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## Services Received and Parental Perception of Quality of Life for Children with Autism Spectrum Disorder

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SERVICES RECEIVED AND PARENTAL PERCEPTION OF QUALITY OF LIFE  
FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

By

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## ABSTRACT

With the rapid increase in the rate of children diagnosed with Autism Spectrum Disorder (ASD), there has been a surge in treatment interventions and outcome measures. Treatment interventions consist of evidence-based practices and programs that lack scientific validation. Parents' selection of a treatment or multiple treatments is often based on the desire to maximize their child's personal well-being (Pituch et al., 2011; Rodger, Braithwaite, & Keen, 2004). Current outcome measures provide valuable information and may demonstrate a change in a standard score. For example, a change in intelligence quotient, is not evidence that this change contributes to the child's personal well-being or quality of life (QOL).

Measures of QOL assesses aspects of health, happiness, self-esteem, mental health, and life satisfaction (Cummins, McCabe, Romeo, & Gullone, 1994). For decades these measures have been used as a means of identifying treatment objectives and improving outcomes for individuals with disability and adults with autism. However, such measures have not been used for selecting treatment or assessing the effect of treatment for young children with ASD.

The purpose of this study was to investigate how parents of children with ASD rate their child's quality of life and determine how specific interventions relate to parental perception of QOL for children with ASD. This study resulted in the development of a QOL scale, which includes indicators specific to characteristics of children with ASD. The scale demonstrated evidence of validity for each subscale as well as for the total

instrument. The data show that the majority of parents (81.9%) perceived their child as having a good or excellent QOL. Parents selected and used between 0 and 9 types of treatment for their child with ASD during the past twelve months. The results of an analysis of variance showed that there was not a significant interaction effect on total number of treatments utilized and parental perception of their child's QOL

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## CHAPTER I

### INTRODUCTION

#### **Autism Spectrum Disorder**

Autism Spectrum Disorder (ASD) is a neurological disability that affects the development of the brain. It is reported to occur in all racial, ethnic and socioeconomic groups (Baio, 2012). The most recent Diagnostic Statistical Manual of Mental Disorders (5<sup>th</sup> ed.) has refined the diagnostic criteria to include characteristics of ASD presented as (A) “persistent deficits in social communication and social interactions across multiple contexts” and (B) “restricted, repetitive patterns of behavior, interests, or activities” (American Psychiatric Association, 2013, p. 50).

Deficits in social communication pertain to social-emotional reciprocity, failure or reduced back-and-forth conversation, and the absence of initiating or responding to social interactions. This criterion also includes deficits in non-verbal communication, abnormality in eye contact, and deficits in the use of gestures or understanding facial expressions in others. Finally, this criterion involves deficits in understanding relationships to include making friends, interest in peers or sharing of imaginative play (American Psychiatric Association, 2013).

Characteristics associated with restricted, repetitive patterns of behavior, interests, or activities include repetitive movements, use of objects or speech. Such behavior may present as lining up toys, flipping objects, echolalia, or idiosyncratic phrases. This criterion also identifies behavior such as ritualized patterns of behavior, difficulties with

change, rigid thinking process, and hyper- or hypo-reactivity to sensory input (American Psychiatric Association, 2013). These defining features of impairments highlight variances in child-developmental areas of social interaction, communication, and flexibility of thought and behavior (Plimley, 2007).

Figures released by the United States Centers for Disease Control and Prevention estimate the increasing prevalence of ASD as 1 in every 68 live births (Principal Investigators, 2014). The scientific literature (King & Bearman, 2009) has reported that in California alone the prevalence of ASD has increased by more than 600% in the past two decades. These figures represent the growing rate of ASD in our communities and hence, the growing rate of individuals experiencing life-long extreme challenges in social-communication and restricted or repetitive patterns of behavior and interests. As state and federal laws mandate treatment for children with ASD, it is essential to consider the impact of various treatments on the child's quality of life.

### **Background of the Problem**

Despite the increase in prevalence of ASD, advances in early detection and emergence of multiple evidence-based practices of interventions and therapeutic approaches, very little is known about the quality of life (QOL) for children with ASD (Burgess & Gutstein, 2007; Kuhlthau et al., 2010). A number of studies have used QOL indicators to evaluate treatment outcomes for adults with ASD (Billstedt, Gillberg, & Gillberg, 2011; Eaves & Ho, 2008; Jennes-Coussens, Magill-Evans, & Koning, 2006; Persson, 2000; Renty & Roeyers, 2006), or family members of children with ASD (Allik, Larsson, & Smedje, 2006; Lee, Harrington, Louie, & Newschaffer, 2008; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Shu, 2009). However, using such indicators to assess

treatment outcomes for children with ASD and the specific aspects of the disorder remains virtually nonexistent (Gómez, de la Fuente Anuncibay, & Conde). Means of evaluating treatment outcomes for children with ASD have traditionally focused on the change in score on a norm-referenced scales, such as an intelligence quotient, or academic scores (Matson, 2007). These standard measures of cognitive performance or academic achievement have not been identified as good predictors of QOL for typically developing children (Kazdin & Weisz, 1998; Sternberg, Wagner, Williams, & Horvath, 1995) or for children with ASD (Burgess & Gutstein, 2007).

To understand the effect of various interventions for children with ASD, researchers, practitioners, family members, and funding agencies need outcome measures and information that demonstrates if the practices and interventions used have changed behaviors and actually affected the individual's well-being (Schalock & Alonso, 2002). This information will assist stakeholders in funding, developing, and selecting interventions with the greatest positive impact. The selection of such interventions will subsequently minimize the use of treatments that merely promote change in one area such as academic performance, but are limited in producing change in vital areas such as community involvement and participation, contribution and citizenship, physical health, personal and social adjustment, responsibility, independence and life satisfaction.

### **Quality of Life**

QOL is a measure of an individual's well-being that considers multiple domains of functioning. QOL is a multidimensional construct that evaluates basic life conditions and individual life values, interests, and social/leisure participation (Schalock & Parmenter, 2000). Measures of QOL assess aspects of health, happiness, self-esteem,

mental health, and life satisfaction (Cummins, McCabe, Romeo, & Gullone, 1994). Although the core domains of QOL vary across disciplines and researchers, there is a general consensus by practitioners in the field of intellectual disabilities that core domains of QOL are Emotional Well-Being, Personal Development, Interpersonal Relations, Social Inclusion, Physical Well-Being, Self Determination, Material Well-Being and Rights (Schalock & Alonso, 2002). Each of these domains includes indicators that are specific to individual characteristics and environmental factors.

For more than three decades QOL measures have been used as a means of improving outcomes and raising the standards for the management and interventions implementation for individuals with disabilities (Burgess & Gutstein, 2007). There are multiple studies, projects, and initiatives that have used QOL measures to analyze effects of treatment and improve service delivery models (Schalock & Alonso, 2002). State agencies have used QOL outcome measures to develop state-level performance standards, plans for improvement, and ongoing staff training sessions. For example, such efforts have led to significant changes in service delivery models and have improved level of life-satisfaction for adults with intellectual disabilities (Keith & Bonham, 2005).

QOL measures have been used for program development and for measuring treatment outcomes for children across the typically developing population and multiple disabilities (Schalock & Alonso, 2002). Giangreco, Cloninger, Yuan, and Ashworth (1995) examined parental perspective of QOL for their children with limited vision and hearing as related to programming in educational and related services. The results of this QOL assessment study led to a better understanding of what services families perceived as limited or overwhelming in order to enhance their child's sense of well-being.



## **Treatment Measures for Children with ASD**

Children with ASD can benefit from myriad practices or interventions. For example, the national project, Evidence-Based Practices for Children, Youth, and Young Adults with ASD (Wong et al., 2013), reported that twenty-seven practices met the criteria as evidence-based and, therefore, have scientific evidence that the practices positively affect behavior or academic outcomes in children with ASD. These practices with supporting research are presented in Appendix A.

Effects of intervention range from decreasing deficits and repetitive behaviors to increasing cognitive and communicative skills (Green et al., 2006). The affect of these changes is traditionally limited to numerical values on psychometric and norm-referenced measures. These assessment methods do not help to understand functional relevance or social validity of the treatment for individuals with ASD.

Early and current methods of assessing treatment outcomes for individuals with ASD have commonly used the intelligence quotient and adaptive skill measures (Eikeseth, Smith, Jahr, & Eldevik, 2002; Lovaas, 1987; Sheinkopf & Siegel, 1998; Smith, Groen, & Wynn, 2000). These assessment methods remain the principle practice of outcome measurement (Matson & Wilkins, 2007). Standardized assessments are norm-referenced instruments, which measure and provide a comparison to the general population in areas such as adaptive behavior, language acquisition, and education achievement (Handleman & Delmolino, 2004). Some commonly used assessments to measure treatment outcomes for children with ASD include the Wechsler Preschool and Primary Scale of Intelligence-Revised – WPPSI (Wechsler, 1989), the Vineland Adaptive Behavior Scale (Sparrow, Cicchetti, & Balla, 1989), the Clinical Evaluation of Language

Fundamentals – Revised (Semel, Wiig, & Secord, 1987), the Peabody Picture Vocabulary Test –PPVT (Dunn & Dunn, 2007), the Expressive Vocabulary Test-EVT (Williams, 1997), and the Child Behavior Checklist (Achenbach & Edelbrock, 1983). Although the data obtained from standardized tests can be useful, it does not provide adequate information about the individual. In order to fully assess the outcome of treatment, it is critical to understand if the acquired skills that are reflected on a standardized assessment have affected the child’s personal well-being.

### **ASD Interventions and the Law**

The Individual with Disabilities Education Act (IDEA) is a federal law that mandates public education service provisions for children with ASD and other disabilities. It has been argued that the original intent of IDEA, emphasized academic outcomes as well as more global outcomes to include Quality of Life measures (Turnbull, Turnbull, Wehmeyer, & Park, 2003). The National Association of State Directors of Special Education has worked with educational stakeholders to develop the Guiding Principles for an Inclusive Accountability System, which identified domains for IDEA outcomes to enhance the individualized education program (IEP) document and direct the accountability process (Billstedt, Gillberg, & Gillberg, 2011). While the outcome domains included (a) academic performance, (b) presence and participation (c) contribution and citizenship, (d) physical health, (e) personal and social adjustment, (f) responsibility and independence, and (g) satisfaction, only one of these domains are addressed through standard-based academic outcomes (Ysseldyke, 1998) or traditional norm reference measures. Without addressing and measuring the other identified domains, there is a danger of not accurately assessing outcomes of services provided for

children with disabilities. QOL assessments can be used as a measurement tool for a number of the domains recognized as vital IDEA outcomes.

### **Problem Statement**

Interventions for children with ASD are being funded, developed, and selected without an analysis of the full impact of the treatment. Some decisions that will affect these children's lives through adulthood are being made without consideration of socially valid outcomes. Using QOL assessments to develop and measure program objectives provides a conceptual framework to fully assess the outcomes of intervention. By understanding the effect of interventions on the QOL of children with ASD, legislators will better understand the impact of federally funded mandates, program coordinators will have vital data to develop and adjust intervention objectives, parents will be better informed during the intervention selection process, and a reduction of money and time will be used for interventions which have a minimal impact on the lives of these citizens.

### **Research Questions**

To further explore the effects of treatment outcomes on children with ASD, the following questions will be addressed:

1. How do parents rate their child's QOL?
2. How do specific interventions relate to parental perception of QOL for children with ASD?

### **Significance**

Service providers in both the medical and mental health field have utilized QOL indicators to assess treatment outcomes for children for decades (Burgess & Gutstein, 2007). There is a significant financial cost and involvement of time when providing

treatment interventions for children with ASD. An estimate of one specific evidence-base treatment for one child with ASD involves 6-10 hours of time a day and an average of \$50,000 per year (Chasson, Harris, & Neely, 2007). Whereas, this time and expense is significant, it is essential to consider the investment of cost and time of providing an intervention that may not enhance a child's QOL (Giazioni-Fialko, 2011). Legislation mandating interventions, agencies providing therapeutic approaches and parents selecting treatments for their child with ASD will benefit from a better understanding of the functional impact of an identified treatment on a child's personal well-being.

Although, there is an increased focus on QOL through research, program development, and policies, the majority of these efforts address QOL in adults. Only 13% of published studies analyzing QOL focus on issues pertaining to children (Wallander, Schmitt, & Koot, 2001). The concept of QOL has been explored with healthy children (Jirojanakul & Skevington, 2000; Landgraf, Abetz, & Ware, 1996), children with chronic illnesses (Daltroy, Liang, Fossel, & Goldberg, 1998; Varni et al., 1998) and in adults with ASD (Eaves & Ho, 2008; Renty & Roeyers, 2006); however, research focusing on QOL in children with ASD remains virtually unexplored.

