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UNIVERSITY OF CALIFORNIA,  
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Children With Autism Spectrum Disorder: Assessing the Relationship Between Services  
Received and Quality of Life

THESIS

Submitted in partial satisfaction of the requirements  
for the degree of

MASTER OF SCIENCE

in Genetic Counseling

by

Shayna Brianne Svihovec

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2017



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## ABSTRACT OF THE THESIS

### Children With Autism Spectrum Disorder: Assessing the Relationship Between Services Received and Quality of Life

By

Shayna Brianne Svihovec

Master of Science in Genetic Counseling

University of California, Irvine, 2017

Professor Jay Gargus, MD, PhD, Chair

This study was designed to explore the relationship between the quality of life of children on the autism spectrum and the services they are receiving. Although there are groups of people who do not believe that children on the spectrum are in need of treatment, therapies have become the expected following a diagnosis of autism spectrum disorder. The aim of this study was to identify whether certain types of therapies and services were associated with better quality of life for children with autism.

An anonymous survey was distributed online to individuals within the autism spectrum disorder community. Participants were parents of one child on the spectrum (2-12 years old); 47 individuals completed the survey. Results indicated that certain therapies are associated with reported improvement in some categories but not others. Applied Behavioral Analysis therapy was associated with reported ability to communicate, happiness in public, and happiness at school. Speech therapy was associated with reported improvement in a child's ability to perform physical tasks. Understanding the relationship between the types of service received or the amount of time participating in services and reported improvement levels in various areas of life will inform health care professionals' perspective regarding the value of therapies. Genetic counselors serve a unique role because they are often the team member first connecting with the family and helping initiate services. This research broadens the understanding of the impact that therapies may have on quality of life and enhance the ability of professionals to provide guidance to families.

# I. Introduction

## *1.1 Defining Autism Spectrum Disorders*

Autism spectrum disorder (ASD) is characterized by impairments in social skills, gross and fine motor delays, language delays and difficulty with communication and stereotypic behaviors (Shaw, 2014). There are often other comorbidities including intellectual disability, seizures, sensory processing disorders, anxiety, depression, aggression and attention deficit, hyperactivity disorder. Signs and symptoms of autism often present before 36 months of age. In approximately 70% of cases these symptoms occur as a delayed but continual progression of developmental milestones, while in approximately 30% of cases there is regression, or loss, of developmental milestones usually occurring between 18 and 24 months of age (Shaw, 2014).

Since its discovery in the 1940s, extensive research has been done focused on autism and its definition. Despite the strides that have been made, there is still a lack of knowledge surrounding the disorder and much progress that needs to be made (Wolff, 2004). As ASD has a continually changing definition, it has been described as a moving target which creates challenges for both professionals and nonprofessionals to understand it and its intricacies. The scientific community first explained autism as a disorder related to schizophrenia (Wolff, 2004) however it has since been defined as a spectrum with an incredibly varying degree of severity and characteristics in the most recent Diagnostic and Statistical Manual for Mental Disorders (American Psychiatric Association, 2013).

Leo Kanner, an American-Austrian psychiatrist and physician, was the first to describe and define autism in his 1943 paper, *Autistic Disturbances of Affective Contact* (Wing, 1997). In this paper he presented eleven (eight boys and three girls) cases that detail the different characteristics of children he believed to be affected with autism. Kanner presented the features

that connected all of these seemingly disparate children together to create the early definition of autism. This definition included the pathognomonic feature of having an “inability to relate themselves in an ordinary way to people and situations”. This characteristic was further described as an intense need for solitude, with outside contact being seen as a disruption that could result in distress. Other features of this early definition of autism include: speech delay or no speech development, adept rote memorization, echolalia (the repetition of learned phrases), a lack of understanding for even common metaphors, refusal of food, dislike for loud noises, obsessive and repetitive behaviors, a violent resistance to change, a need for consistent routine, and anxiety. Despite these features he noted that these children “were endowed with good cognitive potentialities”. Many of these features contributed to the idea that there was a need for a different diagnosis (to be used for children with autistic-like characteristics), similar to schizophrenia. Kanner noted that the difference between disorders of affective contact and schizophrenia lie in that those children with autism experienced these features from a young age rather the gradual development in adolescence and early adulthood seen in those with schizophrenia. He also noted that as long as an object (this refers to an item, a person, a sound, or any other element that may be present in a child’s surroundings) did not interfere with the child’s sense of being alone and need for sameness, the child was able to develop and keep a meaningful relationship with it, which differs from those affected with schizophrenia (Kanner, 1943). This is the beginning of the idea that sensory processing dysfunction is an important part of autism and where the disconnect between ASD and schizophrenia begins. By 1979 the association between autism and schizophrenia had dissipated following a title change to the journal started by Kanner and American psychologist, Stella Cross. The journal was started it was titled *Journal of Autism*

*and Childhood Schizophrenia*, and was switched the *Journal of Autism and Developmental Disorders*, following the separation between the two disorders (Wolff, 2004).

The current definition of autism spectrum disorder is remarkably similar to the definition that Kanner described in 1943 although it has become much more inclusive to incorporate a broader spectrum of symptoms (Lauritsen, 2013). The Diagnostic and Statistical Manual for Mental Disorders (DSM) is the compilation and classification of mental disorders that is published by the American Psychiatric Association (American Psychiatric Association). The APA continually updates definitions, diagnosis criteria, and treatment for the disorders presented in the manual and the most recent edition, the DSM-5, was published in 2013. The DSM-5 defines ASD as a neurodevelopment disorder beginning in early childhood, with deficits in social communication and behavior. Prior to the DSM-5, autism was called autistic disorder and there were separate definitions for similar disorders including Asperger's disorder, childhood disintegrative disorder and pervasive neurodevelopmental disorder not otherwise specified. All of these diagnoses now fall under the current umbrella of ASD which consists of a huge continuum of features that range from mild to severe. The key features documented in the DSM-5 that define ASD are the failure to engage, communicate and interact in a social environment, and abnormal patterns of behavior (Maenner, 2014). Social deficits include speech delays, repetition of words and phrases, inability to understand and follow directions, echolalia, poor eye contact and limited expression of feelings and emotions. Behavioral differences include repetitive motions, constant movement, reliance on routines, coordination problems, sensitive to light and noise, difficulty engaging in imaginative play, and specific food preferences (Nightingale, 2012).



## *1.2 Diagnosing Autism Spectrum Disorder*

Diagnosing an individual with ASD is a difficult task due to the spectrum of severity and presentation that is characteristic of the disorder. A diagnosis is based primarily on a child's behavior and development and can occur as early as 18 months of age but is generally made around age two. Though it is common for the diagnosis to be made early in life, especially as a toddler, many individuals are not diagnosed correctly until much later in life (Center for Disease Control, 2016). There are a number of tools that are used to make an ASD diagnosis including developmental screening and comprehensive diagnostic evaluation. Developmental screening is routinely done through a child's pediatrician at regularly scheduled visits. A comprehensive diagnostic evaluation is much more in depth and often includes medical specialties in addition to a pediatrician. These specialists include an audiologist, an ophthalmologist, a geneticist, and a neurologist. There are also pediatricians who specialize in neurodevelopmental disorders and can assess a child using a number of tests based on the DSM-5 definition of ASD (Center for Disease Control, 2016). (See Appendix A for full DSM-V criteria)

It is currently estimated that about 1 in 68 children in the United States are on the autism spectrum, indicating a prevalence of about 1-2% (Center for Disease Control, 2016). These numbers are significantly higher than estimates in years past and are expected to continue to grow (Nightingale, 2012). In the year 2000 it was estimated that fewer than 1%, or 1 in 150 children, had an ASD (Center for Disease Control, 2016). This increase in the diagnoses of ASD is likely to be a reflection of the broadening criteria, as well as increased awareness amongst both professionals and the public (Miles, 2011). The continually changing diagnostic criteria for ASD may contribute to the increase in diagnosis by broadening the constellation of features that

qualify an individual for an ASD diagnosis (Ramsey, 2016). Despite this, many studies have actually shown that with the new, most broad criteria for diagnosis that have been presented in the DSM-V there will be a decrease in the number of children diagnosed with ASD (Matson, 2012). Despite the inclusion of the aforementioned disorders in the new diagnosis of ASD, it appears that there are fewer children that meet the criteria for ASD as defined by the DSM-5 versus the DSM-IV (Matson, 2012). This could have devastating impacts on the number of children eligible for services afforded to those who have a diagnosis of ASD. Children with an ASD-like presentation who may benefit from services including speech, occupational, physical and behavioral therapies may be ineligible, as they do not meet criteria for a diagnosis of ASD (Maenner, 2014). As we continue to learn more about ASD, the definition and mechanism for diagnosis will continue to change.

With the increasing number of children being diagnosed with ASD, comes an increase in costs and the economic burden of the disorder. A 2015 study by Leigh, reported that the economic burden of autism spectrum disorder that year was \$268 billion in the United States which was similar to the estimated economic burden of diabetes. It was estimated that if this trend continues the cost of autism for the United States is projected to be \$461 billion (Leigh, 2015).

### *1.3 Etiology*

Throughout its history the cause of autism spectrum disorder has been difficult to explain. It is thought that alterations in the formation or destruction of neural synapses contribute to abnormal neural connectivity and changes in the ratios between excitatory and inhibitory synapses, causing differences in the brain's ability to function. Despite the considerable advances

in autism made in the last two decades, the specific etiology of autism is unknown. Many have theorized that there are a number of factors that contribute to the development of ASD including both environmental and genetic contributions. It is suggested that these elements work together in order to create the foundation for the development of autism spectrum disorder (Miles, 2011).

Genetic etiologies of autism may include both single gene mutations, chromosomal copy number variation, as well as the interaction between a number of genes and a genetic cause can be identified in approximately 30-40% of children on the autism spectrum (Schaefer, 2013) although it is thought that 50-60% of autism cases have a genetic etiology (Krumm, 2015). There are a number of chromosomal microdeletions and duplications that have been associated with ASD. Some of these copy number changes result in the sole presentation of autistic-like features and others result in syndromic forms of autism that include other symptoms not generally associated with autism. One such microdeletion is 22q11.2. Healthy individuals have two copies of this chromosomal region; this recognizable condition occurs when one copy of this region is deleted. Individuals with this deletion are known to have 22q11.2 deletion syndrome or DiGeorge syndrome, which confers risk for heart disease, distinct facial features including palatal abnormalities, immune deficiency, developmental delay, schizophrenia and about 20% of these individuals have autism (McDonald-McGinn, 2013).

Other forms of syndromic causes of autism include monogenic disorders such as Fragile X syndrome. Fragile X syndrome is caused by methylation, or inactivation, of the FMR1 gene, which is often caused by a triplet repeat expansion in the gene to more than 200 CGC repeats. This disorder is characterized by cognitive impairment, learning difficulties, ADHD, seizures and about one third of those diagnosed with Fragile X have autistic like features (Saul, 2012). Fragile X testing to quantify an individual's CGG repeats and chromosomal microarray to assess

for the presence of microdeletions and duplications are considered first line testing for a child who is displaying features of ASD in the clinic setting.

There are a number of other monogenic changes and copy number changes that are thought to contribute to the genetic etiology of ASD, however there has been no consistent replication of studies attributing sole cause to any particular gene or group of genes, this inconsistency suggests that the etiology of autism is not Mendelian in nature but, instead, has a multifactorial origin that includes both genetic and environmental influences (Shaw, 2014). Twin studies have showed that this combination of genetics and the environment may more heavily favor a genetic etiology. Some studies have indicated that the concordance rate for monozygotic twins is 64%, as opposed to 9% in fraternal twins (Miles, 2016), while others have suggested that the concordance rate between monozygotic twins is as high as 70-80% (Geschwind, 2011). However, twins also share the same environment in utero thereby not eliminating the environment as a contributing factor in the development of autism (Shaw, 2014).

Although these twin studies have indicated that there is an extensive genetic component involved in the development of autism, the fact that the concordance rate is not approaching 100% has driven investigation into the environmental factors that contribute to autism. Much focus has been placed on the intrauterine environment and potential teratogens including medications taken by women during pregnancy. There are studies indicating a correlation between the use of antiepileptic medication, specifically valproate, and the development of autism (Miles, 2011). A number of other teratogens have been associated with the development of autism including valproic acid, thalidomide, misoprostol and tocolytic drugs. There is also evidence to indicate that the use of assisted reproductive technologies (ART) may be a contributing factor in the development of ASD (Miles, 2011).

A controversial topic surrounding the research into the etiology of autism is that of immunizations. Because immunizations tend to be administered around the age a child may regress and begin to exhibit symptoms of ASD, a study was published that suggested that vaccines are the cause of autism. This study (Wakefield, 1998) has since been widely disproven and retracted (Godlee, 2011). In addition to the retraction, Dr. Wakefield, who led the study, had his medical license revoked. These studies have created concern regarding the safety of vaccines and caused many parents to forgo immunizing their children, which has led to outbreaks of diseases that are easily preventable (Miles, 2011). An example of this is the most recent measles outbreak at a California amusement park in December of 2015. It is thought that a traveler brought the virus from overseas and passed it to unvaccinated children at the park (Halsey, 2015). Numerous studies have been conducted since, finding no correlation between vaccines and ASD (DeStefano, 2007).

#### *1.4 Services Available*

Services that are currently available for children with autism are primarily behavioral and social therapies. Because the specific etiology of autism has not yet been established, there are currently no specific drugs available for treatment. There are, however, drugs aimed at reducing the symptoms of some of the common features of autism, including ADHD, depression, anxiety, and sleep disorders. The medications used are not specific for children with autism but are instead the same drugs used to treat these symptoms in neuro-typical children (Williamson-Swinkles, 2002)

Similarly to the medications currently in use, the social and behavioral therapies recommended for children on the spectrum are intended to address maladaptive behaviors. These

therapies attempt to improve basic communication, ambulation and motor skills as well as help to teach socially acceptable processing of emotions brought on through their environment. The major social and behavioral therapies employed to help children on the autism spectrum are applied behavioral analysis (ABA), speech therapy (ST), occupational therapy (OT), and physical therapy (PT) (Siri, 2011).

