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## The Quality of Life Among Adults with Autism Spectrum Disorder

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**The Quality of Life Among Adults with Autism Spectrum Disorder**

A Thesis Presented  
by  
KATHARINE FRANCES MORONEY

Submitted to the Graduate School of the  
University of Massachusetts Amherst in partial fulfillment  
of the requirements for the degree of

MASTER OF ARTS

MAY 2015

Communication Disorders

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# **The Quality of Life Among Adults with Autism Spectrum Disorder**

A Thesis Presented  
by  
KATHARINE FRANCES MORONEY

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## **ABSTRACT**

### **THE QUALITY OF LIFE AMONG ADULTS WITH AUTISM SPECTRUM DISORDER**

MAY 2015

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Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that may affect several aspects of communication, including social and pragmatic functioning. There is a paucity of research in general involving adults with ASD, especially in the United States. Moreover, the strand of research that is significantly lacking involves the quality of life among adults with ASD. While considering the increase in the prevalence of ASD, it is important to empirically investigate the Quality of Life (QoL) of adults with ASD. The World Health Organization (WHO) defines QoL as, “the individual’s perception of their position in life... ranging from the person’s physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment” (WHO; The WHOQoL Group, 1995). A review of the literature evaluating the QoL of individuals with ASD revealed that the main focus has been on the cognitive functioning and academic achievement; however, these measures alone do not predict QoL (Burgess & Gutstein, 2007). The purpose of this study is to empirically investigate those variables deemed to contribute most to QoL in a sample population of adults (18 years and older) with ASD using a cross-sectional descriptive research method. Participants were age and gender matched with neurotypically developing

individuals. This study identified factors that significantly influenced QoL in a sample population of adults with ASD. Early intervention, including middle and high school transitioning of students with ASD should proactively address those variables that are deemed to yield positive QoL outcomes.

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## CHAPTER 1

### REVIEW OF THE LITERATURE

#### 1.1 Autism Spectrum Disorder

According to the Centers for Disease Control (CDC), one in 68 children are diagnosed with Autism in the United States (CDC, 2014). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published in 2013, defined new criteria for an Autism diagnosis that replaced the previous classifications of Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) with Social (Pragmatic) Communication Disorder (SCD) and Autism Spectrum Disorder (ASD) (American Psychiatric Association, 2013). The DSM-5 (APA, 2013) lists persistent deficits in social aspects of communication and interaction, as well as restricted, repetitive patterns of behavior as characteristics associated with the Autism Spectrum Disorder (ASD). Language abilities are one area that is variable across the spectrum, with skills ranging from non-existent to rather sophisticated (Boucher, 2012; Eigsti, Bennetto, & Dadlani, 2007; Kjelgaard & Tager-Flusberg, 2001; McCabe, Hillier & Shapiro, 2013; Nadig & Shaw, 2012).

The following are the DSM-5's (American Psychiatric Association, 2013) criteria for an ASD diagnosis:

1. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

- a. Deficits in social-emotional reciprocity,
- b. Deficits in nonverbal communicative behaviors used for social interaction,
- c. Deficits in developing, maintaining, and understanding relationships,
- d. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
  - i. Stereotyped or repetitive motor movements, use of objects, or speech,
  - ii. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior.
  - iii. Highly restricted, fixated interests that are abnormal in intensity or focus,
  - iv. Hyper- or hypo activity to sensory input or unusual interest in sensory aspects of the environment.

To qualify for an ASD diagnosis, the aforementioned symptoms must be present currently, or by history in the early developmental period. These symptoms must also contribute to a clinically significant impairment in social, occupational, or other areas of functioning. Finally, these differences should not be better explained by an intellectual disability (intellectual developmental disorder) or a global developmental delay (APA, 2013).

A new diagnostic category in the DSM-5 (2013) includes the symptom complex referred to as Social (Pragmatic) Communication Disorders (SCD). The symptom complex, Asperger's syndrome, no longer appears in the new DSM-5. As

such, the SCD diagnosis may include some individuals who were previously diagnosed with Asperger's syndrome under the DSM-IV (1994). The criteria for a diagnosis of SCD are as follows:

1. Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:
  - a. Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.
  - b. Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on a playground, talking differently to a child than an adult, and avoiding use of overly formal language.
  - c. Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.
  - d. Difficulties understanding what is not explicitly stated (e.g. making inferences) and nonliteral or ambiguous meaning of language (e.g. idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).

These deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination. To qualify for a diagnosis of SCD, the

onset of the symptoms must occur in the early developmental period (but deficits may not fully manifest until social communication demands exceed limited capacities). Also, the symptoms must not be attributable to another medical or neurological condition, or to low abilities in the domains of word structure and grammar, and are not better explained by the Autism Spectrum Disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder (APA, 2013).

## **1.2 Quality of Life**

Considering the increase in prevalence of ASD over the past two decades, it is vital to examine the Quality of Life (QoL) of those affected individuals. The World Health Organization (WHO) defines QoL as, “the individual’s perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns, ranging from the person’s physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment” (WHO; The WHOQoL Group, 1995). A review of the literature regarding the QoL among individuals with ASD revealed a paucity of information on this topic, especially of studies that were completed in the United States. Of the 28 studies reviewed that evaluated QoL measurements for adults and children with ASD, only ten were conducted in the United States (Bastiaansen et al., 2004; Cimeria & Cowan, 2009; Delahaye et al., 2014; Ghaziuddin & Welch, 2013; Lee et al., 2008; Limbers et al., 2009; Marcus et al., 2012; Sheldrick et al., 2012; Sikora et al., 2012;

Tilford et al., 2012). 18 studies were reviewed that were completed outside of the United States. The represented countries are as follows: Amsterdam (Van et al., 2012); Belgium (Renty & Roeyers, 2006); Canada (Jenness-Coussens et al., 2006); France (Cottenceau et al., 2012); Germany (Kamp-Becker et al., 2010); Japan (Kamio et al., 2013); Spain (Garcia-Villamizar et al., 2010; Saldana et al., 2009); Sweden (Billstedt et al., 2011; Persson, 2000); Taiwan (Lin, 2014; Chuang et al., 2014); Turkiye (Kose et al., 2013; Kuhlthau et al., 2010) and the United Kingdom (Totsika et al., 2010; Tavernor et al., 2013).

The review of the literature revealed that the main focus of research completed on this topic focused on the academic achievement and cognitive functioning of individuals with ASD. It was found that these measures alone do not predict QoL (Burgess & Gutstein, 2007). Burgess and Gutstein (2007) suggested that to better study the QoL among adults with ASD, a shift in research to subjective (qualitative) outcome measures should be made. QoL is a multidimensional and subjective phenomenon.

It is clear that a shift to qualitative (subjective) outcome measures to study QoL among those with ASD is needed, especially in adults. Some factors noted to influence QoL included the support from loved ones and friends. For example, Renty and Roeyers (2006) studied 58 adults with High Functioning Autism (HFA) in Belgium and reported that the support these adults received significantly improved their QoL. However, neither the composition of their disability, nor the presence of comorbid conditions influenced QoL. Another study conducted in Belgium (Billstedt, Gillberg, & Gillberg, 2011) revealed that 120 adults between the ages of 18 and 66

diagnosed with ASD reported a relatively high self-perception of QoL among those participants that were still dependent on their parents or guardians for support. These authors reported that occupation and recreational aspects were not studied among for the 120 participants, but should be included in future investigations regarding QoL among adults with ASD. In contrast, an investigation conducted in Spain among adults with ASD reported low levels of QoL, which the authors attributed to ineffective community-based resources (Saldana, Alvarez, Lobaton, Lopez, Moreno, & Rojano, 2009).

A study conducted in China evaluated the health-related quality of life (HRQoL) of children with Autism. Chuang et al. (2014) used the TNO-AZL Preschool Children Quality of Life (TAPQoL-C) to focus on the following domains: physical functioning; social functioning; cognitive functioning; and emotional functioning. Chuang et al. (2014) concluded that children with better physical endurance had increased HRQoL and boys with ASD had a higher HRQoL measure compared to girls with ASD for physical functioning. The authors also conclude that two variables contributed to a higher HRQoL regarding social functioning: children who were less defensive to stimuli; and children whose parents' had a higher socioeconomic status. Another study evaluated the HRQoL for children with ASD. Delahaye et al. (2014) evaluated the relationship between sleep disturbance and health-related quality of life for children with Autism Spectrum Disorder. This study revealed that greater overall sleep problems were associated with a poor physical and psychological HRQoL measure. Sleep duration as well as sleep anxiety were concluded to be negatively associated with the health-related quality of life of their



participants. These studies evaluated different measures of quality of life using a health-related measurement to compare different variables and their effect on the life of a child with Autism Spectrum Disorder.

Regarding the influence of behavior on quality of life, few studies evaluated the relationship between these two variables. Gerber, Baud, Giroud, and Galli (2008) assessed the quality of life of adults with ASD and Intellectual Disability (ID). Gerber et al (2008) concluded that problems with behavior were negatively associated with quality of life of adults with ASD. Gerber et al. (2011) further emphasized this point, agreeing with the negative association between behavior problems and the QoL of adults with ASD. Tilford et al. (2012) studied this topic as well, and concluded that adaptive behavior had a positive correlation with the quality of life of children with Autism Spectrum Disorder. However, Totsika, Hastings, Fece, and Kerr (2010) determined that older adults with Autism Spectrum Disorder presented with fewer behavior problems. Persson (2000) shared insight on the idea that an individual's behaviors reflected how they were feeling, and therefore behaviors could influence an individual's quality of life, whether that was in a positive or negative manner.

The use of control groups has helped to shed light on the relationship the quality of life of individuals' with ASD compared to their peers. The QoL of individuals with Asperger's Syndrome (AS) (now Social (Pragmatic) Communication Disorder) was compared to a control group of individuals without AS. Authors Jennes-Coussens, Magill-Evils and Koining (2006) concluded that the quality of life for individuals with AS was lower, and this group displayed overall QoL, psychological, social, and environmental domain scores that were lower compared

to the group without AS. The domains of social and physical health were found to be significantly lower than the control group. Lee, Harrington, Louie & Newschafer (2008) compared the quality of life of children with ASD compared a control group and found that children with ASD were more likely to repeat a grade in school and miss school for more than one week. This group of children with ASD aged 6-11 were also less likely to participate in activities and events compared to the control group. A group of children aged 12-17 with ASD were found to be more likely to repeat a grade and miss more than a week of school, as well as being less likely to participate in activities, events as well as community service. These factors negatively influenced the quality of life of the children with ASD. Steensel, Bogels, and Dirksen (2012) compared the quality of life of children with ASD to children with Anxiety Disorder (AD). Steensel et al. (2012) concluded that there were no differences in the QoL score between the two groups; however, children with AD over the age of 12 had a higher QoL score compared to the younger children, this effect was not found for the group with ASD.

The quality of life of individual with ASD was commonly compared to the 'healthy population', with findings that represented the QoL of individuals with ASD to be lower compared to the 'healthy population' (Kose et al. , 2013; Kulhthau et al. ,2010; Sheldrick, Neger, Perrin & Perrin, 2012; Sikora, Vora & Rosenberg, 2012; Varni et al. ,2012). An additional study evaluated the quality of life of adults with Autism Spectrum Disorder compared to a control group of typically developing individuals matched for age and sex. The research conducted by Lin (2014), concluded that the adults with ASD scored significantly lower in the domains of:

physical health, psychological health and social relationships. This present study compared a cohort of individuals with ASD to a control group matched for age and gender.

It is important to note that current studies regarding the QoL of adults with ASD do not focus on the same variables that are believed to contribute to QoL. However, literature from Belgium and Spain regarding QoL and ASD revealed a common theme: there is a dire need of the identification of variables that influence QoL, and relating those to the costs of educating and services availability for individuals with ASD. As previously stated, published research supports a shift in the methodology for evaluating QoL in adults with ASD. Future research regarding QoL among adults with ASD should include more subjective outcomes based on the adults' self-perception of QoL and those variables that contribute most to one's quality of life. It is important to evaluate and determine what impact various factors have had on one's perceived QoL and whether some variables, such as educational supports and transition services that these individuals often receive at a younger age, influence QoL among adults with ASD.

An additional consideration in determining QoL is the amount of financial investment in the variables that were found to result in better outcomes regarding college and workforce readiness. The CDC determined that medical expenses were higher for those that have an ASD diagnosis, compared to those that do not. It has been concluded by previously published research that adults diagnosed with ASD typically earn less (and work less) than their neurotypically developing peers. However, it was stated that individuals with ASD were more often employed

compared to other disability groups (Cimera & Cowan, 2009). Despite the challenges faced due to expenses, it is vital that individuals with ASD have the opportunity to enter the workforce and therefore become contributing members of society. As previously stated, there is a significant need to determine which variables contribute most the QoL of individuals with ASD and to evaluate the impact of funding resources that purportedly facilitate positive outcomes in these variables (social skills, job readiness, employment preparation). A more proactive approach is possible, if the content areas that yield better QoL measurements receive adequate focus and attention.

### **1.3 Survey Development Considerations Regarding QoL Measurements**

To develop a survey that examined the content areas that influenced QoL, it was necessary to first review the work previously completed that examined specific variables found to impact QoL. The review of the literature concluded that common methods of recruiting individuals with ASD included: advertisements in ASD advocacy group newsletters; contacting past research participants; mailing questionnaires; and contacting local ASD support groups (Renty & Roeyers, 2006; Kamio et al., 2013; Saldana et al., 2009). These methods were used in this study to recruit participants. Shipman, Sheldrick, and Perrin (2011) indicated that surveys should be issued electronically in that these authors believed that questions asked using an electronic survey method elicited responses that were more accurate in nature. The proposed study was comprised of an electronic survey that was distributed primarily online to the individuals with ASD, and those without.

To date, there is not one specific QoL instrument used for individuals with ASD. In a study completed in Belgium, a QoL measure among adults with ASD utilized the Quality of Life Questionnaire instrument (QoL.Q; Renty & Roeyers, 2006). The QoL.Q was designed to measure the quality of life of individuals with intellectual disabilities, but was modified for a population of individuals with ASD. This questionnaire was made up of four (4) subscales: 1) satisfaction; 2) competency / productivity; 3) empowerment / independence; as well as 4) social belonging / community integration. The QoL instrument utilized by Renty & Roeyers, (2006) was comprised of ten (10) items that were scored using a three-point Likert scale. Other published studies identified in the review of the literature based their instruments on the World Health Organization-Quality of Life-Brief Instrument (WHO-QoL-BREF). This study will follow suit and utilized the WHO-QoL-BREF as a model.

When developing a QoL instrument, it is important to take into consideration the challenges an individual with ASD has when expressing social and emotional ideas. Due to the qualities present in an ASD diagnosis, the individual completing the survey may experience challenges when asked to self-report aspects of their life. A study completed by Shipman, Sheldrick, and Perrin (2011) investigated the reliability, as well as validity, of self-reported data in a QoL survey for adolescents with ASD. These authors noted that even though their subjects reported a QoL score below the population means for all domains, their scores were consistent with their proxy reports completed by the subjects' parents. In conclusion, it is valid to assume

that individuals with ASD can accurately rate aspects of their life in a QoL measurement survey.

#### **1.4 Specific Content Areas That Contribute to QoL**

When developing a survey relating to QoL, it is vital to examine the various content areas that were previously found to contribute to a higher QoL in individuals with ASD. Plimey (2007) purported that the quality of life domains for an individual with Autism Spectrum Disorder included: social interactions; communication; flexibility of thought and behavior; emotional well-being; interpersonal relations; material well-being; personal development; physical well-being; self determination; social inclusion; as well as rights. Burgess and Gutstein (2007) evaluated research that examined QoL literature, specific to individuals with ASD. Burgess and Gutstein (2007) evaluated the 'golden standards' used to evaluate QoL outcomes, and concluded that they agreed with the subjective indicators of physical, emotional, and social functioning measures. Objective measures in the Burgess and Gutstein (2007) study included aspects that were quantifiable (amount of social support) and were noted as important aspects that influenced QoL of individuals with ASD.