This study addressed both of these concerns by considering the types and number of treatment selected for children with ASD and the association of treatment with parental perception of children's QOL. This study will allow parents, educators, and key stakeholders to consider the cost and time required for treatment with the effects of the treatment on the personal well-being of the child with ASD.

## **Definition of Terms**

**ASD Spectrum Disorder.** ASD Spectrum Disorder is defined by two essential features which include: (criterion A) the presence of persistent impairment in reciprocal social communication and social interaction and (criterion B) the presence of restricted, repetitive patterns of behavior, interests, or activities. Both symptoms must be present during early childhood and cause clinically significant impairment in daily functioning (American Psychiatric Association. Task Force on DSM-V, 2013). Severity of characteristics across both social communication and patterns of behaviors will vary among individuals and their life span.

**Intervention for Children with ASD Spectrum Disorder.** The principle emphases of an intervention for children with ASD consist of decreasing characteristics associated with ASD, increasing functional skills, and maximizing quality of life for the child. Multiple interventions are frequently used to treat children with ASD. A number of interventions to treat children with ASD are based on evidence-based practices, while others lack empirical support. Interventions vary in structure, time, cost, and outcomes. Interventions can be categorized by physiological, relationship-based, and skill-based treatments (Green et al., 2006). Examples of physiological interventions include sensory integration and auditory integration. These interventions are designed to address sensory processing issues that may affect behavioral responses of a child with ASD. Examples of relationship-based interventions include: Relationship Development Intervention, Holding Therapy, Floor Time, and Gentle Teaching. These treatments generally take a developmental approach and are geared towards encouraging the child's interest in relating to others and their environment. Some examples of skill-based

interventions include Applied Behavior Analysis, Early Denver Model, and Pivotal Response Therapy. These treatments are based on the principle that antecedents and its consequences govern human behavior. Skill-based interventions are designed to improve socially significant behaviors including social skills, communication, daily living skills, and academics (Roberts & Ridley, 2004).

**Quality of Life.** The term QOL is used to describe satisfaction with basic life conditions of an individual's social, emotional, physical, and personal development. QOL is measured in respect to personal perceptions of life experiences and occurrences of life conditions. QOL of children with disabilities can be experienced when a child has the same opportunities as his or her peers to make choices and accomplish personal goals in various environments to include school, home, and community (Schalock, 1997). Outcomes of QOL measurements encourage stakeholders serving children with disabilities to examine programming options and explore means of change at the individual, organizational, and community levels (Schalock, Gardner, & Bradley, 2007).

## CHAPTER II

### LITERATURE REVIEW

QOL is a broad concept that incorporates multiple dimensions of life satisfaction and has been recognized as a valuable construct in the measurement and evaluation of service delivery systems (Schalock & Alonso, 2002), treatment of medical illnesses, and treatment of chronic disabilities (Burgess & Gutstein, 2007; Gladis, Gosch, Dishuk, & Crits-Christoph, 1999; Varni et al., 1998). This recognition is evident by the increase of published studies over recent years. In the early 1970s, a Medline data base reference search for the keyword “quality of life” yielded only 5 articles (Testa & Simonson, 1996), whereas, a recent PsycInfo data base search using the same keyword resulted in 15,859 articles (Burgess & Gutstein, 2007) addressing the treatment and management across a range of disabilities and medical conditions. In 1948, the World Health Organization (WHO) emphasized that health was not merely the absence of disease but also included factors such as physical, mental, and social well-being (World Health Organization, 1989). WHO further defined QOL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns’ (World Health Organization, 1952).

#### **Quality of Life**

Over the past decades, the concept of QOL has emerged across multiple disciplines to include people with developmental disabilities and special needs. The QOL model varies across discipline and research teams. In the medical field, health-

related quality of life (HRQOL) generally refers to domains related to health status and functional status. A goal of HRQOL is to assess the effect of treatment focusing on the level of health restoration, symptom management, and treatment adherence (Varni et al., 1998). HRQOL may measure an individual's health outcomes, such as psychosocial, emotional well-being, and physical well-being, as related to the treated condition or disease (Kuhlthau et al., 2010). Leading scholars in the field of intellectual and other developmental disabilities, define QOL as a multi-dimensional construct of an individual's personal well being, which is guided by five principles. According to Schalock and Alonso (2002) these principles are: (1) comprised of the same factors and relationships that are important to individuals regardless of personal conditions, (2) experienced when a persons needs and wants are met and life enrichment is experienced across life settings, (3) includes both subjective and objective components, (4) concentrated on individual needs, choices and control, and (5) the elements of the multidimensional construct are influenced by one's environmental and personal factors (Schalock & Alonso, 2002).

The framework of QOL incorporates domains, core indicators, and indicator items. The domains are a set of components that in total form personal well-being. Eight QOL domains have been developed and validated based on an international meta-analysis of QOL literature (Kober, 2011). These eight domains include Emotional Well-Being, Interpersonal Relations, Material Well-Being, Personal Development, Physical Well-Being, Self Determination, Social Inclusion and Rights (Schalock & Alonso, 2002).

These eight domains are comprised of several QOL core indicators, which operationally define each QOL domain. Personal outcomes are derived from the



measurement of these core indicators (Kober, 2011). The QOL core indicators are specific to age and population of concentration. For example, the domain Interpersonal Relations including core indicators such as friendships, intimacy, family life, and public safety (Schalock & Alonso, 2002) and consists of different indicator characteristics for an older and younger population. Indicators of this domain for an older population may center on friendships involving similar interests, while indicators of this domain for a younger population may address the interactions of friends within a school environment or a playground.

Each QOL core indicator is composed of indicator items, which provides a means of measuring perceptions, behaviors, and environmental circumstances to assess personal well-being. Two to three indicator items are generally used to define and measure QOL core indicators resulting in personal outcomes (Kober, 2011). The eight QOL domains are shown in Table 1 along with respective QOL core indicators and examples of QOL indicator items. These QOL core indicators are derived from an analysis of the international QOL literature ranking the most frequently referenced core indicators associated with each domain within the field of human services (Schalock & Alonso, 2002). The example indicator items have been selected from QOL measures to provide examples across varying concentrations and age groups.

Table 2.1

*QOL Domains and Relevant QOL Core Indicators and QOL Indicator Items*

QOL Domain	QOL Core Indicator	QOL Indicator Item	Population
Emotional Well-Being	Contentment Satisfaction Lack of stress*	Trouble Sleeping Worrying about what will happen to him or her	5-7 years

Interpersonal Relations	Interactions* Relationships* Supports	Getting along with other children	5 -7 years
Material Well-Being	Financial status Employment Housing*	Satisfaction with neighborhood	Young adult to adult
Personal Development	Education* Personal competence Performance	Enjoying school activities Level of learning at school	Children and adolescents
Physical Well-Being	Health Activities of daily living* Leisure*	Take bath or shower by him or herself Participating in sports activity or exercise	8-12 years
Self Determination	Autonomy or personal control Goals and personal values Choices*	Satisfaction with routines (i.e.: time for bed, meals, school, work)	Young adult to adult
Social Inclusion	Community integration and participation* Community roles Social supports	Able to do things that other children can do	5 -7 years
Rights	Human* Legal	Allowed privacy when bathing	Adult

Note: QOL Indicator Items from: The Family Quality of Life Index (Becker, Shaw, & Reib, 1995), Multidimensional Students' Life Satisfaction Scale (Huebner, 2001), Pediatric Quality of Life Inventory (Varni et al., 1998), and Personal Wellbeing Index – School Children (Cummins & RLau, 2005). \* QOL Core Indicator represented by listed QOL Indicator Item.

### **Objective and Subjective Assessment of Quality of Life**

There are multiple complex means of measuring QOL domains either as individual components or combined as one unit. In both cases, researchers have recommended the use of both subjective and objective measures to best assess the QOL and improve outcomes for children and adolescents (Wallander et al., 2001). Objective

indicators are considered those that measure life conditions, whereas subjective indicators are considered those that measure level of satisfaction of life under such conditions. For example, when measuring Emotional Well-Being, or an individual's overall happiness, one must consider both the objective perspective of accessing positive experiences as well as the subjective personal interpretation of satisfaction with an experience. Indeed, it is possible for an individual to objectively experience pleasurable stimuli while not subjectively feeling high levels of satisfaction and conversely, a person may experience low levels of objective good fortune while maintaining high levels of subjective satisfaction or happiness (Kahneman, Diener, & Schwarz, 2003). By incorporating both objective and subjective measures, one is able to assess the individual's value of QOL and personal satisfaction as well as an impartial perception of the conditions and circumstances (Felce & Perry, 1995).

Objective measures include data that can be normative to a population (Cummins, 1997). An objective measure of the QOL domain Interpersonal Relations may, for example, include a frequency count of number of friends, involved community outings or communicative exchanges. An objective assessment of the QOL domain Emotional Well-Being may measure the frequency and duration of access to good experiences. Objective measures are obtained directly through observation of external stimuli and can be verified and validated through direct observation by the assessor.

Subjective measures include assessments of value or level of quality through satisfaction ratings, personal opinions or opportunities for personal development (Cummins et al., 1994; Verdugo, Schalock, Keith, & Stancliffe, 2005). Subjective assessments of QOL measure the meaning or importance of access to an objective

measure. These measures assess the QOL through personal satisfaction of own experiences and situations. The value of identified factors may vary for individuals within the same population, for a single individual across multiple points of time as well as vary among differing populations. A subjective measure of the QOL domain Interpersonal Relationships may assess the level of satisfaction of a single or multiple friendships. A subjective assessment of the QOL domain Emotional Well-Being may measure the individual's judgment of happiness when exposed to multiple experiences of objectively interpreted good experiences. The valued subjective interpretation of an experience is obtained indirectly and cannot be verified or validated, but must be considered accurate unless external cues indicate dishonesty (Phillips, 2012).

### **Gathering QOL Data**

In order to obtain the perspective of the individual, it is generally preferable to obtain QOL data from both observations and self-reports; however, it may be challenging to obtain reliable information from very young children, children with cognitive delays (Wallander et al., 2001), and individuals who have minimal or no communication skills (Stancliffe, 2000). In these cases it may be necessary to gather QOL information from a proxy reporter such as the child's parents. It is the consensus of those that work in the field that QOL information obtained by proxy for these children produce valuable information for clinicians (Wallander et al., 2001). In order to better understand QOL and the effects of childhood conditions, it is important that researchers use such assessments to obtain information from children, adolescents, and their parents (Jenney & Campbell, 1997; Wallander et al., 2001). Proxy reports are vital to the treatment plan for pediatric patients (Varni et al., 1998). If researchers choose to ignore proxy reports for

this population, the ability to assess and obtain valuable information that may greatly affect treatment will not be available. Without such data, researchers, practitioners, and key stakeholders will be left to rely on evaluating the impact of treatment for children with ASD solely on conventional yet insufficient means of assessing treatment.

### **Purpose of Quality of Life Assessment**

The concept of QOL offers new insight to people who work in the fields of education, health, and, social services to enhance personal well-being of individuals with disabilities. Information obtained from both subjective and objective QOL measures provides an in-depth understanding of the impact of delivered services. Therefore, the outcomes of the measurements should undoubtedly affect the planning, delivery and evaluation of services to individuals with disabilities (Dennis, Williams, Giangreco, & Cloninger, 1993), including children with ASD. QOL outcome measures may be used to provide guidance at the societal-level, organizational-level, and individual-level. Outcomes of QOL measures have a unique impact on each of these structures, which promotes effective behavioral changes within a culture, system, and personal level. Such differences could positively affect state laws, organization regulations, and individual actions.

**Societal-level (policy makers / macro system).** Stakeholders of this group may be comprised of an advisory body, a quality council, directors of state agencies and a legislative committee. These groups are often committed to efficacy and transparency of services related to the product offered to individuals with disabilities. Assessing service quality assures stakeholders that available resources are utilized at the optimal level. QOL measures facilitates the ability of organizations that are funded and supported by

these stakeholders to be accountable for those services that contribute to their consumers' personal well-being (Schalock et al., 2007). For example, personnel in the state of Maryland used QOL outcome measures to develop state-level performance standards and plans for improvement of agency-level service delivery system. Among other endeavors, this project led to program improvement through training sessions for all providers of state services for individuals with intellectual disabilities. The training sessions included topics such as: emphasizing the state's perspective on the importance of QOL, defining characteristics of QOL, interpreting the results of a QOL measure, and strategies to utilize the data for program development and service implementation. The results of this statewide improvement plan were dramatic. Within one fiscal year, the QOL of these individual with intellectual disability increased significantly across five domains. The most notable increase was evident in the Interpersonal Relations domain, improving by 75.7% - 85.4% (Keith & Bonham, 2005). These statewide assessments and improvement efforts ensured legislators and policy makers that state resources were used in an effective manner and were meaningful to the state's citizens with intellectual disabilities.