ABA is often a primary therapy recommended for children with ASD as well as children with sensory processing disorders and other behavioral disorders. The intention of ABA is to identify a child's behavioral limitations and systematically address them with targeted coping strategies. ABA can be used to target some of the major features seen in children with autism including issues with behavior, deficits in social interaction, rigidity, negative attention seeking, anxiety, self-harm and aggression, and impulsivity. ABA is a very systematic therapy that calls for structure and discrete, repetitive trials aimed at using learning motivation to change behavior patterns. Due to the tendency towards rigidity, many children on the spectrum respond well to structure and routine that ABA provides. However, due to the large variation of presentation, it is becoming more evident that there are a number of children on the spectrum who do not respond to this type of structured trial based learning and there is an emerging need to individualize behavioral therapy (Simpson, 2001).

Speech therapy (ST) is used to target the communication deficits experienced by individuals on the autism spectrum. A hallmark feature of those with ASD is speech delay and many individuals remain nonverbal for the duration of their lives. There is often a misconception that this inability to verbally communicate is an indication of intelligence, and although intellectual disability can be associated with autism, it is by no means a forgone conclusion. ST can be used to help both those individuals who have delayed speech but also those who are

completely nonverbal. Other forms of communication, including sign language, Picture Exchange Communication system (PECs) and more recently use of tablets, are very frequently employed to help improve the communication skills of those on the spectrum. ST is often thought of as an aide to improve expressive language, however, a large part of this therapy involves focusing on one's receptive language as well his or her social skills. Often ST sessions will include a group session in which children can interact with each other and learn to use their language in real-time social situations (Bishop, 2014).

Occupation therapy (OT) and physical therapy (PT) are both used to target deficits in both fine motor and gross motor skills. OT is specifically used to improve abilities to complete everyday functional tasks including dressing and undressing, grasping a pencil, and balance and coordination. OT also incorporates the element of social interaction and helps children learn to use their motor skills more successfully in a social environment (Case-Smith, 2013). This differs from PT in that physical therapy aims to more broadly improve strength and muscle tone. These therapies tend to be used in conjunction with each other in order to improve muscle strength and refine coordination and muscle memory (Autism Speaks, 2010).

Other services offered are individualized education plans (IEP) and 504 plans. These services are written agreements generated by the school and the family that outline the needs and accommodations of the child with the intention to help better their education. Both of these services are intended to extend specific, individualized amenities to children while in school. They offer special education classes, therapies, aides and other features including more time for test taking and extra help with reminders about homework. These plans are not limited to children with autism but are very often utilized by those on the spectrum (Turnbull, 2002).

In sum, there are a great many services currently available for individuals on the autism spectrum and a great many more on the horizon. As we learn more about the etiology of the disorder, new therapies and treatments specific to autism will surface (Weitlauf, 2014).

### *1.5 Measurement of Quality of Life*

There are a number of measures available that attempt to assess the quality of life (QOL) in different populations of people (MacKeigan, 1992). For many of these populations this assessment is straightforward as the cognitive ability of the participants is not affected and they are able to complete the questionnaires independently. However, assessing the QOL of children with autism spectrum disorder becomes complicated for a number of reasons. The first challenge is that this population targets children and children are hard to assess due of their age and maturity level. This is complicated further by the fact that children on the autism spectrum may have learning disabilities, receptive and expressive communication deficits, problems with focus and attention and can have cognitive impairments, all of which make it difficult for them to successfully complete a questionnaire discussing their quality of life. The solution has thus far been to have quality of life questionnaires completed by the parents of these children. This solution comes with its own set of issues and limitations. There is no way to assess the accuracy of the parents' perceptions of their children's QOL. They often answer in terms of how they would feel if they were in their child's shoes rather than how their child truly feels about their situation. This being said, this remains the most accurate measure to assess the QOL of children on the autism spectrum and a number of studies have been done looking at the quality of life of these children (Creemans, 2006).



A 2009 study by Kuhlthau et al. compared the quality of life of children on the spectrum, with a group of children with chronic illness as well as a control group of healthy children. Although the results of this study described an overall lower QOL for children on the spectrum it was not consistently related to the overall autism diagnosis but rather more correlated with repetitive and adaptive behaviors, and social responsiveness as well as other externalizing and internalizing behaviors. Children who exhibited some of these behaviors but were not diagnosed with autism also received similar QOL scores. However, the QOL scores were also broken down into more specific categories including psychosocial health, social functioning, emotion functioning, physical health, and school functioning and the population with ASD did not have lower scores for all of these domains. When examining the scores for both physical health and school functioning, the QOL in children with ASD appeared very similar to that of the group of children with chronic illness. However, for the domains of psychosocial health, social functioning, and emotional functioning, children with ASD had a much lower QOL than both typically functioning children and those with chronic illness. In general it appeared that lower QOL scores were correlated with more repetitive behaviors and impairments in social skills. This data suggests that therapies targeting improvements in these specific behaviors might help improve quality of life for children on the spectrum (Kuhlthau, 2010).

### *1.6 Discussion Surrounding Services and Quality of Life*

While many individuals may categorize autism spectrum disorder as a disability that needs to be treated (Lord, 2000), there are many others who believe that autism is simply another way to experience the world and an important part of an individual's identity. The latter share the message that neurodiversity groups promote, raising awareness about the positive and productive

lives that individuals with autism lead, without any type of intervention (Kapp, 2013). However, public opinion on the subject tends to center around the idea that autism is a deficit and promote interventions and therapies that aim to reduce many of the so-called ‘autistic behaviors’ which are deemed disruptive to a child’s quality of life. Despite this debate very few studies performed have aimed at assessing the relationship between services received and their efficacy and impact on quality of life (Bishop-Fitzpatrick, 2014), and those that have primarily focused on adolescents and adults rather than children.

A 2015 Israeli study led by Eynat Gal, looked at the perception of quality of life among 25 young adults with autism spectrum disorder at different points throughout their participation in an army vocational program. The participants completed a quality of life survey and a personal well-being index before starting the program, immediately upon the completion of the program and then six months later after being integrated into the workplace. The study indicated that there was no improvement in quality of life between the beginning and the end of the program, however there was dramatic improvement between the perceived quality of life immediately after the program and QOL six months post the program. The discussion surrounding these results focused on the idea of job satisfaction. Many young adults on the autism spectrum are ineffective in the conventional workplace which is thought to contribute to their lower quality of life. The vocational program was therefore intended to teach these individuals how to succeed in a very specific professional environment. The conclusions of the study reflect the original hypothesis regarding the relationship between workplace dissatisfaction and lower quality of life. When the participants found that they were able to succeed at their jobs during the six months following the completion of the program, their perception of their QOL increased. (Gal, 2015)

A 2014 systematic review done by Bishop-Fitzpatrick looked at the effectiveness of services and therapies in adults with autism. This review concluded that all of these studies found a favorable outcome following some type of training or therapy. All of these studies addressed the core deficits related to autism and each approached the training portion differently. Some provided routine ABA and social cognitive therapy while others provided more creative methods including computer-based training. Regardless of the training platform used there were benefits to participants reported in all of the studies. Studies that employed any method to target social cognition found the most favorable outcomes with their participants. Although this study was done in adults it seems to similarly reflect the data found by Kuhlthau (2010) in his study discussed earlier that focused on comparing QOL in children with autism and typical children. His study indicated a drastically lower QOL score in the social functioning category than any of the other categories tested between the two subject groups. These two studies suggest that services targeting social interaction and immersion may have a positive effect on quality of life.

It is commonplace for services to begin at a very early age for those children diagnosed with ASD. However, information regarding the efficacy of these therapies in young children is limited. As the diagnoses of autism continue to rise this information becomes increasingly more important.

### *1.7 Aims of this research*

The purpose of this study is to assess the relationship between the quality of life of children on the autism spectrum and the services that they are or are not receiving. Understanding if there are significant relationships between the type of service received or the amount of time that a child is receiving services and their reported improvement levels in various

areas of life will help inform health care professionals' perspective and knowledge in regards to therapies. This will increase rapport and communication between the patient's care team and the patient's family allowing for better overall care for the child. Genetic counselors serve a unique role in that they are often the team member that is first connecting with the family and helping the family initiate services. This research will provide guidance in regards to therapies and provide more opportunity for connection.

There are multiple hypotheses that drive this study:

1. As reported by their parents, children with higher quality of life scores will have participated in more services than those with lower quality of life scores.
2. As reported by their parents, children with a higher quality of life will have participated in more types of services for a longer amount of time than those who have a lower quality of life.
3. Those children who participate in any services will experience higher levels of improvement with respect to communication and social interaction.

## II. Methods

This study was reviewed and classified as exempt through the University of California, Irvine Institutional Review Board (HS# 2016-3230).

### *2.1 Recruitment*

Participants were recruited to take part in a 10-15 minute online survey that was developed through SurveyMonkey. Recruitment strategies included the utilization of social media and participating support group listservs. Neither the lead researcher nor anyone on the research team had any direct contact with participants. There was no identifying information collected, and participants URL's were kept hidden. The survey link along with a short description of the survey including the purpose of the study and exclusion criteria was posted on the lead researcher's Facebook page and was shared by other users. The link along with the same electronic flyer was also sent out to the National Society of Genetic Counselors' (NSGC) listserv. Separate links were used in order to determine which responses came from the NSGC listserv and which came from social media. Those that were obtained through the NSGC listserv may not all have been collected from genetic counselors as respondents were encouraged to share the survey.

### *2.2 Participants*

Participants were eligible to participate in the study and complete the survey if met the following inclusion criteria:

1. Respondents were 18 years of age or older

2. Respondents have a child with autism age 2-12

Participants were ineligible to participate and were disqualified if they met any of the following exclusion criteria:

1. Respondents were under age 18
2. Respondents indicated that their child was under age 2 or over age 12
3. Respondents indicated that they do not have a child with autism
4. Respondents indicated that they have more than one child with autism

Any participant that indicated that they fell into any of the categories in the aforementioned exclusion criteria were redirected to a disqualification page. Internet access was required to complete the survey and the survey was only provided in English. There were no other demographic exclusions.

There were 66 individuals who began the survey and of those 19 were disqualified based on the inclusion and exclusion criteria. Table 1 describes the causes for disqualification from the study. The majority of the respondents who were disqualified indicated that they did not have a child with autism (58%). The remaining disqualified respondents either had more than one child with autism (21%) or they had a child who was over the age of 12 (21%). This left 47 participants who completed the survey and made up the study sample.

Participation was completely voluntary and no respondent was required to complete a question that they felt uncomfortable with. Any participant was able to exit the survey at any

point during their participation. There was no personal information collected and all answer responses were anonymous.

<b>Table 1: Disqualified Respondents</b>		
	Frequencies (N=19)	Percentages
Zero Children with Autism	11	58
2+ Children with Autism	4	21
Child age 13+	4	21
Child under age 2	0	0

### *2.3 Informed consent*

All participants were provided with an IRB approved study information sheet at the beginning of the survey. They were informed that by clicking the ‘next’ button at the bottom of the page they were providing consent to participate in the research study. The study information sheet included information regarding the purpose of the study, inclusion and exclusion criteria, as well as risks and benefits of participating. Risks included possible emotional distress and benefits included contributing to the scientific community in the area of autism research. All participants were encouraged to reach out to the lead researcher with any questions, comments, or concerns.

### *2.4 Survey Construction*

The survey had a total of 26-32 multiple choice or fill in the blank questions. The total number of questions was different for each participant depending on their previous answers. The survey also included four groups of Likert scale questions that were different based on the indicated age of the child. These Likert scale questions came from a previously validated survey called the PedsQOL (Varni, 1998). The Likert scale questions covered physical functioning,

emotional function, school functioning, and social functioning and focused primarily on functioning and quality of life of the child whereas the questions created by the research team targeted demographics and services received by the child.

After the survey was initially opened, a respondent reached out to the lead researcher and voiced her desire to have a question added which clarified if the respondent credited interventional services with the improvements seen in his/her child. A question to this effect was added following IRB approval and the second set of respondents were able to provide feedback on this question. This was ultimately considered a minor change and the first set of responses were included in the data set.

### *2.5 Survey Scoring*

Participants were asked to rate their child's improvement in six individual categories on a 1-3 scale where 1= little to no improvement, 2= some improvement, and 3= a lot of improvement. The categories included happiness at home, happiness at school, happiness in public, ability to perform physical tasks, ability to perform daily living activities, and ability to communicate. In order to capture global reported improvement across the categories, the mean of each child's individual category scores was taken to create a total reported improvement score. This scoring method was developed for this study and has not been previously validated.

### *2.6 Validated Measures*

The pre-validated survey used as a part of the study was developed by Varni (1998) and is parent- reported, meaning that the child's parent indicated to their best judgement how they think their child is feeling and coping. The survey was scored on a 0-100 scale. The survey



covers four individual categories (physical functioning, emotional functioning, social functioning, and school functioning) and within each category there is a set of Likert scale questions that asked how often within the last month did the child have difficulty with a particular task (Appendix F). Options provided on the survey were weighted 0-4 with a score of 0 being 'never' and a score of 4 being 'almost always'. Items were reverse scored so that higher scores indicate a higher QOL of life score. In order to account for missing data the scores are averaged within each category based on the number of items answered to yield an overall QOL score for each category. Responses were disqualified if more than half of the questions were not answered (Varni, 2003).

## *2.7 Statistical Analysis*

The Statistical Package for Social Sciences (SPSS) (IBM Corp, 2014) and the Statistical Analysis Software (SAS) (SAS Inc, 2011) were both employed to conduct data analysis. All data was coded and presented in tables and graphs. The Chi-Square test for association within a contingency table was used to address all three hypotheses and p-values of 0.05 or less were used to determine statistical significance. Nominal p-values were reported and there was no correction made for multiple comparisons. A Fisher's Exact Test was performed when expected values in at least 20% of the cells were less than five. Standard T-test calculations with equal variances assumed were used to compare means and address hypotheses one and two regarding the relationship between the amount of services and time spent participating in services versus QOL. Categorical variables were constructed by group the data based on relationship to the median for QOL as well as hours of service, in order to attempt to circumvent low response numbers.

### **III. Results**

#### *3.1 Demographics of Participants*

Table 2 describes the demographics of the study population. One hundred percent of the participants were female with a majority (56%) being between the age of 35-44. Fourteen of the participants (30%) were between the age of 25-34, while one participant (2%) was between the age of 18-24 and six participants (13%) were between age 45-54. A majority of the participants were Caucasian (79%), married or partnered (94%), and had a graduate or professional degree (51%). A minority of the participants identified as African American (2%) and American Indian/Native American (2%). Five participants identified as Asian American (11%) and three identified as Hispanic (6%). Christianity was most commonly reported religion with 40% of participants identified themselves as such. This was followed closely by those who did not identify with any religion (38%). There were five respondents who identified as being Jewish (11%) and there was one respondent who identified as Hindi (2%).