To further analyze the QoL of adults with ASD in Great Britain, Burgess and Gutstein (2007) assessed the responses of 450 adults with ASD. These authors collected data on the daily life of the individuals with ASD. Burgess and Gutstein (2007) found that only 3% of respondents lived independently and approximately 49% lived at home. With regard to employment status, it was reported that 12% of

individuals worked full time and were paid a salary. In addition to the reported variables, the authors concluded that 31% of the 450 individuals with ASD that were surveyed had no social interaction with others, with the exception of their families, and 32% reported that they had poor mental health (Burgess and Gutstein, 2007).

The literature available on this topic also shed light on how mainstream measures relating to academic achievement and cognitive functioning were found to not accurately predict QoL. For example, it was established that emotional engagement with peers aided in the improvement of social functioning, rather than improving one's IQ level, for individuals with ASD (McGovern & Sigman, 2005). Kazdin and Weisz (1998) suggested that measures of 'real world' functioning often determine how successful treatment will be. These researchers concluded that cultural and individual self-determination, as well as the psychosocial impact of family life often influenced the life significantly of individuals with ASD. Limbers, Heffer and Varni (2009) reported that due to the lack of multidimensional outcomes that have been validated in research concerning the population of individuals with ASD, there has been a barrier in evaluating the effectiveness of interventions for children with Asperger's Syndrome, and how these interventions impact 'real world' functioning. Burgess and Gutstein (2007) suggested that it is improbable that a single domain will affect one's QoL; it is a multidimensional construct.

The multidimensional construct that makes up QoL has many factors that influenced the outcome for individuals with ASD. Meaningful and paid employment was found to be a prime indicator of QoL (Renty & Royers, 2006). Renty and Royers (2006) concluded that respondents yielded a higher QoL score if they had a job or

were currently furthering their education. Mawhood and Howlin (1999) also added to this topic, shedding light on the idea that although it is common that children with ASD complete mainstream education, they often report low levels of employment in long-term outcomes.

Another aspect found to influence QoL was social support. Research conducted in Sweden found that adults with ASD often depended on parents and caregivers for support in accommodations, education, as well as their occupational situations (Billstedt, Gillberg, & Gillberg, 2011). Two years later, it was found that as individuals with ASD aged, their social outcomes decreased, and their social inclusion became more limited (Howlin, Moss, Savage, & Rutter, 2013). Also in 2013, research completed in Japan concluded that individuals with ASD had significantly lower psychological and social aspects of QoL when compared to neurotypically developing and healthy Japanese individuals (Kamio et al., 2013). Kamino et al. (2013) concluded that social interactions were not the prime indicator of QoL in individuals with ASD; however, support as well as the closeness of friendship had a great impact on QoL.

### **1.5 Previous Pilot Research Conducted by Author**

A pilot study was completed by this author titled the '*Work and Well-Being Survey*' (Hall, Moroney & Andrianopoulos, 2014). The purpose of this study was to pilot the variables (reported in the published literature by mostly international authors) that are deemed to contribute most to QoL in a sample population of adults (18 years and older) with High Functioning Autism (HFA) using a cross-sectional



descriptive research design. This study involved developing the *Work and Well-Being Survey* instrument that included 49 items, or questions that targeted areas related to the following variables: 1) work; 2) employment; 3) well-being, and 4) general outlook on life. These variables were based on the QoL framework developed by the WHO (WHO; The WHOQoL Group, 1995). A sample population of 37 adults with HFA participated in this study. The average age was 33 years. Participants included 22 females and 14 males. More than half (n=21) of the participants had other disabilities or medical conditions aside from their primary diagnosis of Autism. This study also revealed that 39% (n=14) of participants reported that they feel anxious or worried during the day almost always.

Regarding employment, 17 (47%) of the 37 participants currently had jobs. Among these 17 employed individuals, nine graduated from college, three were currently attending college, and one was planning on attending college. Of the 19 or 53% not employed, five graduated from college, six were currently attending college, four were planning on attending college, and four did not plan on attending college. The outcomes of this study also supported that a majority of individuals with HFA were happier engaging in individual activities. Close relationships with friends were most often rated as important (n=15; 42%) or extremely important (n=8; 22%). The importance of safety at work and safety at home were most often rated as important (n=15; 42%) and extremely important (n=11; 31%), respectively. This study revealed that employment or college enrollment, social interactions, and perception of safety had the greatest influence on the QoL among a

sample population of adults with HFA between the ages of 18 and 66 years with a mean age of 33 years.

Although this pilot study laid the preliminary groundwork, there were many limitations that included: 1) a small sample size; 2) a self-reported diagnosis; 3) a possible sample bias (technology, international respondents); and 4) no control group, etc. These limitations were addressed in this investigation and contributed to the newly devised '*Moroney Quality of Life Survey*'. Despite the limitations in the '*Work and Well-Being Survey*' pilot study, the proposed investigation benefited from the outcomes and methodological procedures in the pilot study completed over the course of the last year, in that the proposed study included an age and gender matched control group, a revised and robust survey instrument, and a more psychometrically controlled investigation.

## **1.6 Research Questions**

The purpose of this study is to investigate the following research questions:

1. What specific content areas affect the Quality of Life (QoL) in adults with Autism Spectrum Disorder?
  - a. Null Hypothesis I: There are no reported similarities or differences with respect to content areas that affect the QoL among adults with Autism Spectrum Disorder.
  - b. Alternative Hypothesis I: There are reported similarities or differences with respect to content areas that affect the QoL among adults with Autism Spectrum Disorder.

2. How do the content areas that affect the quality of life (QoL) of adults with Autism Spectrum Disorder compared to the content areas that affect the QoL among neurotypically developing adults that are matched for age and gender?
  - a. Null Hypothesis I: There are no reported similarities or differences with respect to the content areas that affect the QoL of adults with Autism Spectrum Disorder compared to the content areas that affect the QoL among neurotypically developing adults that are matched for age and gender.
  - b. Alternative Hypothesis I: There are reported similarities or differences with respect to the content areas that affect the QoL of adults with Autism Spectrum Disorder compared to the content areas that affect the QoL among neurotypically developing adults that are matched for age and gender.

## **CHAPTER 2**

### **METHODOLOGY**

#### **2.1 Research Design**

This study utilized a cross-sectional descriptive research method to empirically investigate those variables that contribute most to QoL in a sample population of adults (18 years and older) with ASD. A newly devised tool was created, the *'Moroney Quality of Life Survey'* instrument, to survey the sample research participants. This instrument is discussed in greater detail in the sections that follow. The study protocol and survey instrument were approved by the Institutional Review Board at the University of Massachusetts Amherst in August of 2014.

Before submitting this study to the Institutional Review Board (IRB), the principal investigators completed the Collaborative Institutional Training Initiative (CITI) certification through the University of Massachusetts Amherst. The research team then submitted the necessary materials to the campus IRB at the University of Massachusetts Amherst. The study was approved and the researchers began to collect data from the survey responses.

## **2.2 Procedures**

### **2.2.1 Participants**

Individuals were recruited to participate in this research if they were over the age of 18 and diagnosed with Autism, Asperger's Syndrome, or Social Communication Disorder. The goal population for this study was adults with High Functioning Autism (HFA); however, it was anticipated that a few subjects with lower IQs (who would most likely have received assistance to access the survey, and thereby received assistance while taking it) would participate in this study. Adults with HFA commonly have average intelligence, or above average intelligence. Therefore, we felt that this population was competent in understanding the instructions, the language in the Informed Consent Form, and nature of the study before giving their consent to participate. If the participants had any questions about the consent form or the nature of the study, they were encouraged to contact the researchers via the telephone number or email address listed. By agreeing to participate, the researchers assumed that the participants or their guardians /caretakers attested to answering the survey to the best of their ability and their responses were genuine and not fabricated.

To recruit participants, various agencies that were approved through the IRB were contacted by the investigators. Recruitment occurred both in-person and online via social networking. Once participants completed the survey the investigators did not contact them further. The primary form of survey administration was through the online link, Qualtrics, with a small number of surveys completed on paper.

### **2.2.2 Recruitment**

For this research study, recruitment was accomplished both digitally and through face-to-face interactions. Participants for both the cohort of individuals with ASD, and individuals for the control group were recruited through the following mechanisms:

1. Email invitation through Disability Services at various Colleges and Universities;
2. Link posted on Dr. Mary Andrianopoulos' US Department of Education Grant dedicated webpage [www.umass.edu/doegrants/](http://www.umass.edu/doegrants/)
3. Email invitation through Community Resources for People with Autism, Massachusetts;
4. Email invitation through various ASD themed Facebook Pages.

Participants were not provided compensation for their participation in this research study.

### **2.2.3 Survey Instrument**

The *'Moroney Quality of Life Survey'* instrument was developed and included content areas that inquired about: 1) demographic information; 2) current living situation; 3) social support; 4) education and employment; 5) general health; and a rating regarding the level of importance per question items. The *'Moroney Quality of Life Survey'* was comprised of a total of 58 questions that inquired specifically about the individuals' employment, social support, education, interests, and previous experiences. Before the participant completed the survey, they were provided with

an Informed Consent Form at the beginning of the survey. Once the participant provided their consent, they were redirected to the first question of the survey. However, if the participant did not provide consent, they were taken to the end of the survey and thanked for the consideration of participation. The principal investigators estimated that the survey would take the participants between 10-15 minutes to complete. This estimate was based on the time it took individuals with ASD who piloted the *Moroney Quality of Life Survey* to complete it on average. Once the participant submitted their responses, their answers were coded with a unique letter and number based code (provided through the Qualtrics software), and thus the investigators protected the confidentiality of each participant's data. Once the window of responses expired, the principal investigators summarized the data for analysis.

The survey was administered both on paper and online through a link to the survey, which was hosted through Qualtrics (Version 12,018; Qualtrics, 2015). Qualtrics was used as the survey host for this study since it is the sponsored platform for survey research recommended by the University of Massachusetts Amherst. Qualtrics is a secure survey platform. Qualtrics generated a unique number and letter code assigned to each participant in the study for confidentiality. The responses collected from the individual were kept on the Qualtrics server, and only the investigators had access to the information.

### **2.3 Data Analysis**

The form of measurements that were collected through this survey study included: nominal, ordinal, as well as frequency data. Data was entered into an Excel spreadsheet for analysis by the investigators. An item analysis was performed on this data sample for the cohort of individuals with Autism, Asperger's Syndrome, and Social Communication Disorder, as well as those without an ASD diagnosis that were part of the control group.

Data was analyzed using the Paired Sample t-Tests, Chi Square, Phi Coefficient, and the Fisher Exact Probability test. The Paired Sample t-Tests, analyzed 35 pairs of data that were studied to see if the relationship between the group of ASD respondents and their control matches was significant. Chi Square was used to analyze the relationship between variables in a 2x2 grid setting, investigating the statistical significance in the sample. The Phi coefficient examined the statistically significant relationship between two variables that were selected for a correlational analysis. The data was analyzed to determine whether there was a correlation between the respondents answering one question, and their likelihood of answering another question a specific way. The Phi-Coefficient was calculated using a table of frequency data cross-classified according to two categorical variables, X and Y, each of which had two levels or subcategories. The Fisher exact probability test was also used to calculate statistical significance. The Fisher test is a non-parametric statistic traditionally used with relatively small samples. If a sample size was less than five ( $n=5$ ) for a unit in the Chi Square 2x2 grid, the Fisher Test



was used instead to calculate statistical significance. For all analyses, the alpha level was set to 0.05 for statistical significance.

## CHAPTER 3

### RESULTS

#### 3.1 Participants

A total of 402 individuals responded to the survey instrument. Among the 402, 154 respondents were adults with ASD and 248 were adults without ASD. The cohort of individuals with ASD was made up of 37% (n=57) males, 56% (n=86) females and 7% (n=11) 'other'. The mean age of the sample was 38.8 years, the mode age was 45 (n=8), and the median age was 39 years. It was reported that 79% (n=122) lived in the United States. The most represented states were Massachusetts with 14% (n=17) and California with 9% (n=11). 21% (n=32) of respondents did not live in the United States. Regarding the age of diagnosis for this sample, the mean age of diagnosis was 30 years, the median age of diagnosis was 24 years and the mode age of diagnosis was 35 years.

Regarding the cohort of individuals without an ASD diagnosis, 28% (n=69) were males, 71% (n=176) were females and 1% (n=3) reported their gender as 'other'. The mean age of this sample was 40 years, the mode age of this group was 25 years (n=16) and the median age was 41. It was reported that 94% (n=235) lived in the United States. The most represented states were Massachusetts with 46% (n=108) and Michigan with 7% (n=16). 6% of this sample (n=14) did not live in the United States.

To create a sound control group, the respondents with ASD were matched to individuals who did not respond 'yes' to a diagnosis of Autism, Asperger's

Syndrome, or Social Communication Disorder. For comparison purposes, the adults with Autism, Asperger's Syndrome, and Social Communication Disorder were compared to the control group of adults without ASD and were matched for age, gender. The comparison groups were comprised of 282 people total (141 with ASD, 141 without ASD). 222 people were matched for their exact age and gender; however, 26 individuals were matched for their gender and their age within one year. Another 12 respondents were matched for their gender and their age within two years, 6 individuals were matched for gender and their age within three years, another 6 people were matched by gender and age within four years. 10 individuals were able to be matched with their gender and their age within five years.

For comparison purposes and statistical analysis, the investigator only had to eliminate 13 respondents with ASD due to the lack of availability of control participants, as they could not be matched for gender or age within five years. As previously stated, the mean age of the group of individuals with ASD was 38.95 and the mean age of individuals without ASD was 38.91. The difference between the two groups was not statistically significant when measured by a Paired Sample t-test ( $p=0.639$ ).

In the section that follows, data are analyzed first for the group of participants with Autism, Asperger's Syndrome, or Social Communication Disorder, second, for the participants in the control population without ASD, and lastly, as a comparison between the two groups.

### **3.2 'Moroney Quality of Life Survey' Instrument**

In the section that follows, each of the 58 survey items will be enumerated and summary statistics will be provided. In total, 402 surveys were completed in total, 390 surveys were completed online, and 12 surveys were completed on paper. A small sample of individuals requested a paper copy (n=12) due to a poor internet connection. The percentage of responses provided by the participants will be provided under each survey item.

#### **3.2 Target population- Autism, Asperger's Syndrome, or Social Communication Disorder**

The following variable inquired about the participant's demographic information:

##### **Question 1: *Are you receiving assistance taking this survey?***

The following results were obtained for this question (n=154): 5% (n=7) reported that they did receive assistance taking this survey; 95% (n=147) reported that they did not receive assistance taking this survey

##### **Question 2: *If yes, what kind of assistance is being provided?***

The following results were obtained for this question (n=7): of the 5% (n=7) reported that they received assistance, the following assistance was provided: help with typing, help with questions, and support from a home worker and mother

##### **Question 3: *What is your gender?***

The following results were obtained for this question (n=154): 37% (n=57) reported that they were male; 56% (n=86) reported that they were female; 7% (n=11) reported that they identify with their gender as 'other'. The most represented gender of this sample was females (n=86).

**Question 4: *What is your age?***

The following results were obtained for this question (n=154): (n=4) 18; (n=6) 19; (n=3) 20; (n=5) 21; (n=7) 22; (n=4) 23; (n=2) 24; (n=3) 25; (n=3) 26; (n=3) 27; (n=2) 28; (n=3) 29; (n=2) 30; (n=3) 31; (n=5) 32; (n=4) 33; (n=3) 34; (n=3) 35; (n=1) 36; (n=2) 37; (n=7) 38; (n=3) 39; (n=3) 40; (n=3) 41; (n=4) 42; (n=5) 43; (n=4) 44; (n=8) 45; (n=5) 46; (n=5) 47; (n=5) 48; (n=4) 49; (n=2) 51; (n=4) 52; (n=1) 53; (n=2) 54; (n=2) 55; (n=3) 56; (n=2) 57; (n=2) 58; (n=1) 59; (n=3) 60; (n=1) 62; (n=2) 63; (n=1) 64; (n=1) 65; (n=1) 69; (n=1) 73; (n=1) 77.

The following results represent the ages of participants in ranges: 18-20 (n=13); 21-25 (n=21); 26-30 (n=13) 31-35 (n=18); 36-40 (n=16); 41-45 (n=24); 46-50 (n=19); 51-55 (n=11); 56-60 (n=11); 61-65 (n=5); 66-70 (n=1); 71-75 (n=1); 76-80 (n=1).

