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Stress for Individuals with Autism Spectrum Disorders: Effects of Age, Gender, and Intelligence Quotient

Kristen Louise Hess

ACCEPTANCE

This dissertation, STRESS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS: EFFECTS OF AGE, GENDER, AND INTELLIGENCE QUOTIENT, by KRISTEN LOUISE HESS, was prepared under the direction of the candidate's Dissertation Advisory Committee. It is accepted by the committee members in partial fulfillment of the requirements for the degree Doctor of Philosophy in the College of Education, Georgia State University.

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ABSTRACT

STRESS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS: EFFECTS OF AGE, GENDER, AND INTELLIGENCE QUOTIENT
by
Kristen Louise Hess

Researchers previously have found that individuals with Autism Spectrum Disorders (ASD) experience higher levels of stress and anxiety than individuals who are typically developing and than those with other disabilities. The purpose of this study was to identify the nature and degree of stress reported for individuals with ASD, with particular attention to the effects of age, gender, and intelligence quotient (IQ). Stressful events were identified by the *Stress Survey Schedule for Persons with Autism and Other Developmental Delays* (*SSS*), the only tool developed specifically to measure perceived stress in individuals with ASD. Clinicians or parents completed the SSS for 313 individuals ages 3-41 with an ASD diagnosis in east and west coast diagnostic and treatment facilities. Multiple regression equations and multivariate analyses of variance were conducted to explore relationships between scores on the *SSS* and their age, gender, and IQ. Analysis of the results revealed that two types of stress, *Changes and Threats (*R^2=.07) and *Unpleasant Events (*R^2=.05), were the greatest overall stressors for these individuals. Age, gender, and IQ correlated significantly with stressors measured in the scales related to *Sensory/Personal Contact (*$F_{(3, 309)} = 9.17$, $p < .01$*)*, *Anticipation/Uncertainty (*$F_{(3, 309)} = 3.08$, $p < .05$*)*, *Food-Related Activity (*$F_{(3, 309)} = 3.21$, $p < .05$*)*, and *Unpleasant Events (*$F_{(3, 309)} = 2.36$, $p < .10$*)*. Significant differences were

found with regard to age as a unitary construct and age by IQ. Results suggest that younger individuals with ASD may experience more stress than their older counterparts. Although higher levels of stress were reported for males across all eight scales, gender was determined to have a significant main effect only with *Pleasant Events (*$F_{(1, 135)}$ = 4.20, $p < .05$*)*. On six of the eight scales, individuals with lower IQ scores were reported to be more stressed and analysis reflected significance for IQ on *Changes and Threats* ($F_{(1, 294)} = 3.85$, $p < .05$) and *Unpleasant Events* ($F_{(1, 294)} = 5.71$, $p < .05$). Normative scores for all scales by age, gender, and IQ were reported. This study was the first to examine individual factors mediating the experience of stress for a large group of individuals with ASD. It also extends the line of research using the SSS, which will aid professionals when developing instructional, behavioral, and medical interventions.

STRESS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS: EFFECTS OF AGE, GENDER, AND INTELLIGENCE QUOTIENT

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TABLE OF CONTENTS

LIST OF TABLES

ABBREVIATIONS

ADI	Autism Diagnostic Interview
APA	American Psychiatric Association
AS	Asperger Syndrome
ASD	Autism spectrum disorders
CARS	Childhood Autism Rating Scale
C-TONI	Comprehensive Tests of Non-Verbal Intelligence
DASH-II	Diagnostic Assessment for Severely Handicapped
DISC-IV	The Diagnostic Interview Schedule for Children-Parent
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders
EEG	Electromyographic
EIC-4	Early Child Inventory-4
GC	Glucocorticoids
GSU	Georgia State University
IQ	Intelligence Quotient
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
SCARED	Screening for Childhood Anxiety and Related Emotional Disorders
SCAS	The Spence Children's Anxiety Scale
SIB	Self injurious behaviors