**Organizational-level (organizations / mesosystem).** Assessing QOL outcome measures for individuals served by an agency is used to enhance services as well as identify trends, recognize positive achievements, and communicate results of services to key constituents (Schalock et al., 2007). This information on trends within a system can be used to alert officials that additional agency training or increased supports are needed. Identifying positive accomplishments within an organization assists management in the replication of such services to enhance programming for all recipients. The dissemination of this information to key constituents provides a means of monitoring the

work of the organization. Identified areas of improvement are used to manage and develop strategic planning on a large scale, while positive outcomes provides accountability and ensure stakeholders of service effectiveness.

**Individual-level (people / microsystem).** As with all citizens, individuals with disabilities have the right to live their lives with quality. By focusing on the individual's perspective of circumstances and environmental factors, it is possible for the individual to apply changes to new situations and to alter behavior to enhance their overall well-being. As individuals access and experience a variety of self-selected activities, motivation and interest increases which leads to a positive behavior change and outlook on life (Brown, Schalock, & Brown, 2009). It is also important for an individual to consider and share their perspective of QOL in order to affect services provided by an organization. The individual's unique perception on interactions, opportunities, and life conditions will enable service providers to alter and manage programs and supports and ultimately enhance the individual's QOL.

## **Quality of Life and Autism Spectrum Disorder**

### **Assessment**

To date, a QOL assessment tool that addresses both the communication difficulties and the specific aspects of ASD has yet to be identified (Gómez, Anuncibay, & Conde, 2010); therefore, it is important to consider facets of similar populations in order to gain meaningful QOL information of a child with ASD. The QOL research found within four fields of study may be pertinent to children with ASD as the population in each of these fields in part may possess similarities to children with ASD by age, behavioral characteristics, intellectual ability, mental health, and program and treatment

services. First, in part, QOL research conducted in the public special education sector may be applicable to children with ASD. The IDEA outlines the standards for providing educational services for students with special needs in the nation’s public schools. The statute requires that all eligible students receive a free appropriate public education (FAPE) based on a program that is designed for students to foster educational benefits and “prepare them for further education, employment, and independent living” (Individuals with Disabilities Education Improvement Act, 20 U.S.C. § 1400). In 1990, the reauthorized IDEA included autism as an eligible category of disability. Thus, students with autism are eligible for special education services. The population of this group may be of similar age and present with similar challenges as a child with ASD. Second, results of QOL research focusing on individuals with intellectual disabilities may be relevant to individuals with ASD. Studies indicate there is a very high rate of covariance with intellectual disabilities and ASD (Matson & Shoemaker, 2009). Third, the results of QOL research in the field of mental health and behavioral health may be applicable to children with ASD as associated with treatment and provision of services. Researchers have suggested that children with ASD commonly present with one or more comorbid psychiatric disorders (Leyfer et al., 2006). Finally, QOL outcomes for Physical Health can be applicable to all children regardless of functional level and age. Table 2.2 shows which domains are most frequently reported in peer-reviewed journals across these fields of study.

Table 2.2

*Core Quality of Life Domains by Discipline and Order of Frequency in Published Journals*



Quality of Life Domains	Field of Study			
	Education and Special Education	Health Physical Health	Mental Health and Behavioral Health	Mental Retardation and Intellectual Disabilities
Emotional Well-Being	1	2	3	5
Personal Development	2	6	2	7
Interpersonal Relations	3	3	1	3
Social Inclusion	4	5	5	1
Physical Well-Being	5	1	4	2
Self-Determination	6	7	6	6
Material Well-Being	7	4	7	4
Rights	8	8	8	8

The information presented in Table 2.2 includes research conducted in both childhood and adult populations. Notably, across the majority of these disciplines, Emotional Well-Being and Interpersonal Relations are consistently reported more frequently than the other domains. This rate of reporting may suggest that the core indicators of these two domains are highly correlated with improved QOL for the age and population of the studies. The importance of these two domains has been supported by the assertion that through human connections and the development of personal relationships, emotional QOL increases across one's lifespan and across cultures (Myers, 2003).

Although, there are fewer published studies on the self-determination domain, the body of research is increasing rapidly (Cannella, O'Reilly, & Lancioni, 2005) because there has been an emphasis on promoting self-determination as a vital outcome for youth with disabilities (Wehmeyer & Schwartz, 1997). This may be in part due to federal funding promoting self-determination for students in special education (Lee, Wehmeyer, Palmer, Soukup, & Little, 2008; Palmer, Wehmeyer, Gipson, & Agran, 2004), an increase in resources and assessment instruments (Cannella et al., 2005), and supporting

evidence regarding the positive impact of self-determination on individuals with disabilities (Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). With these positive outcomes, the body of research addressing self-determination needs to continue to grow. A key principle in QOL is centered on self-determination or individual choices and control; practitioners and researchers continue to be challenged to make the necessary program enrichments across the full lifespan (Turnbull & Turnbull, 2000).

Table B.1, B.2 and B.3 display a multilevel analysis of indicators for three vital domains of QOL across these disciplines that are applicable to children with ASD. Table B.1 reports on Emotional Well-Being by identifying indicators published in research across a macrosystem, mesosystem and microsystem in the fields of Education Mental and Behavioral Health as well as Intellectual Disabilities. Table B.2 presents the same summary of a multilevel analysis of indicators for the domain Interpersonal Relations and the summary represented in table B.3 is associated with the Self-Determination domain. Each figure identifies the differences of QOL indicators within a domain across different societal levels. These figures are located in the Appendix.

Components of QOL outcomes from the three disciplines may be relevant to individuals with ASD because individuals within each population in part have similar characteristics, needs and challenges; however, these parts do not represent the full range of complexities involved with individuals with ASD. Issues related to QOL for this population need to be assessed independently and made relevant and applicable for individuals with ASD (Plimley, 2007).

### **ASD and QOL Research**

Studies conducted of young adults and adults with ASD suggest that the QOL for this population continues to be bleak and implies that treatments and interventions should adopt a holistic approach to enhance outcomes. A semi-structured interview study in 2006 examined the QOL of young men with ASD by using the World Health Organization's Quality of Life measure (Jennes-Coussens et al., 2006). The results of this study revealed that this group of 12 men with ASD ranging in age from 18-21 years experienced a significantly lower social and physical QOL than that of their peers. Although, living arrangements, education, and quantity of friends were similar; the individuals with ASD experienced a dramatic decrease in positive employment and experienced more activities without social interaction (Jennes-Coussens et al., 2006). These findings are similar to a recent study, which assessed the QOL of 108 young adults with ASD 13-22 years post diagnosis (Billstedt et al., 2011). The finding in this study was significant in that it suggested that the majority of the participants lacked independence in education, residential environments, and occupational settings as late adolescences and early adults. Reportedly, only 12% of this cohort had identified friends of varying quality, while 68% lacked the concept of friendship and 11% expressed a desire to have a friend but had yet to form such a relationship. Although data indicate a high correlation between consistent recreational activities and good or very good QOL, a significant majority of this group were not involved in regular daytime employment or recreational activities (Billstedt et al., 2011).

Because of the importance of preparing children with ASD to obtain a high level of QOL in adulthood, it is critical to consider the paradigm of QOL as a developmental framework and not solely as an end-goal (Burgess & Gutstein, 2007). This need suggests

that QOL measures should be valued and used throughout the assessment and treatment procedures across the lifespan of an individual with ASD. QOL assessments have the potential to enhance both services and outcomes for children with ASD by identifying early predictors that will enhance personal well-being across their lifespan and nourish the development of skills needed to achieve high levels of personal well-being as an adult.

To date, studies addressing the QOL of children with ASD are lacking. Considering the dramatic increase in the prevalence of ASD, it has become more critical to better predict and improve the interventions and treatments for children with ASD. Assessing QOL in young children with ASD will possibly assist in the development of improved services across multi-levels including the societal-level, organizational-level, and individual-level. This can affect allocation of federal and stated funds, service provider policies, and family selection of services.

### **Measuring Autism Spectrum Disorder Interventions**

Although, many studies include a one-dimensional outcome domain emphasizing a change in scores such as intelligence quotient, there is no evidence that the intelligence quotient contributes to the predictive value of QOL (Renty & Roeyers, 2006). Traditional methods of assessing treatment outcomes for children with ASD utilize norm-reference assessment instruments in a pre- and post-test approach. Researchers using such measurements as evidence of effective treatment, report an improved intellectual ability or an increase in level of functioning through a change of standard scores. Although, these scores may represent a positive outcome and provide valuable information, researchers, policy makers, clinicians, and parents should be hesitant to rely on these

standard scores alone. There are several reasons to be hesitant about these findings. First, a limitation in demonstrating treatment outcomes through the use of changed intelligence quotient scores involves the accuracy of the pretreatment tests. Children with ASD often struggle with social difficulties, atypical use of language, inattentiveness, and noncompliant behavior that make testing challenging. Therefore, the change in intelligent quotient may be due to treatment effects on compliance and attention (Granpeesheh, Tarbox, Dixon, Carr, & Herbert, 2009; Matson, 2007), which produces a more accurate score at the time of post-treatment assessment. Second, intelligent quotient scores tend to be more stable and accurate for children who are tested at an older age (Lord & Schopler, 1989). Increased scores may be an artificial effect of development and time. Third, results of intelligent quotient testing can be affected by the selection of test administered to the individual with ASD. Test selection must be appropriate to age and development level of the individual with ASD. Additionally, motivation can dramatically affect the results of the test score. The selection of test which embeds low levels of reinforcement may produce lower results than a selected test which promotes high rapid levels of reinforcement (Koegel, Koegel, & Smith, 1997).

### **Autism Spectrum Disorder Service Selection**

Although, the value of a treatment may be influenced by parent's perception of effectiveness (Schreibman, 2000) or by the rate of skill acquisition for identified targets; it is conceivable that the greatest significance of treatment may be related to the effect on QOL. Parental consideration of treatment is not based on scientific validation (Green, 2006). Researchers have shown that parents consistently choose goals that are correlated

with increased levels of personal well-being (Pituch et al., 2011; Rodger, Braithwaite, & Keen, 2004).

Several studies have been conducted to identify specific parental priorities and reasons for selecting a particular treatment. For example, Green et al. (2006) conducted study to determine the number and types of interventions and programs being used to intervene with individuals with ASD. The study further details the number and types of treatments being selected based upon the characteristics of parents and of the children with ASD. Through a MEDLINE and PsycInfo electronic search, Green et al. reviewed 111 intervention approaches being used to treat children with ASD. Of these treatments, Green and her colleagues found that speech therapy was most commonly used followed by visual schedules, sensory integration, applied behavior analysis, and social stories. On average, respondents indicated the use of seven individual treatments at any one time. Multiple treatments often incorporated selections across numerous categories combining approaches such as standard therapies, skill based therapies, medications, and alternative diets. The number of treatment selected by the parents was influenced by the severity of the disability and the age of the child with ASD. The data indicated that parents of younger children with ASD and parents who defined their child as having a more severe form of ASD tended to select a greater number of treatments. The results of the Green et al. (2006) study concluded that parents were selecting treatments that were both supported by empirical evidence and treatments that had not been defined as evidence-based practices. Scientific validation of an intervention, therefore, was not the prevailing selection criteria (Green et al., 2006).

In a 2011 study, researchers examined the possible reasons for parental selection of goals within a particular intervention. Pituch et al. (2011) examined the validity of a strength-based logic verses a deficit- or needs-based logic by analyzing the child's skills and deficits in relation to parent treatment priorities. This survey consisted of 90 parents of children with ASD who rated, on a scale from 0 (not a problem) to 4 (major problem), a total of 54 adaptive skills and problem behaviors as pertaining to their child. Additionally, using a scale from 0 – 4 parents rated the level of priority of the need for the particular adaptive skill or aberrant behavior to be addressed in their child's intervention program. Data from this study indicated that the highest priority domains included: social skills, communication, academic, community living, vocational, and recreation/leisure skills. Pituch et al. (2011) found that parents did not tend to select treatment priorities based on the child's greatest skills, but often generated treatment priorities founded on the child's deficits/excesses.

Similar supporting research concluded that parents of young children with ASD were most interested in addressing skills in the area of communication, behavior, social interaction, and play (Rodger et al., 2004). Priorities in the area of communication included requesting, following basic instructions, and expressing basic needs. These same parents sought to address behavioral issues such as self-stimulation, tantrums, and unusual behaviors as well as play skill such as independent play and increasing play repertoire (Rodger et al., 2004). In a large survey study, other researchers found social skills, behavior, and child's happiness to comprise of the highest parental priorities for treatment. Of these parents, the emphasis of their child's happiness was most prevalent

by those parents dissatisfied with intervention services; whereas those parents satisfied with intervention services regarded this domain as established (Whitaker, 2007).