The most represented age group was 41-45 (n=24) with 15% of the sample.

The mean age in this sample was 38.8. The mode age in this sample was 45 (n=8).

The median age was 39.

**Question 5: *During the academic year, do you currently live in the United States?***

The following results were obtained for this question: 79% (n=122) reported that they do live in the United States during the academic year; 21 % (n=32) reported that they do not live in the United States during the academic year.

**Question 6: *What state do you live in?***

The following results were obtained from this question (n=122): 14% (n=17) Massachusetts; 9% (n=11) California; 7% (n=8) New York; 6% (n=7) Texas; 3% (n=4) New Jersey; 3% (n=4) Florida; 3% (n=4) Alabama; 3% (n=4) Colorado; 3%

(n=4) Pennsylvania; 2% (n=3) North Carolina; 2% (n=3) Idaho; 2% (n=3) Michigan; 2% (n=3) Tennessee; 2% (n=3) Utah; 2% (n=3) Wisconsin; 2% (n=2) Alaska; 2% (n=2) Georgia; 2% (n=2) Arizona; 2% (n=2) Connecticut; 2% (n=2) South Carolina; 2% (n=2) Indiana; 2% (n=2) Oregon; 2% (n=2) Vermont; 2% (n=2) Mississippi; 2% (n=2) Nevada; 2% (n=2) Virginia; 2% (n=2) Illinois; 1% (n=1) Delaware; 1% (n=1) Arkansas; 1% (n=1) New Mexico; 1% (n=1) Kentucky; 1% (n=1) Louisiana; 1% (n=1) New Hampshire; 1% (n=1) West Virginia; 1% (n=1) Nebraska; 1% (n=1) Minnesota; 1% (n=1) Hawaii; 1% (n=1) Missouri; 1% (n=1) Montana; 1% (n=1) Iowa; 1% (n=1) Maryland; 1% (n=1) Kansas; 1% (n=1) Rhode Island; 1% (n=1) Washington;

**Question 7: *During the academic year, what country do you currently live in?***

The following results were obtained from this question (n=32): 25% reported they lived in (n=8) Australia; 25% (n=8) Canada; 19% (n=6) United Kingdom; 9% (n=3) England; 9% (n=3) South Africa; 1% (n=1) France; 1% (n=1) Mexico; 1% (n=1) Sweden; 1% (n=1) Netherlands. The most popular response was a tie between Australia (n=8) and Canada (n=8).

The following variables inquired about the participant's current living situation:

**Question 8: *During the academic year, where do you currently live?***

The following result were obtained from this question (n=152): 66% (n=100) reported living in a house; 28% (n=42) apartment; 7% (n=10) residence hall; 0% (n=0) residential home. The most popular response was living in a house (n=100).

**Question 9: *During the academic year, who do you currently live with?***

The following results were obtained from this question (n=154): 44% (n=68) reported that they live with a spouse or partner; 25% (n=39) live with children; 24% (n=37) live alone; 18% (n=27) live with parents or guardians; 6% (n=9) live with a friend; 4% (n=6) live with an assigned roommate; 1% (n=2) live with a sibling; 1% (n=1) lives with tenants. The most popular response was living with a spouse or partner (n=67).

**Question 10: *During the academic year, do you own or rent the place where you currently live?***

The following results were obtained from this question (n=154): 36% (n=55) reported renting their home or apartment; 38% (n=59) own their own home or apartment; 17% (n=26) live free of cost; 7% (n=11) live in University housing; 2% (n=3) reported 'other'. The most popular response was renting an apartment or home (n=59).

**Question 11: *Do you currently have a driver's license?***

The following results were obtained from this question (n=154): 79% (n=121) reported that they do have a driver's license; 21% (n=33) do not have a driver's license. The most popular response was having a driver's license (n=121).

**Question 12: *Are you registered to vote?***

The following results were obtained from this question (n=154): 87% (n=129) reported that they are registered to vote; 13% (n=25) are not registered to vote. The most popular response was being registered to vote (n=129).

**Question 13: *Do you currently have a pet?***

The following results were obtained from this question (n=154): 70% (n=108) reported that they do have a pet; 30% (n=46) reported that they do not have a pet. The most popular response was having a pet (n=108).

**Question 14: *Are you formally diagnosed with Autism, Asperger's Syndrome, or Social Pragmatic Communication Disorder?***

The following results were obtained from this question: 100% (n=154) reported that they are formally diagnosed with Autism, Asperger's Syndrome, or Social Pragmatic Communication Disorder.

**Question 15: *At what age were you formally diagnosed with Autism, Asperger's Syndrome, or Social Pragmatic Communication Disorder?***

The following results were obtained from this question (n=151): 10% (n=15) reported being diagnosed between the ages of 1-5; 5% (n=8) between the ages of 6-10; 5% (n=8) between the ages of 11-15; 9% (n=14) between the ages of 16-20; 9% (n=13) between the ages of 21-25; 7% (n=10) between the ages of 26-30; 12% (n=18) between the ages of 31-35; 15% (n=23) between the ages of 36-40; 13% (n=20) between the ages of 41-45; 7% (n=10) between the ages of 46-50; 5% (n=7) between the ages of 51-55; 1% (n=2) between the ages of 56-60; 2% (n=3) between the ages of 61-65.

The mean age of participant's diagnosis was 30.2. The median age of diagnosis was 34. The mode age of diagnosis was 35.

**Question 16: *Is anyone in your immediate family (mother, father, brother, sister) formally diagnosed with Autism?***



The following results were obtained from this question (n=154): 56% (n=87) reported that no one in their immediate family is formally diagnosed with Autism; 31% (n=47) have someone in their immediate family formally diagnosed with Autism; 13% (n=20) do not know if someone in their immediate family is formally diagnosed with Autism. The most represented response was not having someone in the immediate family with a formal Autism diagnosis (n=87).

The following variables inquire about the participant's feelings on social support:

**Question 17: *Do you agree with this statement: My family supports me.***

The following results were obtained from this question (n=154): 11% (n=17) reported that they Strongly Disagree with this statement; 11% (n=17) Disagree; 24% (n=37) Neither Agree nor Disagree; 34% (n=52) Agree; 20% (n=31) Strongly Agree.

The mean value was 3.4 (Neither Agree nor Disagree) with a Standard Deviation of 1.24. The most popular response was that individuals agreed with the statement: My family supports me.

**Question 18: *How often do you casually talk with a close friend?***

The following results were obtained from this question (n=154): 8% (n=13) never talk to a close friend; 16% (n=25) talk to a close friend less than once per month; 7% (n=11) talk to a close friend once per month; 18% (n=28) talk to a close friend 2-3 times per month; 14% (n=21) talk to a close friend once per week; 19% (n=30) reported that they talk to a close friend 2-3 times per week; 17% (n=26) talk to a close friend daily.

The mean was 4.3 (2-3 times per month) with a Standard Deviation of 1.95. The most popular response was talking to a close friend 2-3 times per week (n=30).

**Question 19: *If you are feeling sad or depressed, what do you most likely do?***

The following results were obtained from this question (n=154): 69% (n=107) reported that they keep to his or herself when they are sad or depressed; 14% (n=22) talk to a spouse or partner; 10% (n=15) talk to a friend; 6% (n=10) talk to a family member.

The mean response was 3.3 (talk to a family member) with a Standard Deviation of 1.05. The most popular response among individuals diagnosed with ASD was to keep to themselves when feeling sad or depressed (n=107).

**Question 20: *Who do you prefer to spend time with during your free time?***

The following results were obtained from this question (n=152): 48% (n=73) reported that during free time, the respondent prefers to keep to him or herself; 25% (n=38); prefers to spend time with a spouse or partner; 14% (n=22) prefer to spend time with a friend; 8% (n=12) prefer to spend time with a family member; 4% (n=6) prefer to spend time with their pet; 1% (n=1) prefers to spend time with a mentor; 0% (n=0) prefer to spend time with a roommate. The most popular response was spending time alone (n=73).

The following variables inquired about the participant's experiences regarding education and intervention history:

**Question 21: *Were you, or are you currently on an education plan?***

The following results were obtained from this question (n=154): 74% (n=114) reported that while in school they were not, or are currently not on an education

plan; 13% (n=20) were on, or are on an Individualized Education Plan (IEP); 8% (n=13) were on, or are currently on a 504 (Modifications and Accommodations Plan); 5% (n=7) reported 'other'. The most popular response that individuals were not, or are currently not on an education plan (n=113).

**Question 22: *Did you, or do you receive services at school?***

The following results were obtained from this question (n=154): 66% (n=101) reported that they did not, or are not receiving services while in school; 25% (n=39) reported receiving guidance or counseling services; 12% (n=19) reported receiving speech therapy; 7% (n=11) reported receiving occupational therapy; 7% (n=11) reported receiving 'other'; 5% (n=7) reported receiving physical therapy. The most popular response from participants was not receiving services while in school (n=100).

**Question 23: *Did you, or do you receive services outside of school?***

The following results were obtained from this question (n=154): 50% (n=77) reported that they did not, or are not receiving services outside of school; 40% (n=61) reported receiving psychotherapy; 3% (n=5) reported receiving tutoring; 3% (n=4) reported receiving 'other'; 2% (n=3) reported receiving occupational therapy; 1% (n=2) reported receiving speech therapy; 1% (n=2) reported receiving physical therapy. The most popular response from participants was not receiving services outside of school (n=77).

**Question 24: *Did you graduate from high school?***

The following results were obtained from this question (n=154): 90% (n=139) reported that they did graduate from high school; 10% (n=15) reported that they did not graduate from high school.

**Question 25: *Did you go, or are you planning on going to college?***

The following results were obtained from this question (n=139): 55% (n=76) reported they graduated from college; 23% (n=32) reported that they were currently attending college; 16% (n=22) reported that they do not plan on attending college; 6% (n=9) plan on attending college in the future). The most popular response was that participants had already graduated from college (n=76).

**Question 26: *What is your highest degree achieved?***

The following results were obtained from this question (n=139): 32% (n=45) reported some college (one year or more with no degree received); 27% (n=38) earned a Bachelor Degree; 17% (n=23) earned a Master Degree; 12% (n=17) earned their high school diploma; 9% (n=13) reported 'other'; 2% (n=3) earned a Ph.D. The most popular response was participants completing some college (one year or more with no degree received) (n=44).

The following variables inquired about the participants' experiences with employment:

**Question 27: *Do you currently have a job, or did you have a job in the past month?***

The following results were obtained from this question (n=154): 59% (n=91) reported that they do have a job, or have had a job in the past month; 41% (n=63) reported that they do not have a job, or have not had a job in the past month.

**Question 28: *How many hours per week do you, or did you work in the past month?***

The following results were obtained from this question (n=91): 9% (n=8) reported working 0-10 hours per week; 11% (n=10) reported working 11-20 hours per week; 13% (n=12) reported working 21-30 hours per week; 35% (n=32) reported working 31-40 hours per week; 12% (n=11) reported working 41-50 hours per week; 7% (n=6) reported working 51-60 hours per week; 13% (n=12) reported working over 60 hours per week.

The mean response was 4.0 (31-40 hours per week) with a Standard Deviation of 1.72. The most popular response was working 31-40 hours per week (n=31).

**Question 29: *Do you, or did you get paid for your work in the past month?***

The following results were obtained from this question (n=91): 96% (n=87) reported that they do get paid for their work; 4% (n=4) reported that they do not get paid for their work.

**Question 30: *How happy do you, or did you usually feel at work?***

The following results were obtained from this question (n=91): 15% (n=14) reported feeling very happy at work; 35% (n=32) reported feeling happy at work; 30% (n=27) reported feeling neither happy or unhappy at work; 16% (n=15) reported feeling unhappy at work; 3% (n=3) reported feeling very unhappy at work.

The mean response was 2.5 (Happy) with a Standard Deviation of 1.05. The most popular response was feeling happy at work (n=32).

**Question 31: *Do you, or did you have friends at work?***

The following results were obtained from this question (n=91): 58% (n=53) reported having friends at work; 42% (n=38) reported not having friends at work.

**Question 32: *Do you, or did you look forward going to work?***

The following results were obtained from this question (n=91): 63% (n=57) reported looking forward to going to work; 37% (n=34) reported not looking forward to going to work.

**Question 33: *Please share the job that you have, or have had in the past month:***

The following results were obtained from this question (n=89): 3% (n=3) reported working in Accounting / Finance / Insurance positions; 7% (n=6) reported working in Administrative / Clerical positions; 2% (n=2) reported working in Biotech / R&D / Science positions; 2% (n=2) reported working in Business / Strategic Management positions; 7% (n=6) reported working in Creative / Design positions; 8% (n=7) reported working in Customer Support / Client Care positions; 16% (n=14) reported working in Education / Training positions; 2% (n=2) reported working in Engineering positions; 6% (n=5) reported working in Food Services / Hospitality positions; 13% (n=12) reported working in IT / Software Development positions; 3% (n=3) reported working in Legal positions; 2% (n=2) reported working in Logistics / Transportation positions; 11% (n=10) reported working in Medical / Health positions; 3% (n=3) reported working in Project / Program Management positions; 13% (n=12) reported working in Sales / Retail / Business Development positions.

The most represented field of work from this cohort of individuals with ASD was positions regarding Education / Training (n=14).

The following variables inquired about participant's feelings about their general health:

**Question 34: *How would you rate your health?***

The following results were obtained from this question (n=154): 31% (n=48) reported that they are usually very healthy; 51% (n=78) reported that they are usually somewhat healthy; 18% (n=28) reported that they are not usually healthy. The mean response was 1.8 (Usually very healthy) with a Standard Deviation of 0.69. The most popular response was participants reporting that they are usually somewhat healthy (n=78).

**Question 35: *If you have any other disabilities or medical conditions, please chose those found on this list***

The following results were obtained from this question (n=154): 35% (n=54) reported Attention Deficit Disorder / Attention Deficit Hyperactive Disorder; 72% (n=111) Anxiety; 19% (n=29) Asthma; 6% (n=9) Bipolar Disorder; 64% (n=98) Depression; 8% (n=12) Diabetes; 10% (n=15) Hearing Loss; 26% (n=40) Muscular / Joint Pain; 20% (n=31) Obsessive Compulsive Disorder; 13% (n=20) Visual Impairment; 27% (n=41) I do have other disabilities or medical conditions, but none found on this list; 6% (n=10) I do not have other disabilities or medical conditions. The most popular disability or medical condition that participant's recorded was Anxiety (n=111), followed by Depression (n=98).

**Question 36: *Do you take prescribed medication, or have you taken any prescribed medication in the past six months?***

The following results were obtained from this question (n=154): 72% (n=111) reported taking prescribed medication in the past six months; 28% (n=43) reported not taking prescribed medication in the past six months.

The participants rated the following statements on importance:

**Question 37: *How safe you feel at home***

The following results were obtained from this question (n=153): 0% (n=0) reported Not Important; 3% (n=5) reported Slightly Important; 7% (n=10) reported Somewhat Important; 22% (n=33) reported Important; 69% (n=105) reported Extremely Important.

The minimum value was 2 (Slightly Important), the maximum value was 5 (Extremely Important). The mean response was 4.5 (Important- Extremely Important) and the Standard Deviation was 0.76. The most popular response was that home safety was extremely important (n=105).

**Question 38: *How safe you feel at work***

The following results were obtained from this question (n=153): 6% (n=9) reported Not Important; 1% (n=2) reported Slightly Important; 13% (n=20) reported Somewhat Important; 42% (n=64) reported Important; 38% (n=58) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 4.(Important) and the Standard Deviation was 0.76. The most popular response was that participants felt work safety was important (n=64).

**Question 39: *Close relationships with family***



The following results were obtained from this question (n=153): 5% (n=8) reported Not Important; 13% (n=20) reported Slightly Important; 25% (n=38) reported Somewhat Important; 31% (n=48) reported Important; 25% (n=39) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 3.5 (Somewhat Important- Important) and the Standard Deviation was 1.16. The most popular response was that participants felt that close relationships with family was somewhat important (n=48).