SSS	Stress Survey Schedule for Persons with Autism and Other Developmental Delays
WAIS-III	Wechsler scales
WISC-III	Wechsler scales

A LITERATURE REVIEW OF ANXIETY AND INDIVIDUALS WITH ATUSIM SPECTRUM DISORDERS

Autism is a pervasive developmental disorder (PDD) that is diagnosed by direct observations of an individual's behavior (Maurice, Green, & Luce, 1996). While the methods of diagnosis, manifestation of behaviors, and effectiveness of educational programs continue to be explored and refined, some identified components of autism have remained consistent since the initial observations of children with autism. Kanner first identified the link between autism and anxiety in 1943. He hypothesized anxiety as the driving factor behind the insistence on sameness and repertoire of fixed behaviors, routines, and obsessions in individuals with autism, stating specifically that, "the child's behavior is governed by an anxiously obsessive-desire for the maintenance of sameness" (Kanner, p. 245). Autobiographical accounts from individuals with ASD clearly depict experiences of high anxiety (Grandin & Scariano, 1986; Volkmar & Cohen, 1985).

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR; American Psychiatric Association, 2000) does not use the words "stress" or "anxiety" in the criteria for diagnoses; however, the presence of anxiety in autism is indicated through the behavioral descriptors. For example, the DSM-IV-TR criteria for autism outlines the inclusion of restricted and repetitive behaviors as demonstrated, with preoccupation with restricted interests, stereotypic, repetitive motor interests, and a restricted range of interests. Temple Grandin, an individual with high functioning autism explains this link

between anxiety and behaviors in her own words, “anxiety fueled my fixations and acted as a motivator” (Grandin, 2006, p. 71). The DSM-IV criteria for Asperger's Disorder (typically called Asperger Syndrome or AS) include impairments in social interaction but also restricted, repetitive, and stereotypical patterns of interest which, as Kanner observed, could be indicated by stress and anxiety. While there are some diagnostic differences identified between Autism, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), the broader term, Autism Spectrum Disorders (ASD), will be used in this paper to encompass all three diagnoses.

A review of literature that investigates the relationship between individuals with ASD and stress/anxiety will be provided in this paper. The theoretical bases of stress and anxiety will be explored first along with a discussion of the biologic impact of stress. The characteristics (i.e. age, gender, intelligence quotient [IQ], and disability) that can affect an individual's experience of stress will be explored second. Various methods for measuring anxiety in individuals with ASD will be described followed by a discussion of the implications of this information for educational settings and practice.

Theoretical Bases of Stress and Anxiety in the Human Experience Defining Stress

Stress is defined as an organism’s physiological reaction to life’s events and situations (Selye, 1956). The events experienced may be positive or negative in nature; however, all require that the organism works to recreate the equilibrium which existed previously. All living organisms experience stress and will inherently attempt to preserve internal constancy, also known as homeostasis (Baron, Lipsitt, & Goodwin, 2006). Anything that attempts to disrupt homeostasis is known (or viewed or defined) as a stressor (Cullinan, Herman, Helmreich, & Watson, 1995; Michelson, Licinio, & Gold,

1995). Stressors are the specific environmental factors that elicit the stress response. Selye (1975), one of the theorists responsible for the current understanding of stress, explained this interaction as follows:

> …all agents to which we are exposed also produce a nonspecific increase in the need to perform adaptive functions and thereby to re-establish normalcy. This is independent of the specific activity that caused the rise in requirement. The nonspecific demand for activity as such is the essence of stress. (p. 15)

Over time, stress researchers have refined the concept of homeostasis and many prefer to use the team allostasis (Sapolsky, 2004). The literal definition of allostasis is "maintaining stability (or homeostasis) through change" (McEwan & Seeman, 1999, p. 6). Allostasis emphasizes the dynamic nature of the human body's functioning; there is not one exact point of homeostatsis, but instead a variable range of effective functioning to which the human body intentionally adjusts.