While research has demonstrated which interventions are most frequently selected and the reason behind the treatment selection for children with ASD, no research has been done to determine the relation of these interventions to the child's QOL. Further research must be conducted to determine if a specific treatment or treatments relate to the child's QOL. Such studies will allow policy makers, clinicians, and educators to take these outcomes into consideration to provide cost effective and high quality services to children with ASD. Focusing on QOL may bridge the gap between the existing program design and meaningful outcomes for children with ASD.



## CHAPTER III

### METHODS

In this study, I examined the relationship between treatments received by elementary school children with ASD in South Carolina and the parental perception of QOL for these children. To do this, I developed two instruments to obtain the necessary data. I uploaded these instruments into Qualtrics, a survey software, in order to collect the data needed for this study, which included: (a) types of treatments selected by parents and (b) parent perception of child's level of QOL.

#### **Participant Recruitment**

Parents of young children with ASD living in South Carolina formed the target population. I included the following eligibility criteria for participation in this study: a parent who had a child with ASD who (a) is between the age of 5 years and 10 years, (b) has received treatment or intervention services within the past 12 months, and (c) has lived with his or her child with ASD during the past 12 months. I selected these parameters as the focus on this study because they represented the population who most frequently had access to and funding for behavioral therapies provided in the home, and the elementary educational system in South Carolina.

I distributed the instruments to parents of children with ASD across the state of South Carolina in an on-line format. Both instruments were distributed through the local chapter of the ASD Society and multiple ASD specific parent groups within the state. For the first organization, I contacted the CEO of the South Carolina Chapter of the

Autism Society of America (ASA), provided a description and intent of the survey, and requested assistance in distributing the instruments to their group members. The CEO of the South Carolina ASA distributed the survey through their state listserv. In order to access additional relevant organizations, I conducted an inquiry on nationally recognized search engines to identify groups that were serving individuals with ASD and family members throughout South Carolina. The descriptors used for the electronic search, included 'ASD support groups', 'ASD groups', 'ASD support groups', 'ASD therapy', 'ASD services', and 'ASD groups.' Key terms were used in conjunction with 'South Carolina' and 'SC'. Social media sites for each identified organization was located. At each site, I posted a brief description of the survey intent, explanation of qualifications for participation, and the URL link for the survey. In cases in which a social media site was closed to public posting, I identified the founder, co-founder or other named contact person and related e-mail addresses. A brief statement describing the survey and requested assistance in the distribution of the survey was sent to their group's membership. The brief description of the survey, criteria for participants, and request for participant letter is located in Appendix Figure C. Appendix D includes a list of organizations where the survey was posted. The organizations are listed in time order of posting. The URL link to the survey was posted on each site three times. Unexpectedly, a number of family members who saw the survey posted on a social media site, Facebook, independently 'shared the link' to their personal Facebook profile.

Data received via electronic surveys automatically loaded into the survey software. The participants were limited to those who received the URL and

independently selected to respond or those parents who received the information from another individual who read the posting pertaining to the survey.

## **Instrument Development**

### **Development of the ASD Service Inventory (ASI)**

I developed the ASI to assess information on the selection and use of interventions for children with ASD. The ASI consisted of a list of treatments commonly accessible to parents of children with ASD in the public setting and frequently offered in a public education system.

The ASI was prepared by synthesizing the findings of intervention reviews from the Internet Survey of Treatments used by Parents of Children with ASD (Green et al., 2006) and ASD Treatment Survey: Services Received by Children with ASD in Public School Classrooms (Hess, Morrier, Heflin, & Ivey, 2008). I used the findings of these studies to identify treatments that are used by children with ASD because they provided a thorough analysis of treatments available to young children with ASD and are regularly referenced throughout the literature. The reported treatments within these intervention reviews were also considered available through community early intervention programs and used in public educational settings.

The ASI included treatments that had been selected by 10.0% or greater of the population for each identified study. Based on the findings, I considered interventions utilized by less than 10% of the population to be inconsistently available across settings. This inclusion criteria contained results of both parent selected treatments and educator selected treatment options. I included behavior and communication treatment options because the Center for Disease Control and Prevention supports this intervention

methodology within the first of four main treatment classification categories ("Autism Spectrum Disorder - Treatment," 2014; Keith & Bonham, 2005). I excluded treatments or interventions that prescribed medications, surgical procedures or were considered to be an alternative therapy such as diet or vitamin supplement. Treatments were excluded that involved medications, surgical procedures, alternative therapy, and diet and vitamin supplement because these interventions are not commonly viewed as legitimate treatment options in community early intervention programs or educational settings. This produced the final list of treatments, which included those that are most consistently available in the community and educational environments. To avoid sequence effect of services that have been reported as most commonly used, I randomly selected treatment options for order of presentation in each category.

### **Development of the Quality of Life for Children with ASD Spectrum Disorder (QOLASD-C)**

I developed the QOLASD-C to elicit the viewpoints of parents of children with ASD regarding their child's level of satisfaction of emotional well-being, interpersonal relations, and self-determination. As supported in literature (Plimley, 2007), I designed the QOLASD-C by considering the range of variance within developmental levels of social interaction, communication and patterns of thought and behavior of children with ASD. Three domains for the QOLASD-C were developed based on the findings that core QOL features are shaped by the fundamental dimensions of satisfaction, perception of well-being, social belonging, and control over one's life (Epstein & McPartland, 1976; Keith & Schalock, 1994). These domains (a) reflected the most frequently studied domains of similar populations, (b) focused on key features of QOL, and (c) were

relevant to the developmental process for children with ASD. Table 3.1 provides a summary and description of each of these domains. The QOLASD-C was intended for children age 5 years to 10 years old. The QOLASD-C was comprised of 21 questions evenly divided across each domain.

Table 3.1

*Quality of Life for Children with Autism Spectrum Disorder (QOLASD-C)*

Domains	Description
1. Emotional Well-Being	Characterized by levels of self-concept, happiness, spirituality, contentment, satisfaction, feeling of well-being and family life.
2. Interpersonal Relationships	Characterized by levels of interactions, family life, affection, group membership, social supports and friendships.
3. Self-Determination	Characterized by levels of opportunities for choice, opportunities for making decisions, personal control, preferences and choice.

I developed indicators for each domain through a content analysis of published QOL instruments. I selected the final compilation of instruments, which I used in the content analysis, based on frequency of use for similar populations, rate of referencing in comparable studies, and relevance to age and setting, to include home and education environment. I analyzed the indicators of these instruments across the three major domains for consistent themes and modified indicators based on format, terminology and relevance. Adaptations as vital to promote consistency, responder accuracy, and functionality to the population were also identified.

I modified indicators in a consistent format. First, because a self-reporting questionnaire format may be considered above the comprehension and ability level of young children with ASD, I tailored all questions into a proxy format. In order to maintain a uniformed structure, I transformed questions, which required detailed answers such as: ‘invites you to activities’ or ‘avoid you, bother you, etc.’, to ascertain the same information on a Likert scale. Second, I made modification to terminology of original questions that used descriptive terms that are difficult to judge by proxy in consideration of young children with deficits in communication, social-emotional reciprocity, and expressing distinct emotions. I modified terms such as rewarding, acceptable, and disappointing to equivalent terms such as likes and happy. Finally, I eliminated or modified questions when the relevance exceeds the everyday functioning of a young child with ASD. For instance, when considering young child with developmental delays with deficits in social interactions and excessive restricted interests, I considered questions such as “How successful do you think you are compared to others?” and “Do you have more or fewer problems than other people?” as low relevance to the level of life satisfaction for the population of this study.

**Emotional Well-Being Domain.** I designed indicators of the QOLASD-C emotional well-being domain to meet the needs of this targeted population. Table 3.2 consists of a summary of QOLASD-C indicators and corresponding indicators from identified QOL instruments pertaining to the emotional well-being domain. The summary includes variations of the questions across core themes within this domain. For example, I modified ‘How satisfied are you with your current school?’ (QSLQ) and ‘I look forward to going to school’ (MSLSS), to ‘My child likes going to school.’ This

modification established level of emotional well-being in a specified location, satisfied the needed proxy format, and eliminated terminology that may be challenging for a parent of this population to determine. I modified the questions ‘My parents treat me fairly’ (MSLSS) and ‘How satisfied or dissatisfied are you with the activities you do with your family?’ (WQLCQ) to ‘My child enjoys family activities.’ In this version of the question, I utilized the predictor that fulfillment with family life was strongly associated with life satisfaction (Huebner, 1991) for emotional well-being, simplified the terminology in order to promote proxy response accuracy, and considered the deficits in social communication and social interactions (American Psychiatric Association. Task Force on DSM-V, 2013) of a child with ASD.

Table 3.2

*Summary of Development to Quality of Life for Children with Autism Spectrum Disorder (QOLASD-C) – Emotional Well-Being*

QOLASD-C Indicators	Supporting Indicators	References
1. My child regularly feels sad.	Do you feel sad?	Pediatric Quality of Life Inventory (PedsQL) – Child Report - <i>Emotional Functioning</i>
	[problems with] Feeling afraid or scared.	Pediatric Quality of Life Inventory (PedsQL) – Parent Report - <i>Emotional Functioning</i>
2. My child shows pleasure when learning new skills.	How well do you feel you do in school?	Quality of Student Life Questionnaire – <i>Well-Being</i>
	I like to try new things. There are lots of things I can do well. I learn a lot at school.	Multidimensional Students’ Life Satisfaction Scale (MSLS)

3. My child likes going to school.	How satisfied are you with your current school?	Quality of Student Life Questionnaire
	I feel bad at school. I look forward to going to school.	Multidimensional Students' Life Satisfaction Scale (MSLS)
4. My child is generally happy.	Are most things that happen to you: rewarding acceptable or disappointing?	Quality of Student Life Questionnaire – <i>Well-Being</i>
	I like myself. Most people like me.	Multidimensional Students' Life Satisfaction Scale (MSLS)
5. My child sleeps well.	Do you have trouble sleeping?	Pediatric Quality of Life Inventory (PedsQL) – Child Report - <i>Emotional Functioning</i>
6. My child is relaxed when at home.	My family is better than most. I enjoy being at home with my family. I wish I lived in a different house. Members of my family talk nicely to one another.	Multidimensional Students' Life Satisfaction Scale (MSLS)



7. My child enjoys family activities.	What about your family members? Do they make you feel:...	Quality of Student Life Questionnaire – <i>Well-Being</i>
	I like spending time with my parents. My family gets along well together. My parents treat me fairly. My parents and I do fun things together.	Multidimensional Students' Life Satisfaction Scale (MSLS)
	How satisfied or dissatisfied are you with your relationship with your family? How satisfied or dissatisfied are you with the activities you do with your family?	Wisconsin Quality of Life Client Questionnaire

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**Interpersonal Relations Domain.** I established indicators of the QOLASD-C interpersonal relations domain based on defining characteristics of children with ASD and the QOL predictors across each published instrument within this domain. Table 3.3 consists of the summary of QOLASD-C interpersonal relations indicators that were modified based on corresponding indicators from significant QOL instruments. For example, I revised ‘Do you actively participate in recreational activities?’ (QSLQ) to ‘My child likes to do activities with other.’ The original question specified recreational activities to include large structured social events (parties, dances, concerts or plays). My intent of this modification considered the premise that a child with ASD may not participate in large group activities due to his or her “deficits in social-emotional reciprocity,” “deficits in nonverbal communicative behaviors used for social interaction” or “hypo-reactivity to sensory input” (American Psychiatric Association, 2013); however, the child with ASD may achieve a similar level of satisfaction by participating in various

small scale activities with other people. Because children with ASD experience “deficits in developing and maintaining relationships” (American Psychiatric Association, 2013), I was sensitive to the interpretation of friendship as a predictor for QOL. Studies have found that the quality of friends as oppose to the number of friends has a higher rate of predicting QOL (Burgess & Gutstein, 2007); therefore, I modified the question ‘How many times per day do you talk to (associate with) your classmates?’ (QSLO) to ‘My child shows pleasure when interacting with other children.’ In this modification, I used the established indicator of friendships as a predictor for increased QOL, while minimizing the specificities of a friendship for the child with deficits in developing and maintaining relationships.