<b>Table 2: Demographics</b>		
	Frequencies (N=47)	Percentages
<b>Gender</b>		
Female	47	100
Male	0	0
Other	0	0
<b>Ethnicity</b>		
African American	1	2
American Indian/Native Alaskan	1	2
Asian/Asian American	5	10
Caucasian	37	78
Hispanic	3	6
Middle Eastern/Persian	0	0
Other	0	0
<b>Relationship Status</b>		
Single, never married	1	2
Married/Partnered	44	94
Divorced/Separated	2	4
Widowed	0	0
<b>Education Level</b>		
Elementary School and/or some High School	0	0
High School Graduate	1	2
Associate degree/some college	5	11
College graduate or equivalent	17	36
Graduate/Professional degree	24	51
<b>Age of Participants</b>		
18-24	1	2
25-34	14	30
35-44	26	55
45-54	6	13
65-74	0	0
75 or older	0	0
<b>Religious Affiliation</b>		
No Religion	18	38
Buddhist	0	0
Christian	19	40
Hindu	1	2
Jewish	5	11
Muslim	0	0
Other	0	0

Table 3 describes the structure of the households of the individuals that participated in the study. Fifteen participants indicated that their yearly income is greater than \$150,000, fourteen of the participants (30%) indicated that their household income is in the range of \$50,000-\$100,000, twelve participants indicated that their income is in the range of \$100,000-\$150,000, three participants (6%) indicated a yearly income of \$25,000-\$50,000, and one participant (2%) indicated a yearly income of less than \$25,000. A majority of the respondents (94%) had at least two adults living in the home, whereas 6% were part of a single parent household. A majority of the participants (66%) indicated that they have two or three children in their household, whereas 23% have only one child and 11% have four or more children. A majority of the respondents (78%) have only one child with special needs (their child with ASD), however 22% of the participants indicated that they have a second or third child with special needs in addition to their child with ASD.

<b>Table 3: Household Structure</b>		
	Frequencies	Percentages
Yearly Income	(N=45)	
Under \$25,000	1	2
\$25,000-\$50,000	3	6
\$50,000-\$100,000	14	30
\$100,000-\$150,000	12	26
Above \$150,000	15	32
Adults in Household	(N=47)	
Single Parent household	3	6
2+ Adults in Household	44	94
Children in Household	(N=47)	
1 child	11	23
2-3 children	31	66
4+ children	5	11
Children with Special Needs	(N=46)	
Only my Child with Autism	36	78
1 or more other children with special needs	10	22

### 3.2 Demographics of the Children with ASD

Table 4 describes the demographics of the children with ASD that are the subject of the study. A large number of the parents (43%) indicated that their child was currently between the ages of five and seven, while 30% of the children were age 8-12, and 28% of the children were age 2-4. The majority of the children (72%) were diagnosed between the ages of one and four. Of the children discussed in the study 19% were diagnosed between the ages of five and seven and only 9% were diagnosed between the ages of eight and twelve. A majority (67%) of the participants indicated that their child was diagnosed by a neurodevelopmental specialist. The rest of the participants indicated that their children were diagnosed by a psychologist (11%), by a neurologist (9%), by their pediatrician (7%), or by their school counselor (7%). A majority of the

children (74%) did not have genetic testing whereas 26% of the children did have genetic testing. Educational style was examined in depth. Most of the children (72%) were attending a public school; of these 38% were participating in a special education program, 19% were in mainstream classes with no aide, 13% were in mainstream classes with the help of an aide, and 2% were in an inclusion program. Two children (4%) were attending a special private institute specifically for children with autism, two children were attending daycare or preschool, 13% were homeschooled, two (4%) children were not in school and one child (2%) was attending private school in a mainstream classroom with the help of an aide. Thirty-six of the children (77%) are utilizing an individualized education program (IEP). Although 94% of the children are verbal, parents indicated that their children communicated with them in a variety of different ways. Parents were instructed to indicate all of the different means their child uses to communicate and because of this, percentages do not add up to one hundred. Forty-four of the children (94%) use verbal language to communicate, 38% use gestures and crying, 13% use sign language, 9% use an iPad or tablet and 6% use a picture exchange program (PECs).

<b>Table 4: Child Demographics</b>		
	Frequencies	Percentages
Child Age	(N=47)	
2-4 years old	13	28
5-7 years old	20	43
8-12 years old	14	30
Age at Diagnosis	(N=47)	
1-4 years old	34	72
5-7 years old	9	19
8-12 years old	4	9
13+	0	0
Diagnosed by	(N=46)	
Pediatrician	3	7
School Counselor	3	7
Neurodevelopmental Specialist	31	67
Neurologist	4	9
Other		
Psychologist	5	11
Genetic Testing	(N=46)	
Yes	12	26
No	34	74
Type of School	(N=47)	
Public school, mainstream, no aide	9	19
Public school, mainstream, with aide	6	13
Public school, special education program	18	38
Private school, mainstream, no aide	0	0
Private school, mainstream, with aide	1	2
Private school, special education program	0	0
Homeschool	6	13
Daycare/Preschool	2	4
Not in school	2	4
Other		
Public school inclusion program	1	2
Private Institute for children with ASD	2	4
IEP?	(N=47)	
Yes	36	77
No	11	23
Verbal?	(N=47)	
Yes	44	94
No	3	6

Communication	(N=47)	
Verbal Language	44	94
Sign Language	6	13
Gestures/Crying	18	38
iPad	4	9
PECs (Picture Exchange Communication system)	3	6
Other	0	0

### 3.3 Frequency of Services

Depicted in Table 5 is breakdown of the services the children participated in as reported by their parents. Many children participated in multiple therapies and parents were able to indicate all the services that their child was receiving. Twenty-three children (49%) were participating in one to two therapies, while twenty children (43%) participated in three or more services. Speech therapy was the most commonly reported service with 31 children (66%) participating. Thirty children (64%) were reported to be participating in occupational therapy, 24 children (51%) were participating in applied behavior analysis (ABA) therapy, 10 (21%) were enrolled in social group therapy, nine (19%) were attending physical therapy, and eight (17%) participated in recreational therapy. Half of the children spent five and half hours or less a week participating in services while the other half spent more than five and a half hours a week in various types of therapies. A majority of the children (87%) were currently participating in services at the time that their parents participated in the study, where as 6% had never received services and another 6% had been receiving services and stopped their participation. All three of these children ceased services for different reasons including having moved to a different location in which there were no adequate services available, participants could no longer afford continued participation in services, and aging out of the currently available services. Of those children currently receiving services 34% of them had been participating in therapies for one to two years, 27% had been enrolled in therapy for less than one year, 22% of the children had been



receiving services for three to five years, and 17% had been participating in services for more than five years. Parents were asked why they sought services for their child and 63% reported that they felt these services would benefit their child, 53% indicated that therapy was recommended by a doctor or a teacher, and 3% of the participants had services recommended by a family member. These percentages do not add up to one hundred because parents were allowed to select multiple answer choices. Parents were also asked how these services were being financed and the majority of the participants (66%) indicated that insurance was covering the costs. Twenty-two parents (47%) indicated that they were utilizing free services and nineteen parents (47%) indicated they were paying for therapies out of pocket. Percentages do not add up to 100% because respondents were able to select more than one answer.

<b>Table 5: Services</b>		
	Frequencies	Percentages
Type of Service	(N=47)	
Applied Behavioral Analysis (ABA)	24	51
Speech Therapy	31	66
Physical Therapy	9	19
Occupational Therapy	30	64
Recreational Therapy	8	17
Social Group Therapy	10	21
Number of Different Services	(N=47)	
1-2 different Services	23	49
3 or more services	20	43
Hours of Service per week	(N=40)	
0-5.5 hours	20	50
More than 5.6 hours	20	50
Paying for Services	(N=47)	
Out of Pocket	19	40
Insurance	31	66
Free Services	22	47
Other	0	0
Why seek Services?	(N=38)	
I felt as though my child would benefit	24	63
Recommended by a doctor or teacher	20	53
Recommended by another family member	1	3
Other	0	0
Length of time receiving services	(N=41)	
Less than 1 year	11	27
1-2 years	14	34
3-5 years	9	22
More than 5 years	7	17
Currently receiving services?	(N=47)	
Currently receiving services	41	87
Never received services	3	6
Stopped services	3	6
Do you feel that services contributed to any improvement seen in your child? **	(N=10)	
Yes	10	100
No	0	0

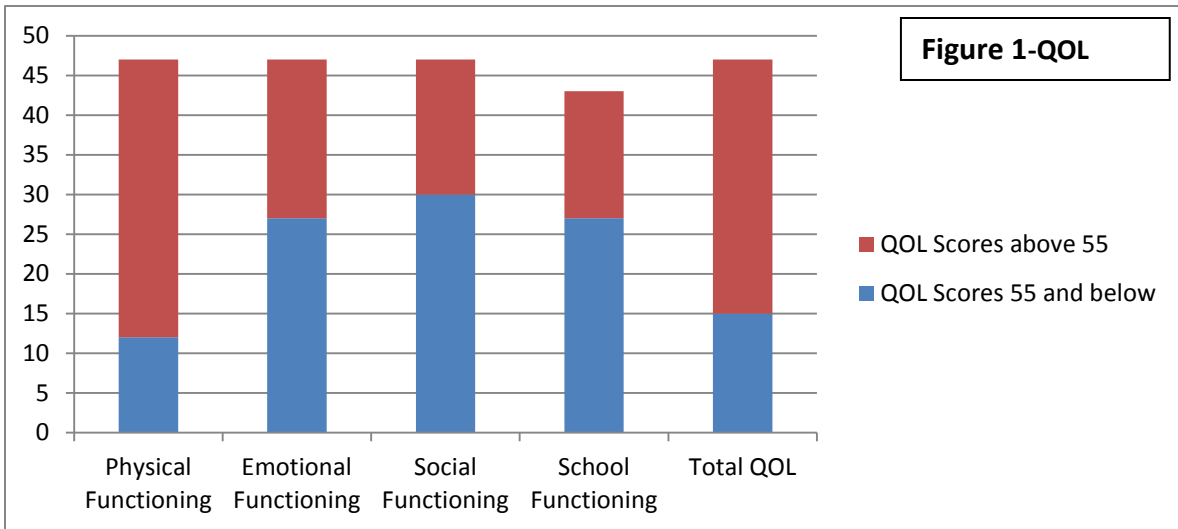
\*\*Written answers can be found in Appendix E

### *3.4 Quality of Life Scores*

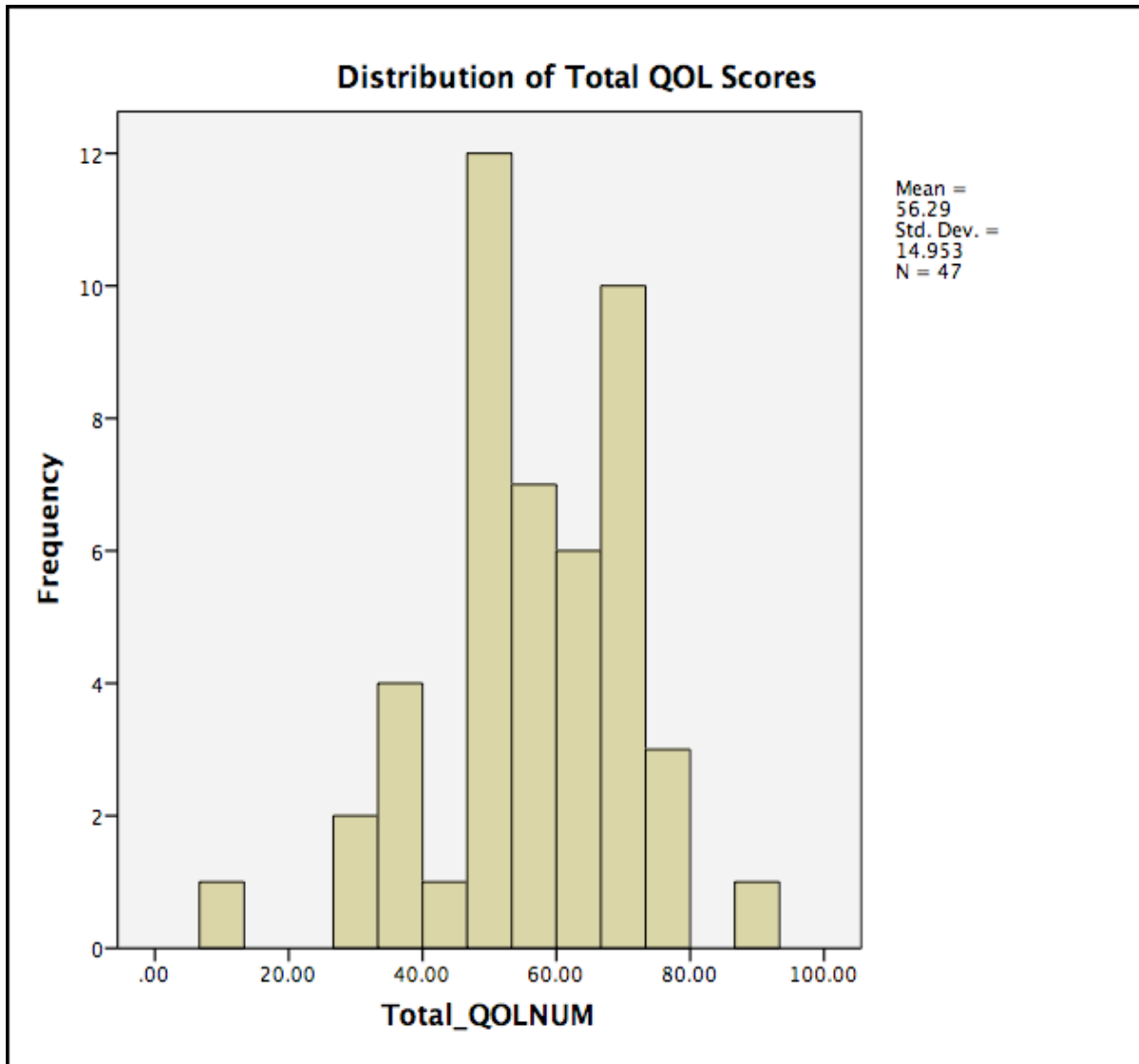
Table 6 depicts the breakdown of quality of life scores across the four different sections presented on the parent reported version of the PedsQOL quality of life survey (Varni, 2003). All forty-seven participants completed the first three sections of the survey including the physical, emotional, and social QOL sections. The fourth section, indicating the quality of life of the children while in school, was completed by forty-three of the participants because four of the children were not yet in school or daycare. Total quality of life scores were able to be calculated for all forty-seven participants as the scores were averaged and more than 50% of the survey was completed by all participants. Quality of life was scored on a one to a one hundred scale with scores closer to zero indicating a lower quality of life and scores closer to one hundred indicating a higher quality of life. For physical functioning the highest percentage of children (41%) were reported to have a quality of life score between 51-75, and the smallest percentage (9%) were reported to have a QOL score of 0-25. For emotional functioning, 49% of the parents' answers indicated that their child had a QOL score between 26-50, in comparison to the 4% that were reported to have a QOL score above 75. When looking at social functioning a majority of the children (53%) were reported to have scores that fell in between 26-50, whereas only 2% of the children were reported to have a QOL score above 75. For school functioning, the highest percentage of children (35%) fell in the lowest quartile with QOL scores between 0-25. This compares to the 7% of children who were reported to have QOL scores above 75. QOL scores were combined to give an overall quality life score. Thirty children (64%) had total QOL scores between 51-75, 30% of the children scored between 26-50, 4% had scores between 76-100, and 2% of the children and scores that fell between 0-25. Quality of life scores for physical functioning were the highest amongst the four different categories with 75% of the children

scoring above fifty. Scores for social functioning were generally the lowest with 30 children (64%) scoring between 0-50. Emotional functioning categories and school functioning categories also had a majority of the children receive scores between 0-50 (54% and 63%, respectively). This compares to total QOL scores where 62% of children received scores above 50 (Figure 1). Figure 2 depicts the distribution of the total QOL scores, with the mean of the data set being 56.