Sources of Stress

Holmes and Rahe (1967) identify specific stressful life events that could be interpreted as positive or negative in nature. Some of the events which typically have a more significant impact on the level of stress include death of a spouse, divorce, personal injury or illness, marriage, retirement, and pregnancy. At times, an individual's perception of the event determines the positive or negative nature of the stressor. For example, the birth of child could be perceived as positive when in the context of a loving, safe environment, but could be negative as a result of a sexual crime or assault. Additionally, an individual's biological response to stress can be modulated by the context in which it is experienced. The additional stressors or protective factors present

can minimize or ameliorate the intensity of the stress experienced (Lazarus, DeLongis, Folkman, & Gruen, 1985).

Stress is an unavoidable part of the human condition (Baron, Lipsitt, & Goodwin, 2006). Many theorists describe stress and anxiety as strong motivating forces in individual development, accomplishment, and success (Selye, 1975; Walker & Diforio, 1997). For example, Barlow (1988) asserts:

> Without anxiety, little would be accomplished. The performance of athletes, entertainers, executives, artisans, and students would suffer; creativity would diminish; crops might not be planted. And we would all achieve that idyllic state long sought after in our fast-paced society of whiling away our lives under a shade tree. This would be as deadly for the species as nuclear war. (p. 12)

As personal experiences and surrounding contexts change, so do the stress and anxiety present. Throughout human evolution, the body's fight-or-flight response was necessary to combat the physical challenges and threats present in daily life. Over time, the type of stress humans have experienced has evolved from primarily physical stressors (such securing food) toward the increasing presence of psychological stressors (such as a reprimand from a boss). Both types of stressors elicit the same biological response in the organism and prepare it for superior physical responsiveness.

Selye (1956) outlines a few of the common stressors present in everyday life: driving, crowding, boredom, isolation and loneliness, relocation and travel, increased noise levels, pollution, and catastrophes including bombings and combat. Another evolutionary change humans have experienced is the increase in frequency of stressors in daily life. For example, the constant accessibility to and contact with others as a result of new technology, such as text messaging, email,

instant messenger, and so forth, and the fast-paced nature of contemporary life have added stressors that never before existed.

Stress Response

The challenge of effective individual functioning lies in maximizing the positive effects and outcomes of stress while minimizing the harmful effects. The biological response to stress, also known as the fight-or-flight response, results in profound changes in the organism as it is being prepared for emergency action (Murkoff, Eisenberg, & Hathaway, 2002). After being (or having been) alerted by the hypothalamus, the body moves quickly to action. The sympathetic nervous system releases adrenaline, cortisol, and norepinephrine into the blood stream. As a result, heart rate increases, blood pressure and blood sugar elevate, and nonessential bodily functions are suppressed; specifically, the digestive and reproductive systems and growth process slow down and immune response is inhibited. Behaviors identified in animals and humans experiencing stress include hypervigilance, sleeplessness, distractibility, social withdrawal, heightened fearfulness, increased arousal, difficulty being soothed, poor decision making and problem solving abilities, memory impairment, confusion, and rage (Henry, Sloan, & Black-Pond, 2007; Morgan, 2006).

The biological response to stress is self-regulating within the organism. Many individuals can experience and successfully recover from high levels of stress (Sapolsky, 2004). Not only do individuals possess the means to adapt and adjust to the stress around them, individual characteristics (including age, personality, and temperament) and learned implementation of intentional coping strategies (including exercise, meditation,

social support, spiritual practices, etc.) can contribute to the degree of the stress response. Once the stressor passes, the organism returns to normal.

However, when stress is not well managed by an individual, the detrimental effects of long-term and/or frequent activation of the stress response are well documented. Allostatic load is the natural consequence to the organism resulting from recurring cycles of allostasis as well as the consequence when the organism fails to effectively cope with the stressor (McEwan, 2002; Sapolsky, 2004).