**Question 40: *Close relationships with friends***

The following results were obtained from this question (n=153): 7% (n=11) reported Not Important; 14% (n=22) reported Slightly Important; 33% (n=50) reported Somewhat Important; 31% (n=47) reported Important; 15% (n=23) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 3.3 (Somewhat Important) and the Standard Deviation was 1.12. The most popular response was that participants felt that close relationships with family was slightly important (n=50).

**Question 41: *Being in a romantic relationship***

The following results were obtained from this question (n=153): 16% (n=25) reported Not Important; 16% (n=25) reported Slightly Important; 22% (n=33) reported Somewhat Important; 25% (n=38) reported Important; 21% (n=32) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 3.1 (Somewhat Important) and the Standard Deviation was 1.37. The most popular response was that participants felt that being in a romantic relationship was somewhat important (n=38).

**Question 42: *Being a part of an online community (Facebook, Twitter etc.)***

The following results were obtained from this question (n=153): 16% (n=25) reported Not Important; 20% (n=31) reported Slightly Important; 18% (n=28) reported Somewhat Important; 27% (n=41) reported Important; 18% (n=28) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 3.1 (Somewhat Important) and the Standard Deviation was 1.86. The most popular response was that participants felt that being a part of an online community was important (n=41).

These variables asked the respondent to rate the following statements on how happy they would make them feel:

**Question 43: *Attending a nightclub alone***

The following results were obtained from this question (n=154): 61% (n=94) reported Very Unhappy; 16% (n=25) reported Unhappy; 8% (n=12) reported Somewhat Unhappy; 9% (n=14) reported Neither Happy nor Unhappy; 5% (n=7) reported Somewhat Happy; 1% (n=2) reported Happy; 0% (n=0) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 6 (Happy). The mean response was 1.84 (Very Unhappy- Unhappy) and the Standard Deviation was

1.29. The most popular response was that participants felt that going to a nightclub alone made them feel very unhappy (n=94).

**Question 44: *Attending a nightclub with friends***

The following results were obtained from this question (n=154): 26% (n=40) reported Very Unhappy; 16% (n=24) reported Unhappy; 12% (n=18) reported Somewhat Unhappy; 20% (n=31) reported Neither Happy nor Unhappy; 16% (n=25) reported Somewhat Happy; 8% (n=13) reported Happy; 2% (n=3) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 3.2 (Somewhat Happy) and the Standard Deviation was 1.76. The most popular response was that participants felt that going to a nightclub with friends made them feel very unhappy (n=40).

**Question 45: *Attending a live sporting event alone***

The following results were obtained from this question (n=154): 49% (n=75) reported Very Unhappy; 12% (n=19) reported Unhappy; 10% (n=15) reported Somewhat Unhappy; 14% (n=21) reported Neither Happy nor Unhappy; 10% (n=16) reported Somewhat Happy; 5% (n=7) reported Happy; 1% (n=1) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 2.41 (Unhappy) and the Standard Deviation was 1.67. The most popular response was that participants felt that attending a live sporting event alone made them feel very unhappy (n=75).

**Question 46: *Attending a live sporting event with friends***

The following results were obtained from this question (n=154): 24% (n=37) reported Very Unhappy; 9% (n=14) reported Unhappy; 11% (n=17) reported Somewhat Unhappy; 18% (n=27) reported Neither Happy nor Unhappy; 24% (n=37) reported Somewhat Happy; 12% (n=19) reported Happy; 2% (n=3) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 3.53 (Somewhat Unhappy) and the Standard Deviation was 1.83. The most popular response was that participants felt that attending a live sporting event with friends made them feel very unhappy and neither unhappy nor happy (n=37).

**Question 47: *Going to restaurants alone***

The following results were obtained from this question (n=154): 17% (n=26) reported Very Unhappy; 12% (n=19) reported Unhappy; 8% (n=12) reported Somewhat Unhappy; 32% (n=49) reported Neither Happy nor Unhappy; 16% (n=24) reported Somewhat Happy; 10% (n=16) reported Happy; 5% (n=8) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 3.69 (Somewhat Unhappy- Neither Happy nor Unhappy) and the Standard Deviation was 1.75. The most popular response was that participants felt that going to restaurants alone made them feel neither happy nor unhappy (n=49).

**Question 48: *Going to restaurants with friends***

The following results were obtained from this question (n=154): 3% (n=4) reported Very Unhappy; 3% (n=5) reported Unhappy; 8% (n=12) reported Somewhat Unhappy; 13% (n=20) reported Neither Happy nor Unhappy; 36% (n=55) reported Somewhat Happy; 27% (n=42) reported Happy; 10% (n=16) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 4.99 (Somewhat Happy) and the Standard Deviation was 1.36. The most popular response was that participants felt that going to restaurants with friends made them feel somewhat happy (n=55).

**Question 49: *Watching television / movies alone***

The following results were obtained from this question (n=154): 2% (n=3) reported Very Unhappy; 1% (n=1) reported Unhappy; 5% (n=7) reported Somewhat Unhappy; 20% (n=31) reported Neither Happy nor Unhappy; 21% (n=32) reported Somewhat Happy; 24% (n=37) reported Happy; 28% (n=43) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.41 (Somewhat Happy) and the Standard Deviation was 1.4. The most popular response was that participants felt that watching televisions or movies alone made them feel very happy (n=43).

**Question 50: *Watching television / movies with friends***

The following results were obtained from this question (n=154): 4% (n=6) reported Very Unhappy; 3% (n=4) reported Unhappy; 5% (n=7) reported Somewhat Unhappy; 23% (n=35) reported Neither Happy nor Unhappy; 27% (n=41) reported Somewhat Happy; 24% (n=37) reported Happy; 16% (n=24) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5 (Somewhat Happy) and the Standard Deviation was 1.46. The most popular response was that participants felt that watching television or movies with friends made them feel somewhat happy (n=41).

**Question 51: *Playing video games alone***

The following results were obtained from this question (n=154): 6% (n=10) reported Very Unhappy; 6% (n=10) reported Unhappy; 3% (n=4) reported Somewhat Unhappy; 25% (n=39) reported Neither Happy nor Unhappy; 18% (n=28) reported Somewhat Happy; 19% (n=30) reported Happy; 21% (n=33) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 4.86 (Neither Happy nor Unhappy- Somewhat Happy) and the Standard Deviation was 1.74. The most popular response was that participants felt that playing video games alone made them feel neither happy nor unhappy (n=39).

**Question 52: *Playing video games with friends***

The following results were obtained from this question (n=154): 8% (n=13) reported Very Unhappy; 9% (n=14) reported Unhappy; 8% (n=13) reported Somewhat Unhappy; 29% (n=45) reported Neither Happy nor Unhappy; 18% (n=27) reported Somewhat Happy; 16% (n=25) reported Happy; 11% (n=17) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 4.31 (Neither Happy nor Unhappy) and the

Standard Deviation was 1.72. The most popular response was that participants felt that playing video games with friends made them feel neither happy nor unhappy (n=45).

**Question 53: *Using the computer***

The following results were obtained from this question (n=154): 1% (n=1) reported Very Unhappy; 1% (n=1) reported Unhappy; 0% (n=0) reported Somewhat Unhappy; 12% (n=18) reported Neither Happy nor Unhappy; 19% (n=29) reported Somewhat Happy; 25% (n=39) reported Happy; 43% (n=66) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.95 (Somewhat Happy- Happy) and the Standard Deviation was 1.16. The most popular response was that participants felt that using the computer made them feel very happy (n=66).

**Question 54: *Listening to music***

The following results were obtained from this question (n=154): 0% (n=0) reported Very Unhappy; 1% (n=1) reported Unhappy; 1% (n=1) reported Somewhat Unhappy; 6% (n=10) reported Neither Happy nor Unhappy; 19% (n=30) reported Somewhat Happy; 29% (n=44) reported Happy; 44% (n=68) reported Very Happy. The minimum value was 2 (Unhappy), the maximum value was 7 (Very Happy). The mean response was 6.07 (Happy) and the Standard Deviation was 1.03. The most popular response was that participants felt that listening to music made them feel very happy (n=68).

**Question 55: *Exercising***

The following results were obtained from this question (n=154): 5% (n=8) reported Very Unhappy; 5% (n=7) reported Unhappy; 5% (n=7) reported Somewhat Unhappy; 23% (n=35) reported Neither Happy nor Unhappy; 27% (n=41) reported Somewhat Happy; 20% (n=31) reported Happy; 16% (n=25) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 4.86 (Neither Happy nor Unhappy- Somewhat Happy) and the Standard Deviation was 1.58. The most popular response was that participants felt that exercising made them feel somewhat happy (n=41).

**Question 56: *Cooking***

The following results were obtained from this question (n=154): 7% (n=11) reported Very Unhappy; 6% (n=10) reported Unhappy; 7% (n=11) reported Somewhat Unhappy; 19% (n=30) reported Neither Happy nor Unhappy; 21% (n=32) reported Somewhat Happy; 24% (n=37) reported Happy; 15% (n=23) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 4.72 (Neither Happy nor Unhappy- Somewhat Happy) and the Standard Deviation was 1.73. The most popular response was that participants felt that cooking made them feel happy (n=37).

**Question 57: *If you had services or other support available to you, what do you think you would benefit from?***

The following results were obtained from this question (n=121): 5% (n=6) reported they would benefit from an Advocate; 1% (n=1) Anxiety Support; 2% (n=2) Audio Therapy; 5% (n=6) Career Counseling; 2% (n=3) Cognitive Behavioral Therapy;



15% (n=18) Psychotherapy; 2% (n=2) Disability Support- Education; 1% (n=1) Employment Support; 7% (n=8) Executive Functioning; 1% (n=1) Exercise / Fitness Support; 6% (n=7) Family / Public Education; 2% (n=2) Financial Assistance; 1% (n=1) Healthcare Support; 1% (n=1) Homecare Support; 1% (n=1) Immediate Support- Emergencies; 2% (n=3 )Mentoring; 1% (n=1) Nutritionist; 4% (n=5) Occupational Therapy; 5% (n=6) Physical Therapy; 1% (n=1) Recreational Activities; 1% (n=1) Relaxation / Stress Management; 2% (n=2) Residential Support; 1% (n=1) Respite; 1% (n=1) Sensory Integration Therapy; 1% (n=1) Sexual Counseling; 34% (n= 41) Social Group; 2% (n=3) Speech Therapy; 35% (n=42) Support Group; 1% (n=1) Technology Classes; 2% (n=3) Transportation Services; 1% (n=1) Tutoring; 1% (n=1) Vision Therapy.

The most requested service were support groups (n=42) and social groups (n=41).

The total responses received for this question was 174 .

**Question 58: *Do you still want your responses recorded for this study?***

The following results were obtained from this question: 100% (n=154) reported that they do want their responses recorded for this study; 0% (n=0) reported that they did not want their responses recorded for this study.

**3.3 Control population- Not diagnosed with Autism, Asperger's Syndrome, or Social Communication Disorder**

The following variable inquired about the participant's demographic information:

**Question 1: *Are you receiving assistance taking this survey?***

The following results were obtained for this question: 1% (n=1) reported that they did receive assistance taking this survey; 99% (n=247) reported that they did not receive assistance taking this survey

**Question 2: *If yes, what kind of assistance is being provided?***

The following results were obtained for this question: of the 1% (n=1) reported that they received assistance, the following assistance was provided: another person for help with questions.

**Question 3: *What is your gender?***

The following results were obtained for this question: 28% (n=69) reported that they were male; 71% (n=176) reported that they were female; 1% (n=3) reported that they identify with their gender as 'other'. The most represented gender of this sample was females (n=176).

**Question 4: *What is your age?***

The following results were obtained for this question: (n=4) 18; (n=2) 19; (n=4) 20; (n=5) 21; (n=7) 22; (n=10) 23; (n=14) 24; (n=16) 25; (n=2) 26; (n=9) 27; (n=5) 28; (n=5) 29; (n=5) 30; (n=7) 31; (n=2) 32; (n=1) 33; (n=4) 34; (n=4) 35; (n=2) 36; (n=4) 37; (n=4) 38; (n=1) 39; (n=3) 40; (n=4) 41; (n=3) 42; (n=7) 43; (n=4) 44; (n=8) 45; (n=7) 46; (n=7) 47; (n=4) 48; (n=6) 49; (n=9) 50; (n=3) 51; (n=7) 52; (n=7) 53; (n=10) 54; (n=3) 55; (n=6) 56; (n=7) 57; (n=2) 58; (n=4) 59; (n=5) 60; (n=2) 61; (n=3) 62; (n=2) 63; (n=2) 64; (n=2) 65; (n=2) 66; (n=2) 69.

The following results represent the ages of participants in ranges: 18-20 (n=10); 21-25 (n=52); 26-30 (n=26) 31-35 (n=18); 36-40 (n=14); 41-45 (n=26); 46-50 (n=33);

51-55 (n=30); 56-60 (n=24); 61-65 (n=11); 66-70 (n=4); 71-75 (n=0); 76-80 (n=0).

The most represented age group was 21-25 (n=52).

The mean age in this sample was 40. The median age in this sample was 41.5. The mode age was 25 (n=16).

**Question 5: *During the academic year, do you currently live in the United States?***

The following results were obtained for this question: 94% (n=235) reported that they do live in the United States during the academic year; 6% (n=14) reported that they do not live in the United States during the academic year

**Question 6: *What state do you live in?***

The following results were obtained from this question (n=234): 46% reported they lived in (n=108) Massachusetts; 4% (n=10) California; 3% (n=6) New York; 1% (n=2) Ohio; 2% (n=5) Texas; 2% (n=4) Florida; 1% (n=2) Colorado; 1% (n=2) New Jersey; 1% (n=3) Pennsylvania; 1% (n=2) Maine; 7% (n=16) Michigan; 1% (n=2) Wisconsin; 1% (n=2) North Carolina; 3% (n=6) Georgia; 3% (n=7) Connecticut; 6% (n=14) Alaska; <1% (n=1) Arizona; <1% (n=1) South Carolina; <1% (n=1) Mississippi; 3% (n=6) Virginia; <1% (n=1) Vermont; <1% (n=1) Oregon; 3% (n=6) Illinois; <1% (n=1) Missouri; <1% (n=1) Iowa; 3% (n=7) Maryland; 1% (n=2) Washington; 1% (n=3) Rhode Island; <1% (n=1) Kansas; <1% (n=1) Hawaii; 2% (n=5) New Hampshire; <1% (n=1) West Virginia; <1% (n=1) Nebraska; <1% (n=1) Arkansas; 1% (n=2) Minnesota. The most popular response was Massachusetts with 46% (n=108)

**Question 7: *During the academic year, what country do you currently live in?***

The following results were obtained from this question (n=17): 31% reported they lived in (n=4) Australia; 23% (n=3) Brazil; 8% (n=1) Canada; 15% (n=2) South Africa; 8% (n=1) Guatemala; 8% (n=1) Columbia; 8% (n=1) Netherlands. The most popular response was Australia (n=4).

The following variables inquired about the participant's current living situation:

**Question 8: *During the academic year, where do you currently live?***

The following result were obtained from this question (n=248): 71% (n=175) reported living in a house; 23% (n=58) apartment; 3% (n=8) residence hall; 2% (n=6) residential home; <1% (n=1) mobile home. The most popular response was living in a house (n=100).

**Question 9: *During the academic year, who do you currently live with?***

The following results were obtained from this question (n=248): 55% (n=137) reported that they live with a spouse/ partner; 27% (n=67) live with children; 11% (n=28) live alone; 11% (n=27) live with parents or guardians; 12% (n=30) live with a friend; 4% (n=9) live with an assigned roommate; 2% (n=4) live with a sibling. The most popular response was living with a spouse or partner (n=137).

**Question 10: *During the academic year, do you own or rent the place where you currently live?***

The following results were obtained from this question (n=248): 31% (n=78) reported renting their home or apartment; 53% (n=132) own their own home or apartment; 10% (n=26) live free of cost; 4% (n=11) live in University housing; <1% (n=1) 'other'. The most popular response was owning a home or apartment (n=132).

**Question 11: *Do you currently have a driver's license?***

The following results were obtained from this question (n=248): 98% (n=242) reported that they do have a driver's license; 2% (n=6) do not have a driver's license. The most popular response was having a driver's license (n=242).