<b>Table 6: Quality of Life</b>		
	<b>Frequencies</b>	<b>Percentages</b>
<b>Physical QOL</b>	(N=47)	
0-25	4	8
26-50	8	17
51-75	19	40
76-100	16	34
<b>Emotional QOL</b>	(N=47)	
0-25	4	9
26-50	23	49
51-75	18	38
76-100	2	4
<b>Social QOL</b>	(N=47)	
0-25	5	11
26-50	25	53
51-75	16	34
76-100	1	2
<b>School QOL</b>	(N=43)	
0-25	15	35
26-50	12	28
51-75	13	30
76-100	3	7
<b>Total QOL</b>	(N=47)	
0-25	1	2
26-50	14	30
51-75	30	64
76-100	2	4



**Figure 1** depicts the breakdown of QOL scores in each of the four categories of functioning based on the mean value of 55.



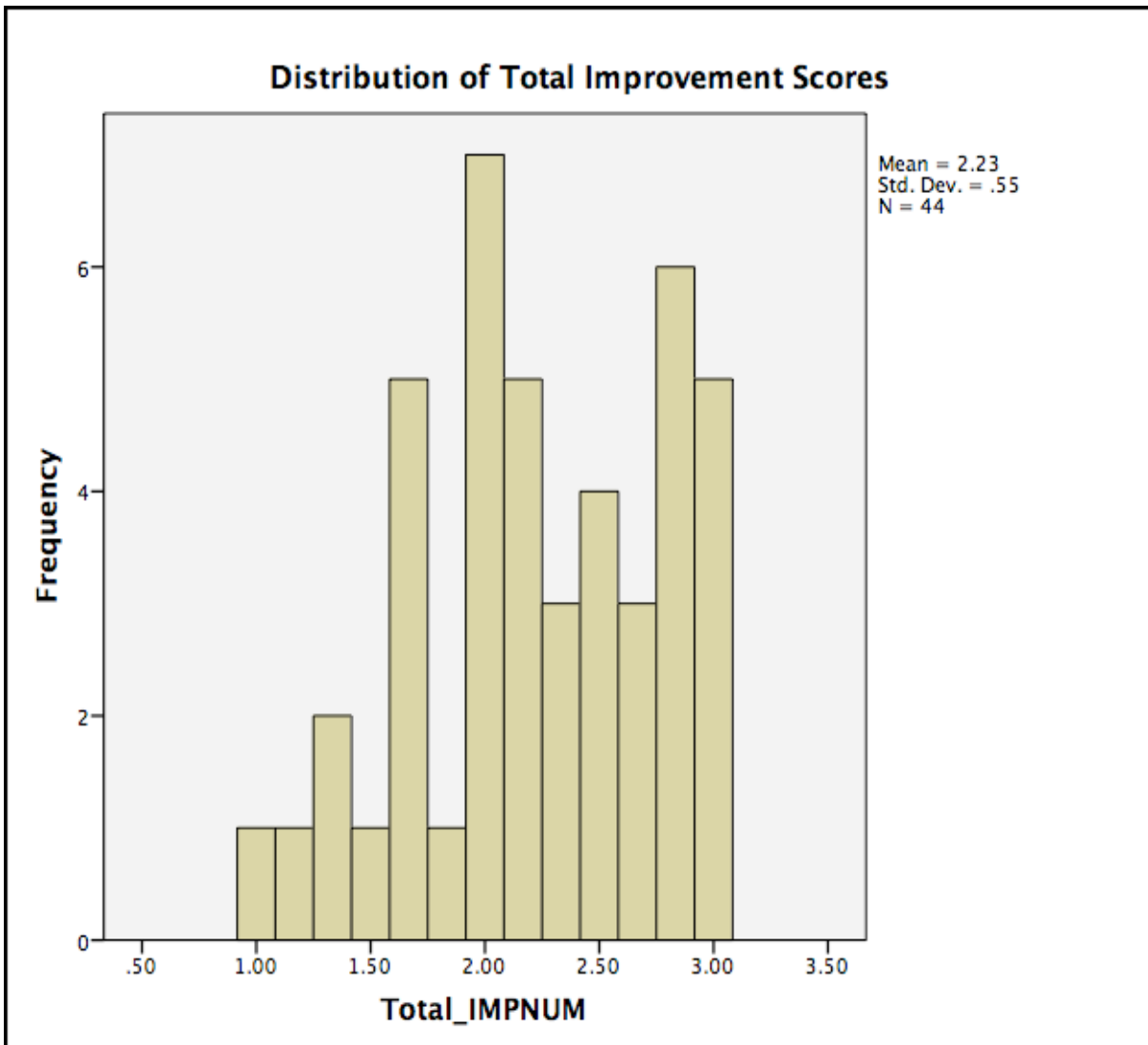
**Figure 2** depicts the distribution of the total QOL scores. The median value is 56.29, the standard deviation is 14.953 and N=47.

### *3.5 Reported Improvement Scores*

Parents were asked to rate the level of improvement they felt their children had after the start of services. The improvement levels were broken down into categories: happier at home, happier at school, happier in public, better able to perform physical tasks, better able to perform daily living tasks. A total improvement score was also generated by taking the mean of all of the individual reported improvement scores. Table 7 describes the frequencies of the improvement scores across the children who were the subject of the study. A majority of the children (55%) were reported to have some improvement in regards to being happier at home. In regard to improvement with being happier in public, happier at school, and being better able to perform physical tasks, a majority of children were indicated to have had some improvement in each of these categories. In the category of better able to perform daily living activities there were equal number of children reported to have some improvement (41%) and a lot of improvement (41%).



<b>Table 7: Reported Improvement Scores</b>		
	<b>Frequencies</b>	<b>Percentages</b>
<b>Happier at Home</b>	(N=44)	
Little to no Improvement	7	16
Some Improvement	24	55
A Lot of improvement	13	30
<b>Happier in Public</b>	(N=44)	
Little to no Improvement	4	9
Some Improvement	25	57
A Lot of improvement	15	34
<b>Happier in School</b>	(N=42)	
Little to no Improvement	4	10
Some Improvement	24	57
A Lot of improvement	14	33
<b>Better Able to Perform Physical Tasks</b>	(N=44)	
Little to no Improvement	9	20
Some Improvement	23	52
A Lot of improvement	12	27
<b>Better Able to Perform Daily Living Activities</b>	(N=44)	
Little to no Improvement	8	18
Some Improvement	18	41
A Lot of improvement	18	41
<b>Better Able to Communicate</b>	(N=43)	
Little to no Improvement	6	14
Some Improvement	10	23
A Lot of improvement	27	63
<b>Total Improvement</b>	(N=44)	
Below Average Improvement	23	52
Above Average Improvement	21	48



**Figure 3** is a histogram that describes the distribution of total improvement scores for the children who were the subject of this study. The mean value is 2.23, the standard deviation is .55 and N=44.

### 3.6 Comparison Between Reported Improvement Scores and Services

Table 8 compares total improvement scores of those children receiving each type of service versus the total levels of improvement of those children not receiving that particular type of service. Of those children who were receiving ABA therapy 54% had below average improvement. This compares to the 50% of children not receiving ABA therapy who fell into the below average improvement category. A chi –square test was performed on this comparison and a p-value of 0.783 was calculated indicating that

there is not a statistically significant correlation. Of the children who were receiving speech therapy, 45% had below average reported improvement, while 69% of those who did not receive ST fell into this category. This difference was not statistically significant (Fisher's exact test,  $p=0.194$ ). Of those receiving OT, 50% were reported to have above average improvement whereas 57% of those who were not receiving OT were reported to have had below average improvement. The p-value generated by this comparison was 0.659 and therefore not statistically significant. Looking at the group of children enrolled in PT, 33% of them were reported to have had below average improvement. This compares to the 57% of those children who were not receiving PT and fell into the same category. This comparison received a Fisher's exact p-value of 0.272, making it out of the range of a statistically significant comparison. Of the children on the spectrum who were receiving recreational therapy, 38% had below average improvement whereas 56% of the children not receiving RT fell into the below average reported improvement category. The p-value generated by performing a Fisher's exact calculation on this comparison generated a p-value of 0.448. Finally, of those participating in social group therapy 60% were reported to have had below average improvement whereas 50% of those not receiving social group therapy were reported to have below average improvement. The p-value generated by a Fisher's exact calculation for this comparison is 0.724, making it not significant.

<b>Table 8: Reported Improvement With/Without Service Type</b>									
	Below average Improvement		Above average Improvement		Total	Chi-Square Test			Fisher's Exact Test
	N	%	N	%		N	Chi-square value	df	p-value
Receiving ABA Not receiving ABA	13 10	54 50	11 10	46 50	24 20	0.076	1	0.78 3	
Receiving speech therapy Not receiving speech therapy	14 9	45 69	17 4	55 31	31 13				0.19 4
Receiving occupational therapy Not receiving occupational therapy	15 8	50 57	15 6	50 43	30 14	0.195	1	0.65 9	
Receiving physical therapy Not receiving physical therapy	3 20	33 57	6 15	66 43	9 35				0.27 2
Receiving recreational therapy Not receiving recreational therapy	3 20	38 56	5 16	63 44	8 36				0.44 8
Receiving social group therapy Not receiving social group therapy	6 17	60 50	4 17	40 50	10 34				0.72 4

Table 9 presents a comparison of total reported improvement scores for those who did or did not receive each of the individual services. Similarly to the comparisons seen in Table 20 none of these proved to be statistically significant, however the comparison between participation in ST and total improvement is approaching statistical significance with a p-value of 0.063. The children receiving ST had a mean total improvement score of 2.33 in comparison to the mean score of 1.99 for those who are not receiving ST. For the remaining therapies (ABA,

OT, PT, RT, SG), there was no significant difference in Total Reported improved based on whether the child was receiving that therapy. It is interesting to note that the mean Total Improvement Score for those receiving therapy was greater than that for those not receiving therapy (for all expect Social Group therapy); however, the means did not differ significantly, and therefore this observation should be treated with caution.

**Table 9: T-Test Comparison Between Total Reported Improvement and Services**

	N	Mean	SD	SEM	t-value	df	p-value
Receiving ABA	24	2.28	0.384	0.078	0.574	42	0.569
Not Receiving ABA	20	2.18	0.708	0.158			
Receiving ST	31	2.33	0.529	0.095	1.91	42	0.063
Not Receiving ST	13	1.99	0.543	0.150			
Receiving OT	30	2.29	0.517	0.094	1.03	42	0.307
Not Receiving OT	14	2.11	0.615	0.164			
Receiving PT	9	2.40	0.418	0.139	1.07	42	0.290
Not Receiving PT	35	2.19	0.576	0.097			
Receiving RT	8	2.52	0.409	0.145	1.65	42	0.107
Not Receiving RT	36	2.17	0.561	0.094			
Receiving Social Group	10	2.13	0.702	0.222	-0.667	42	0.509
Not Receiving Social Group	34	2.26	0.505	0.087			

Parents were also asked to determine how many hours per week their child participated in each service in which they were enrolled. Table 10 describes the comparison between the amount of time each child spent participating in each service and the amount of total improvement reported by their parents. The median number of hours spent in ABA therapy per

week across the data set was seven hours. There was no significant difference in the proportion of children who had above average total improvement between those who received less than seven hours of ABA per week and those who received more (Fisher's exact test,  $p = 1.0$ ). The median number of hours spent participating in ST, OT, PT, RT, and social group each week was one hour. Of the children receiving one or fewer hours of speech therapy on a weekly basis, 50% were reported to have below average improvement in comparison to 38% of those who were receiving more than one hour of ST a week. The p-value generated by this comparison statistically insignificant at 0.534. Of those children participating in less than one hour of OT weekly, 44% were reported to have below average improvement in comparison to 58% of those who were participating in OT for one or more hours per week. This comparison generated a statistically insignificant Fisher's exact p-value of 0.689. There were very few children receiving recreational therapy and only one was receiving less than one hour of the therapy each week. This child had reported improvement that was above the average. Five children were receiving one or more hours of RT and three of these children were reported to have had above average improvement versus two children who were reported to have had below average improvement. The p-value generated by a Fisher's exact calculation for this comparison was 1.00, which is a statistically insignificant difference. There were also a small number of respondents who indicated that their child participated in social group therapy (7). Four of these children received 0-1 hours of social group therapy a week and half of them were reported to have had below average improvement and half above average. All three of the children who were participating in social group therapy for more than one hour per week were reported to have below average total improvement. This difference was not statistically significant (Fisher's Exact Test,  $p = 0.429$ ).