Effects of Stress

As presented by Broom and Johnson (1993) in their model of response to stressful events, there are three possible consequences of stress. Two of the three consequences are inherently part of the stress response, the individual's change in biological functioning and the development of a pre-pathological state. The third possible consequence, the individual's development of pathology, is sometimes, but not always, an outcome in stressful situations. Several factors contribute to this third possible outcome. First, as an organism experiences stress, an increased sensitivity to arousal is established, subsequently adding to the likelihood of future experiences of stress (Morgan, 2006). When this occurs, even mild stressors can initiate a significant stress reaction in an individual (Gunner & Donzella, 2002). Second, when an individual continues to experience stress, the biological stress response continues, as do the physiological changes within the organism. Specifically, extended periods of stress result in continuous release of glucocorticoids (GC: including cortisol) into the organism. As a result, metabolism in the brain slows (Horner, Packan, & Sapolsky, 1990). In the hippocampus, the concentration of GC receptors lowers (Barbazanges, Piazza, LeMoal, & Maccari,

1996), the generation of new neurons slows (Duman, Malberg, & Nakagawa, 2001), and cell death may occur (Arbel, Kadar, Silbermann, & Levey, 1994). These are just a few examples of the long term biological changes as a result of stress. When prolonged stress occurs, it is difficult, if not impossible, for the organism to return to a pre-stress biological state (Arborelius, Owens, Plotsky, & Nemeroff, 1999). Third, over time, extended or intense stress can lead to a state of constant anxiety as well as to irreversible, psychological, and developmental damage to the organism (Kaufman, Plotsky, Nemeroff, & Charney, 2000; Lazarus & Folkman, 1984).

In summary, stress is "the pressure that life exerts on us *and* the way this pressure makes us feel" (McEwen, 2002, p. 3). Although stress is a protective force (i.e., the body's natural form of defense), chronic experiences of stress can lead to physical and emotional harm. Research has demonstrated that prolonged exposure to the stress response can be more damaging to the organism than the actual stressor (Sapolsky, 2004). The number and intensity of external stressors present in daily life are on the rise, making it increasingly important to understand the role of stress within individual's daily lives.

Individual Factors and Stress

While the body's physical reaction to stress remains constant across organisms, many factors mediate an individual's reaction to various stressors at any given time. Individual factors such as age, gender, intelligence, and temperament all contribute to a person's experience of stress (Steiner et al., 2007). As previously mentioned, the organism's interpretation of the stressor (as a challenge versus a threat) can affect the physical response. Additionally, other protective and/or risk factors within the

environment can influence an individual's interpretation of the stressor. Theorists (Patterson & Neufeld, 1989; Turner, 1994) have identified specific parameters that can moderate the stress response. These parameters include: severity (possible impact), temporal feature (how long until stressor occurs), probability (likelihood of incident), novelty (prior experience), duration (how long lasts), ambiguity (with regard to all of these factors), and controllability (can one affect outcome?).

Selye (1975) outlined the various factors which can influence an individual's stress reaction. Following introduction of the stimulus, or stressor, the individual has two forces simultaneously interacting with the stimulus and contributing to the body's response to the stressor; these are outer and inner conditioning. The outer conditioning factors, as described by Selye, would include diet, physical environment, or drugs. Inner conditioning factors are hereditary factors or prior experiences. Groden, Baron, and Groden (2006) also clarify this distinction with the terms exogenous (environmental) stimuli or endogenous (response patterns of an individual or group) stimuli. Groden et al. as well as Selye distinguished between stimuli that are elicited separate from an individual (exogenous and outer conditioning factors) as well as stimuli that occur within the individual (endogenous and inner conditioning factors). In contrast, Selye focused upon the conditioning factors of these external or internal agents and the reactions that are built over repeated experiences over extended time. When evaluating the stressors involved in an individual's life, it is imperative to recognize the presence and interaction of the internal and external individual factors directly interacting with the stressor. Each individual factor that will be explored here (i.e., gender, age, intelligence quotient, and disability) begins as an endogenous contributor to the stressful stimuli. However, once an

organism emits a response to the stimuli, exogenous and external factors become involved in the experience of the organism.