**Question 12: *Are you registered to vote?***

The following results were obtained from this question (n=248): 93% (n=231) reported that they are registered to vote; 7% (n=17) are not registered to vote. The most popular response was being registered to vote (n=231).

**Question 13: *Do you currently have a pet?***

The following results were obtained from this question (n=248): 64% (n=158) reported that they do have a pet; 36% (n=90) reported that they do not have a pet. The most popular response was having a pet (n=158).

**Question 14: *Are you formally diagnosed with Autism, Asperger's Syndrome, or Social Pragmatic Communication Disorder?***

The following results were obtained from this question (n=248): 100% (n=248) reported that they are not formally diagnosed with Autism, Asperger's Syndrome, or Social Pragmatic Communication Disorder.

**Question 15: *At what age were you formally diagnosed with Autism, Asperger's, or Social Pragmatic Communication Disorder?***

N/A

**Question 16: *Is anyone in your immediate family (mother, father, brother, sister) formally diagnosed with Autism?***

The following results were obtained from this question (n=248): 85% (n=211) reported that no one in their immediate family is formally diagnosed with Autism; 13% (n=31) have someone in their immediate family formally diagnosed with Autism; 2% (n=6) do not know if someone in their immediate family is formally diagnosed with Autism. The most represented response was not having someone in the immediate family with a formal Autism diagnosis (n=211).

The following variables inquire about the participant's feelings on social support:

**Question 17: *Do you agree with this statement: My family supports me.***

The following results were obtained from this question (n=248): 8% (n=21) reported that they Strongly Disagree with this statement; 3% (n=8) Disagree; 9% (n=22) Neither Agree nor Disagree; 28% (n=70) Agree; 51% (n=127) Strongly Agree.

The mean value was 4.1 (Agree) with a Standard Deviation of 1.22. The most popular response was that individuals strongly agreed with the statement: My family supports me.

**Question 18: *How often do you casually talk with a close friend?***

The following results were obtained from this question (n=248): 3% (n=7) never talk to a close friend; 8% (n=19) talk to a close friend less than once per month; 4% (n=9) talk to a close friend once per month; 11% (n=27) talk to a close friend 2-3 times per month; 13% (n=31) talk to a close friend once per week; 29% (n=72) reported that they talk to a close friend 2-3 times per week; 33% (n=83) talk to a close friend daily.

The mean response was 5.4 (once per week) with a Standard Deviation of 1.69. The most popular response was talking to a close friend daily (n=83).

**Question 19: *If you are feeling sad or depressed, what do you most likely do?***

The following results were obtained from this question (n=248): 25% (n=62) reported that they keep to his or herself when they are sad or depressed; 30% (n=75) talk to a spouse or partner; 12% (n=30) talk to a friend; 33% (n=81) talk to a family member.

The mean response was 2.5 (talk to a spouse or partner- talk to a family member) with a Standard Deviation of 1.19. The most popular response among individuals was talking to a family member (n=81).

**Question 20: *Who do you prefer to spend time with during your free time?***

The following results were obtained from this question (n=248): 20% (n=49) reported that during free time, the respondent prefers to keep to him or herself; 47% (n=116); prefers to spend time with a spouse or partner; 21% (n=53) prefer to spend time with a friend; 12% (n=29) prefer to spend time with a family member; 0% (n=0) prefer to spend time with their pet; <1% (n=1) prefers to spend time with a roommate; 0% (n=0) prefer to spend time with a. The most popular response was spending time with a spouse or partner 32% (n=116).

The following variables inquire about the participant's experiences regarding education and intervention history:

**Question 21: *Were you, or are you currently on an education plan?***

The following results were obtained from this question (n=248): 97% (n=240) reported that while in school they were not, or are currently not on an education

plan; 1% (n=3) were on, or are on an Individualized Education Plan (IEP); 2% (n=5) were on, or are currently on a 504 (Modifications and Accommodations Plan); 0% (n=0) reported 'Other'. The most popular response was not from individuals not on, or not currently on an education plan (n=240).

**Question 22: *Did you, or do you receive services at school?***

The following results were obtained from this question (n=248): 84% (n=213) reported that they did not, or are not receiving services while in school; 7% (n=17) reported receiving guidance or counseling services; 7% (n=17) reported receiving speech therapy; 0% (n=0) reported receiving occupational therapy; 2% (n=5) reported receiving 'other'; 1% (n=3) reported receiving physical therapy. The most popular response from participants was not receiving services while in school (n=213).

**Question 23: *Did you, or do you receive services outside of school?***

The following results were obtained from this question (n=248): 84% (n=209) reported that they did not, or are not receiving services outside of school; 8% (n=20) reported receiving psychotherapy; 4% (n=10) reported receiving tutoring; <1% (n=1) reported receiving 'other'; 0% (n=0) reported receiving occupational therapy; 0% (n=0) reported receiving speech therapy; 3% (n=8) reported receiving physical therapy. The most popular response from participants was not receiving services outside of school (n=209).

**Question 24: *Did you graduate from high school?***



The following results were obtained from this question (n=248): 95% (n=236) reported that they did graduate from high school; 5% (n=12) reported that they did not graduate from high school.

**Question 25: *Did you go, or are you planning on going to college?***

The following results were obtained from this question (n=236): 70% (n=166) reported they had had graduated from college; 13% (n=31) reported that they were currently attending college; 13% (n=30) reported that they do not plan on attending college; 4% (n=9) plan on attending college in the future). The most popular response was that participants had already graduated from college (n=166).

**Question 26: *What is your highest degree achieved?***

The following results were obtained from this question (n=236): 19% (n=45) reported some college (one year or more with no degree received); 39% (n=91) earned a Bachelor Degree; 26% (n=62) earned a Master Degree; 7% (n=17) earned their high school diploma; 5% (n=11) reported 'Other'; 4% (n=10) earned a Ph.D. The most popular response was participants completing a Bachelor Degree (n=91).

The following variables inquired about the participant's experiences with employment:

**Question 27: *Do you currently have a job, or did you have a job in the past month?***

The following results were obtained from this question (n=248): 81% (n=201) reported that they do have a job, or have had a job in the past month; 19% (n=47) reported that they do not have a job or have not had a job in the past month.

**Question 28: *How many hours per week do you, or did you work in the past month?***

The following results were obtained from this question (n=201): 6% (n=12) reported working 0-10 hours per week; 7% (n=15) reported working 11-20 hours per week; 8% (n=17) reported working 21-30 hours per week; 28% (n=57) reported working 31-40 hours per week; 27% (n=55) reported working 41-50 hours per week; 8% (n=17) reported working 51-60 hours per week; 14% (n=28) reported working over 60 hours per week.

The mean response was 4.45 (31-40 hours per week) with a Standard Deviation of 1.61. The most popular response was working 31-40 hours per week (n=57).

**Question 29: *Do you, or did you get paid for your work in the past month?***

The following results were obtained from this question (n=201): 96% (n=193) reported that they do get paid for their work; 4% (n=8) reported that they do not get paid for their work.

**Question 30: *How happy do you, or did you usually feel at work?***

The following results were obtained from this question (n=201): 16% (n=33) reported feeling very happy at work; 60% (n=120) reported feeling happy at work; 18% (n=37) reported feeling neither happy or unhappy at work; 4% (n=9) reported feeling unhappy at work; 1% (n=2) reported feeling very unhappy at work.

The mean response was 2.14 (Happy) with a Standard Deviation of 0.77. The most popular response was feeling happy at work (n=120).

**Question 31: *Do you, or did you have friends at work?***

The following results were obtained from this question (n=201): 88% (n=177) reported having friends at work; 12% (n=24) reported not having friends at work.

**Question 32: *Do you, or did you look forward going to work?***

The following results were obtained from this question (n=201): 79% (n=158) reported looking forward to going to work; 21% (n=43) reported not looking forward to going to work.

**Question 33: *Please share the job that you have, or have had in the past month:***

The following results were obtained from this question (n=183): 3% (n=5) reported working in Accounting / Finance / Insurance positions; 16% (n=30) reported working in Administrative / Clerical positions; 5% (n=10) reported working in Biotech / Research and Design / Science; 4% (n=8) reported working in Business / Strategic Management positions; 3% (n=5) reported working in Creative / Design positions; 1% (n=1) reported working in Editorial / Writing; 2% (n=4) reported working in Customer Support / Client Care positions; 33% (n=61) reported working in Education / Training positions; 1% (n=1) reported working in Engineering positions; 5% (n=9) reported working in Food Services / Hospitality positions; 1% (n=1) reported working in Human Resources; 5% (n=10) reported working in IT / Software Development positions; 1% (n=1) reported working in Legal positions; 2% (n=4) reported working in Logistics / Transportation positions; 11% (n=20) reported working in Medical / Health positions; 2% (n=4) reported working in Project / Program Management positions; 5% (n=9) reported working in Sales / Retail / Business Development positions. The most represented field from this

cohort of individuals without ASD were positions regarding Education / Training 25% (n=61).

The following variables inquired about participant's feelings about their general health:

**Question 34: *How would you rate your health?***

The following results were obtained from this question (n=248): 64% (n=158) reported that they are usually very healthy; 31% (n=77) reported that they are usually somewhat healthy; 5% (n=13) reported that they are not usually healthy. The mean response was 1.42 (Usually very healthy) with a Standard Deviation of 0.59. The most popular response was participants reporting that they are usually somewhat healthy (n=158).

**Question 35: *If you have any other disabilities or medical conditions, please chose those found on this list***

The following results were obtained from this question (n=248): 9% (n=23) reported Attention Deficit Disorder / Attention Deficit Hyperactive Disorder; 27% (n=66) Anxiety; 12% (n=30) Asthma; 3% (n=8) Bipolar Disorder; 20% (n=49) Depression; 3% (n=7) Diabetes; 6% (n=14) Hearing Loss; 16% (n=39) Muscular / Joint Pain; 6% (n=15) Obsessive Compulsive Disorder; 8% (n=20) Visual Impairment; 23% (n=57) I do have other disabilities or medical conditions, but none found on this list; 38% (n=95) I do not have other disabilities or medical conditions. The most popular disability or medical condition that participant's recorded was Anxiety, followed by Depression.

**Question 36: *Do you take prescribed medication, or have you taken any prescribed medication in the past six months?***

The following results were obtained from this question (n=248): 60% (n=150) reported taking prescribed medication in the past six months; 40% (n=98) reported not taking prescribed medication in the past six months.

The participants rated the following statements on importance:

**Question 37: *How safe you feel at home***

The following results were obtained from this question (n=248): 2% (n=5) reported Not Important; 2% (n=4) reported Slightly Important; 6% (n=14) reported Somewhat Important; 18% (n=45) reported Important; 73% (n=180) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 4.5 (Important- Extremely Important) and the Standard Deviation was 0.84. The most popular response was that home safety was extremely important (n=189).

**Question 38: *How safe you feel at work***

The following results were obtained from this question (n=248): 2% (n=5) reported Not Important; 4% (n=11) reported Slightly Important; 7% (n=17) reported Somewhat Important; 31% (n=76) reported Important; 56% (n=139) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 4.34 (Important) and the Standard Deviation

was 0.93. The most popular response was that participants felt work safety was extremely important (n=139).

**Question 39: *Close relationships with family***

The following results were obtained from this question (n=248): 2% (n=4) reported Not Important; 1% (n=3) reported Slightly Important; 9% (n=22) reported Somewhat Important; 24% (n=59) reported Important; 65% (n=160) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 4.48 (Important) and the Standard Deviation was 0.83. The most popular response was that participants felt that close relationships with family was extremely important (n=160).

**Question 40: *Close relationships with friends***

The following results were obtained from this question (n=248): 2% (n=4) reported Not Important; 4% (n=11) reported Slightly Important; 13% (n=31) reported Somewhat Important; 36% (n=90) reported Important; 45% (n=112) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 4.19 (Important) and the Standard Deviation was 0.93. The most popular response was that participants felt that close relationships with family was extremely important (n=112).

**Question 41: *Being in a romantic relationship***

The following results were obtained from this question (n=248): 6% (n=16) reported Not Important; 8% (n=20) reported Slightly Important; 25% (n=62)

reported Somewhat Important; 34% (n=85) reported Important; 26% (n=65) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 3.66 (Somewhat Important- Important) and the Standard Deviation was 1.14. The most popular response was that participants felt that being in a romantic relationship was important (n=85).

**Question 42: *Being a part of an online community (Facebook, Twitter etc.)***

The following results were obtained from this question (n=248): 28% (n=70) reported Not Important; 29% (n=71) reported Slightly Important; 25% (n=61) reported Somewhat Important; 11% (n=27) reported Important; 8% (n=19) reported Extremely Important.

The minimum value was 1 (Not Important), the maximum value was 5 (Extremely Important). The mean response was 2.41 ( Slightly Important) and the Standard Deviation was 1.22. The most popular response was that participants felt that being a part of an online community was slightly important (n=71).

These variables asked the respondent to rate the following statements on how happy they would make them feel:

**Question 43: *Attending a nightclub alone***

The following results were obtained from this question (n=248): 38% (n=95) reported Very Unhappy; 22% (n=54) reported Unhappy; 10% (n=24) reported Somewhat Unhappy; 23% (n=58) reported Neither Happy nor Unhappy; 4% (n=11) reported Somewhat Happy; 2% (n=5) reported Happy; <1% (n=1) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 2.42 (Unhappy) and the Standard Deviation was 1.44. The most popular response was that participants felt that going to a nightclub alone made them feel very unhappy (n=95).

**Question 44: *Attending a nightclub with friends***

The following results were obtained from this question (n=248): 6% (n=16) reported Very Unhappy; 5% (n=13) reported Unhappy; 10% (n=25) reported Somewhat Unhappy; 14% (n=34) reported Neither Happy nor Unhappy; 30% (n=74) reported Somewhat Happy; 25% (n=62) reported Happy; 10% (n=24) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 4.69 (Neither Happy nor Unhappy- Somewhat Happy) and the Standard Deviation was 1.61. The most popular response was that participants felt that going to a nightclub with friends made them feel somewhat happy (n=74).

**Question 45: *Attending a live sporting event alone***

The following results were obtained from this question (n=248): 24% (n=60) reported Very Unhappy; 18% (n=45) reported Unhappy; 14% (n=34) reported Somewhat Unhappy; 21% (n=53) reported Neither Happy nor Unhappy; 13% (n=31) reported Somewhat Happy; 8% (n=21) reported Happy; 2% (n=4) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 3.12 (Somewhat Unhappy) and the Standard



Deviation was 1.7. The most popular response was that participants felt that attending a live sporting event alone made them feel very very unhappy (n=60).

**Question 46: *Attending a live sporting event with friends***

The following results were obtained from this question (n=248): 4% (n=9) reported Very Unhappy; 5% (n=13) reported Unhappy; 4% (n=11) reported Somewhat Unhappy; 8% (n=21) reported Neither Happy nor Unhappy; 16% (n=39) reported Somewhat Happy; 38% (n=93) reported Happy; 25% (n=62) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.4 (Somewhat Happy) and the Standard Deviation was 1.59. The most popular response was that participants felt that attending a live sporting event with friends made them feel happy (n=93).

**Question 47: *Going to restaurants alone***

The following results were obtained from this question (n=248): 10% (n=26) reported Very Unhappy; 16% (n=39) reported Unhappy; 17% (n=43) reported Somewhat Unhappy; 30% (n=75) reported Neither Happy nor Unhappy; 17% (n=42) reported Somewhat Happy; 8% (n=21) reported Happy; 1% (n=2) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 3.56 (Somewhat Unhappy- Neither Happy nor Unhappy) and the Standard Deviation was 1.46. The most popular response was that participants felt that going to restaurants alone made them feel neither happy nor unhappy (n=75).

**Question 48: *Going to restaurants with friends***

The following results were obtained from this question (n=248): 1% (n=3) reported Very Unhappy; 2% (n=4) reported Unhappy; 1% (n=2) reported Somewhat Unhappy; 4% (n=10) reported Neither Happy nor Unhappy; 14% (n=35) reported Somewhat Happy; 44% (n=108) reported Happy; 35% (n=86) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.98 (Somewhat Happy-Happy) and the Standard Deviation was 1.13. The most popular response was that participants felt that going to restaurants with friends made them feel happy (n=108).