Table 10: Reported Improvement vs Hours of Service Per Week									
	Below average Improvement		Above average Improvement		Total	Chi-Square Test			Fisher's Exact Value
	N	%	N	%		N	Chi-square value	df	p-value
ABA									1.00
<7 hours	4	57	3	43	7				
7 or more	6	46	7	54	13				
Speech Therapy						0.386	1	0.534	
1 or fewer hours	8	50	8	50	16				
> 1 hour	5	38	8	62	13				
Occupational Therapy									0.689
< 1hour	4	44	5	56	9				
1 or more	11	58	8	42	19				
Physical Therapy									1.00
<1 hour	1	33	2	66	3				
1 or more	1	25	3	75	4				
Recreational Therapy									1.00
<1 hour	0	0	1	100	1				
1 or more	2	40	3	60	5				
Social group therapy									0.429
1 or fewer hours	2	50	2	50	4				
> 1 hour	3	100	0	0	3				

Table 11 presents a comparison of the total reported improvement score based on the amount of time spent in each individual service per week and total time spent in services per week. Those children receiving more than 5.5 hours of total services per week had an average total improvement score of 2.38 compared to the mean improvement score of 2.08 for those who were participating in 5.5 or fewer hours of total services per week. Although this comparison was not statistically significant, it approached significance with a p-value of 0.086. None of the

comparisons for individual services and total improvement generated a statistically significant p-value.

<b>Table 11: T-Test Comparison Between Total Reported Improvement and Hours of Service Per Week</b>							
	N	Mean	SD	SEM	t-value	df	p-value
ABA					0.475	18	0.640
<7 hours	7	2.38	0.438	0.166			
7 or more	13	2.29	0.376	0.104			
Speech Therapy					-0.680	27	0.502
1 or fewer hours	16	2.27	0.626	0.157			
> 1 hour	13	2.41	0.403	0.112			
Occupational Therapy					0.688	26	0.498
< 1 hour	9	2.36	0.531	0.177			
1 or more	19	2.21	0.519	0.119			
Physical Therapy					0.378	5	0.721
<1 hour	3	2.56	0.419	0.242			
1 or more	4	2.42	0.518	0.259			
Recreational Therapy					0.724	4	0.509
<1 hour	1	2.83					
1 or more	5	2.47	0.462	0.207			
Social group therapy					0.694	5	0.518
1 or fewer hours	4	2.20	0.741	0.370			
> 1 hour	3	1.89	0.192	0.111			
Total					-1.763	38	0.086
5.5 or fewer hours	20	2.08	0.668	0.149			
More than 5.5 hours	20	2.38	0.373	0.083			

Respondents were asked to indicate if their child was receiving multiple services. There was no relationship between the number of services received (1-2 types of service vs. 3 or more) and whether the reported improvement was above or below average (p-value: 0.887). Parents were asked to estimate the total amount of time that their child spent participating in all of their



therapies and the median number of hours was 5.5 hours. The percentage of those with above average reported improvement did not differ between the groups defined by whether they were receiving more or less than the median amount of services ( $p = 0.634$ ). Respondents were asked how many years their child had been receiving services and the median number of years was two. Of those children who had received between zero and two years of services, 56% were reported to have had below average improvement. This compares to the 50% of children who were participating in services for two or more years who were also reported to have below average improvement. The p-value generated by performing a chi-squared test on this comparison was 0.739, making it statistically insignificant (Table 12).

<b>Table 12: Total Reported Improvement and Services</b>								
	Below Average Improvement		Above Average Improvement		Total	Chi-Square Test		
	N	%	N	%	N	Chi-square value	d f	p-value
Receiving 1-2 different	12	52	11	48	23	0.020	1	0.887
Receiving 3 or more services	10	50	10	50	20			
Receiving 5.5 or fewer hours per week	12	60	8	40	20	0.902	1	0.342
Receiving more than 5.6 hours per week	9	45	11	55	20			
Receiving services for 0-2 years	14	56	11	44	25	0.604	2	0.739
Receiving services for 2 or more years	8	50	8	50	16			

Respondents were asked to report how much improvement they felt their child had in individual categories and Table 13 discusses the comparison between each individual category and whether or not the child was receiving ABA therapy. The individual categories include: happier at home, happier at school, happier in public, better able to perform physical tasks, better able to perform daily living tasks. There was no significant association between receiving ABA and reported improvement in the category of happier at home (p-value: 0.846). Of those children receiving ABA, a majority of them (78%) were described to have some improvement when it comes to being happier in school and there were no children receiving ABA who were indicated to have little to no improvement. This is in comparison to the 21% of children who were not receiving ABA and were indicated to have little to no improvement. This comparison is statistically significant with a p-value of 0.004. Examining the category of happier in public revealed that no children who were participating in ABA therapy were indicated to have little to no improvement and the majority were indicated to have some improvement (75%). This comparison generated a statistically significant p-value of 0.007. There was no statistically significant relationship between those children participating in ABA and the child's ability to perform physical tasks (p-value: 0.402). The comparison between those children receiving ABA and their improvement with regards to ability to perform daily living tasks was approaching statistical significance (p-value: 0.091) as the majority of children who were receiving ABA therapy had at least some improvement (90%). Of the children receiving ABA therapy there were no children who were reported to have had little to no improvement. This comparison generated a statistically significant p-value of 0.006.

<b>Table 13: ABA and Reported Categorical Improvement</b>					
	Yes		No		Fisher's Exact Test
	N	%	N	%	p-value
<b>Happier at home</b>					0.846
Little to no improvement	3	13	4	20	
Some improvement	14	58	10	50	
A lot of improvement	7	29	6	30	
Total	24		20		
<b>Happier at School</b>					0.004*
Little to no improvement	0	0	4	21	
Some improvement	18	78	6	32	
A lot of improvement	5	22	9	47	
Total	23		19		
<b>Happier in Public</b>					0.007*
Little to no improvement	0	0	4	20	
Some improvement	18	75	7	35	
A lot of improvement	6	25	9	45	
Total	24		20		
<b>Better able to perform physical tasks</b>					0.402
Little to no improvement	4	17	5	25	
Some improvement	15	63	8	40	
A lot of improvement	5	21	7	35	
Total	24		20		
<b>Better able to perform daily living activities</b>					0.091†
Little to no improvement	2	10	6	30	
Some improvement	13	54	5	25	
A lot of improvement	9	38	9	45	
Total	24		20		
<b>Better able to communicate</b>					0.007*
Little to no improvement	0	0	6	32	
Some improvement	8	33	2	11	
A lot of improvement	16	67	11	58	
Total	24		19		

\*indicates statistical significance (p-value < 0.05)

†indicates approaching statistical significance (p-value < 0.100)

Table 14 compares children receiving speech therapy and their improvement in each individual category described above. There was a statistically significant relationship found between those receiving ST and the child's ability to perform (p-value: 0.008). Of the children receiving ST a majority of them were reported to have had at least some improvement in their ability to perform physical tasks (87%). Of the children who were not receiving ST, none of them were reported to have had a lot of improvement in their ability to perform physical tasks. There were no statistically significant relationship seen between receiving ST and happiness at home (p-value: 0.254), happiness at school (p-value: 0.607), happiness in public (p-value: 0.775), ability to communicate (p-value: 0.313), or ability to perform daily living activities (0.314).

<b>Table 14- ST and Reported Categorical Improvement</b>					
	Yes		No		Fisher's Exact Test
	N	%	N	%	p-value
<b>Happier at home</b>					0.254
Little to no improvement	3	10	4	31	
Some improvement	18	58	6	46	
A lot of improvement	10	32	3	23	
Total	31		13		
<b>Happier at School</b>					0.607
Little to no improvement	2	7	2	17	
Some improvement	17	57	7	58	
A lot of improvement	11	37	3	25	
Total	30		12		
<b>Happier in Public</b>					0.775
Little to no improvement	2	6	2	15	
Some improvement	18	58	7	54	
A lot of improvement	11	35	4	31	
Total	31		13		
<b>Better able to perform physical tasks</b>					0.008 *
Little to no improvement	4	13	5	38	
Some improvement	15	48	8	62	
A lot of improvement	12	39	0	0	
Total	31		13		
<b>Better able to perform daily living activities</b>					0.314
Little to no improvement	5	16	3	23	
Some improvement	11	35	7	54	
A lot of improvement	15	48	3	23	
Total	31		13		
<b>Better able to Communicate</b>					0.313
Little to no improvement	3	10	3	23	
Some improvement	6	20	4	31	
A lot of improvement	21	70	6	46	
Total	30		13		

\*indicates statistical significance relationships (p-value <0.05)

Table 15 discusses the comparison between participation in OT and improvement made in each of the categories discussed above. There were no significant relationships seen between those children receiving OT and any of the categories that are discussed.

<b>Table 15: OT and Reported Categorical Improvement</b>					
	Yes		No		Fisher's Exact Test
	N	%	N	%	p-value
<b>Happier at home</b>					<b>0.748</b>
Little to no improvement	5	17	2	14	
Some improvement	15	50	9	64	
A lot of improvement	10	33	3	21	
<b>Total</b>	<b>30</b>		<b>14</b>		
<b>Happier at School</b>					<b>0.549</b>
Little to no improvement	2	7	2	14	
Some improvement	15	54	9	64	
A lot of improvement	11	39	3	21	
<b>Total</b>	<b>28</b>		<b>14</b>		
<b>Happier in Public</b>					<b>0.706</b>
Little to no improvement	2	7	2	14	
Some improvement	17	57	8	57	
A lot of improvement	11	37	4	29	
<b>Total</b>	<b>30</b>		<b>14</b>		
<b>Better able to perform physical tasks</b>					<b>0.272</b>
Little to no improvement	4	13	5	36	
Some improvement	17	57	6	43	
A lot of improvement	9	30	3	21	
<b>Total</b>	<b>30</b>		<b>14</b>		
<b>Better able to perform daily living activities</b>					<b>0.407</b>
Little to no improvement	4	13	4	29	
Some improvement	14	47	4	29	
A lot of improvement	12	40	6	43	
<b>Total</b>	<b>30</b>		<b>14</b>		
<b>Better able to communicate</b>					<b>0.363</b>
Little to no improvement	4	14	2	14	
Some improvement	5	17	5	36	
A lot of improvement	20	69	7	50	
<b>Total</b>	<b>29</b>		<b>14</b>		

Table 16 describes the comparison between participation in PT and reported improvement in each of the individual categories. None of the individual categories that were looked at in this study saw any significant relationships with a child's participation in PT.



<b>Table 16: PT and Reported Categorical Improvement</b>					
	Yes		No		Fisher's Exact Test
	N	%	N	%	p-value
<b>Happier at home</b>					0.588
Little to no improvement	1	21	6	17	
Some improvement	4	44	20	57	
A lot of improvement	4	44	9	26	
Total	9		35		
<b>Happier at School</b>					0.861
Little to no improvement	0	0	4	12	
Some improvement	6	67	18	55	
A lot of improvement	3	33	11	33	
Total	9		33		
<b>Happier in Public</b>					0.864
Little to no improvement	0	0	4	11	
Some improvement	6	67	19	54	
A lot of improvement	3	33	12	34	
Total	9		35		
<b>Better able to perform physical tasks</b>					0.788
Little to no improvement	1	11	8	23	
Some improvement	5	56	18	51	
A lot of improvement	3	33	9	26	
Total	9		35		
<b>Better able to perform daily living activities</b>					0.383
Little to no improvement	0	0	8	23	
Some improvement	5	56	13	37	
A lot of improvement	4	44	14	40	
Total	9		35		
<b>Better able to communicate</b>					0.485
Little to no improvement	0	0	6	18	
Some improvement	2	22	8	24	
A lot of improvement	7	78	20	59	
Total	9		34		

Table 17 describes the comparison between participation in RT and reported improvement in each of the individual categories. There were no significant relationships seen between receiving RT and any of the six individual categories looked at with this study.

<b>Table 17: RT and Reported Categorical Improvement</b>					
	Yes		No		Fisher's Exact Test
	N	%	N	%	p-value
<b>Happier at home</b>					0.178
Little to no improvement	2	25	5	14	
Some improvement	2	25	22	61	
A lot of improvement	4	50	9	25	
Total	8		36		
<b>Happier at School</b>					0.372
Little to no improvement	0	0	4	11	
Some improvement	3	43	21	60	
A lot of improvement	4	57	10	29	
Total	7	100	35	100	
<b>Happier in Public</b>					0.503
Little to no improvement	0	0	4	11	
Some improvement	4	50	21	58	
A lot of improvement	4	50	11	31	
Total	8		36		
<b>Better able to perform physical tasks</b>					0.768
Little to no improvement	1	13	8	22	
Some improvement	4	50	19	53	
A lot of improvement	3	38	9	25	
Total	8		36		
<b>Better able to perform daily living activities</b>					0.350
Little to no improvement	0	0	8	22	
Some improvement	3	38	15	42	
A lot of improvement	5	63	13	36	
Total	8		36		
<b>Better able to Communicate</b>					0.316
Little to no improvement	0	0	6	17	
Some improvement	1	13	9	26	
A lot of improvement	7	88	20	57	
Total	8		35		

Table 18 describes the comparison between participation in social group therapy and the amount of improvement in each individual category. There were no statistically significant comparisons amongst the group of children receiving social group therapy. The comparison between participation in social group therapy and being happier at home was approaching statistical significance with a p-value of 0.068. While overall most of the children were reported to have at least some improvement in being happier at home, the proportion of those with little or no improvement was higher among those who are receiving social group therapy however this difference did not reach statistical significance.

<b>Table 18: Social Group and Reported Categorical Improvement</b>					
	Yes		No		Fisher's Exact Test
	N	%	N	%	p-value
<b>Happier at home</b>					0.068†
Little to no improvement	4	40	3	9	
Some improvement	3	30	21	62	
A lot of improvement	3	30	10	29	
Total	10		34		
<b>Happier at School</b>					0.145
Little to no improvement	2	22	2	6	
Some improvement	3	33	21	64	
A lot of improvement	4	44	10	30	
Total	9		33		
<b>Happier in Public</b>					0.212
Little to no improvement	2	20	2	6	
Some improvement	4	40	21	62	
A lot of improvement	4	40	11	32	
Total	10		34		
<b>Better able to perform physical tasks</b>					0.349
Little to no improvement	3	30	6	18	
Some improvement	6	60	17	50	
A lot of improvement	1	10	11	32	
Total	10		34		
<b>Better able to perform daily living activities</b>					0.293
Little to no improvement	3	30	5	15	
Some improvement	2	20	16	47	
A lot of improvement	5	50	13	38	
Total	10		34		
<b>Better able to Communicate</b>					0.858
Little to no improvement	1	11	5	15	
Some improvement	3	33	7	21	
A lot of improvement	5	56	22	65	
Total	9		34		

† indicates approaching statistical significance (p-value: <0.100)

### 3.7 Comparison Between QOL Scores and Services

Table 19 discusses the comparison between total QOL score and whether or not a child was receiving a particular service. Of those children receiving PT a majority of them (78%) had a total QOL score below the median of 55; for those not receiving PT, 46% had a total QOL score below the median. This comparison approaches statistical significance (Fisher's exact test,  $p = 0.072$ ). There was no significant relationship seen between QOL scores and receipt of ABA (p-value: 0.188), ST (p-value: 0.917), OT (p-value: 0.846), RT (p-value: 1.00), or social group therapy (p-value: 0.286).