Table 3.3

*Summary of Development to Quality of Life for Children with Autism Spectrum Disorder (QOLASD-C) – Interpersonal Relations*

QOLASD-C Indicators	Supporting Indicators	References
1. My child shows pleasure when interacting with another children.	How many times per day do you talk to (associate with) your classmates?	Quality of Student Life Questionnaire – <i>Social Belonging</i>
	This town is filled with mean people.	Multidimensional Students’ Life Satisfaction Scale (MSLS)
	[problem with] Getting along with other children.	Pediatric Quality of Life Inventory (PedsQL) – Parent Report - <i>Social Functioning</i>

2. My child has other children that will help him or her when needed.	How do your fellow students treat you?	Quality of Student Life Questionnaire – <i>Social Belonging</i>
	My friends are nice to me. My friends help me if I need it.	Multidimensional Students' Life Satisfaction Scale (MSLS)
3. My child enjoys playing with groups of children.	How many schools clubs or organizations do you belong to?	Quality of Student Life Questionnaire – <i>Social Belonging</i>
	Do you ever feel out of place in social situations?	
	[problems with] Getting teased by other children	Pediatric Quality of Life Inventory (PedsQL) – Parent Report – <i>Social Functioning</i>
	It is hard for you to keep up when you play with other kids.	Pediatric Quality of Life Inventory (PedsQL) – Child Report - <i>Social Functioning</i>
4. My child enjoys spending time with family members.	How satisfied or dissatisfied are you with how you get along with your friends?	Wisconsin Quality of Life Client Questionnaire
	Are there people living with you who sometimes hurt you, pester you, scare you or make you angry?	Quality of Student Life Questionnaire – <i>Well-Being</i>
	How happy are you about getting on with the people you know?	Personal Wellbeing Index-School Children (PWI-SC) – <i>Personal Relationships</i>
5. My child is happy to work with his or her teacher.	School is interesting.	Multidimensional Students' Life Satisfaction Scale (MSLS)

6. My child likes to do many activities with others.	Do you actively participate in (those) recreational activities?	Quality of Student Life Questionnaire – <i>Social Belonging</i>
7. My child would like more friends.	How many times a month do you feel lonely?	Quality of Student Life Questionnaire – <i>Social Belonging</i>
	I have lots of fun with my friends.	Multidimensional Students' Life Satisfaction Scale (MSLS)
	How satisfied or dissatisfied are you with the number of friends you have?	Wisconsin Quality of Life Client Questionnaire

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**Self-Determination Domain.** I established the indicators for the QOLASD-C self-determination domain by using the same subject content from published instruments that addressed the concept of self-determination for young children. Table 3.4 contains a summary of the QOLASD-C modified questions pertaining to the self-determination domain. The overriding theme within the established indicators focused on control and selection. Items of control ranged from daily activities, visits from friends, individual purchases, and sharing of ideas. Items of selection included activities, clothes, decorations, and food. In order to maintain the concept of these indicators for the needs of this population, I revised 'How satisfied or dissatisfied are you with the clothing you wear?' (QSLQ) to 'My child selects his or her clothes for the day.' In this modification, I used the concept of individual choice of clothing in a proxy format. I used the concept of satisfaction with food selection by revising 'How satisfied or dissatisfied are you with the food you eat?' (WQLCQ) and 'How much control do you have over things you do everyday (Like going to bed, eating, and what you do for fun)?' (QSLQ) to 'My child

selects what he or she wants to eat.’ Beyond the concept of freedom to choose an item or activity, I included an indicator that addressed the liberty to express ideas and feelings. In doing this, I revised the recognized indicator ‘I do what I do because it interest me’ (SDS) to ‘My child shows pleasure about a particular activity.’ I made this modification to support the overall notion of satisfaction with a selected activity while using terminology and a format that elicited proxy response accuracy.

Table 3.4

*Summary of Development to Quality of Life for Children with ASD Spectrum Disorder (QOLASD-C) – Self-Determination*

QOLASD-C Indicators	Supporting Indicators	References
1. My child relies on others to select his or her activities.	How satisfied or dissatisfied are you with the way you spend your time?	Wisconsin Quality of Life Client Questionnaire
2. My child is able to express likes.	I generally feel free to express my ideas and opinions.	Basic Need Satisfaction Scale
3. My child selects his or her clothes for the day.	How much control do you have over things you do every day (like going to bed, eating, and what you do for fun)?	Quality of Student Life Questionnaire – <i>Empowerment/Control</i>
	How satisfied or dissatisfied are you with the clothing you wear?	Wisconsin Quality of Life Client Questionnaire
4. My child shows preferences for places he or she would like to go.	I always feel like I choose the things I do.	The Self-Determination Scale (SDS)

5. My child can initiate several tasks independently.	I am free to do whatever I decide to do. I often do things that I don't choose to do.	The Self-Determination Scale (SDS)
6. My child shows pleasure about a particular activity.	I do what I do because it interests me.	The Self-Determination Scale (SDS)
7. My child selects what he or she wants to eat.	How much control do you have over things you do every day (like going to bed, eating, and what you do for fun)?	Quality of Student Life Questionnaire – <i>Empowerment/Control</i>
	How satisfied or dissatisfied are you with the food you eat?	Wisconsin Quality of Life Client Questionnaire

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The QOLASD-C is in Appendix Figure E.

### **Validity and Reliability**

An expert panel and focus group were used to collect evidence of validity on the instrument. These groups were asked to assess the concepts of the instrument, determine user feasibility, and verify the functionality of the dissemination method.

**Expert Review.** To collect evidence to support the validity associated with the QOLASD-C, I obtained agreement from three scholars, who were familiar with ASD research and QOL literature. These experts examined the instrument for content validity, comprehensiveness, and any potential threats to the collection of information. The experts provided evidence of content validity through the assessment of the relevance of each item to the associated domain. Their task included evaluating all 21 questions, by domain, in three categories: relevance (the degree to which the indicator is applicable for the age and population of the study participants), significance (the degree to which the

indicator is suitable for the associated domain) and proxy format (the degree to which the indicator can be rated by a parent). All feedback from the expert review was considered for instrument changes. Modifications made to the QOLASD-C resulted in another round of the expert review process. The review process was completed when all reviewers were in agreement with relevance, significance, and format for each indicator.

**Focus Group and Field Test.** Colleagues provided a total of 35 contacts of parents of children with ASD who were between the ages of 11 years and 14 years. I selected this age range because the parents of this group would not be selected to participate in the study, yet would be knowledgeable with the QOLASD-C content and serves as a similar cohort to those who were selected to participate in the study. Five of these parents reviewed the study invitation, instructions, and the survey for format and ease of the questions in the QOLASD-C. Because I used parents for the field test, who were not experts in testing methodologies, validity was assessed by parents' confirmation of relevance of each question to their child's daily life of previous years. This information confirmed that the test was sensible to the given audience. In order to obtain these data, I provided each parent with the following discussion questions: (a) Do you think the content of the item/indicator was important to your child's happiness? (b) Do you think the content of the item/indicator was relevant to young children with ASD? (c) Do you think a parent could assess the item/indicator based on their child's observable behavior? and (d) Do you think there were important indicators not included in the instrument? I formatted questions based on feedback with consistent themes from the focus group.

After I incorporated the feedback from both the expert review and parent focus group, I emailed the survey invitation and URL to five additional parents from this cohort. This sample group completed the QOLASD-C and ASI and provided feedback regarding usability and confirmed the functionality of the on-line survey. This process verified that the answers provided on QOLASD-C were processed and collected into the database system. I asked the remaining 25 parents to complete the survey to investigate internal reliability.

**Internal Reliability.** I evaluated internal reliability by computing the Cronbach's alpha index ( $\alpha$ ) constructs for the total QOLASD-C and each subscale. For this statistical analysis, I used SPSS (Statistical Package for the Social Sciences) software to calculate alpha and its associated properties. Prior to conducting the reliability analysis, I adjusted scores accordingly for reverse phrased items. I used  $\alpha$  to determine level of consistency among items within the same construct. For each subscale domain, I determined evidence of reliability when the value of alpha has a magnitude near .7. Also, for each item I assessed the value of alpha with the item deleted. In the item analysis, when an item was deleted and the value of alpha was greater than the overall domain Cronbach's alpha, the item was considered for removal to strengthen the reliability of the domain. When the items were removed, I reran the Cronbach's alpha to ensure that the deleted item had not affected the alpha calculation. For the full QOLASD -C, I determined evidence of reliability when the value of Cronbach's alpha was near .70. I compared the total scale overall alpha with the alpha if item deleted to determine the change in the Cronbach's alpha if an item was omitted. When a value was greater than the overall



alpha, I considered removing the item to increase Cronbach's alpha and strengthen reliability.

**Internal Reliability Outcome.** Table 3.5 represents the descriptive values of those completing the QOLASD-C survey and for whom the QOLASD-C survey was completed. Analyses of these descriptive values lead to two major changes in the final QOLASD-C product. The original question 'Does your child with ASD attend school?' allowed for the response of 'yes' or 'no.' Because the students within this focus group were well within the age frame of attending a school program but that not all children in the group actually intended school, a third option of 'home school' was included in the final version of the QOLASD-C. In the category of School Placement, the original question 'While at school, is your child included in the regular education program for 50% or more each day?' provided the force choice of 'yes' or 'no.' Because the focus group had 5 null responses in this category, the final question included a third response choice of 'I don't know.'

Table 3.5

*Descriptive Statistics of Focus Group Survey*

Descriptive Statistics of Focus Group Survey		
	Frequency	Percentage of All
Gender of Individual with ASD		
Male	18	72%
Female	7	28%
Total	25	100%

School Attendance		
Attends School	20	80%
Does Not Attend School	5	20%
School Placement		
≥ 50% Regular Education	12	48%
< 50% Regular Education	8	32%
Null	5	20%
Gender Completing Survey		
Male	18	72%
Female	7	28%

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After analyzing the responses from the 25 parents focus group, the Emotional Well-being subscale Cronbach's alpha was found to be .743, the Interpersonal Relations subscale Cronbach's alpha was found to be .742, and the Self-Determination subscale Cronbach's alpha was found to be .647 after removing one question (My child can initiate several tasks independently). The full-scale Cronbach's alpha was found to be .835, which suggested a strong internal consistency. The full survey including the ASI and QOLASD-C is in Appendix Figure F.

### **Data Analysis**

Data were used from each case where the responses met the criteria of opening the survey and 'last question was viewed' by the responder. I evaluated internal reliability of the QOLASD-C for the age group of this study. I calculated the sum of quality of life (SOQ) for each individual. I sorted the SOQ into four categories, which identified the following levels of SOQ: poor (21-36), fair (37-52), good (53-68) and excellent (69-84). The range of scores was calculated based on total number of scores divided by number of total possible categories. The number of possible categories and category classifications were developed based on composite outcome rating scores found in the literature addressing QOL outcomes for adults with ASD (Billstedt, et al., 2011). I

computed the descriptive analysis across multiple factors. These factors consisted of gender, treatment types, and effect on QOL.

## **ANOVA**

I assessed the data to determine if there were consistent groups of treatments that were used by individuals within the population. The stable independent variable across age and gender consisted of the total number of treatments (TNOT). I converted the TNOT score into three categories. These categories identified the number of treatments that each individual used during the past 12-month period and were identified as ‘low’ (0-3 treatments), ‘medium’ (4-7 treatments), and ‘high’ (8-11) treatments. The range of TNOT was calculated based on the number of possible treatments divided by the total possible categories.

I conducted a one-way Analysis of Variance (ANOVA) between-subjects to compare the difference in Sum of QOL (SOQ) values between TNOT categories. This analysis determined if there was a significant difference in perceived QOL and each of the conditions or number of treatments utilized with respect to this population. I used the Levene’s Test of Equality of Variances to test for homogeneity of variances to determine if the assumption of normality was violated. I used the result of this test to verify that the population variances across each group were equal at a  $p$  value  $>.05$ . I used the  $F$  value from the ANOVA calculation to determine if TNOT was statistically significant at  $p <.05$ .

## **Summary**

This study contributed to the existing QOL literature pertaining to emotional well-being, personal relations and self-determination by developing an assessment instrument specific to the unique characteristics and needs of children with ASD. This instrument

promoted the use of an alternative method of assessing program needs and treatment outcomes. The results of the individual QOL assessment complemented current ASD outcome measures by providing insight to how parents of children with ASD perceive their child's QOL after participating in numerous treatment options. By doing this, policy makers, clinicians, and educators will be able to use this information in providing interventions with consideration of socially valid outcomes. Understanding the effect of intervention based on socially valid outcomes will provide legislators with the critically important insight of the impact of federally funded mandates, provide educators with vital data to design and adjust programs, and reduce the amount of time and funding allotted for treatment that have little impact on the lives of these children with ASD.

## CHAPTER IV

### RESULTS

The purpose of this study was to assess how parents of children with ASD rate their child's QOL and to determine if a particular treatment or number of treatments was related to a higher or lower QOL level. I developed the ASI to assess types and number of treatments used by young children with ASD in South Carolina. I developed the QOL scale to address the characteristics of young children with ASD. I used ANOVA to determine if there were statistically significant differences between high, medium, and low QOL scores and treatment categories used by children with ASD.

#### **Demographics**

Table 4.1 describes the sample population according to age, gender, school status, and region within South Carolina of surveys completed. Responders opened a total of 103 surveys. Data was used from surveys where the responses met the criteria of (a) survey being opened and (b) 'last question was viewed' by the responder. A total of 83 surveys met these criteria. Data from this survey shows information pertaining to 75.9% males with ASD, 13.3% females with ASD, and 10.8% of children with ASD not identified as either male or female. 78.1% of the individuals with ASD attended a regular school program while 17.8% were educated in a homeschool program. Of the students attending a regular education program, 61.1% were participating in 50% or more of the regular education program. These students received treatment services from public and

private education centers across South Carolina including the Low Country (50%), Midlands (20%), Piedmont (18.6%) and the Pee Dee region (8.6%).