**Question 49: *Watching television / movies alone***

The following results were obtained from this question (n=248): 2% (n=6) reported Very Unhappy; 2% (n=6) reported Unhappy; 2% (n=5) reported Somewhat Unhappy; 23% (n=57) reported Neither Happy nor Unhappy; 21% (n=52) reported Somewhat Happy; 33% (n=83) reported Happy; 16% (n=39) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.21 (Somewhat Happy) and the Standard Deviation was 1.36. The most popular response was that participants felt that watching televisions or movies alone made them feel happy (n=83).

**Question 50: *Watching television / movies with friends***

The following results were obtained from this question (n=248): <1% (n=1) reported Very Unhappy; 2% (n=4) reported Unhappy; 2% (n=5) reported Somewhat Unhappy; 12% (n=29) reported Neither Happy nor Unhappy; 20% (n=49) reported Somewhat Happy; 48% (n=120) reported Happy; 16% (n=40) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.58 (Somewhat Happy-Happy) and the Standard Deviation was 1.1. The most popular response was that participants felt that watching television or movies with friends made them feel happy (n=120).

**Question 51: *Playing video games alone***

The following results were obtained from this question (n=248): 15% (n=37) reported Very Unhappy; 6% (n=15) reported Unhappy; 4% (n=9) reported Somewhat Unhappy; 36% (n=89) reported Neither Happy nor Unhappy; 17% (n=41) reported Somewhat Happy; 15% (n=36) reported Happy; 8% (n=21) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 4.1 (Neither Happy nor Unhappy) and the Standard Deviation was 1.77. The most popular response was that participants felt that playing video games alone made them feel neither happy nor unhappy (n=89).

**Question 52: *Playing video games with friends***

The following results were obtained from this question (n=248): 12% (n=30) reported Very Unhappy; 6% (n=14) reported Unhappy; 3% (n=8) reported Somewhat Unhappy; 30% (n=74) reported Neither Happy nor Unhappy; 20% (n=49) reported Somewhat Happy; 18% (n=45) reported Happy; 11% (n=28) reported Very Happy.

The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 4.39 (Neither Happy nor Unhappy) and the Standard Deviation was 1.77. The most popular response was that participants felt

that playing video games with friends made them feel neither happy nor unhappy (n=74).

**Question 53: *Using the computer***

The following results were obtained from this question (n=248): 1% (n=2) reported Very Unhappy; 1% (n=2) reported Unhappy; 1% (n=3) reported Somewhat Unhappy; 31% (n=78) reported Neither Happy nor Unhappy; 17% (n=42) reported Somewhat Happy; 27% (n=67) reported Happy; 22% (n=54) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.31 (Somewhat Happy) and the Standard Deviation was 1.27. The most popular response was that participants felt that using the computer made them feel very neither happy nor unhappy (n=78).

**Question 54: *Listening to music***

The following results were obtained from this question (n=248): % (n=0) reported Very Unhappy; <1% (n=1) reported Unhappy; 2% (n=5) reported Somewhat Unhappy; 6% (n=16) reported Neither Happy nor Unhappy; 15% (n=38) reported Somewhat Happy; 42% (n=105) reported Happy; 33% (n=83) reported Very Happy. The minimum value was 2 (Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.90 (Somewhat Happy- Happy) and the Standard Deviation was 1.0. The most popular response was that participants felt that listening to music made them feel very happy (n=105).

**Question 55: *Exercising***

The following results were obtained from this question (n=248): 4% (n=9) reported Very Unhappy; 2% (n=6) reported Unhappy; 4% (n=11) reported Somewhat

Unhappy; 15% (n=37) reported Neither Happy nor Unhappy; 18% (n=45) reported Somewhat Happy; 33% (n=82) reported Happy; 23% (n=58) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.34 (Somewhat Happy) and the Standard Deviation was 1.51. The most popular response was that participants felt that exercising made them feel happy (n=82).

**Question 56: *Cooking***

The following results were obtained from this question (n=248): 3% (n=7) reported Very Unhappy; 2% (n=6) reported Unhappy; 4% (n=11) reported Somewhat Unhappy; 14% (n=35) reported Neither Happy nor Unhappy; 23% (n=56) reported Somewhat Happy; 30% (n=75) reported Happy; 23% (n=58) reported Very Happy. The minimum value was 1 (Very Unhappy), the maximum value was 7 (Very Happy). The mean response was 5.35 (Somewhat Happy) and the Standard Deviation was 1.45. The most popular response was that participants felt that cooking made them feel happy (n=75).

**Question 57: *If you had services or other support available to you, what do you think you would benefit from?***

The following results were obtained from this question (n=109): 1% (n=1) Career Counseling; 1% (n=1) Cognitive Behavioral Therapy; 11% (n=12) Psychotherapy; 1% (n=1) Executive Functioning; 9% (n=10) Exercise / Fitness Support; 1% (n=1) Homecare Support; 2% (n=2) Mentoring; 2% (n=2) Occupational Therapy; 9% (n=10) Physical Therapy; 30% (n= 33) Social Group; 2% (n=2) Speech Therapy; 29% (n=32) Support Group; 1% (n=1) Dating Coach; 1% (n=1) Massage Therapist.

The most requested service were support groups (n=32) and social groups (n=33).  
The total responses received for this question was 109.

**Question 58: *Do you still want your responses recorded for this study?***

The following results were obtained from this question: 100% (n=248) reported that they do want their responses recorded for this study; 0% (n=0) reported that they did not want their responses recorded for this study.

**3.4 Comparison of the sample of adults with Autism, Asperger's Syndrome, Social Communication Disorder to the control population:**

The participants with ASD and the control participants without ASD were compared to determine if there was a relationship and statistical significance between the variables, or groups. The methods of evaluating the data included the following parametric and non-parametric statistics: Paired Sample t-Tests; Phi Coefficients; Fisher Exact Probability Tests; and Chi Squares.

When the data was analyzed using Paired Sample t-Tests, 35 pairs were studied to determine if the relationship between the group of ASD respondents and their control matches was significant.

The following variables were analyzed comparing the two cohorts:

1. Where individuals lived
2. The perception of family support
3. How often they spoke to a close friend
4. What the individual did when depressed
5. Who they chose to spend time with in their free time

6. If they graduated high school
7. If they were college graduates
8. The highest degree achieved
9. Employment status
10. How many hours the individuals worked per week on average
11. If they were paid for their work
12. How happy they felt at work
13. If they felt they had friends at work
14. If they looked forward to going to work
15. How they rated their health
16. The importance of perceived work safety
17. The importance of perceived home safety
18. The importance of relationships with close friends
19. The importance of relationships with family
20. The importance of romantic relationships
21. The importance of belonging to an online community
22. The happiness one felt from attending a club alone
23. The happiness one felt from attending a club with friends
24. The happiness one felt from attending a sports game alone
25. The happiness one felt from attending a sports game with friends
26. The happiness one felt from attending a restaurant alone
27. The happiness one felt from attending a restaurant with friends
28. The happiness one felt from watching television or movies alone

29. The happiness one felt from watching television or movies with friends
30. The happiness one felt from playing video games alone
31. The happiness one felt from playing video games with friends
32. The happiness felt from using the computer
33. The happiness felt from listening to music
34. The happiness felt from exercising
35. The happiness felt from cooking.

Please see the complete list of tables for the results.

The following comparisons for a Paired Sample t-Test proved to have statistical significance: what do you do when you are depressed, did you graduate high school, and what is your perception of the importance of safety at home.

The question: *If you are feeling sad or depressed, what do you do?* yielded a statistical significance of  $p=0.02$  when the cohort of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder, was compared to the age and gender matched peers without an ASD diagnosis. The sample of individuals with ASD had a mean of 3.3 (Talk to a family member) with a Standard Deviation of 1.05, while the control sample had a mean of 2.5 (talk to a spouse or partner) with a Standard Deviation of 1.16. These results support that there was a statistically significant difference between the actions of individuals with and without ASD when they felt sad or depressed.

The question: *Did you graduate from high school?* yielded a statistical significance of  $p=0.02$  when the cohort of individuals with Autism, Asperger's



Syndrome, or Social Communication Disorder, was compared to the age and gender matched peers without an ASD diagnosis. The sample of individuals with ASD had a mean of 1.1 (graduated high school) with a Standard Deviation of 0.31, while the control sample had a mean of 1.06 (graduated high school) with a Standard Deviation of 0.24. These results support that there was a statistically significant difference between the graduation rate of high school between individuals with and without Autism, Asperger's Syndrome, or Social Communication Disorder.

The question: *How important is how safe you feel at home?* yielded a statistical significance of  $p=0.008$  when the cohort of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder, was compared to the age and gender matched peers without an ASD diagnosis. The sample of individuals with ASD had a mean of 4.550 (Important-Extremely Important) with a Standard Deviation of 0.77, while the control sample had a mean of 4.557 (Important-Extremely Important) with a Standard Deviation of 0.84. These results support that there was a statistically significant difference between the perceived importance of home safety between individuals with and without Autism, Asperger's Syndrome, or Social Communication Disorder.

Chi Square statistics were calculated to examine the relationship between two variables for individuals with and without Autism, Asperger's Syndrome, and Social Communication Disorder. Relationships between two variables were examined for the Pearson value,  $p$  value and the Phi Coefficient. If the sample had less than five individuals in one subset, the Fisher Exact Probability Test was completed to test for statistical significance.

Relationships were studied on the basis if an individual wanted Social or Support Groups; if they were on an education plan; if they preferred to spend time with others (compared to keeping to oneself); if they sought out social support when depressed (compared to keeping to oneself); the age they were diagnosed with Autism, Asperger's Syndrome, or Social Communication Disorder; if they were employed; their current status in college enrollment; how often they spoke to a close friend; the importance of close friends; if they were on an education plan (IEP or 504); if the individual felt that their family supported them; and if close relationships with family were valued as important. Please see the list of tables for the complete list of Chi Square statistics completed, with their significance values and Phi Coefficients.

For the cohort of individuals with ASD, four relationships yielded statistically significant results. The first relationship found to have statistical significance examined the effect being on an education plan had on the desire to have a Social or Support group available. 12% (n=18) of individuals with ASD were (or had been) on an education plan and wanted a Social or Support group, 9% (n=13) of individuals with ASD were (or had been) on an education plan and did not want a Social or Support group, 29% (n=42) of individuals with ASD were not (or had been not) on an education plan and wanted a Social or Support group, and 48% (n=68) of individuals with ASD were not (or had been not) on an education plan and did not want a Social or Support group. The statistically significant relationship between these two variables was found to be  $p=0.04$ .

The second relationship that yielded statistically significant was the importance of close friends and the frequency of talking to a close friend. 29% (n=41) of individuals with ASD reported that they value close friends and talk often to a close friend, 15% (n=22) of individuals with ASD reported that they value close friends but talk to a close friend less often, 19% (n=27) of individuals with ASD reported that they do not see close friends as important but talk to a close friend often, and 35% (n=50) of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder do not see close friends as important, and talk to a close friend less often. The statistically significant relationship between these two variables yielded a  $p=0.0004$ .

The third relationship that was found to be statistically significant was the importance of close relationships with family members, and the perceived feeling of support from family members. 40% (n=57) reported that close relationships with family was important and they had a perceived feeling of support from their family, 7% (n=11) reported that they had a close relationship with their family but no perceived support from their family, 15% (n=22) perceived close relationships with family not as important but felt their families supported them, and 14% (n=21) perceived close relationships with family were not as important and felt that they did not have their families' support. The statistically significant relationship between these two variables yielded a  $p=0.002$ .

Regarding the individuals not diagnosed with Autism, Asperger's Syndrome, or Social Communication Disorder, one relationship was found to be statistically

significant. Please see the complete list of tables for the relationships that were analyzed for the control population that was matched for age and gender.

The relationship between if an individual was on an education plan, and if they attended college, or had no plans on attending college was found to have statistical significance. 4% (n=6) were (or had been) on an education plan and had attended (or were currently attending) college, 0% (n=0) were not (or had not been) on an education plan and were not attending (or had not attended) college, 81% (n=102) of individuals were not (or had not been) on an education plan and were attending (or had already attended) college, and 14% (n=18) were not (or had not been) on an education plan and were not planning on attending college. The statistically significant relationship between these two variables yielded a  $p=0.01$

## CHAPTER 4

### DISCUSSION

#### 4.1 Quality of Life Variables

The results of this study helped to outline variables that contribute to the quality of life of a sample population of adults with Autism, Asperger's Syndrome, or Social Communication Disorder both independently, and when compared to a cohort of peers without an Autism diagnosis matched for age and gender. Magill-Evils and Koining (2006) also included an aged and gender matched control group to compare their findings between individuals with ASD to controls without ASD. These researchers concluded that the quality of life for individuals with Asperger's Syndrome (AS) was lower, and this group displayed overall QoL, psychological, social, and environmental domain scores that were lower compared to the control group without AS. One other study that investigated the quality of life among individuals with ASD included a control group of typically developing individuals matched for age and sex (Lin, 2014). These researchers concluded that the adults with ASD scored significantly lower in the domains of: physical health, psychological health and social relationships. The current study is a third investigation that compared outcomes regarding perceptions of quality of life between two cohorts, one comprised of adults with ASD compared to an age- and gender-matched control group matched.

In the section that follows, the relationships of this sample population of adults with ASD compared to the control of adults without ASD will be discussed

regarding family support, social relationships, employment, safety, education, as well as perceived health rating. The results of this research study will also be compared to published empirical findings on quality of life among those with and without ASD based on a comprehensive review of the literature.

#### **4.2 Family Support:**

The *'Moroney Quality of Life'* survey included questions to solicit perceptions about how supportive the respondent perceived his or her family to be. Kazdin and Weisz (1998) suggested that the psychosocial impact of family life often influenced the life significantly of individuals with ASD. When probed with this question, the sample of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder reported that the majority agreed with the statement in that: *my family supports me*. This finding is consistent with the results reported by Renty and Roeyers (2006), who studied 58 adults with High Functioning Autism (HFA) in Belgium. These researchers found that the support adults with ASD received significantly improved their QoL.

With respect to the perceptions provided by the control population this same question, the majority of individuals responded that they strongly agreed with the statement: *my family supports me*. This difference in support can affect an individuals' perception on the quality of interactions in their life, and thus their overall quality of life. Although not statistically significant, this difference in support has clinical significance. When working with individuals diagnosed with ASD, family counseling should be labeled as a priority and should be recommended following a

diagnosis of ASD. It is a possibility that the lack of understanding of the challenges and difficulties accompanied with an Autism diagnosis is lost in translation between the individual and a family. When asked the question: if you had services or other support available to you, what do you think you would benefit from; one participant responded: *"I would like support from my family, I was in outsider in my family as a child"*. This statement further emphasizes the need for a strengthened connection between individuals with ASD and their families.

For the cohort of adults with ASD, the relationship between the importance of close relationships with family members, and the perceived feeling of support from family members was statistically significant in this study. The majority of individuals reported that close relationships with family were important and they that they did perceive support from their families. However, it should be noted that even though the majority of individuals reported that they felt support from their family, when asked about the possibility of support services, this population often responded that they would benefit from a Social Group or a Support Group.

#### **4.3 Social Relationships:**

Social relationships were examined to study an individual's perception of the importance of friends and family. Howlin et al. (2013) found that as individuals with ASD aged, their social outcomes decreased, and their social inclusion became more limited. This study aimed to solicit perceptions about the social life, and social inclusion among individuals with ASD.

When probed with the question: if you are feeling sad or depressed, what do you do; the sample of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder reported that on average, they prefer to talk to a family member. On the other hand, the control population on average reported that when feeling depressed, a spouse or partner is sought for support. The statistical analyses supported that there was a statistically significant difference between the actions of individuals with and without ASD when they felt sad or depressed. However, it should be noted, the mode response for the group of individuals with ASD was to keep to his or herself when sad or depressed (n=107), and the control group reported that when feeling sad or depressed the mode response was to talk to a family member (n=81). This difference in socialization may influence an individual's quality of life due to the lack of support typically sought from individuals with ASD.

