in her academic life. All schools except one. I have an understanding with my daughter's teachers that I will be very closely involved and can be in the classroom whenever I feel I needed to be.

8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?

I would say it is something they cannot understand, just like I would not understand what it is like for parents of Sped children who are diagnosed with incurable or progressively deteriorating medical conditions.

It is a challenge and parents need to be on board. Parents should be on the same page. It should not be a blame game. I would say it does get better with time for many and we learn to celebrate little successes in life!

9. Could you share one or two of the best experiences you have had as a parent with a child with autism?

VOICES OF PARENTS

Thousands of such experiences such as the first time she successfully told a funny joke to the time she enrolled in a talent show in school for hula contest. I was so scared, dropped everything to be there with her. She performed confidently and wonderfully. I was so proud.

When she finished her first harry potter book at age 7. When she did not throw a single tantrum when on a four day science camp with class and the last night instead of sleeping on my bunk bed, she opted to join her friends who invited her. It was a pleasure to see her succeeding. When I realized she did not have a single pee or potty accident at night. When she makes her stick figure stories and all her hugs.

10. What advice would you offer to others who have just learned they have a child diagnosed with autism?

Deal with it. Take some time to check your feelings but then get onboard and put your child's feelings and life as a priority. Early Intervention is the key to how well a child lives their life. Realize that not only the professionals but parents are responsible for working with their children and make sure they are best advocates for their child. The time a child spends with family can be very fulfilling and a learning experience. It will be excruciatingly hard but push through it. Find a hobby for yourself but always come back to helping your child improve and get the best they can out of their education.

11. If you could change anything about the whole experience of the assessment process what would it be-and why?

VOICES OF PARENTS

I would make sure that at least 2 hours are allocated to parents with a caring specialist who can answer any questions the parents may have right after they are handed the diagnosis. They may want to go through frequently asked questions without the parents having to ask since sometimes they do not even know the appropriate questions.

I would have a follow up scheduled a week or two later. Talk about available therapies and point out difference between evidence based therapies and the others.

I would provide a list of all resources available.

Third of fourth week, I would want to follow up with phone appointment. Some parents need more of a nudge to get the kids started on service acquisition. It was not the case with us, but many parents I meet and council are incapable of initiating this step on their own.

Appendix D

1. How did you feel when you first learned your child was diagnosed with autism?

I was very overwhelmed because my son had already been diagnosed with bipolar disorder. I thought another diagnosis. I didn't think I could handle anything else because bipolar was enough. It did make sense though. I mean the behaviors like no eye contact, repetitive behaviors and some sensory needs. I felt really afraid of my son's future.

Would he be able to grow up and be on his own or would he require my care for the rest of his life? I grieved for my son because I knew the road ahead would be long and uncertain.

2. How did your family and friends react to an autism diagnosis?

Well, my family is from the Los Angeles area so they didn't all know too much. Because W is the middle child, it was hard on the older kids.

Why was it harder?

They did not want to go with us to appointments but were not old enough to stay home alone. They also would get embarrassed when we would go out in public because W's behavior was unpredictable.

3. In what ways would you say life for you changed when you learned of the diagnosis?

It is tough to admit but it has been hard financially. We have hospital bills and therapist bills that seem to never end. My life changed in many ways. I have to stay on top of appointments and make sure W takes his medication daily.

4. What support options were offered to your child by the school/district?

W was transferred to the county program for emotionally disturbed kids. He was placed in a classroom with 6 other boys and many staff members. He was there from 2-8 grades. He didn't want to stay in the program so he was transferred to the high school. The district offered a full time aide that is with him throughout his day.

5. How satisfied have you been with those options?

So far, I have been pleased with the support. I do wish I was given more information about my son's day. When he was in the county program, the staff provided tons of details about his day and progress. Now I feel out of the loop. One thing that is probably the most helpful is that he meets with a county behavioral health therapist once a week.

The therapist checks in with me to see how things are going at home. I appreciate it so much.

6. What support options were offered to you personally (law, academic, peer, etc.)?

I have not been offered any support personally.

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?

If I had been offered something I may have taken it. It depends on the offer.

8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?

My life is exhausting. I spend much of my day guessing how my son is feeling. He likes everything a particular way. He does not like crust on his sandwiches and only likes peanut butter that is creamy and not crunchy. One time I guess I bought the crunchy kind and he had a meltdown at school and refused to eat. He has to be reminded to do things like brush his teeth or take a shower. These things do not come naturally to him. He also forgets things very easily. We can have a conversation and then I will ask him a question about something we talked about and he does not remember what we talked about. He is so worried about fitting in at school. It breaks my heart when he tells me he wants to be normal. I don't even know how to respond to that.