Table 4.1

*Demographic Descriptions of Survey*

	Description of Survey		
	<u>Survey Respondents (N=83)</u>		
	N	% Reported	% of All
Gender of Child with ASD			
Male	63	85.1%	75.9%
Female	11	14.9%	13.3%
Null	09		10.8%
Age of Child with ASD			
5 years	11	17.2%	13.3%
6 years	5	7.8%	6%
7 years	7	10.9%	8.4%
8 years	18	28.1%	21.7%
9 years	6	9.4%	7.2%
10 years	17	26.6%	20.5%
Null	19		22.9%
School Placement of Child with ASD			
Attend school	57	78.1%	68.7%
Does not attend school	3	4.1%	3.6%
Homeschool	13	17.8%	15.7%
Null	10		12%
≥ 50% Regular Education	37	66.1%	44.6%
< 50% Regular Education	18	32.1%	21.7%
Don't know	1	1.8%	1.2%
Null	27		32.5%
Gender Completing Survey			
Male	9	12%	10.8%
Female	65	88%	78.3%
Null	9		10.8%

Region			
Low Country	35	50%	42.2%
Midlands	14	20%	16.9%
Pee Dee	6	8.6%	7.2%
Piedmont	13	18.6%	15.7%
Unknown	2	2.9%	2.4%
Null	13		15.7%

### Validation of QOLASD-C

Cronbach's alpha index was computed on the QOLASD-C and each QOLASD-C subscale for this data set to provide evidence of reliability of the instrument. Although, the QOLASD-C had evidence of reliability through a pilot study analysis, in order to assess how parents perceive their child's QOL, it was important to evaluate similar reliability with this population. Cronbach's alpha was computed for the 83 participants of this study. Table 4.2 presents the outcome of this analysis.

Table 4.2

#### *QOLASD-C Cronbach's Alpha Full Survey Scale*

<i>QOLASD-C Cronbach's Alpha (N=83)</i>			
Item	N of Items	Cronbach's Alpha	Cronbach's Alpha if Item Deleted
Emotional Well-Being	7	.709	
My child is generally happy.			.611
My child regularly feels sad._1			.646
My child is relaxed when at home.			.644
My child likes going to school.			.715
My child sleeps well.			.673
My child shows pleasure when learning new skills.			.721
My child enjoys family activities._1			.706

Interpersonal Relations	7	.540 (.762)	
My child shows pleasure when interacting with other children.			.369
My child likes to do many activities with others.			.357
My child has other children that will help him or her when needed.			.465
My child is happy to work with his or her teacher._1			.393
My child enjoys playing with groups of children_1.			.477
My child would like more friends. _1			.762
My child enjoys spending time with family members. _1			.478
Self-Determination	7	.743	
My child selects what he or she wants to eat.			.729
My child is able to express likes.			.685
My child can initiate several tasks independently.			.670
My child relies on others to select their activities.			.718
My child selects his or her clothes for the day.			.750
My child shows pleasure about a particular activity.			.729
My child shows preferences for places he or she would like to go._1			.706
Full QOLASD-C	21	.825	
Full QOLASD-C	20	.845	

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The Emotional Well-being subscale Cronbach's alpha was .709, the Interpersonal Relations subscale Cronbach's alpha was .762 after removing one question (My child would like more friends), and the Self-Determination subscale Cronbach's alpha was .743. The full-scale Cronbach's alpha was .825, which suggests a strong internal consistency. This full-scale Cronbach's alpha was consistent with the full scale



Cronbach alpha of .835 for the pilot test. The results of the QOLASD-C were used to determine parental perception of their child's level of QOL.

### **Question #1. How do parents rate their child's QOL?**

Parents completed the QOLASD-C instrument and rated their child's QOL based on three domains: Emotional Well-Being, Interpersonal Relations, and Self-Determinations. Domain scores for each individual were combined to compute a total QOL score. Table 4.3 displays the mean and standard deviation of the QOLASD-C for the Total QOL scale and for each QOL subscales.

On questions where individual parents failed to respond to a specific item, I calculated replacement for missing values. These missing values were replaced by recoding to the original item mean through the SPSS missing values function. This process allowed questions that had missing data to be included in the analysis as complete data sets. Due to missing responses, each subscale had one to four questions where items were recoded to the mean. The number of adjusted items varied per QOL subscale. These items are identified as \_1 in Table 4.2.

Table 4.3

#### *Descriptive Statistics of QOL Scale*

Statistics of QOL Scale			
	Number of Items	Scale Statistics (N=83)	
		Means	Standard Deviation
Emotional Well-Being	7	21.06	3.7
Interpersonal Relationships	7	18.4	3.1
Self-Determination	7	21.7	3.8
Total	21	61.18	8.6

Each score for the QOL subscale had a possible range of seven minimum and 28 maximum. The scores for the QOL Total scale had a possible range of 21 minimum and 84 maximum. The results of the responses indicated the parental perception of QOL of this data set ranged between 37 minimum and 76 maximum with a mean of 61.18 and a standard deviation of 8.6.

QOLASD-C scores were converted into the following levels of QOL: poor (21-36), fair (37-52), good (53-68) and excellent (69-84). I developed these categories classifications based on categories used in the QOL literature (e.g., Billstedt, et al., 2011). The range of scores was calculated based on the number of total scores divided by the number of total possible categories. Table 4.4 presents the percentage of participants, according to gender, whose QOL scores were within each category. The data show that the majority of parents (66.3%) perceived their child as having a good QOL.

Table 4.4

*Statistics of QOL Categories*

Categories of QOL (N=83)									
	Poor		Fair		Good		Excellent		
	N	%	N	%	N	%	N	%	
Gender									
Male	0	0	12	19.01%	41	65.01%	10	15.8%	
Female	0	0	2	18.18%	8	72.7%	1	.09%	
Null	0	0	1	11.11%	6	66.67%	2	11.11%	
Total	0	0	15	18.1%	55	66.3%	13	15.7%	

## Question #2. How do specific interventions relate to parental perception of QOL for children with ASD?

The information from the QOLASD-C was used to analyze a relationship between QOL and intervention utilization. This analysis was based on the results of the ASI. The ASI consists of 11 interventions that have been found in the literature to be most commonly available in the community and education settings for young children with ASD. By completing the ASI, parents identified which interventions their child had used within the past 12-month period and which interventions their child had not used within this time frame. For the treatments that had been utilized, parents indicated if the identified treatment had a perceived impact on their child's QOL.

### Treatment Modality and QOL

QOL scores were analyzed based on frequency of treatment selection and the perceived effect of treatment on QOL. This analysis established the percentage of parents who indicated that their child had participated in the specific treatment and if parents perceived the effect of treatment to be positive, negative, or not at all influential on their child's QOL. Table 4.5 represents this analysis.

Table 4.5

#### *Treatment Utilization of Young Children with ASD*

Treatment Utilization Based on Autism Service Inventory (N=83)						
Treatment	Frequency	% Reported	% of All	Effect on Quality of Life % Reported		
				Positive	Negative	Not at All
ABA	49	63.6%	59%	91.8%	0%	8.2%

Speech	49	63.6%	59%	89.8%	0%	10.2%
Gentle Teaching	24	32.1%	28.9%	91.7%	0%	8.3%
Occupational Therapy	47	61%	56.6%	89.4%	0%	10.6%
Augmentative Communication	13	17.3%	15.7%	27.5%	0%	72.5%
Floor Time	22	28.6%	26.5%	95.5%	0%	4.5%
Visual Schedules	43	55.8%	51.8%	95.3%	0%	4.7%
Cognitive Behav. Therapy	14	18.2%	16.9%	78.6%	0%	21.4%
Music Therapy	8	10.4%	9.6%	100%	0%	0%
Social Stories	47	61%	56.6%	86.7%	0%	13.3%
TEACH	1	1.3%	1.3%	N/A	N/A	N/A

The Percentage Reported category includes data from all responders who identified their child as either participating in the treatment or as not participating in the treatment. The Percentage Of All category includes null responders. Null responders are parents who responded to the survey, but did not indicate if their child had or had not utilized the identified treatment over the past 12 month period. For each treatment type, the null responders were comprised of .8% to 4.6% of all responders. The Effect on QOL category represents parents who reported participation in a particular treatment.

### **Number of Treatments and QOL**

To further analyze the parental perceptions of the affect of treatment on a child's QOL, Total Number of Treatments (TNOT) was calculated for each participant. TNOT

identified the number of treatments that each individual had used during the past 12 months.

The scores for the TNOT scale had a possible range of 0 minimum and 11 maximum. Responses of TNOT for this data set ranged between 0 minimum and 9 maximum. TNOT scores were categorized as low (0-3), medium (4-7), and high (8-11). These classifications were calculated based on total possible number of treatments divided by total number of categories used in this study. Table 4.6 displays the statistical information of all groups who comprised of the various TNOT categories and the associated mean and standard deviation for QOL scores.

Table 4.6

*Average Quality of Life Score based on Sum Number of Treatments*

<i>Quality of Life (N=83)</i>			
<i>Number of Treatments</i>	N	QOL Mean	Std. Dev.
Low	25	57.28	9.38
Medium	50	61.25	7.55
High	8	55.15	10.03

The information from the combined QOLASD-C and ASI was further analyzed to assess if there was relationship between QOL and children who participated in low, medium, and high levels of treatment. An ANOVA was computed to analyze the group mean variance between TNOT categories and parental perception of child's QOL. Table 4.7 displays the results of the ANOVA.

Table 4.7

*Analysis of Variance for the Effect of TNOT on SQOL*

ANOVA: Effect of TNOT on SQOL					
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	428.991	2	214.496	3.061	.052
Within Groups	5605.890	80	70.074		
Total	6034.882	82			

The Levene's Test for Equality of Error Variances was conducted to test for homogeneity. In this study, homogeneity means that the variance of QOL is equal across each of the TNOT groups. When the variance is the same across each group, the ANOVA calculations are valid using one pooled estimate of variance value. This calculation will determine if a contrast between QOL and TNOT group exists. At a significant level of .479, homogeneity was greater than .05 and not did violate homoscedasticity. This means the variance of the SQOL within each TNOT groups were consistent with one another. This homogeneity validates the ANOVA calculation for this set of data. The statistical test computed through the ANOVA showed that there was not a significant interaction effect of TNOT on SQOL at  $p < .05$  level for the three conditions [ $F(2, 80) = 3.061, p = .052$ ]. The results of this analysis indicate that there is not a statistical relationship between TNOT and QOL.

### Summary

This study provided evidence of reliability of the QOLASD-C instrument, which I used to determine parental perception of child's level of QOL. Parents reported their child as having an overall good QOL. Parents indicated that their child has received

between 0 and 9 types of treatments over the past 12-month period. For all but one of these treatments, parents believe that the treatments have had a positive effect on their child's QOL. Though each treatment individually has been identified as having an impact on QOL, there is not a relationship between the number of treatments used and the child's QOL.

## CHAPTER V

### DISCUSSION

The purpose of this study was to examine how parents of children with ASD rated their child's QOL and to assess the effect of interventions on QOL. I developed a QOL scale, which included indicators to address characteristics of young children with ASD. I tested this instrument for evidence of validity. I developed the ASI to assess the types of treatments used with young children with ASD. Using these two instruments, I conducted an internet survey in which 83 parents rated their child's QOL and identified treatments that have been used with their child. I calculated an ANOVA to determine if there was a relationship between level of QOL and treatment categories used by children with ASD.

Parents reported that their child participated in 0-9 treatments over the past 12-months. Parents rated all but one of these treatments (augmentative communication) as having a positive effect on their child's QOL. Although this study did not find a significant relationship between QOL and treatment use, this study did reveal an overall good QOL for children who did receive treatment services.

QOL assessment instruments have been used with children across disabilities to improve program quality and outcomes; however, their use is significantly limited for children with ASD (Gómez, de la Fuente Anuncibay, & Conde). When QOL is assessed for adults with ASD (Billstedt, Gillberg, & Gillberg, 2011; Eaves & Ho, 2008; Jennes-Coussens, Magill-Evans, & Koning, 2006; Persson, 2000; Renty & Roeyers, 2006), the



results indicate poor QOL with individual outcomes lacking independence, socialization and overall well-being. These results are currently being used to improve legislative initiatives, instructional techniques, and outcome based services for adults. For example, personnel in Maryland Department of Education used QOL outcome information to change state-level performance standards, enhanced staff training and modify service delivery models. These changes lead to an improved QOL for their citizens with intellectual disabilities (Keith & Bonham, 2005).