	QOL score 0-55		QOL score 56-100		Total	Chi-Square Test			Fisher's Exact Test
	N	%	N	%		N	Chi-Square value	df	p-value
Receiving ABA Not receiving ABA	14 9	58 39	10 14	42 61	24 23	1.73	1	0.188	
Receiving speech therapy Not receiving speech therapy	15 8	48 50	16 8	52 50	31 16	0.011	1	0.917	
Receiving occupational therapy Not receiving occupational therapy	15 8	50 47	15 9	50 53	30 17	0.038	1	0.846	
Receiving physical therapy Not receiving physical therapy	7 16	78 42	2 22	22 58	9 38				0.072†
Receiving recreational therapy Not receiving recreational therapy	4 19	50 49	4 20	50 51	8 39				1.00
Receiving social group therapy Not receiving social group therapy	3 20	30 43	7 17	70 46	10 37				0.286

† indicates approaching statistical significance (p-value <0.100).

Table 20 presents the results of a T-test calculation to compare the raw total QOL scores with the types of services being received. None of the comparisons proved statistically significant. The comparison with participation in social group therapy was approaching significance with a QOL mean of 63.3 for those receiving social group therapy and 54.4 for those who were not receiving social group (p-value: 0.097).

<b>Table 20: T-Test Comparison Between Total QOL and Services Received</b>							
	N	Mean	SD	SEM	t-value	df	p-value
Receiving ABA	24	54.6	13.4	2.7	-0.767	45	0.447
Not Receiving ABA	23	58.0	16.6	3.5			
Receiving ST	31	57.2	14.8	2.7	0.606	45	0.548
Not Receiving ST	16	54.4	15.5	3.9			
Receiving OT	30	56.4	11.4	2.1	0.091	45	0.928
Not Receiving OT	17	56.0	20.2	4.9			
Receiving PT	9	52.4	13.5	4.5	-0.875	45	0.386
Not Receiving PT	38	57.2	15.3	2.5			
Receiving RT	8	56.8	13.6	4.8	0.101	45	0.920
Not Receiving RT	39	56.2	15.4	2.5			
Receiving Social Group	10	63.3	13.4	4.2	1.69	45	0.097
Not Receiving Social Group	37	54.4	15.0	2.5			

† indicates approaching statistical significance (p-value <0.100).

Table 21 describes the comparison between the amount of time spent participating in each service and the total QOL score of the children. None of these comparisons generated a p-value that conveyed statistical significance. However, time spent receiving ST compared to total

QOL was approaching statistical significance with a Fisher's exact value of 0.066. Of the children receiving one or fewer hours of ST per week, 31% had QOL scores that fell below the mean, in comparison with the 69% of children receiving more than one hour of ST who fell into the same category.

<b>Table 21: QOL vs Hours of Service</b>						
	QOL score 0-55		QOL score 56-100		Total	Fisher's Exact Test
	N	%	N	%	N	p-value
<b>ABA</b>						0.374
Less than 7 hours per week	5	71	2	29	7	
7 or more hours per week	6	46	7	54	13	
<b>Speech Therapy</b>						0.066†
1 or fewer hours per week	5	31	11	69	16	
More than 1 hour per week	9	69	4	31	13	
<b>Occupational Therapy</b>						1.00
Less than 1 hour per week	5	56	4	44	9	
1 or more hours per week	9	47	10	53	19	
<b>Physical Therapy</b>						0.429
Less than 1 hour per week	3	100	0	0	3	
1 or more hours per week	2	50	2	50	4	
<b>Recreational Therapy</b>						1.00
Less than 1 hour per week	0	0	1	100	1	
1 or more hours per week	3	60	2	40	5	
<b>Social group therapy</b>						0.429
1 or fewer hours per week	2	50	2	50	4	
More than 1 hour per week	0	0	3	100	3	

† indicates a relationship approaching statistical significance (p-value <0.100).

A T-test calculation was used to analyze the comparison between total QOL scores and the time spent participating in each service each week. Again, none of these comparisons generated a statistically significant p-value. However, those participating in ST for 0-1 hours per



week had a mean total QOL score of 61.8 in comparison with the mean total QOL score of 52.8 for those who were participating in more than 1 hours of ST per week. This comparison approached statistical significance with a p-value of 0.092 (Table 22).

<b>Table 22: T-Test Comparison Between Total QOL and Hours of Service Per Week</b>							
	N	Mean	SD	SEM	t-value	df	p-value
ABA							
<7 hours	7	54.5	9.93	3.75	-0.362	18	0.722
7 or more	13	56.7	14.1	3.91			
Speech Therapy							
1 or fewer hours	16	61.8	12.7	3.16	1.75	27	0.092†
> 1 hour	13	52.8	15.1	4.20			
Occupational Therapy							
< 1 hour	9	53.7	8.27	2.76	-0.808	26	0.426
1 or more	19	57.5	12.5	2.88			
Physical Therapy							
<1 hour	3	49.2	0.687	0.397	-1.30	5	0.250
1 or more	4	61.11	15.4	7.71			
Recreational Therapy							
<1 hour	1	57.6			-0.004	4	0.997
1 or more	5	57.7	14.9	6.66			
Social group therapy							
1 or fewer hours	4	56.7	13.5	6.75	-0.994	5	0.366
> 1 hour	3	65.3	7.16	4.13			

† indicates a relationship approaching statistical significance (p-value <0.100).

Looking at the number of services each child was participating in, there was no significant relationship seen with QOL (p-value: 0.172). Similarly, there was no significant relationship seen between the amount of years a child had been receiving services and their QOL

(p-value: 0.165) or the total number of hours spent in services per week and QOL (p-value: 0.204) (Table 23).

<b>Table 23: Total QOL and Services</b>								
	QOL score 0-55		QOL score 56-100		Total	Chi-Square Test		
	N	%	N	%	N	Chi-Square value	df	p-value
Receiving 1-2 different services	9	39	14	61	23	1.87	1	0.172
Receiving 3 or more services	12	60	8	40	20			
Receiving 0-5.5 hours per week	7	35	13	65	20	1.62	1	0.204
Receiving more than 5.6 hours per week	11	55	9	45	20			
Receiving services for 0-2 years	9	36	16	64	25	3.61	2	0.165
Receiving services for more than 2 years	10	63	6	38	16			

Looking at the comparison between total improvement and total QOL, a majority of the children who scored below the median on the QOL scale were reported to have had above average improvement (57%) whereas 61% of the children who garnered QOL scores above the median were reported to have had below average improvement (67%). However, this comparison was not statistically significant with a p-value of 0.232 (Table 24).

<b>Table 24: Total QOL and Total Reported Improvement</b>							
	QOL score 0-55		QOL score 56-100		Chi-Square Test		
	N	%	N	%	Chi-Square Value	df	p-value
Below Average Improvement	9	43	14	61	1.43	1	0.232
Above Average Improvement	12	57	9	39			
Total	21		23				

## IV. Discussion

This study was designed to explore the relationship between the quality of life of children on the autism spectrum and the services they are receiving. Although there are groups of people who do not believe that children on the spectrum are in need of treatment, therapies have become the expected following a diagnosis of autism spectrum disorder. The aim of this study was to identify whether certain types of therapies and services were associated with better quality of life for children with autism.

### *4.1 Quality of Life and Services Received*

We initially hypothesized that children with higher QOL scores would have received more services than those children who had lower QOL scores. Interestingly however, there was no statistically significant relationship seen between receiving a particular service and having a QOL score that fell above the median QOL of score. Similarly, there was no significant association seen when looking at total number of services and higher QOL. This absence of a significant relationship may be explained if those children with higher QOL scores were not thought to need these therapies because of their apparent functioning level. For example, a child who is doing well socially and behaviorally may not be perceived to be likely to receive any benefit from participating in ABA therapy and therefore the data would reflect that those children not receiving services have a higher QOL score. The absence of significance for this comparison could also indicate that the services assessed in this study simply do not have any type of relationship with higher QOL. In addition, the small sample size negatively impacted the power of the study and may have contributed to an inability to detect relationships seen between QOL and participation in individual services. More respondents would increase the power of the

study and may allow for an increased likelihood of statistical significance which may provide more concrete information regarding the relationship between participation services and QOL.

Similarly, there was no significant relationship seen when looking at the comparison between the amount of time spent participating in each service and QOL scores. Again this does not support our original hypothesis that those children who participated in services for a longer amount of time will have a higher quality of life. The overall lack of significant relationships seen may be a result of the small sample size. Although not significant (p-value: 0.066), there were more children who were reported to have a QOL score below the median value of 55 who were receiving more than one hour of ST per week (69%) in comparison to those who were receiving between zero and one hour of service per week (31%). ST was the therapy that the most children had participated in which may be the reason that the comparison looking at ST and hours of participation was approaching significance. Interestingly however, this relationship appears to be in the opposite direction of what was originally hypothesized. This may be the case because the children with a more severe phenotype may be more likely to be participating in ST and are also more likely to have lower parent-reported QOL scores. This suggestive association may be seen between these two variables due to the third, unmeasured variable, severity. The borderline significance suggests that there may be limited power in this sample to detect the relationships that may exist between QOL and the therapies received. With a larger population of respondents, it may be possible to better understand these relationships.

In an attempt to further investigate the comparison between the time spent participating in services and QOL, we assessed the number of years each child had been receiving services and compared their QOL scores. Again this comparison was not statistically significant and no relationship was seen. While this result may reflect that there is truly no relationship between the

time spent in services and QOL for a particular child, there are a number of other possible explanation for the lack of significant association found in these data. First, those children who are higher functioning and receiving higher QOL scores may not appear to require the assistance of as much therapy as those children who are lower functioning. Secondly, lower functioning children may have come to attention as having deficits earlier than those children who have a higher quality of life meaning that they would have the opportunity to be participating in services for more years than those children who were diagnosed later. The limited sample size also plays a role and larger future studies would be helpful in determining significant correlations.

#### *4.2 Reported Improvement and Services*

We originally hypothesized that those participating in services will have higher reported improvement scores than those who were not participating in services. Analysis of both participation in each service and time spent each week receiving a particular service identified no statistically significant relationship between reported improvement and any of the individual services. Similarly, assessing the comparison between total number of services (or total time spent in receiving services) and reported improvement revealed no significant relationships. It is possible that there truly is no relationship between services and improvement however the lack of significance may also be due to the small sample size which limited the statistical power of the study. Had there been an adequate number of participants a significant difference may have been seen and provided important information. However, it is also possible that because improvement scores were generated via parent report and parental interpretation of improvement

can be vastly different from individual to individual there is room for inconsistency which has the potential to reduce the power to detect a significant relationship.

#### *4.2.1 ABA and Improvement*

To look more in depth at the relationship between services and QOL, we assessed each of the services and their relationship with each individual category of reported improvement. This is an exploratory analysis, and it is possible that the significant results achieved significance by chance given the large number of comparisons made. However, some of these findings are intriguing and merit discussion. There was a significant relationship between participation in ABA and being happier at school (p-value: 0.004), happier in public (p-value: 0.007), and reported improvement with ability to communicate (p-value: 0.006). ABA is a therapy that focuses on a broad spectrum of deficits that is somewhat individualized to each child's needs. It focuses on implementing structure and changing behavior patterns that make social interaction difficult (Simpson, 2001). Structure and social interaction are crucial to being successful at school, in public, and with communication. This study revealed that although there was no relationship between overall reported improvement and participation in ABA, improvement was made in the individual categories that correlate to the specific areas of life targeted by ABA therapy. This may indicate that there is a distinct difference in how each particular service might impact improvement rather than generalizing services as a whole and provides an interesting idea for studies in the future.

#### *4.2.2 Speech Therapy and Improvement*

Interestingly, in analysis of ST and reported improvement in individual categories, there was a significant relationship between participation in ST and a child's ability to perform physical tasks (p-value: 0.008). The expectation would be that ST would improve a child's ability to communicate, however there was no significant relationship appreciated between those two variables. ST not only targets expressive language and outward communication but it also focuses on receptive language which corresponds to a child's ability to follow directions and understand the environment around them (Bishop, 2014). The ability to perform physical tasks is a skill that not only requires physical competency but also receptive language competency. ST therapy increases a child's ability to understand what is being asked of him or her. This may explain why participation in ST was correlated with reported improvement in a child's ability to perform physical tasks.

#### *4.2.3 Occupational Therapy, Physical Therapy, Recreational Therapy, Social Group Therapy and Improvement*

There was no statistically significant relationship seen between participation in OT, PT, RT, or social group therapy and any of the individual areas of reported improvement that were targeted in this study. There were fewer individuals who were reported to have been receiving these services making it difficult to adequately assess the potential association between these services and reported improvement for a child.

Given that there was no significant relationship with the comparisons across all categories of improvement with each therapy, one possible explanation may be a 'response bias'



in which participants may have been likely to provide the same answer to all questions with respect to improvement. However, looking at the distribution of each respondent's answers in regards to their child's improvement it was evident, in general, that participants did not provide the same answer choice for every question regarding reported improvement. This indicates that with a larger, broader sample size there would likely be more respondents indicating that their children were in receipt of these services giving these comparisons more power to detect significant relationships with specific areas of improvement.

#### *4.3 Limitations of this study*

This study was primarily distributed via social media which, in theory, allowed for its exposure to a broad and varied group of respondents. In reality it is likely that the survey was passed throughout friend and therapy groups to participants who shared their environment with each other. This may have ultimately limited the sample population and skewed the results towards less variability in regards to participant demographics. This is evident by the fact that there was very limited variation in terms of ethnicity, socioeconomic status and education level among the respondents. The majority of the participants reported themselves to be Caucasian (78%), have a graduate or professional degree (51%), and have a yearly household income of more than \$150,000 (32%). The lack of variation in demographics could potentially limit the range and diversity of the children represented in the research.