9. Could you share one or two of the best experiences you have had as a parent with a child with autism?

There is a recent experience that happened last year. W was chosen to be a class representative. He was so proud because he got to go to meetings once a month and

VOICES OF PARENTS

discuss school issues. His aide would help him take notes and then he would read them to the class. I cried when I found out he was chosen. Gosh, it was a wonderful feeling. Another thing that happened was he became friends with a couple of kids. They are all best friends now and they come over to visit him. It is so nice to see him interact with kids his age. I really look forward to those days.

10. What advice would you offer to others who have just learned they have a child diagnosed with autism?

Look for support groups. There are many days when I feel so alone and like no one understands.

11. If you could change anything about the whole experience of the assessment process what would it be-and why?

I would want the questions asked to be explained a little better. The assessments all seemed so rushed. It felt like they wanted us in and out. I would also want a follow up assessment or check in to see how things have progressed.

Appendix E

1. How did you feel when you first learned your child was diagnosed with autism?

I always knew that something was different about J. I am not saying that I am happy that he's autistic, I was just happy to finally have a diagnosis of something. It was so hard wondering what was wrong with J. He was so different from my other kids and I found myself going crazy trying to figure it out.

VOICES OF PARENTS

2. How did your family and friends react to an autism diagnosis?

They did not say much. I am not sure if it was because they didn't know much about autism or what? I do feel that everyone was really different.

Can you explain what you mean by different?

They began to stare at J every time he would walk into the room. It's like they were waiting to see how he would behave or what he would do. This really bothered me and I began to stay away and avoid phone calls.

3. In what ways would you say life for you changed when you learned of the diagnosis?

Life is busy. I have to keep up with appointments for J. I try to work on the same things he learns at speech like sounds. He gets easily frustrated and doesn't want to do it. I feel like I need to push him but then he gets upset and I just cry. It's still new to me. I am trying to learn how to help him but some days are hard and I don't have the energy. I feel like a bad mom when I get frustrated with J.

4. What support options were offered to your child by the school/district?

He was given speech therapy and occupational therapy. He was also placed in a district autism program.

Can you explain more about the program?

He is in a class with about 7 other kids, a teacher and 3 aides. It is a full day program.

5. How satisfied have you been with those options?

I am satisfied but I would like him to spend time in the general education classes as well.

VOICES OF PARENTS

6. What support options were offered to you personally (law, academic, peer, etc.)?

I was not offered any support personally.

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?

n/a

8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?

Life is like a balancing act. I have my schedules, J's schedule and I have to make sure my other kids get help with their homework, and I drive everyone around to school, practice, and J's appointments. I never have time for myself. I can't remember the last time I had time alone to read or watch TV. Life is tough but J needs me and I will never give up on him.

9. Could you share one or two of the best experiences you have had as a parent with a child with autism?

The day J pointed to his hug icon and gave me a hug I knew that was his way of saying I love you. It may seem like a small thing but in my eyes, it was the best experience so far. I'm not sure anything can match that day.

10. What advice would you offer to others who have just learned they have a child diagnosed with autism?

Hang in there. Do not ever give up on your child even though some days are tough. Your child is depending on you to lead the way.

11. If you could change anything about the whole experience of the assessment process what would it be-and why?

I would have liked more support or someone I could call to talk to or ask questions.

Sometimes it feels like I have to figure things out on my own.

Appendix F

1. How did you feel when you first learned your child was diagnosed with autism?

I was in shock because my son hit all the milestones. He walked early, began to talk before he was a year old. He liked to play alone and was fixated on trains or cars. Then at about 2 years old the talking decreased. I was in disbelief. How could he just stop talking? I never thought of autism even though he liked to be alone because his language was abundant. Once it was confirmed, it felt like someone died. It is like the son I knew was gone. I wanted to wake up from the nightmare and have my baby back.

2. How did your family and friends react to an autism diagnosis?

They were in shock because it was like G changed overnight. They were very supportive and available anytime I needed them but it wasn't enough I wanted G back.

3. In what ways would you say life for you changed when you learned of the diagnosis?

To go from hearing, "love you" to nothing is heart breaking. I cannot even describe what that feels like. If I could go back in time I would have recorded it.