Traditional assessment methods for children with ASD have largely been limited to standardized normative instruments (Matson, 2007), which do not accurately measure all variables that are significant and practical for the child or parent. Because the use of QOL assessments have proven useful for children across disabilities (Burgess & Gutstein, 2007) and adults with autism, it stands to reason that the use of these tools would equally benefit children with ASD. In order to explore the relevance of QOL for children with ASD we must determine first how parents rate QOL for their children and second how they perceive their child's treatment modality affect their QOL.

### **Question #1. How do parents rate their child's QOL?**

The QOLASD-C scale used in this study allowed parents to assess their child's QOL across three domains with four quality levels ranging from poor to excellent. In the subdomains of the QOLASD-C, parents rated their children as having the highest level of satisfaction within the area of Self-Determination, followed by Emotional Well-Being, and Interpersonal Relations. Though the mean difference between each subdomain was not statistically significant, the findings suggest greater difficulty in Interpersonal Relations relative to Self-Determination and Emotional Well-Being. This is supported by

previous research, which provides evidence that children with ASD struggle socially and have few friendships (Howlin et al. 2004). The results of this study suggest that professionals and family members may increase an overall QOL by developing effective programming goals in the individual's early life stages with a focus of increasing relationship skills.

Overall QOL scores were converted to 'poor', 'fair', 'good', or 'excellent'. Of all parents responding, 0% scored their child's QOL within the poor category, 18.91% scored their child's QOL within the fair category, 66.22% scored their child's QOL within good category, and 14.9% scored their child's QOL within the excellent category. In total, only 18.91% of parents rated their child's QOL as poor or fair. In contrast, results of this study were not consistent with the Billstedt et al. (2005) study which found 78% of adults with ASD had poor or very poor outcomes. However, the distinct difference between the research conducted by Billstedt et al., and this study is the age of the population. Results from this survey provide a unique contribution to the field because it suggests that parents do not perceive their children with ASD as having a bleak QOL during childhood. This leads to the notion that QOL should be assessed across the individual's lifespan beginning at early childhood with the intent of proactively providing effective services before the demise of the individual's QOL. This concept is supported by Burgess and Gutstein (2007) who advocated that the QOL paradigm should be viewed as a developmental model and not merely an end-goal.

Further analysis shows that 65.01% of all boys and 72.7% of all girls fall within the good range. Interestingly, 15.8% of all boys scored within the excellent category, whereas only .09% of the girls scored within the excellent category. Though there

appears to be a discrepancy between boys and girls within the highest category, it is important to recognize the sample size for girls was much smaller than that of the boys. Results from this sample of girls may be interpreted with caution when their data is drawn separately from the group as a whole.

Because research has demonstrated that the QOL levels for adults with ASD are poor (Billstedt et al., 2011; Jennes-Coussens et al., 2011) it is logical to predict that QOL outcomes for children would also be poor. Results of this study did not substantiate this supposition. Potential reasons for this discrepancy includes number of autism services for children relative to those for adults and personality traits of the responders. Green et al. (2006) found that that the younger the child, the greater number of treatment options parents tended to secure. It is possible to surmise, that QOL is directly related to the intensity or frequency of treatment or interactions between the providers and the child. QOL for adults with autism may decrease as a result of having limited or the lack of continual service options. This issue opens itself to future longitudinal studies focusing on treatment options and QOL across the lifespan.

Because this study was conducted on-line and promoted via social media, respondents may possess specific characteristics that allow for a higher QOL for their children. Due to available resources and social connectivity, responses obtained from these parents may not be applicable to families with limited resources. Green et al. (2006) found that their study was restricted by internet literate parents. Despite this constraint, this study gained valuable information regarding QOL, an unaddressed subject, from parents of children with ASD across the entire state of South Carolina. In the future, researchers should consider reaching out to disenfranchised populations to effectively

assess the ASD population as a whole and the specific characteristics and treatment implications of these particular subcultures.

Furthermore, 85.1% percent of the children in this study were male. Since autism has statistically been noted at a higher level in males at a ratio of 4 to 1, these numbers were not unexpected. Studies that focus specifically on outcomes in QOL for females are warranted to determine if there are differences in what indicators comprise QOL for each gender.

**Question #2. How do specific interventions relate to parental perception of QOL for children with ASD?**

The ASI assessed the array of treatments used with children with ASD over the past 12-month period. The treatment that was implemented most frequently was speech and ABA, followed by OT and Social Stories, and then visual schedules. These results are consistent with the Green et al. (2006) study, which assessed treatment option utilization on an international internet survey. The similarities between results provide evidence that families in South Carolina are treating symptoms of ASD in a similar fashion as families worldwide.

In this study, parents indicated that all but one treatment had a positive effect on their child's QOL. TEACCH was not reported as having a positive or negative effect on their child's QOL. It is notable that all of these treatment options are not considered as evidence-based practices. This reported outcome is consistent with the findings of the Hess, Morrier, Hefflin and Ivey (2007). These researchers assessed treatment types that were selected and used by teachers of children with ASD. The researchers found that the strategy most reported as being used within the Georgia public school system had

‘limited support’ as an evidence-based practice. In fact, only 7.70% of teachers reported implementing interventions that were identified as evidence-based. It has been suggested that parent perception of effectiveness and rate of skill acquisition are likely reasons for treatment selection (Schreibman, 2000). Results of this QOL study further suggested that parent selection of treatment is conceivably related to their perception of the effect of treatment on the child’s QOL. Further studies may consider investigating additional reasons for treatment selection to include: parental-peer influence, availability, ease of implementation, or evidence of social validity.

Overall, parents most frequently reported a perceived positive QOL. This result is novel as it expands the literature beyond assessing types of treatments used and includes the effect of the selected treatment on the child’s QOL. Research has not yet identified level of QOL in children with ASD nor have researchers assessed the relationship between treatment and QOL. Whereas few parents reported the treatment had a neutral effect on their child’s QOL, the majority of parents (72.5%) who relied on augmentative communication treatments reported that this treatment did not have an effect on their child’s QOL.

Augmentative communication interventions were the only intervention in this study to rely on assistive technology, which may have had an affect on treatment implementation. As in previous studies, this survey did not assess the application of the strategy (Hess, Morrier, Heflin & Ivey, 2007) or the specific skills that are targeted through the use of the intervention, which may affect the value of the treatment (Green et al., 2006) or the perceived influence on QOL. Treatment implementation concerns for assistive technology strategies can range from limited technical training, lack of

generalization across environment to simply minimal initiative to carrying the required device. The lack of any these components would conceivably minimize the effect of the treatment and in turn diminish parental perception of effect on QOL. The need to assess treatment fidelity of augmentative communication interventions is particularly important, especially considering that Hess, Morrier, Hefflin & Ivey (2007) found that classroom teachers reported the most frequently implemented intervention used was assistive technology.

Of all treatments that were reported as having a positive affect on QOL, it is notable that treatments that had the highest frequency of use did not necessarily have the highest reported positive affect on QOL. Speech therapy, which was one of the most frequently used intervention reported in this study and previous studies (Green et al., 2006; Hess et al., 2008), ranked below other treatments pertaining to affect on QOL. Parents reported the interventions that had the greatest positive effect on their child's QOL were music therapy (100% positive effect), floor time (95.5% positive effect), visual schedules (95.3 positive effect), ABA (91.8% positive effect) and gentle teaching (91.7% positive effect).

It is not surprising that speech therapy is reported to be the most used intervention, because it addresses communication and social skill deficits which have consistently been found to be a high priority for parents (Green et al., 2006; Pituch et al., 2011). One plausible explanation for a lower positive parental perception of effect on QOL may be related to parental expectations of outcomes, particularly for those children who do not develop speech. QOL can be measured in part by feelings of competency and independence (Keith & Schalock, 1994) and parents may closely link lack of speech with

an inability to achieve these QOL outcomes. One possible limitation for this study is that parents interpret QOL differently. Future studies may focus on QOL for children with ASD using an instrument that scores indicators both in the objective and subjective domain.

It is important to recognize that the eleven therapies identified in this study represent different levels of treatment and therefore are not necessarily interchangeable or comparable with each other. For example, ABA is a system which consists of many techniques that have virtually unlimited application whereas visual schedules are specifically designed to help individuals follow a sequence of events to effectively manage their day.

Furthermore, because participants simultaneously used more than one treatment it is not possible to isolate variables in order to determine which combinations of treatments had the greatest impact on the child's QOL. In order to identify the true impact of a treatment further research should be done on specific treatment components such as time, location, satisfaction with curriculum, therapist/child compatibility, and level of fidelity of implementation. This would allow parents to better determine which therapies would be a good fit for their child's specific needs based on a more complete understanding of each treatment modality.

Because each treatment package was individualized, this sample population did not produce consistent combinations of interventions for analysis. This study categorized respondents according to number of treatments to determine if this variable affected QOL. Researchers have suggested that the number of hours of treatment affects normative scores (Lovaas, 1987; Sallows & Graupner, 2005). I speculated that the total

number of treatments might also affect individual treatment outcomes and QOL. Total number of treatments was divided into three categories, “low”, “medium”, and “high”. These groups were analyzed to determine if there was a relationship among number of treatments and QOL, which was categorized into four levels; “poor”, “fair”, “good” and “excellent”. The outcome of the analysis in this study indicated each group achieved a good level of QOL regardless of number of treatments. The variance in the between group QOL score was not statistically significant between the number of treatment categories. This means that the average QOL score between those children participating in low, medium and high numbers of treatments were on average the same. Therefore, the number of treatments used by a child did not affect the level of the child’s QOL. It is important to note that number of treatments does not indicate number of hours, so a child with seven treatments could receive less total hours of treatment than a child receiving one or two intensive therapies. It is also important to note that the number of treatment categories did not distinguish between evidence-based practices, emerging practices or practices without empirical support. Future studies may analyze the causal relationship between number of hours and type of identified intervention affecting the child’s QOL. This analysis would direct funding agencies and stakeholders to determine most effective combination of hours and treatment types which would result in greater personal well-being for their constituents and recipients of services.

### **Summary**

In summary, this study shows that parents’ perception of their child’s QOL levels range from fair to excellent with the majority of QOL scores falling within the good range. Parents reported that child’s emotional well-being, interpersonal relationships and



self-determination were positively affected by their treatment choices for 10 of the 11 treatments. These parents used individualized combinations of treatments, varying in number of treatments, and methodology. Parents reported positive QOL levels for their children regardless of the number of treatments received.

Prior to this study, there was not a QOL assessment instrument specifically designed for the unique characteristics (e.g., deficits in social and emotional reciprocity, deficits in verbal and nonverbal communication, restrictive patterns of interest) of young children with ASD. This study resulted in a preliminary QOL assessment specifically for children with ASD ranging in age from 5-10. This instrument demonstrated evidence of validity across two groups within this population. Additional psychometrics on this instrument should be investigated to strengthen the body of research focusing on QOL for children with ASD. The use of reliable QOL assessments specific for this population will ultimately improve policy, service delivery, and individual programs by providing stakeholders and service providers with an understanding of what goals and treatments parents perceive as positively affecting their child's overall wellbeing.