Relationships between the importance of close relationships and the presence of such relationships in individuals' lives were also studied. Two relationships yielded statistically significant findings: the importance of close friends and the frequency of talking to a close friend, and the importance of close relationships with family members, and the perceived feeling of support from family members. When these relationships were examined, the results suggest that the majority (n=50) of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder do not see close friends as important and therefore talked to a close friend less often. These results are similar to the research findings reported by Burgess and Gutstein (2007), who concluded that 31% of the 450 individuals with ASD that were surveyed had no social interaction with others, with



the exception of their families. Moreover, the majority of individuals with ASD (n=57) reported that close relationships with family were important and they had a perceived feeling of support from their family. These findings are consistent with those reported by Kamino et al. (2013), who concluded support as well as the closeness of friendship had a great impact on QoL.

#### **4.4 Employment:**

With respect to Employment and employment status, including feelings associated with going to work, Mawhood and Howlin (1999) reported that although it is common that children with ASD complete mainstream education, they often report low levels of employment in long-term outcomes. Although statistically significant relationships between the two samples of individuals with and without ASD were not evidenced in the current investigation, it is important to evaluate the differences between their responses.

When probed to examine if participants were employed, individuals with an Autism, Asperger's Syndrome, or Social Communication Disorder diagnosis had a 59% employment rate, while the cohort of individuals without an ASD diagnosis had an 81% employment rate. Cimera and Cowan (2009) also reported that adults diagnosed with ASD typically earn less (and work less) than their neurotypically developing peers.

With respect to employment and levels of happiness at or from their work, the individuals with Autism, Autism, Asperger's Syndrome, or Social Communication Disorder reported that 35% of them usually feel happy at work, while 60% of the

individuals without an ASD diagnosis reported feeling happy at work. Another probe of the '*Moroney Quality of Life*' survey queried whether the individuals perceived that they had friends at work. The individuals with ASD reported that 58% of them felt they have friends at work, while 88% of individuals without ASD felt that they did have friends at work. Individuals were then queried whether they looked forward going to work. 63% of the sample of individuals with ASD reported that they do look forward to going to work, while 79% of individuals without ASD reported that look forward to attending their job.

The differences between the samples did not yield statistical significance; however, a trend was observed in this domain ( $p=0.4$ ). This study found that individuals with ASD were employed less often, looked forward to going to work less, and did not feel they had friends at work. Burgess and Gutstein (2007) also addressed employment status in that they reported only 12% of individuals worked full time and were paid a salary. This trend was further emphasized in the current study, which supports that individuals responded that career support was desirable if such services were available to them. A group of individuals ( $n=7$ ) expressed an interest in receiving career counseling.

With respect to education, participants in this study were queried to share perceptions regarding their the current job, or have had in the past month. The most represented form of education reported by the cohort of individuals with ASD in the current study included positions regarding education or training (15%), followed by IT or software development (13%) and sales or retail (13%). The most frequently reported job for individuals without an Autism, Asperger's Syndrome, or Social

Communication Disorder was education or training (30%) followed by administrative or clerical (14%).

#### **4.5 Safety:**

In the Hall, Moroney & Andrianopoulos pilot study (2014), safety was found to be a focus area for evaluating the quality of life of individuals with ASD. In the current study, safety was examined based on an individual's perception of the importance of safety at home and in the work place. When probed with the question: how important is how safe you feel at home; the sample of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder reported that on average, it was important- extremely important (mean=4.55), similar to the control sample which reported that safety at home was valued important- extremely important on average (mean=4.557). This finding was statistically significant between groups with and without Autism, Asperger's Syndrome, or Social Communication Disorder respect to the perceived importance of home safety.

#### **4.6 Education:**

Education was also studied to determine the similarities and differences between the population of adults with Autism, Asperger's Syndrome, and Social Communication Disorder when compared to an age- and gender-matched cohort without ASD. When probed with the question: did you graduate high school; the sample of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder reported that on average, (mean=1.1) less individuals graduated high school (90% high school graduates), while the control sample on average

(mean=1.06) produced more high school graduates (95% high school graduates). These findings support that there was a statistically significant difference between the graduation rate of high school between individuals with and without Autism, Asperger's Syndrome, or Social Communication Disorder. Renty and Royers (2006) also concluded that respondents with ASD yielded a higher QoL score if they had a job or were currently furthering their education.

Relationships between the likelihood of an individual having an individualized education plan (IEP) the desire for the availability of support or social groups was analyzed. This relationship was found to be statistically significant for the cohort of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder ( $p=0.04$ ).

The relationship between if an individual was on an education plan, and if they attended college, or had no plans on attending college was also found to be statistically significant. The majority of individuals with ASD ( $n=102$ ) were not (or had not been) on an education plan (IEP) and were attending (or had already attended) college. The second relationship that was found to be statistically significant examined the effect that being on an education plan had on the desire to have a Social or Support group available. The majority of individuals with ASD ( $n=68$ ) were not (or had been not) on an education plan and did not want a Social or Support group. Mawhood and Howlin (1999) also suggested that although it is common that children with ASD complete mainstream education, they often report low levels of employment in long-term outcomes.

#### **4.7 Perceived Health Rating:**

Questions regarding the individuals' perceived health rating were examined to determine the similarities and differences between the population of adults with Autism, Asperger's Syndrome, and Social Communication Disorder when compared to an age- and gender-matched cohort. The domains of social and physical health were found to be significantly lower than the control group in the studies completed by Kulhthau et al. (2010); Sheldrick, Neger, Perrin & Perrin, (2012); Sikora, Vora & Rosenberg (2012); and Varni et al. (2012). Delahaye et al. (2014) also evaluated health-related quality of life for children with Autism Spectrum Disorder. These authors reported that sleep duration, as well as sleep anxiety were negatively associated with the health-related quality of life of their participants. Similar to findings reported in the literature,, individuals with ASD reported having more disabilities and medical conditions compared to their age and gender matched peers in the current study. For example, in the sample of individuals with ASD, 72% reporting anxiety, and 64% of the sample reporting depression, compared to their age- and gender-matched peers in that 27% had anxiety, and 20% reported having depression.

A list of medical conditions or other disabilities were summarized from responses provided by participants in Hall, Moroney & Andrianopoulos (2014) pilot study. These findings from the pilot study were used as choices for the '*Moroney Quality of Life*' survey, as well as other options that allowed the participants to share whether they had other disabilities or medical conditions. For the cohort of individuals already diagnosed with Autism, Asperger's Syndrome, and Social

Communication Disorder, the most frequent disability or medical condition that participant's reported was anxiety, followed by depression. Of note is that the same two responses reported by the group of individuals with an ASD diagnosis were also reported by the control group without ASD. This finding did yield a statistical significance.

#### **4.8 Support Services**

Individuals from both cohorts of adults with Autism, Asperger's Syndrome, and Social Communication Disorder and without ASD were probed regarding: If you had services or other support available to you, what do you think you would benefit from? This survey question did not yield a statistically significant difference; however, it did shed light on the compelling desire for services in the adult stage of life. An investigation conducted in Spain among adults with ASD found that low levels of QoL, which the authors attributed to ineffective community-based resources (Saldana et al., 2009).

In the current study, the most frequently reported services that were requested for participants with ASD were support groups (n=42) and social groups (n=41). The total responses received for this survey question was 174 . Other frequent types of referrals for services included: an advocate (n=6), career counseling (n=6), psychotherapy (n=18), executive functioning therapy (n=8), and family or public education (n=7). The referral for these services for the sample population of adults with ASD in this study sheds light regarding the areas that the

cohort of individuals with ASD felt that they need additional support or guidance within their day to day lives.

#### **4.9 Gender Differences**

It is important note that in both the pilot study and the current investigations completed by the author, more females completed the surveys. The 'Work and Well-being Survey' received 37 responses, 22 of whom were female and 14 male. The '*Moroney Quality of Life Survey*' was similar with respect to response rate on the basis of gender. Of individuals diagnosed with ASD, 57 males, 86 females, and 11 individuals that identified as 'other' participated in this study'. This finding that suggests that more females were the most represented gender in this sample and the pilot study by Hall, Moroney & Andrianopoulos (2014). It is important to note that other published studies regarding the quality of life among individuals with ASD did not show this gender-bias. Of the research reviewed concerning quality of life measures for adults with ASD, all of the studies had more males participate than females (Billstedt et al., 2011; Cimera et al., 2009; Gerber et al., 2008; Gerber et al., 2011; Jennes-Coussens et al., 2006; Kamio et al., 2013; Kemp-Becker et al., 2010; Lin, 2014; Persson, 2000; Renty & Roeyers, 2006; Saldana et al., 2009; Totsika et al, 2010). The work of Garcia-Villamisar (2010) had an nearly equal spread of male to female participants with 22 males that participated, and 15 females.

This finding regarding that more females completed the '*Moroney Quality of Life Survey*' instrument is contrary to the current diagnosis rates of ASD. The CDC estimates that males outnumber females by 4:1 who are diagnosed with ASD (CDC, 2013). The authors of the current study predicted that more males would complete

the *'Moroney Quality of Life Survey'* given the incidence of ASD among males; however, female participants outnumbered males in this study, including the pilot study by Hall et al., (2014).

#### **4.9 Limitations of this study**

It is important to discuss potential limitations to this study that may have influenced the outcomes of this investigation. This research study was modified given the limitations found in the pilot study (Hall et al., 2014). The first limitation that was modified was the sample size. The pilot study by Hall et al., (2014), the *'Work and Well-Being Survey'*, included a sample size of 37 adults participants with ASD. The *'Moroney Quality of Life Survey'* received significantly more responses (n=154) that allowed researchers to have a more representative view of the day-to-day life of adults with ASD.

Another limitation of the current study that was modified on the basis of the outcomes of the *'Work and Well-Being Survey'* was the manner in which the survey question items were queried regarding the participant's diagnosis. The pilot study did not query whether the participant was formally diagnosed, therefore, the sample could have included some individuals who have self-diagnosed or identified with having ASD. The *'Moroney Quality of Life Survey'* took this factor into consideration by querying participant if they had a formal diagnosis of Autism, Asperger's Syndrome, or Social Communication Disorder.

Another limitation that was modified in the current study on the basis of outcomes from the *'Work and Well-Being Survey'* was the number of 'other' open



ended questions present in the survey. The '*Moroney Quality of Life*' instrument adjusted for this limitation by adding options that were commonly reported in the '*Work and Well-Being Survey*' in the form forced options that used a Likert scale for rating purposes.

The completion of the Hall et al., (2014) pilot survey solely online was another limitation of the '*Work and Well-Being Survey*'. The '*Moroney Quality of Life Survey*' was administered both online through a secure link and on paper. The responses collected through a paper survey were later imputed using the online software. This allowed researchers to have a less biased population for those question items related to one's use of a computer, and feeling of enjoyment with using a computer.

Another positive attribute of the *Moroney Quality of Life Survey* was its development; however, some areas warrant attention. For example, one limitation is the lack of a definitive confirmation regarding a participant's diagnosis of ASD. Since this survey was completed anonymously, there was no mechanism to follow-up and confirm, or validate, that individuals who reported a diagnosis of ASD and participated in this study did indeed have a formal diagnosis of Autism, Asperger's Syndrome, or Social Communication Disorder. The results of this study should be viewed with caution given this limitation.

Another limitation unique to the Hall et al., (2014) pilot study, was that participants were not queried what they preferred to do in their spare time if the forced option was not among the selection for that item. It is plausible that the outcomes of this study would have yielded different results if open-ended responses

were an option. However, based on the Hall et al., (2014) pilot study, an unlimited number of open ended responses were deemed to be troublesome in terms of finding a critical mass of responses for that variable. That is, there was a lack of consistency to open ended questions in the pilot study. Nonetheless, in retrospect, the researchers acknowledge that there is no “one size fits all” regarding participants’ perceptions of the quality of life among adults with Autism, Asperger’s Syndrome, or Social Communication Disorder and adults without ASD.

#### **4.10 Suggestions for further research**

Further research is needed to better study the quality of life of individuals with Autism, Asperger’s Syndrome, and Social Communication Disorder. The *‘Moroney Quality of Life Survey’* investigation found similarities to published empirical findings regarding the quality of life among individuals with ASD. However, more research is needed to better explore the variable, employment. It is suggested that future research investigate the types of services and assistance that individuals with disabilities are receiving and whether supplemental services are also provided through other financial support mechanisms, such as from family or friends. Other important variables that should be investigated include the length of time and types of support and intervention services an individual with Autism received, the beneficial effects of these support and intervention services on long-term outcomes with respect to employment, the length of time at one’s current job, and whether individuals with ASD perceived adequate training and education for the job market given their strengths.

Another, a more challenging area of study involves how many individuals identified with having Autism, Asperger's Syndrome, or Social Communication Disorder. For example, the '*Moroney Quality of Life Survey*' queried if a participant was formally diagnosed with ASD; however, this survey question could have probed further to determine whether the participant (if they reported 'no') identified with having Autism, Asperger's Syndrome, or Social Communication Disorder. Such information could shed light on how many individuals have not received a formal diagnosis, but identify as having ASD based on their awareness of the behaviors consistent with Autism, Asperger's, and Social Communication Disorders.

Future research should also explore the effects of sexual orientation on the quality of life of individuals with Autism, Asperger's Syndrome, or Social Communication Disorder. Due to the known challenges and difficulties individuals with these diagnoses often have in regard to social interactions, sexual orientation more present a greater challenge to those on the spectrum and his or her integration and acceptance in society. For example, in the current study, a small subset selected the option as "other" for gender. Future studies should explore sexual orientation with respect to levels of perceived support among society in general and among others who have Autism, Asperger's Syndrome, or Social Communication Disorder, and how one's sexual orientation affects their quality of life, secondary to ASD.

## **CHAPTER 5**

### **CONCLUSION**

This study found that specific content areas statistically differed among a cohort of individuals with and without Autism Spectrum Disorder in relation to one's perceived quality of life. Variables, such as, education, social support, safety, services desired, and social relationships yielded statistically significant outcomes in the current study. A female preponderance among responders was found in this study in that the number of females that participated in this study exceeded the number of male participants. Contrary to published literature that shows Autism is more prevalent in males than females, female responders outnumbered males in this investigation.

It is suggested that a proactive approach should be undertaken to differentially diagnose and engage individuals on the spectrum earlier in age to maximize outcomes in adulthood. To maximize the quality of life among individuals with ASD, it is recommended that support services be provided early and over the course of one's education. Moreover, professionals working with children with ASD should focus on a plan of action that yields long-term outcomes after graduation in high school and into adulthood. If individuals are aware of resources for support and services available with respect to early childhood, early intervention, transition programs in middle and in high school, and well into adulthood, it is possible that the next generation of individuals with ASD will yield a higher quality of life.