This study was also limited with regard to sample size. Numerous support groups and online forums were approached for survey distribution, however none were able to participate in the study. This limited distribution led to a small sample size which did not allow for in depth

analysis. Had there been an adequate number of study participants additional comparisons may have approached statistical significance and provided for more concrete analysis.

This study was conducted via parent proxy, meaning that parents used their own judgement to report their child's QOL. This limits the study in that we are relying on someone other than the child to gather an accurate assessment of their QOL. This also begs the question of what QOL truly is and how appropriate and accurate it is for another person to assess an individual's QOL. The same limitation exists for reported improvement, as this was also done via parent-proxy. Although this is the most feasible way to ascertain this information, it is a limitation of this study.

The exclusion criteria for this study only allowed for participants with one child with Autism Spectrum disorder and placed age restrictions on the children who were the focus of the study. These restrictions were placed in order to obtain a more homogenous sample, and the trade-off is a smaller sample size. This limited the extent to which this study could analyze the entirety of the population of children with ASD.

Finally, a study participant provided feedback after the start of the survey regarding the addition of a question to specifically address her feelings about whether services had an impact on any improvements that were seen in her child. The changes were put forth to the IRB committee and were added to the survey. Because the question was added after the initial launch of the survey a majority of the participants were not exposed to that question. This substantially limited the responses, and therefore analysis of the answers to this question is limited.

#### *4.4 Future Studies*

This is an important topic of research and could benefit from further studies with more participation in order to garner a larger sample size. A larger sample size could be garnered by expanding the inclusion criteria and allowing children over age 12. Expanding the method of distribution may also help to increase the sample size within the 2-13 age group as well outside of it. This would help to increase the statistical power of the study and make for more meaningful conclusions.

This study looked at a small subset of children with ASD as it excluded families with multiple affected children and only allowed for the participation of families with children aged 2-12. It is important for future studies to broaden the inclusion criteria to incorporate more children and gain a more expanded perspective.

This study asked the participants to report QOL for only their child with ASD. It would be interesting to conduct a study in which these parents also report the QOL for their other, neurotypical, children. This would serve as a control and help to better understand how these parents are interpreting QOL. Further understanding what QOL means to families may help to more fully assess the relationship between QOL and participation in services.

Due to the small sample size, exploring the QOL and improvement of those who were not receiving any services was not possible. It would be important to study this population and compare with those who are receiving services to control for factors such as improvement with age and natural developmental progression.

A longitudinal study, to more accurately measure improvement, would also be worthwhile future research. This would allow us to bypass the parent reported improvement levels and control for severity allowing for more accurate data.

#### *4.5 Conclusion*

This study provides insight into the relationship between both quality of life and reported improvement following participation in services. Services were divided into the most common therapies received by children on the autism spectrum including: applied behavioral analysis (ABA), speech therapy (ST), occupational therapy (OT), physical therapy (PT), recreational therapy (RT), and social group therapy. Participation in these services was compared with total quality of life scores as well as reported total improvement scores. Total reported improvement scores were calculated from reported improvement scores in six categories: happier at home, happier at school, happier in public, ability to perform physical tasks, ability to perform daily living activities, ability to communicate. The improvement in the individual categories was also assessed for association with participation in services.

The original hypotheses of study centered around the idea that more services received and more time spent participating in these services would correlate with higher QOL and higher reported improvement scores. In contrast to our hypotheses, there was no statistical significant relationship seen between higher QOL scores and participation in services. One possible explanation for this finding could be that it may be less outwardly apparent that children with higher QOL are in need of services and therefore they may receive fewer services and spend less time participating in services.

There were, however, some significant conclusions that came from this study. It was clear that certain therapies showed a relationship with particular categories of reported improvement but not with other categories. A significant relationship was seen between ABA therapy and three out of the six categories of reported improvement, including happier in school, happier in public, and ability to communicate. This therapy was significantly associated with reported improvement in more areas than any of the other therapies. A significant relationship was also seen between ST and reported improvement in a child's ability to perform physical tasks. This relationship was unexpected because ST is generally associated with communication rather than motor skills, however, it expresses the versatility and the broad importance of ST.

This study delved into the most basic relationship between participation in services and the quality of life of children with autism spectrum disorder and the impact services may have on the reported improvement seen in a child. Understanding the relationship between the types of service received or the amount of time participating in services and reported improvement levels in various areas of life will inform health care professionals' perspective regarding the value of therapies. This research broadens the understanding of the impact that therapies may have on quality of life and enhance the ability of professionals to provide guidance to families. However, future studies are needed to further explore this important topic and elaborate on this relationship.

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## APPENDIX A: Criteria For Diagnosis of ASD

Autism Spectrum Disorder      299.00 (F84.0)

### Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp.

119-120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table 2 Severity levels for autism spectrum disorder

Severity level

Social communication

Restricted, repetitive behaviors

Level 3

"Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social

overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches

Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

## Level 2

"Requiring substantial support"

Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.

Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.

## Level 1

"Requiring support"

Without supports in place, deficits in social communication cause noticeable impairments.

Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but

whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Inflexibility of behavior causes significant interference with functioning in one or more contexts.

Difficulty switching between activities. Problems of organization and planning hamper independence.

## APPENDIX B

### Welcome to My Survey

You are being asked to participate in a research study. The purpose of this research study is to determine if there is an association between the amount and type of services participated in and quality of life in children with Autism Spectrum Disorder. This survey intends to explore the relationship between the services that children have/are receiving and their quality of life. Understanding this relationship will help genetic counselors and health care professionals expand their perspectives with regards to approaching autism and the therapies surrounding it.

You are eligible to participate in this study if you are at least 18 years of age or older and a parent, or guardian of one child with autism between the ages of 2 and 12. If you have multiple children on the spectrum you are ineligible to participate in this study.

Participation involves an electronic, anonymous survey. The survey will take approximately 10-15 minutes to complete.

There is no known harm or distress associated with completing this survey or the study in general, other than those affiliated with normal daily life. Possible discomfort could include; invasion of privacy, anxiety, embarrassment, and/or social stigma. If, at any time, you feel uncomfortable discussing anything addressed in the survey you may discontinue your participation. You are under no obligation to answer any question that you find yourself uncomfortable with. You will not be compensated for your participation in this research study.

All research data collected will be stored securely and confidentially. Research data will be stored electronically on a password protected laptop computer. The research team, authorized UCI personnel, and regulatory entities may have access to your study records to protect your safety and welfare. Any information derived from this research project that personally identifies you will not be voluntarily released or disclosed by these entities without your separate consent, except as specifically required by law.

If you have any comments, concerns, or questions regarding the conduct of this research please contact the researchers listed on the bottom of this form.

Please contact UCI's Office of Research by phone, (949) 824-6662, by e-mail at [IRB@research.uci.edu](mailto:IRB@research.uci.edu) or at 5171 California Avenue, Suite 150, Irvine, CA 92617 if you are unable to reach the researchers listed at the bottom of the form and have general questions; have concerns or complaints about the research; have questions about your rights as a research subject; or have general comments or suggestions.

Participation in this study is voluntary. There is no cost to you for participating. You may refuse to participate or discontinue your involvement at any time without penalty. You are free to withdraw from this study at any time.

By clicking 'Next' you are indicating you consent as a research participant.

**For more information please contact:**

**Lead Researcher**

**Shayna Svihovec, Genetic Counseling Graduate Student**

**UCI Department of Pediatrics**

**(714) 456-5837 or [ssvihove@uci.edu](mailto:ssvihove@uci.edu)**



\* 1. How many children with autism do you have?

- 0
- 1
- 2+

2. What is your age?

- Under 18
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or older

3. What is your gender?

- Male
- Female
- Other/prefer not to disclose

4. Which of the following best describes your current relationship status?

- Single, never married
- Married/Partnered
- Divorced/Separated
- Widowed

5. What is your religious affiliation, if any?

- No religion
- Buddhist
- Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- Hindu
- Jewish
- Muslim
- Other (please specify)

6. What is your ethnicity?

- African American/Black
- American Indian/Alaska Native
- Asian/Asian American
- Native Hawaiian/Pacific Islander
- Caucasian/non-Hispanic/European Ancestry
- Hispanic/Latino/Chicano
- Middle Eastern/Persian
- Other (please specify)

7. What is the highest level of education you have achieved?

- Elementary school and/or some high school
- High school graduate or equivalent
- Associate degree/some college
- College graduate or equivalent
- Graduate/professional degree or equivalent

8. What is the yearly income of your household?

- Under \$25,000
- \$25,000-\$50,000
- \$50,000-\$100,000
- \$100,000-\$150,000
- Above \$150,000

9. How many children do you have and how many are financially dependent on you? Include your child with autism.

Total number of children

Number of children financially dependent on you

10. How many people live in your household? Include yourself and your child.

Number of Adults 18+

Number of Children under 18

11. How many children with special needs do you have? **Do not** include your child with autism.

12. At what age was your child diagnosed with autism?

\* 13. How old is your child now?

The following is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by choosing:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.  
If you do not understand a question, please ask for help.

### In the past one month how much of a problem has your child had with...

#### 14. Physical Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Walking more than one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Running	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participating in sports activities or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting something heavy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking a bath or shower by him or herself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing chores around the house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having hurts or aches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low energy level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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15. Emotional Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Feeling afraid or scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling sad or blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying about what will happen to him or her	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Social Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Getting along with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other kids not wanting to be his or her friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting teased by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not able to do things that other children his or her age can do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping up when playing with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. School Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Paying attention in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Forgetting things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping up with schoolwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missing school because of not feeling well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missing school to go to the doctor or hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by choosing:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.  
If you do not understand a question, please ask for help.

### In the past one month how much of a problem has your child had with...

#### 18. Physical Functioning (problems With...)

	Never	Almost Never	Sometimes	Often	Almost Always
Walking more than one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Running	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participating in sports activities or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting something heavy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking a bath or shower by him or herself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing chores, like picking up his/her toys	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having hurts or aches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low energy level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Emotional Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Feeling afraid or scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling sad or blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying about what will happen to him or her	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. Social Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Getting along with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other kids not wanting to be his or her friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting teased by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not able to do things that other children his or her age can do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping up when playing with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. School Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Paying attention in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Forgetting things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping up with schoolwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missing school because of not feeling well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missing school to go to the doctor or hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by choosing:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers.  
If you do not understand a question, please ask for help.

### In the past one month how much of a problem has your child had with...

#### 22. Physical Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Walking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Running	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participating in play or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting something heavy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping to pick up his/her toys	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having hurts or aches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low energy level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### 23. Emotional Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Feeling afraid or scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling sad or blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



24. Social Functioning (problems with...)

	Never	Almost Never	Sometimes	Often	Almost Always
Playing with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other kids not wanting to be his or her friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting teased by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not able to do things that other children his or her age can do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping up when playing with other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. School Functioning (problems with...)

Complete if your child attends school or daycare

	Never	Almost Never	Sometimes	Often	Almost Always
Doing the same school activities as peers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missing school because of not feeling well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Missing school to go to the doctor or hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. Who first diagnosed your child with autism?

- Primary Care/Pediatrician
- School Counselor
- Teacher
- Neurodevelopmental specialist
- Geneticist
- Neurologist
- Other (please explain)

27. Has your child had any genetic testing in relation to his/her autism?

- Yes
- No

28. What type of school does your child attend? public school vs private vs homeschool

- Public School, mainstream classroom, no aide
- Public School, mainstream classroom, with aide
- Public School, special education program
- Private School, mainstream classroom, no aide
- Private School, mainstream classroom, with aide
- Private School, special education program
- Homeschool
- Daycare/Preschool
- Not in school
- Other (please explain)

29. Does your child have an Individualized Education Plan (IEP)?

Yes

No

30. Is your child verbal (uses spoken language to communicate)?

Yes

No

31. How does your child communicate with you? *Mark all that apply*

Verbal speech

Sign Language

Gestures

Ipad

PECs (Picture Exchange Communication system)

Other (please explain)

\* 32. Is your child CURRENTLY receiving any services (i.e. ABA therapy, speech therapy etc) related to their autism diagnosis?

Yes

No

33. What type of services is he/she receiving? Indicate how many hours per week your child receives each service, give your best estimate - *Mark all that apply*

	Hours	Minutes
Applied Behavioral Analysis (ABA) therapy	<input type="text"/>	<input type="text"/>
Speech therapy	<input type="text"/>	<input type="text"/>
Physical therapy	<input type="text"/>	<input type="text"/>
Occupational therapy	<input type="text"/>	<input type="text"/>
Recreational therapy	<input type="text"/>	<input type="text"/>
Diet management	<input type="text"/>	<input type="text"/>
Partial hospitalization program	<input type="text"/>	<input type="text"/>
Clinical trial	<input type="text"/>	<input type="text"/>

Other (please explain)

34. How many hours per week does your child receive services total?

35. Where are these services being received? *Mark all that apply*

- Through their school
- At home
- At a private therapy center
- At a public therapy center
- Through the regional center
- Other (please explain)

36. How long has your child been receiving these services?

- Less than a year
- 1-2 years
- 3-5 years
- More than 5 years

37. Why did you seek out these services for your child? *Mark all that apply*

- I felt as though my child would benefit from them
- Recommended by a doctor or health care professional
- Recommended by another family member or friend
- Other (please explain)

38. How are you paying for services? *Mark all that apply*

- Out of pocket
- Insurance
- Free services (school services, regional center etc)
- Other (please explain)

39. Please rate the amount of improvement that you have felt your child has made since beginning services in respects to the following areas:

	No Improvement	Some Improvement	A lot of Improvement
My child is happier at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is happier in public	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is happier at school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is better able to perform physical tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is better able to communicate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is better able to perform daily living activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

40. Do you feel that the services your child received contributed to any improvement that you have seen in your child?

- Yes
- No

Please Explain

---

\* 41. Has your child EVER received services related to their autism?