4. What support options were offered to your child by the school/district?

Speech and language services

5. How satisfied have you been with those options?

VOICES OF PARENTS

Yes, G has a wonderful speech therapist that is great at what she does. She is the most supportive person in our lives because she has a son with autism so she gets it.

6. What support options were offered to you personally (law, academic, peer, etc.)?

Besides the support from Ms. Michelle, his speech therapist, none.

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?

I speak with Ms. Michelle and email her often. She is my life line.

8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?

In my case, from going from having a very verbal son to minimum speech is hard to believe. It is like I was given a different child. He is easily agitated when he cannot communicate his needs or I do not understand fast enough. I have icons all over the house that represent what things are like fridge or table. My life and time are consumed with helping G. He is my only child, he's my world. There are days when I am overly emotional and everything makes me cry but then I realize how lucky I am to have G. He is a gift.

9. Could you share one or two of the best experiences you have had as a parent with a child with autism?

The best experience I have had so far is the day when G put together a sentence frame with picture cards. I knew then that he was on track to acquiring his speech again.

10. What advice would you offer to others who have just learned they have a child diagnosed with autism?

VOICES OF PARENTS

Be patient. As a mom, I feel overwhelmed and exhausted carrying for G but I stop and think how difficult life is for him so I just keep going. Find someone who you can connect with, life line like Ms. Michelle.

11. If you could change anything about the whole experience of the assessment process what would it be-and why?

I would have liked the person that assessed G to take their time. It was rushed and overwhelming.

Appendix G

1. How did you feel when you first learned your child was diagnosed with autism?

I took my son to the pediatrician and he asked questions like does he talk, does he play with others? I had never really thought about those things. I answered no. He gave a referral for the San Andreas Regional Center and that's where the story begins. He was assessed over the next few weeks and was diagnosed at 3.5 years old. I was so scared. I had no clue what autism was and didn't know what to do.

2. How did your family and friends react to an autism diagnosis?

They were supportive. I do feel like they do not understand and explaining things over and over about autism gets annoying after a while.

3. In what ways would you say life for you changed when you learned of the diagnosis?

I feel like when people find out that A has autism they look at him differently. I am not sure if people are just uneducated about autism and are curious or if they are waiting to

VOICES OF PARENTS

see how he acts or reacts to things. My life is very hectic. It seems like I do not have time to do the things I used to do. A's needs are my priority. He comes first no matter what.

4. What support options were offered to your child by the school/district?

He is in an SDC preschool class. There is a teacher and 2 aides. The class has other autistic kids and kids with other disabilities. A seems to like his class. He receives occupational and speech therapy twice a week.

5. How satisfied have you been with those options?

I am satisfied. He has a really good teacher and I am grateful for that.

6. What support options were offered to you personally (law, academic, peer, etc.)?

None

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?

N/A

8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?

Life feels like a roller coaster. Some days are good and some are bad but you have to keep going and trust that there will be more good days than bad.

9. Could you share one or two of the best experiences you have had as a parent with a child with autism?

The best experience was when A's teacher told me that he plays well with one of his classmates. I went to observe him on the playground and to see him interact was wonderful. He was just being a kid.

VOICES OF PARENTS

10. What advice would you offer to others who have just learned they have a child diagnosed with autism?

In time things get easier so try to be patient even though it is hard to.

11. If you could change anything about the whole experience of the assessment process what would it be-and why?

I was pleased with the assessment process but it was so long and tiring, especially for A.

Appendix H

1. How did you feel when you first learned your child was diagnosed with autism?

We went through IVF to have children; we worked so hard, went through emotional roller coasters and were thrilled when we learned we'd be raising a son. I had become very close to some amazing woman with whom I cycled with. Some of them were raising multiples and were having an easier time. We were struggling at everything, feeding was a nightmare, sleeping was nonexistent, and no one could help us. The appointments with his, daily visits to the pediatrician, seeing nutritionists, and no one could offer any help. We first received the diagnosis of SPD (sensory processing disorder) and started with an occupational therapist. I dove head first into learning as much as I could, some of the books I read could of been written about my boy. The things that should of been easy for him were a struggle, walking on grass, food on his tongue, going to the park, the beach, everything was too hard. The OT recommended a neuro eval., and I agreed that it was a good next step. Driving to the eval, I cried, just little tears, I knew no matter what they said, it wouldn't change my son. The doctors saw a pretty good example of him at the visits; it was an easy diagnosis for them. When we left,

I cried in the parking lot, and had to pull over on the way home to throw up. Devastated, Autism, now what? You have the diagnosis, but there is no map that comes along with it.