Table 1: Paired Samples Correlations

Paired Samples Correlations				
		N	Correlation	Sig.
Pair 1	ASD where do you live TD where do you live	141	.004	.961
Pair 2	ASD perceived family support TD perceived family support	141	.062	.465
Pair 3	ASD how often do you talk to a friend TD how often do you talk to a friend	141	-.035	.680
Pair 4	ASD what do you do when depressed TD what do you do when depressed	141	.195	.020
Pair 5	ASD who do you prefer to spend time with TD who do you prefer to spend time with	141	-.027	.750
Pair 6	ASD did you graduate high school TD did you graduate high school	141	.192	.022
Pair 7	ASD did you go to / graduate from college TD did you go to / graduate from college	120	-.029	.751
Pair 8	ASD highest degree achieved TD highest degree achieved	120	.071	.439
Pair 9	ASD do you have a job TD do you have a job	141	.061	.469
Pair 10	ASD how many hours typically worked TD how many hours typically worked	74	.027	.818
Pair 11	ASD do you get paid for your work TD do you get paid for your work	74	-.034	.772

Pair 12	ASD are you happy at work TD are you happy at work	74	-.213	.069
Pair 13	ASD do you have friends at work TD do you have friends at work	74	-.139	.238
Pair 14	ASD do you look forward to going to work TD do you look forward to going to work	74	-.008	.948
Pair 15	ASD how would you rate your health TD how would you rate your health	141	-.027	.754
Pair 16	ASD importance of home safety TD importance of home safety	140	.223	.008
Pair 17	ASD importance of work safety TD importance of work safety	140	.148	.080
Pair 18	ASD importance of family relationships TD importance of family relationships	140	.045	.597
Pair 19	ASD importance of friend relationships TD importance of friend relationships	140	.013	.881
Pair 20	ASD importance of romantic relationships TD importance of romantic relationships	140	-.133	.119
Pair 21	ASD importance of online community TD importance of online community	140	.114	.180
Pair 22	ASD happiness attending a club alone TD happiness attending a club alone	141	.005	.954
Pair 23	ASD happiness attending a club with friends TD happiness attending a club with friends	141	.029	.733
Pair 24	ASD happiness attending sports alone TD happiness attending sports alone	141	.002	.979

Pair 25	ASD happiness attending sports with friends TD happiness attending sports with friends	141	.010	.911
Pair 26	ASD happiness attending a restaurant alone TD happiness attending a restaurant alone	141	-.034	.689
Pair 27	ASD happiness attending restaurant with friends TD happiness attending a restaurant with friends	141	.021	.803
Pair 28	ASD happiness watching TV alone TD happiness watching TV alone	141	.035	.678
Pair 29	ASD happiness watching TV with friends TD happiness watching TV with friends	141	.065	.442
Pair 30	ASD happiness playing video game alone TD happiness playing video game alone	141	.051	.545
Pair 31	ASD happiness playing video game with friends TD happiness playing video game with friends	141	.066	.435
Pair 32	ASD happiness using the computer TD happiness using the computer	141	.071	.406
Pair 33	ASD happiness listening to music TD happiness listening to music	141	.065	.441
Pair 34	ASD happiness exercising TD happiness exercising	141	-.014	.866
Pair 35	ASD happiness cooking TD happiness cooking	141	-.003	.971

**Chi Square Analysis-** Autism, Asperger’s Syndrome, Social Communication Disorder

Table 2: Relation of requesting support and being on an education plan

	On an education plan	Not on an education plan
Requested a Social / Support Group	18	42
Did not request a Social / Support Group	13	68

Phi Coefficient: -0.17, Pearson’s: 3.9,  $p=0.04$ , Statistically Significant

Table 3: Relation of requesting support and free time activities

	Spend time with others	Keep to self
Requested a Social / Support Group	36	24
Did not request a Social / Support Group	43	38

Phi Coefficient: -0.07 ,Pearson’s: 0.67,  $p=0.41$ , Not Statistically Significant

Table 4: Relation of requesting support and actions when depressed

	Talk to others when depressed	Keep to self when depressed
Requested a Social / Support Group	19	41
Did not request a Social / Support Group	24	57

Phi Coefficient: -0.02 ,Pearson’s: 0.67,  $p=0.41$ , Not Statistically Significant

Table 5: Relation of requesting support and age of diagnosis

	Diagnosed before 18	Diagnosed at 18 or later
Requested a Social / Support Group	17	42
Did not request a Social / Support Group	16	62

Phi Coefficient: -0.1,Pearson’s: 1.27,  $p=0.26$ , Not Statistically Significant



Table 6: Relation of requesting support and being on an education plan

	Have a job	Unemployed
Was on an education plan	20	11
Wasn't on an education plan	68	42

Phi Coefficient: -0.02 ,Pearson's: 0.08,  $p=0.77$ , Not Statistically Significant

Table 7: Relation of being on an education plan and attending college

	College	No College
Was on an education plan	21	4
Wasn't on an education plan	77	17

Phi Coefficient: -0.02,  $p=0.41$ , Not Statistically Significant

Table 8: Relation of importance of close friends and how often talk to close friend

	Talk often to a close friend	Talk less often to a close friend
Close friends are important	41	22
Close friends aren't important	27	50

Phi Coefficient: 0.3, Pearson's: 12.5,  $p=0.0004$ , Statistically Significant

Table 9: Relation of importance of close family and family support

	Family supports me	Family doesn't support me
Close family is important	57	11
Close family is not important	22	21

Phi Coefficient: -0.35 ,Pearson's: 13.7,  $p=0.0002$ , Statistically Significant

Table 10: Relation of age of diagnosis and employment status

	Have a job	Unemployed
Diagnosed before 18	19	14
Diagnosed at 18 or later	66	38

Phi Coefficient: 0.05, Pearson's: 0.37,  $p=0.54$ , Not Statistically Significant

Table 11: Relation of age of diagnosis and education level

	College	No college
Diagnosed before 18	22	3
Diagnosed at 18 or later	74	16

Phi Coefficient: -0.06,  $p=0.76$ , Not Statistically Significant

Table 12: Relation of age of diagnosis and perceived family support

	My family supports me	My family doesn't support me
Diagnosed before 18	24	4
Diagnosed at 18 or later	55	27

Phi Coefficient: -0.18, Pearson's: 3.58,  $p=0.058$ , Not Statistically Significant

**Chi Square Analysis-** Control population

Table 13: Relation of requesting support and being on an education plan

	On an education plan	Not on an education plan
Requested a Social / Support Group	2	26
Did not request a Social / Support Group	4	109

Phi Coefficient: -0.07,  $p=0.34$ , Not Statistically Significant

Table 14: Relation of requesting support and free time activities

	Spend time with others	Keep to self
Requested a Social / Support Group	21	7
Did not request a Social / Support Group	88	25

Phi Coefficient: 0.03, Pearson's: 0.11,  $p=0.41$ , Not Statistically Significant

Table 15: Relation of requesting support and actions when depressed

	Talk to others when depressed	Keep to self when depressed
Requested a Social / Support Group	18	10
Did not request a Social / Support Group	77	36

Phi Coefficient: 0.03 ,Pearson's: 0.15,  $p=0.41$ , Not Statistically Significant

Table 16: Relation of requesting support and being on an education plan

	Have a job	Unemployed
Was on an education plan	6	0
Wasn't on an education plan	110	25

Phi Coefficient: -0.1,  $p=0.59$ , Not Statistically Significant

Table 17: Relation of being on an education plan and attending college

	College	No college
Was on an education plan	6	0
Wasn't on an education plan	102	18

Phi Coefficient: -0.09 ,  $p=0.01$ , Statistically Significant

Table 18: Relation of importance of close friends and how often talk to close friend

	Talk often to a close friend	Talk less often to a close friend
Close friends are important	77	34
Close friends aren't important	25	5

Phi Coefficient:0.13,Pearson's: 2.3,  $p=0.13$ , Not Statistically Significant

Table 19: Relation of importance of close family and family support

	My family supports me	My family doesn't support me
Close family is important	88	17
Close family is not important	18	2

Phi Coefficient: 0.07,  $p=0.73$ , Not Statistically Significant

## APPENDIX A

### MORONEY QUALITY OF LIFE SURVEY

You are being invited to participate in a research study titled “Moroney Survey”. This study is being done by Katharine Moroney B.S., B.A. and Mary Andrianopoulos Ph.D CCC-SLP from the University of Massachusetts Amherst. You were selected to participate in this study because researchers are interested in your opinions and experiences. The purpose of this research study is to explore aspects that contribute to a person’s work, well-being, and general outlook of adults with Autism. We are interested in studying adults with Autism, since there is not enough research on this topic. Of what research has been done on adults with Autism, most research involves studying physical and genetic topics. This research will help determine if there are any particular areas that contribute to a person’s work, well-being, and general outlook such as formal and informal education, support from family and friends, services that a person has received etc.. If you agree to take part in this study, you will be asked to complete an online survey. This survey will ask about your education, employment, medical history, and daily activities. This survey will take you approximately 10-15 minutes to complete. You may not directly benefit from this research; however, we hope that your participation in the study may shed light on the work, work, well-being, and general outlook of people with Autism. We believe there are no known risks associated with this research study; however, as with an online related activity the risk of a breach of confidentiality is always possible. To the best of our ability your answers in this study will remain confidential. We will minimize any risks by not asking for your name, keeping responses on a secure server with the account to the survey password protected. Your participation in this study is completely voluntary and you can withdraw at any time. If you have questions about this project or if you have a research-related problem, you may contact the researchers through Mary Andrianopoulos at (413) 545-0551. If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or [humansubjects@ora.umass.edu](mailto:humansubjects@ora.umass.edu). By clicking “I agree” below you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study. Please print a copy of this page for your records.

- By clicking this box I authorize my consent. (1)
- I do not authorize my consent. (2)

If I do not authorize my consent. Is Selected, Then Skip To End of Survey

## Personal Information

Q4 Are you receiving assistance taking this survey?

- Yes (1)
- No (2)

If Yes Is Selected, Then Skip To If yes, what kind of assistance is being provided? If No Is Selected, Then Skip To Gender

Q53 If yes, what kind of assistance is being provided?

Q5 Gender

- Male (1)
- Female (2)
- Other (3)

Q6 Age

Q57 During the academic year, do you currently live in the United States?

- Yes (1)
- No (2)

If Yes Is Selected, Then Skip To Current Living Situation If No Is Selected, Then Skip To What country do you live in?

Q58 During the academic year, what country do you currently live in?

If What country do you live in? Is Not Empty, Then Skip To Where do you currently live?

Q12 During the academic year, where do you currently live?

- House (1)
- Apartment (2)
- Residence Hall (3)
- Residential Home (4)
- Other- please specify (5) \_\_\_\_\_

Q13 During the academic year, who do you currently live with?

- I live alone. (1)
- Parents/ Guardians (2)
- Spouse/ Partner (3)
- Friend (4)
- Assigned Roommate (5)
- Sibling (6)
- Care-taker (7)
- Children (8)
- Other- please specify (9) \_\_\_\_\_

Q14 During the academic year, do you own or rent the place where you currently live?

- I own my home/ apartment. (1)
- I rent my home/ apartment. (2)
- I live free of cost. (3)
- I live in University housing. (4)
- I live in a (5)

Q15 Do you currently have a driver's license?

- Yes (1)
- No (2)

Q17 Are you registered to vote?

- Yes (1)
- No (2)

Q18 Do you currently have a pet?

- Yes (1)
- No (2)

Q52 Are you formally diagnosed with Autism/ Asperger's/ Social Pragmatic Communication Disorder?

- Yes (1)
- No (2)

If Yes Is Selected, Then Skip To At what age were you formally diagnos...If No Is Selected, Then Skip To Do you have any siblings with Autism?

Q19 At what age were you formally diagnosed with Autism/ Asperger's/ Social Pragmatic Communication Disorder?

Q46 Does anyone in your immediate family (mother, father, brother, sister) have Autism?

- Yes (1)
- No (2)
- I don't know (3)

### Social Support

Q23 Do you agree with this statement: My family supports me.

- Strongly Disagree (1)
- Disagree (2)
- Neither Agree nor Disagree (3)
- Agree (4)
- Strongly Agree (5)

Q25 How often do you casually talk with a close friend?

- Never (1)
- Less than Once a Month (2)
- Once a Month (3)
- 2-3 Times a Month (4)
- Once a Week (5)
- 2-3 Times a Week (6)
- Daily (7)

Q26 If you are feeling sad or depressed, what do you most likely do?

- Talk to a friend (1)
- Talk to a spouse/ partner (2)
- Talk to a family member (3)
- Keep to myself (4)

Q28 Who do you prefer to spend time with during your free time?

- Friend (1)
- Spouse/ Partner (2)
- Family Member (3)
- I usually keep to myself (4)
- Roommate (5)
- Other (6) \_\_\_\_\_

### Education

Q31 Were you, or are you currently on an education plan?

- IEP (Individualized Education Plan) (1)
- 504 (Modifications and Accommodations Plan) (2)
- No (3)
- Other (4)

Q32 Did you, or do you receive services at school?

- Speech Therapy (1)
- Occupational Therapy (2)
- Physical Therapy (3)
- Guidance/ Counseling (4)
- No (5)
- Other (6)

Q54 Did you, or do you receive services outside of school?

- Tutoring (1)
- Psychotherapy (2)
- Speech Therapy (3)
- Occupational Therapy (4)
- Physical Therapy (5)
- No (6)
- Other (7)

Q33 Did you graduate from high school?

- Yes (1)
- No (2)

If No Is Selected, Then Skip To Employment

Q34 Did you go, or are you planning on going to college?

- I am planning on attending college (1)
- I am currently attending college (2)
- I graduated from college (3)
- I do not plan on attending college (4)

Q35 What is your highest degree achieved?

- High school diploma (1)
- Some College (One year or more, no degree achieved) (2)
- Bachelor Degree (3)
- Master Degree (4)
- Ph.D. (5)
- Other (6)



## Employment

Q37 Do you currently have a job, or did you have a job in the past month?

- Yes (1)
- No (2)

If No Is Selected, Then Skip To General Health

Q38 How many hours per week do/did you work in the past month?

- 0-10 (1)
- 11-20 (2)
- 21-30 (3)
- 31-40 (4)
- 41-50 (5)
- 51-60 (6)
- 60+ (7)

Q39 Do/did you get paid for your work in the past month?

- Yes (1)
- No (2)

Q40 How happy do/did you usually feel at work?

- Very Happy (1)
- Happy (2)
- Neither Happy nor Unhappy (3)
- Unhappy (4)
- Very Unhappy (5)

Q41 Do/did you have friends at work?

- Yes (1)
- No (2)

Q42 Do/did you look forward going to work?

- Yes (1)
- No (2)

Q43 Please share the job that you have/ have had in the past month:

## General Health

Q45 How would you rate your health?

- Usually very healthy (1)
- Usually somewhat healthy (2)
- Not usually healthy (3)

Q48 If you have any other disabilities or medical conditions, please chose those found on this list

- ADD/ ADHD (1)
- Anxiety (2)
- Asthma (3)
- Bipolar Disorder (4)
- Depression (5)
- Diabetes (6)
- Hearing Loss (7)
- Muscular/ Joint Pain (8)
- OCD (9)
- Visual Impairment (10)
- None found on this list (11)
- I do not have other disabilities or medical conditions. (12)

Q49 Do you take prescribed medication, or have you taken any prescribed medication in the past six months?

- Yes (1)
- No (2)

**Q51 Please rate the following statements on importance:**

	Not Important	Slightly Important	Somewhat Important	Important	Extremely Important
How safe you feel at home (1)	Answer 1 (1)	Answer 1 (1)	Answer 1 (1)	Answer 1 (1)	Answer 1 (1)
How safe you feel at work (2)					
Close relationships with family (3)					
Close relationships with friends (4)					
Being in a romantic relationship (5)					
Being a part of an on-line community (Facebook, Twitter etc.) (6)					

**Q45 Please rate the following statements on how happy they would make you feel:**

	Very Unhappy (1)	Unhappy (2)	Somewhat Unhappy (3)	Neither Happy nor Unhappy (4)	Somewhat Happy (5)	Happy (6)	Very Happy (7)
Attending a night club alone (1)							
Attending a night club with friends (2)							
Attending a live sporting event alone (3)							
Attending a live sporting event with friends (4)							
Going to restaurants alone (5)							
Going to restaurants with friends (6)							
Watching television/movies alone (7)							
Watching television/movies with friends (8)							
Playing video games alone (9)							
Playing video games with friends (10)							
Using the computer (11)							
Listening to music (12)							
Exercising (13)							
Cooking (14)							

**Q47 If you had services or other support available to you, what do you think you would benefit from? (examples: support group, social groups, speech therapy, physical therapy)**

Q48 Do you still want your responses recorded for this study?

- Yes (1)
- No (2)

If No Is Selected, Then Skip To Debriefing form: Thank you for your pa...

Q49 Debriefing form:

Thank you for your participation! All records will be retrieved from this online survey managing software and kept on local hard drives physically and digitally secured by investigators through encryption which will also be kept in a locked location at all times. Only the PI and co-PI will have access to the locked location. This study will contribute to science and contribute to research concerning the work and well being of adults with Autism/ Social Pragmatic Communication Disorder.

## **APPENDIX B**

### **INSTITUTIONAL REVIEW BOARD FORMS**

#### **Approval Notice**

The following human subjects protocol submission has been approved by the IRB, effective 09/09/2014:

Protocol Director: Katharine Moroney

Protocol Title: Work and Well-being Survey

Protocol Number: 2014-2174

Attachments include: Flier 8.18, Email Body- Recruitment, faculty sponsor statement, Moroney Qualtrics Survey

Review Type: NEW - EXPEDITED

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