Yes

No

42. Why has your child never received services?

- I do not feel that it is necessary
- I cannot afford services
- There are not available services in my area
- My responsibilities do not allow me enough time to follow through with services
- There is a wait list for the services that I would like to enroll my child in
- Other (please explain)



43. If your child has received services in the past but is no longer receiving services, why were the services stopped?

- I could no longer afford services
- I no longer had time for services
- My child aged out of his/her available services
- I did not feel as though the services were benefiting my child
- My child told me that he/she was no longer interested in services
- Other (please explain)

44. What type of services was he/she receiving? - *Mark all that apply*

- Applied Behavioral Analysis (ABA therapy)
- Speech therapy
- Physical therapy
- Occupational therapy
- Recreational therapy
- Diet management
- Partial hospitalization program
- Clinical Trial
- Other (please explain)

45. Where were these services being received?

- Through their school
- At home
- At a private therapy center
- At a public therapy center
- Through the regional center
- Other (please explain)

46. Please rate the amount of improvement that you have felt your child has made since beginning services in respects to the following areas:

	No Improvement	Some Improvement	A lot of Improvement
My child is happier at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is happier in public	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is happier at school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is better able to perform physical tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is better able to communicate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is better able to perform daily living activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

47. Do you feel that the services your child received contributed to any improvement that you have seen in your child?

Yes

No

Please Explain

Thank you!

**Your responses have been recorded. Thank you for your participation in this survey.**

**For more information please contact:**

**Lead Researcher**

**Shayna Svihovec, Genetic Counseling Graduate Student**

**UCI Department of Pediatrics**

**(714) 456-5837 or [ssvihove@uci.edu](mailto:ssvihove@uci.edu)**

## APPENDIX C



OFFICE OF RESEARCH  
INSTITUTIONAL REVIEW BOARD  
PAGE 1 OF 2

### CONFIRMATION OF EXEMPT RESEARCH REGISTRATION

December 14, 2016

SHAYNA BRIANNE SVIHOVEC  
PEDIATRICS

RE: HS# 2016-3230 *Children With Autism: Assessing the Relationship Between Quality of Life and Participation in Services*

The human subjects research project referenced above has been registered with the UC Irvine Institutional Review Board (UCI IRB) as Exempt from Federal regulations in accordance with 45 CFR 46.101. This exemption is limited to the described activities in the registered UCI IRB Protocol Narrative and extends to the performance of such activities at the sites identified in your UCI IRB Protocol Application. Informed consent from subjects must be obtained unless otherwise indicated below. UCI IRB conditions for the conduct of this research are included on the attached sheet.

Information provided to prospective subjects to obtain their informed consent should, at a minimum, consists of the following information: the subject is being asked to participate in research, what his/her participation will involve, all foreseeable risks and benefits, the extent to which privacy and confidentiality will be protected, that participation in research is voluntary and the subject may refuse to participate or withdraw at any time without prejudice.

Questions concerning registration of this study may be directed to the UC Irvine Office of Research, 141 Innovation Drive, Suite 250, Irvine CA 92697-7600; 949-824-0665 (biomedical committee) or 949-824-6662 (social-behavioral committee).

Level of Review: Exempt Review, Category 2

Beverly W. Alberola, CIP  
Alt. Member, Institutional Review Board  
Registration valid from 12/14/2016 through 12/13/2021  
UCI (FWA) 00004071, Approved: January 31, 2003

#### Determinations as Conditions of Exemption:

##### *Informed Consent Requirements:*

1. Signed Informed Consent Not Required
  - a. Study Information Sheet Required / Script as Part of Survey Required

### APPROVAL CONDITIONS FOR ALL UCI HUMAN RESEARCH PROTOCOLS

#### UCI RESEARCH POLICIES:

All individuals engaged in human-subjects research are responsible for compliance with all applicable [UCI Research Policies](#). The Lead Researcher (and Faculty Sponsor, if applicable) of the study is ultimately responsible for assuring all study team members adhere to applicable policies for the conduct of human-subjects research.

#### LEAD RESEARCHER RECORDKEEPING RESPONSIBILITIES:

Lead Researchers are responsible for the retention of protocol-related records. The following web pages should be reviewed for more information about the Lead Researcher's recordkeeping responsibilities for the preparation and maintenance of research files: [Lead Researcher Recordkeeping Responsibilities](#) and [Preparation and Maintenance of a Research Audit File](#).

#### PROTOCOL EXPIRATION:

The UCI IRB approval letter references the protocol expiration date under the IRB Chair's signature authorization. A courtesy email will be sent approximately 60 to 90 days prior to expiration reminding the Lead Researcher to apply for continuing review. For studies granted Extended IRB Approval, a courtesy e-mail will be sent annually to verify eligibility for the continuation of extended approval. It is the Lead Researcher's responsibility to apply for continuing review to ensure continuing approval throughout the conduct of the study. Lapses in approval must be avoided to protect the safety and welfare of enrolled subjects.

#### MODIFICATIONS & AMENDMENTS:

Per federal regulations, once a human research study has received IRB approval, any subsequent changes to the study must be reviewed and approved by the IRB prior to implementation *except when necessary to avoid an immediate, apparent hazard to a subject*. Accordingly, no changes are permissible (unless to avoid an immediate, apparent hazard to a subject) to the approved protocol or the approved, stamped consent form without the prior review and approval of the UCI IRB. All changes (e.g., a change in procedure, number of subjects, personnel, study locations, new recruitment materials, study instruments, etc.) must be prospectively reviewed and approved by the IRB before they are implemented.

#### APPROVED VERSIONS OF CONSENT DOCUMENTS, INCLUDING STUDY INFORMATION SHEETS:

Unless a waiver of informed consent is granted by the IRB, the consent documents (consent form; study information sheet) with the UCI IRB approval stamp must be used for consenting all human subjects enrolled in this study. Only the current approved version of the consent documents may be used to consent subjects. Approved consent documents are not to be used beyond the expiration date provided on the IRB approval letter. Current consent documents are available on the [IRB Document Depot](#).

#### UNANTICIPATED PROBLEMS REPORTING:

In accordance with Federal regulations and HRP policies, only internal (where UCI serves as the IRB of record), Unanticipated Problems must be reported to the UCI IRB. Unanticipated Problems should also be reported to the UCI IRB when UCI is relying on an external IRB, and the incident occurred at UCI or the incident occurred at an offsite location on a study conducted by a UCI LR. Unanticipated Problems must be submitted to the IRB via the Unanticipated Problems (UP) Report within 5 business days upon the Lead Researcher's (LR) knowledge of the event. For additional information visit the updated HRP webpage on [Unanticipated Problems](#).

#### CHANGES IN FINANCIAL INTEREST:

Any changes in the financial relationship between the study sponsor and any of the investigators on the study and/or any new potential conflicts of interest must be reported immediately to the UCI Conflict of Interest Oversight Committee (COIOC). If these changes affect the conduct of the study or result in a change in the text of the currently-approved informed consent document, these changes must also be reported to the UCI IRB via a modification request. Research subject to COIOC oversight is not eligible for Extended IRB Approval.

#### CLOSING REPORT:

A closing report should be filed with the UCI IRB when the research concludes. Visit the HRP webpage [Closing a Protocol](#) for complete details.

## APPENDIX D



OFFICE OF RESEARCH  
INSTITUTIONAL REVIEW BOARD  
PAGE 1 OF 1

March 20, 2017

SHAYNA BRIANNE SVIHOVEC  
PEDIATRICS

RE: HS# 2016-3230 *Children With Autism: Assessing the Relationship Between Quality of Life and Participation in Services*

Electronic Modification Request # 20469

The following modification(s) for the human subjects research protocol referenced above has/have been approved by the UC Irvine Institutional Review Board (UCI IRB). Below is a summary of the approved changes requested via e-modification request number 20469\*\*:

### Change in Recruitment:

Addition of one question to the end of my survey

Reason: Feedback from a respondent made me realize that this information is important to gather

\*\*The IRB may not have approved all changes proposed in the e-modification request. Review the above summary of approved changes and any revised documents provided with this letter. If a requested change does not appear in the summary or in the revised documents, the IRB did not approve that change. Please consult with an IRB Administrator for further information. Changes to approved protocols may not be made without prior approval by the IRB.

Note: If the approved modification(s) includes changes to the informed consent document, the approved stamped consent form is enclosed with this letter. Please discontinue use of any previous versions of the informed consent document and use only the most updated version for enrollment of all new subjects. Questions concerning approval of this study may be directed to the UC Irvine Office of Research, 141 Innovation Drive, Suite 250, Irvine, CA 92697-7600; 949-824-6068 or 949-824-2125 (biomedical committee) or 949-824-6662 (social-behavioral committee).

Level of Review of Modification: Expedited Review 03/20/2017

Le'Quan Jackson, CIP  
Member, Institutional Review Board

Approval Issued: 03/20/2017  
Expiration Date: 12/13/2021

(FWA) 00004071, Approved: January 31, 2003

## APPENDIX E

The following are respondents written answers from table 4 (answers are reported exactly as they were written):

1. “My son was primarily hindered in the areas of social and verbal language development, with some sensory sensitivities and stimming. He has gone from being completely unable to stand grocery stores, public areas, and any social interaction with peers, to now greeting his friends (generally after they initiate (and talking to some adults as promotes by a trusted individual.”
2. “My son has gone from nonverbal who was resistant to communication to an outgoing child who loves people. He’s able to function a lot more independently and I actually had someone be surprised recently at his diagnosis because she didn’t even realize he was different.”
3. Being in a self-contained classroom for kids with normal intelligence but with behavioral issues was great. He started there full time and is now up to almost half a day mainstreamed (with breaks to go back to his self-contained class). His self-control at school and ability to transition between tasks is completely different. We went from being sent home on a regular basis to being able to stay at school reliably. SLP [speech and language pathology] has really helped his ability to communicate his thoughts. It has also helped with his ability to remember directions for a longer period of time. So I really do feel like some day we will be able to give him two directions and he’ll remember and complete both! OT has helped immeasurably with his sensory sensitivity. We thought he was afraid of most stairs, elevators, and escalators but it turned out it was the sensation of those things and worry about falling that was the issue. With years of OT he can now



tolerate elevators well enough that we can use them. Escalators are still not an option most of the time. Stairs we are down to only having problems when you can see through the railing or the steps to other floors. If it is a solid staircase he can do it alone! With years of therapy (Play therapy, therapy, OT, etc.) he is finally starting to recognize his emotional states and able to verbalize some of his feelings rather than acting out. He still can't use his coping strategies but he at least knows them, so when he is calm he can describe what he should do (or should have done). SO maybe we will get there someday?!?"

4. "I feel that social skills group with 11 other children with autism has helped the most with communication and speech."
5. My child is verbal but his ability to process his feelings and put to words what he is experiencing was only through therapy. This has helped decrease behaviors and outburst. Social stories and OT interventions have heled to make daily living streamlined."
6. "She seems more social and less likely to outburst then before."
7. "ABSOLUTELY. For years before we got the diagnosis we went from therapist to therapist trying to get help for his anxiety. It was preventing him from doing things he otherwise enjoyed and really getting in his way. But everything we tried just seemed to make it worse. Then we got the diagnosis and the treatment team changed – and things started getting better. Now, instead of giving him prizes for 'being brave,' we were advised to create schedules with pictures (now words) so that he always knows what's next, to teach him how to cover his ears if noises are loud, and what sort of situations might be overwhelming for him. Knowing how to help has made a world of difference. And now that he's more verbal (just because he's gotten older), he's better able to

communicate what exactly is worrying him, so that we're better able to address his concerns. He used to be terrified of public bathrooms, so whenever we had to go it was a nightmare. We eventually figured out that he was scared of the loud noise of the air blowing hand dryers, so now I check for dryers and ask people to please not use them, and it's SO much better. Increased knowledge and understanding on my part and increased communication on his part has made a huge difference.”

## APPENDIX F

PARENT REPORT for CHILDREN (ages 8-12) .

### DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

0 if it is never a problem

1 if it is almost never a problem

2 if it is sometimes a problem

3 if it is often a problem

4 if it is almost always a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past one month how much of a problem has your child had with...

#### Physical Functioning (problems with...)

1. Walking more than one block
2. running
3. participating in sports activities or exercise
4. Lifting something heavy
5. Taking a bath or shower by him or herself
6. Doing chores around the house
7. having hurts or aches
8. low energy level

#### Emotional Functioning (problems with...)

1. Feeling afraid or scared
2. Feeling sad or blue
3. Feeling angry
4. Trouble sleeping
5. Worrying about what will happen to him or her

#### Social Functioning (problems with...)

1. Getting along with other children
2. Other kids not wanting to be his or her friend
3. Getting teased by other children
4. Not able to do things that other children his or her age can do
5. Keeping up when playing with other children

#### School Functioning (problems with...)

1. Paying attention in class
2. Forgetting things
3. Keeping up with schoolwork

4. Missing school because of not feeling well
5. Missing school to go to the doctor or hospital

#### PARENT REPORT for YOUNG CHILDREN (ages 5-7)

#### DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

0 if it is never a problem

1 if it is almost never a problem 2 if it is sometimes a problem

3 if it is often a problem

4 if it is almost always a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

#### Physical Functioning (problems with...)

1. Walking more than one block
2. running
3. participating in sports activities or exercise
4. Lifting something heavy
5. Taking a bath or shower by him or herself
6. Doing chores, like picking up his/her toys
7. having hurts or aches
8. low energy level

#### Emotional Functioning (problems with...)

1. Feeling afraid or scared
2. Feeling sad or blue
3. Feeling angry
4. Trouble sleeping
5. Worrying about what will happen to him or her

#### Social Functioning (problems with...)

1. Getting along with other children
2. Other kids not wanting to be his or her friend
3. Getting teased by other children
4. Not able to do things that other children his or her age can do
5. Keeping up when playing with other children

#### School Functioning (problems with...)

1. Paying attention in class
2. Forgetting things
3. Keeping up with schoolwork
4. Missing school because of not feeling well
5. Missing school to go to the doctor or hospital

## PARENT REPORT for TODDLERS (ages 2-4)

### DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

0 if it is never a problem

1 if it is almost never a problem 2 if it is sometimes a problem

3 if it is often a problem

4 if it is almost always a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past one month how much of a problem has your child had with...

#### Physical Functioning (problems with...)

1. Walking
2. Running
3. participating in play or exercise
4. Lifting something heavy
5. Bathing
6. Helping to pick up his/her toys
7. having hurts or aches
8. Low energy level

#### Emotional Functioning (problems with...)

1. Feeling afraid or scared
2. Feeling sad or blue
3. Feeling angry
4. Trouble sleeping
5. Worrying

#### Social Functioning (problems with...)

1. playing with other children
2. Other kids not wanting to be his or her friend
3. Getting teased by other children
4. Not able to do things that other children his or her age can do
5. Keeping up when playing with other children

Complete if your child attends school or daycare

#### School Functioning (problems with...)

1. Doing the same school activities as peers
2. Missing school because of not feeling well
3. Missing school to go to the doctor or hospital