2. How did your family and friends react to an autism diagnosis?

Raising Aidan had become a daily struggle, along with this struggle came complete isolation, people that I talked with, or had any social interaction had become nonexistent. Aidan's grandparents were the only ones who would see the daily in and outs of our struggles, mainly because I would show up at their doorstep, a few times a week, sobbing and sobbing because that piece of paper I stared each morning to track his calories, would still be zero at one or two in the afternoon. The doctors had repeated, his brain needs fat to develop, try mashed potatoes, try butter, put oil in everything he eats, try chocolate pudding, great ideas to get fat into a five month old, but not so great if you can't get a spoon in his mouth, bottles were not an option, he was done with them, did I try different spoons, did I try different foods? I can't tell you the things I tried, I knew how much a half of scoop of neonate was, I knew how many calories were in the creamed corn, or the apple supreme, and I knew how much fat I could sneak into them. I shopped at three different grocery stores because I knew where the things were that he might eat. My parents saw this, and they saw his obsession with pouring water, from bottle to bottle without spilling a drop, they saw his cute behaviors. I don't think they were shocked at the diagnosis either. The family that didn't know Aidan, I feel, were judgmental, nonsupportive, and our invites to many things ceased.

3. In what ways would you say life for you changed when you learned of the diagnosis?

VOICES OF PARENTS

Life changed, it sure did, after the battle with our insurance company denying him services, or limiting how long he could receive them, and struggles to learn what was the right thing to do, we jumped head first into therapy. ABA therapy & more therapy...we hammered him with ABA, speech and occupational therapy. The progress was slow, really slow, but it gave us hope. Everyone needs hope.

4. What support options were offered to your child by the school/district?

I was terrified of Aidan "aging out" of services at the age of three. I only heard nightmares about 504's, IEP's, graduating out of our comfy world of IFSP's but our local school was amazing. I sat with all of these strangers, who didn't know my son, he was a baby, he was three, and they were going to take over his therapy. Everything and everyone that Aidan knew, was about to disappear. They were so incredible. The care and the services were better than I could have dreamed of. I was terrified, sending a nonverbal out of the house, without me, I was his translator, I was the only one who understood him but it was an entire new world, and entire new horizon of hope. They continued his ABA, they continued his speech, and were going to add into the mix, friends. He'd never had a friend before, and this made me cry happy tears many nights, he deserved this.

5. How satisfied have you been with those options?

Incredibly satisfied so much so, that when Aidan's younger twin brothers were diagnosed, I immediately started down the same exact path. Educators call Aidan a, success story so who wouldn't want to follow the same path and try for the same results?

6. What support options were offered to you personally (law, academic, peer, etc.)?

VOICES OF PARENTS

None

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?

N/A

8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?

You can't expect your experience with autism to mean much to anyone, because no two people who struggle with it are the same. I can tell them to get ready for the ride of their life, because it's mind blowing. When your child reaches milestones, simple milestones, you celebrate, and you celebrate big! You don't share these celebrations with many, because most just won't "Get It", imagine seeing a post on Facebook that reads, "My son walked on grass!" Or, "My son ate a cashew!" You celebrate, but just in a different way. You will have experiences that not many understand, but you will also miss out on other things. I have a mommy group, friends now, who are sending their five year olds to school, they are celebrating this milestone, I'll miss this one, because my son has been in school for two years. Some days, I feel bad for Aidan, because he has worked so hard, and doesn't get to take a break, Summer school is a given, vacations probably won't happen because we can't pack his room, the sensory issues have to be experienced to be understood. If someone wants to get an idea of my shoes, they'll have to walk in them.

9. Could you share one or two of the best experiences you have had as a parent with a child with autism?

VOICES OF PARENTS

Best experiences, having your nonverbal ASD son call you mommy for the first time, being released from speech because he falls within normal range for his age, people learning about Aidan and saying, "I would have never known", watching him be socially appropriate in public, when he initiates play at the park, seeing his self-confidence soar in the past few years, his hugs. I could answer this one for hours.

10. What advice would you offer to others who have just learned they have a child diagnosed with autism?

Services, services, services! If you can't get them, call someone else, if they say no, call tomorrow, never take no for an answer, you are their advocate, you are their lifeline, don't lay down, and don't give up. If you can't get the eval, go somewhere else. If your pediatrician says to wait, don't! Trust your instincts.

11. If you could change anything about the whole experience of the assessment process what would it be-and why?

I would have liked an instruction manual on what to do next.