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# APPENDIX A: EFFECTIVE PRACTICES FOR INDIVIDUALS WITH ASD AND SUPPORTING RESEARCH IDENTIFIED THROUGH THE NATIONAL PROFESSIONAL DEVELOPMENT CENTER ON AUTISM SPECTRUM DISORDERS

Table A.1

## *Evidence-Based Practices for Individuals with ASD*

Evidence-Based Practice	Empirical Support
1 Antecedent-based Intervention	<p>Ahearn, W. H. (2003). Using simultaneous presentation to increase vegetable consumption in a mildly selective child with ASD. <i>Journal of Applied Behavior Analysis</i>, 36(3), 361-365. doi: 10.1901/jaba.2003.36-361</p> <p>Cale, S. I., Carr, E. G., Blakeley-Smith, A., &amp; Owen-DeSchryver, J. S. (2009). Context-based assessment and intervention for problem behavior in children with ASD spectrum disorder. <i>Behavior modification</i>, 33(6), 707-742. doi: 10.1177/0145445509340775</p>
2 Cognitive behavioral intervention	<p>Drahota, A., Wood, J. J., Sze, K. M., &amp; Van Dyke, M. (2011). Effects of cognitive behavioral therapy on daily living skills in children with high-functioning ASD and concurrent anxiety disorders. <i>Journal of ASD and Developmental Disorders</i>, 41(3), 257-265. doi: 10.1007/s10803-010-1037-4</p> <p>Singh, N. N., Lancioni, G. E., Manikam, R., Winton, A. S., Singh, A. N., Singh, J., &amp; Singh, A. D. (2011). A mindfulness-based strategy for self-management of aggressive behavior in adolescents with ASD. <i>Research in ASD Spectrum Disorders</i>, 5(3), 1153-1158. doi:10.1016/j.rasd.2010.12.012</p>

- 3 Differential reinforcement of Alternative, Incompatible, or Other Behavior
 

Call, N. A., Pabico, R. S., Findley, A. J., & Valentino, A. L. (2011). Differential reinforcement with and without blocking as treatment for elopement. *Journal of Applied Behavior Analysis*, 44(4), 903-907. doi: 10.1901/jaba.2011.44-903

Charlop, M. H., Kurtz, P. F., & Milstein, J. P. (1992). Too much reinforcement, too little behavior: Assessing task interspersal procedures in conjunction with different reinforcement schedules with autistic children. *Journal of Applied Behavior Analysis*, 25(4), 795-808. doi: 10.1901/jaba.1992.25-795
- 4 Discrete trial teaching
 

Gould, E., Tarbox, J., O'Hora, D., Noone, S., & Bergstrom, R. (2011). Teaching children with ASD a basic component skill of perspective-taking. *Behavioral Interventions*, 26(1), 50-66. doi: 10.1002/bin.320

Jahr, E. (2001). Teaching children with ASD to answer novel wh-questions by utilizing a multiple exemplar strategy. *Research in Developmental Disabilities*, 22(5), 407-423. doi: 10.1016/S0891-4222(01)00081-6
- 5 Exercise
 

Celiberti, D. A., Bobo, H. E., Kelly, K. S., Harris, S. L., & Handleman, J. S. (1997). The differential and temporal effects of antecedent exercise on the self-stimulatory behavior of a child with ASD. *Research in Developmental Disabilities*, 18(2), 139-150. doi: 10.1016/S0891-4222(96)00032-7

Fragala-Pinkham, M. A., Haley, S. M., & O'Neil, M. E. (2011). Group swimming and aquatic exercise program for children with ASD spectrum disorders: A pilot study. *Developmental Neurorehabilitation*, 14(4), 230-241. doi: 10.3109/17518423.2011.575438
- 6 Extinction
 

Banda, D. R., McAfee, J. K., & Hart, S. L. (2009). Decreasing self-injurious behavior in a student with ASD and Tourette syndrome through positive attention and extinction. *Child & Family Behavior Therapy*, 31(2), 144-156. doi: 10.1080/07317100902910604

Grow, L. L., Kelley, M. E., Roane, H. S., & Shillingsburg, M. A. (2008). Utility of extinction-induced response variability for the selection of mands. *Journal of*

Applied Behavior Analysis, 41(1), 15-24. doi: 10.1901/jaba.2008.41-15

7 Functional behavior assessment

Dunlap, G., & Fox, L. (1999). A demonstration of behavioral support for young children with ASD. *Journal of Positive Behavior Interventions*, 1(2), 77-87. doi: 10.1177/109830079900100202

Kodak, T., Fisher, W. W., Clements, A., Paden, A. R., & Dickes, N. R. (2011). Functional assessment of instructional variables: Linking assessment and treatment. *Research in ASD Spectrum Disorders*, 5(3), 1059-1077. doi: 10.1016/j.rasd.2010.11.012

8 Functional communication training

Mancil, G. R., Conroy, M. A., Nakao, T., & Alter, P. J. (2006). Functional communication training in the natural environment: A pilot investigation with a young child with ASD spectrum disorder. *Education and Treatment of Children*, 29(4), 615-633.

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9 Modeling

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APPENDIX B: RESEARCH AREAS OF QOL DOMAINS ACROSS 3 CLASSIFICATIONS

Table B.1

*Research Areas of QOL Domain Emotional Well-Being Across 3 Classifications (Education, Mental and Behavior Health & Intellectual Disabilities)*

Emotional Well-Being				
Level of Analysis	Exemplary QOL indicators	Education	Mental and Behavioral Health	Intellectual Disabilities
Macrosystem (Social Indicators)	Religious Freedom Family Life Legislation			
Mesosystem (Functional Assessment)	Safety* Freedom from Stress* Freedom to Worship Supports	Safety: Free from mortal danger, safe environment, stability	Freedom from Stress: reaction to distressful situations, anxiety, nervousness, restlessness, Restiveness, relaxation, coping, tolerance	Safety: supports, stability
Microsystem (Personal Appraisal)	Self-Concept* Happiness* Spirituality* Contentment	Self-Concept: Identity, Personality, self-worth, self-esteem Happiness & Trust	Self-Concept: self-awareness, self-esteem, body image, personal knowledge	Self-Concept: self-esteem, personal perceptions, self, self-image.

Satisfaction  
Feeling of Well-Being  
Mental Health

Contentment: with  
school, home, life  
satisfaction, supports,  
self-satisfaction  
Well-Being: negative  
affect, positive affect

Contentment: Satisfaction,  
Pleasure/enjoyment,  
frustration, psychological  
distress

Contentment: with work,  
residence, supports,  
community satisfaction,  
satisfaction with services  
Well-Being: general  
well-being, personal  
well-being,  
psychological well-being

Table B.2

*Research Areas of QOL Domain Interpersonal Relations Across 3 Classifications (Education, Mental and Behavior Health & Intellectual Disabilities)*

Interpersonal Relations				
Level of Analysis	Exemplary QOL indicators	Education	Mental and Behavioral Health	Intellectual Disabilities
Macrosystem (Social Indicators)	Public Safety			
Mesosystem (Functional Assessment)	Interactions* Family Life* Affection* Group membership Social Supports Marital Status	Interactions: with peers and teachers Family: satisfaction, support, involvement Friendship: satisfaction	Interactions: social life, social behavior, isolation, loneliness, communication, social networks, conflicts, hostility Support: Affection: feelings, emotions, empathy, love Help/aids/assistance	Interactions: work relations, social relations, with staff, quality of interpersonal relationships Family: marital relations, parent-child relations, extended family relations Supports: social network
Microsystem (Personal Appraisal)	Friendships* Intimacy*			Affiliations, loneliness Intimacy: sexuality Emotional relationships



Table B.3

*Research Areas of QOL Domain Self-Determination Across 3 Classifications (Education, Mental and Behavior Health & Intellectual Disabilities)*

Self-Determination				
Level of Analysis	Exemplary QOL indicators	Education	Mental and Behavioral Health	Intellectual Disabilities
Macrosystem (Social Indicators)	Guardianship Laws Consumer Empowerment			
Mesosystem (Functional Assessment)	Opportunities for Choice Making/Decisions* Allowance for Choice/Personal Control Person-Centered Planning		Goals / Personal Values: personal projects of life, expectations, desires, aspirations, hope, dreams	Decisions: Opportunities
Microsystem (Personal Appraisal)	Autonomy* Self-Direction* Personal Control* Preferences Choice*	Autonomy: independence	Autonomy: independence, self-sufficiency, self-support, self-maintenance, self-care	Autonomy: Independent functioning, independence, Choice: opportunities, options, preferences Personal Control: environmental control, empowerment Self-Direction: Personal planning

\*Individual Exemplary Core Indicators

## APPENDIX C: SERVICES AND QUALITY OF LIFE FOR CHILDREN WITH ASD WEB-BASE INVITATION



### Services and Quality of Life for Children with ASD

I am conducting a research study on traditional treatments available to children with ASD and the effects on their Quality of Life. The goal of this study is to help families understand which treatments might most benefit their children.

Your responses to this 5 minute survey will be invaluable if:

- you live in South Carolina
- you have a child with a diagnosis of ASD between 5 years and 10 years
- you have lived with this child over the past 12 months

If you meet all three of these conditions, please click the link below to respond to this brief survey. No identifying information will be collected and all responses will remain anonymous.

Thank you,  
Jodi Cholewicki, MRC, BCBA  
PhD Candidate  
Department of Educational Studies: Special Education  
University of South Carolina

Figure C.1 *Services and Quality of Life for Children with ASD Web-Base Invitation*

APPENDIX D: SERVICES AND QUALITY OF LIFE FOR CHILDREN WITH ASD  
SURVEY DISTRIBUTION SOCIAL MEDIA SITE LOCATIONS

Table D.1

*Services and Quality of Life for Children with ASD Survey Distribution Social Media Site Locations*

Social Media Sites		
1. SC ASD Society	17. ASD Speaks	33. Asperger's Syndrome Awareness
2. SC Special Olympics -6	18. Camp T.A.L.K.	34. ASD Awareness
3. SC Mothers of Special Needs	19. Camp M.A.T.E.S.	35. Carolina Children's Charity
4. Surfers Healing Folly Beach	20. Project Rex	36. World ASD Awareness Day
5. IEP Special Education Lowcountry	21. ASD Friends	37. Temple Grandin
6. ASD Discussion Page	22. Charleston County Public Schools	38. Center for Occupational and Environmental Medicine
7. Charleston ASD Academy	23. ASD Parent Support & Discussion Group	39. Palmetto Audiology and Speech
8. Lowcountry ASD Consortium	24. SOS ASD at Charleston	40. Charleston Children Therapy
9. Charleston Walk for ASD	25. World ASD Awareness Day	41. Carolina Speech Associates
10. Family Resource Center	26. ASD Awareness Month is April	42. Bright Start
11. Greenville County DSN	27. Walk for ASD	43. McCullon Therapeutic Solutions
12. Loving Unconditionally Children with ASD Support	28. ASD Friends	44. Advanced Therapy Solutions
13. ASD Awareness Movements North and South Carolina	29. ASD Friends	45. Easter Seals SC
14. ASD Charter School in the Lowcountry	30. Tricounty Speech and Language	46. Lowcountry ASD Foundation
15. Family Connections of South Carolina	31. Carolina Speech and Language Center	47. Winston's Wish

Lowcountry & Coastal  
Area

16. Camp Good Times

32. Aspergers Experts

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APPENDIX E: QUALITY OF LIFE FOR CHILDREN WITH AUTISM SPECTRUM DISORDER ACROSS 3 DOMAINS  
(EMOTIONAL WELL-BEING, INTERPERSONAL RELATIONS & SELF-DETERMINATION)

Table E.1

*Quality of Life for Children with Autism Spectrum Disorder Across 3 Domains*

	Strongly Disagree	Moderately Disagree	Moderately Agree	Strongly Agree
<i>Emotional Well-Being</i>				
My child regularly feels sad.	1	2	3	4
My child shows pleasure when learning new skills.	1	2	3	4
My child likes going to school.	1	2	3	4
My child is generally happy.	1	2	3	4
My child sleeps well.	1	2	3	4
My child is relaxed when at home.	1	2	3	4
My child enjoys family activities.	1	2	3	4
<i>Interpersonal Relations</i>	Strongly Disagree	Moderately Disagree	Moderately Agree	Strongly Agree
My child shows pleasure when interacting with other children.	1	2	3	4
My child has other children that will help him or her when needed.	1	2	3	4
My child enjoys playing with groups of children.	1	2	3	4
My child enjoys spending time with family members.	1	2	3	4
My child is happy to work with his or her teacher.	1	2	3	4
My child likes to do many activities with others.	1	2	3	4
My child would like more friends.	1	2	3	4
<i>Self-Determination</i>	Strongly	Moderately	Moderately	Strongly

	Disagree	Disagree	Agree	Agree
My child relies on others to select his or her activities.	1	2	3	4
My child is able to expresses likes.	1	2	3	4
My child selects his or her clothes for the day.	1	2	3	4
My child shows preferences for places he or she would like to go.	1	2	3	4
My child can initiates several tasks independently.	1	2	3	4
My child shows pleasure about a particular activity.	1	2	3	4
My child selects what he or she wants to eat.	1	2	3	4

## APPENDIX F: QUALITY OF LIFE FOR CHILDREN WITH AUTISM SPECTRUM DISORDER SURVEY

Qualtrics Survey Software

8/25/15, 4:22 PM

### Introduction



Thank you for taking the Quality of Life for Children with Autism Spectrum Disorder survey. The information you provide today will help other parents select effective treatments for their children. It should take approximately 5-10 minutes to complete this survey.

For each question, please select the answer that best describes your child during the past 12 months. This survey consists of two main parts. Part 1 assesses your child's quality of life and Part 2 assesses services or treatments your child has received.

### Part 1 Quality of Life

#### Part 1: Quality of Life

My child is generally happy.

Strongly Disagree

Moderately Disagree

Moderately Agree

Strongly Agree

Strongly Agree

Strongly Disagree      Moderately Disagree      Moderately Agree      Strongly Agree



oderately Agree      Strongly Agree

		e	Moderately Agree	Strongly Agree
Strongly Disagree	Moderately Disagree		Moderately Agree	Strongly Agree

Yes

No

hing

ion"  
affect your child's quality of life?

Floor Time

0

Positively

Negatively

Not At All

ositively                      Negatively                      Not At All

5 years old      6 years old      7 years old      8 years old      9 years old      10 years old

Male

Female

survey.

rum Disorder

Figure F.1 *QOL for Children with ASD Survey*