Appendix I

1. How did you feel when you first learned your child was diagnosed with autism?

Devastated, heartbroken. It felt like the world was ending. Worried about the future.

Confused.

Can you explain what types of things you were confused about?

Up until that point, I didn't even know what autism was. Angry of course too because I wanted to know what caused it. Guilty, I guess. I felt like I caused it or exposed him to

something that caused it. Being a man I just wanted to fix it. You know if something is broken, you just fix it. But there was no fixing in this case. Yeah, I just wanted to fix it.

2. How did your family and friends react to an autism diagnosis?

Family was in disbelief. They didn't believe that it was accurate. They believed it was just that he was spoiled. They just didn't believe it.

3. In what ways would you say life for you changed when you learned of the diagnosis?

Well, of course after I wanted to find out what caused it. Of course I was angry at first and looking for someone to blame. I learned a lot from it with doing research on my own. It also made me look at my son differently. You can't be angry with a baby but sometimes you get frustrated that he can't stop crying and it seems like there's nothing you can do to get their attention but now there was a reason for it. Even if I didn't know exactly what it was or what caused it, I knew there was something there. There was some reasoning for his behavior.

4. What support options were offered to your child by the school/district?

The regional center offered one on one assistance with him. Honestly, it's hard to remember exactly what they offered. I know they offered speech services and wanted to place him in an autism program.

5. How satisfied have you been with those options?

Yes, because I don't know what else they could have done to help. I still don't know. Even being more educated now and knowing more about it, I still don't know exactly what they could have done.

6. What support options were offered to you personally (law, academic, peer, etc.)?

None

7. Have you taken advantage of any of those options? If so, how satisfied have you been with those options? If not, why?

If support was offered I don't think I would have taken it. At that time it hurt so much that it was hard to talk about it. It's hard to talk about it now and it has been over 10 years. I can't imagine sitting with other people in a room and talking about it.

8. How would you describe what it is like to be a parent of a child with autism, if you were talking to someone who had not idea at all about this?

I would want to tell the person that it gets easier in time but that is just in my own experience because I happen to have a child on the more mild range and he was able to overcome many obstacles. I would say to just educate yourself on what it is. There are things out there that I wish I would have known then. People are trying holistic approaches now like changing the diet. I would be willing to try anything except for medication. Do your homework and research the disorder so you can help your child and how you can help them.

9. Could you share one or two of the best experiences you have had as a parent with a child with autism?

I can but I can't right now because I get too emotional just thinking about it. When my wife first called me and gave me his diagnosis. The first official diagnosis when the psychologist said he is not going to be able to do a lot of things. She said he would never be able to ride a bike on his own. The first time that he was able to ride a bike on his own was a real special moment because it showed me that they were wrong. They were

wrong. He's going to be able to do anything he wants to do and continues to do great things.

10. What advice would you offer to others who have just learned they have a child diagnosed with autism?

Do your research, ask questions. I guess on a personal level, have patience. As a person with a child with autism you have to have an extreme amount of patience. With any kid really, you have to be patient but especially with kids that have autism. You are not going to get the outcome you desire you may never get it. Just be patient with your child.

11. If you could change anything about the whole experience of the assessment process what would it be-and why?

There's a lot of things. The prognosis when you are going through with a parent, try not to be too concrete with the information that you give a parent in terms of what the child cannot do. I don't know if the person that diagnosed my son was a parent but I don't know how any parent can look another parent in the face and give a long list of limitations and not feel empathy. Maybe there should be a counselor that could give the prognosis to comfort the parents. The whole testing thing is ridiculous. You stick a 3 year old in a room with a stranger and expect him to be social is a crazy idea.

Appendix J

VOICES OF PARENTS

	Theme: Isolation		Theme: Support			Theme: Grief			Theme: Resiliency	
	Sub-theme		Sub-theme			Sub-theme			Sub-theme	
Parent	Preoccupied with Caring for Children	Judgment	Support Offered to Participants' Children	Lack of Support	Support from Family and Friends	Emotions	Blame	Grief for Children	Hope	Children's Victories
P1	x	x	x		x	x			x	x
P2	x	x	x	x	x	x			x	x
P3	x		x	x	x	x		x	x	x
P4	x	x	x	x	x	x			x	x
P5	x		x	x	x	x			x	x
P6	x	x	x	x	x	x			x	x
P7	x	x	x		x	x	x	x	x	x
P8	x	x	x	x	x	x	x	x	x	x