Gender. Gender has been determined to be an important individual factor with regard to stress (Van Well, Kolk, & Klugkist, 2008). The presence of some stressors can be dependent on gender (such as pregnancy), while others are highly correlated with a specific gender (such as the achievement of power and status). While is it well accepted that different stressors may be uniquely related to being male versus being female, research also reveals that females demonstrate an increased heart rate in response to stressors (Schmaus, Laubmeier, Boquiren, Herzer, & Zakoski, 2008), report more overall stress (Allgood-Merten, Lewinsohn, & Hops, 1990; Davies & Windle, 1997), and are more likely to experience stressors as negative in nature when compared to matched males (Hankin, Mermelstein, & Roesch, 2007). Furthermore, the nature of stressors identified most frequently by males relates to achievement and self-reliance while females tend to identify stressors in the area of interpersonal relationships (friends, romance, family, etc.; Leadbeater, Blatt, & Quinlan, 1995; Rudolph, 2002). As demonstrated by the research mentioned above, gender has apparent endogenous and inner conditioning factors such as the genetic and hormonal differences unique to males and females. However, exogenous and external conditioning factors also can contribute to an individual's experience or perception of stress. For both males and females, the perception of stressors as negative could be either a hormonal reaction (such as variations in levels of estrogen in females, or testosterone in males) or it could be a learned response, modeled by siblings, parents, teachers, and other important role models.

Age. Chronological age is another individual factor that can influence what is

perceived as a stressor and the reaction to specific stressors. As previously determined, stress is an unavoidable part of life and is present each day throughout the entire life span. However, what elicits a stress response varies by age. Even in utero, infants demonstrate biological reactions associated with stress (Murkoff et al., 2002). Maternal stress (ranging from daily hassles or lack of social support to depression, famine, or drug use) produces both hormonal and neurochemical responses which subsequently impair the fetus' developing central nervous system (Anhalt, Telzrow, & Brown, 2007). Stress in infancy centers around getting one's basic needs met (hunger, shelter, warmth). As Baron et al. (2006) explain:

> The saliency of different kids of stress at different developmental ages is often cited: the stress of an infant, for example, may relate to hunger and hurt; the toddler is stressed by his or her inability to reach a coveted object on a high table; the preschooler is stressed by the hoarding behavior of his playmate; the adolescent is stressed by the appearance of acne on his face; and the stresses of adults are too numerous to cite. (p. 44)

At each developmental stage, as new skills are gained and expectations change, new types of stress are introduced. Erikson (as cited in Nelson, Erwin, & Duffy, 2007) describes development as requiring interaction of the body (genetic) programming, the mind (psychological), and cultural influences. While age, as biological and genetic programming, provides an approximate framework for this theory, it is recognized that some individuals may not transition through the developmental stages at the same ages as others. Erikson created a developmental eight-stage theory that outlines the stressors and conflict inherent in each developmental skill set (Erikson, 1963). As individuals move through the critical tasks to be mastered, they are faced with the particular developmental stressors. For example, the first stage Erikson outlines for infants is trust versus mistrust. During this developmental stage individuals are forming a basic sense of trust or mistrust

in the world and the individuals around them. To ensure the capacity for trust, an infant needs to experience that he or she can consistently rely on others to meet basic needs. This constant stressor (getting his or her needs met) is the focus of the infant's energy and attention. As individuals move through the life span, new stressors are experienced and new types of mastery must be developed. The remaining seven stages, in order of occurrence are autonomy versus shame (18 months to 3 years), initiative versus guilt (3 to 5 years), industry versus inferiority (6 to 12 years), identify versus role confusion (12 to 18 years), intimacy and solidarity versus isolation (18 to 35 years), generativity versus self absorption or stagnation (35 years to 55/ 65 years), and integrity versus despair (55/65 to death).

It is possible that adolescence is the most stressful stage of development. To illustrate, research has documented that stress levels significantly increase during adolescence (Gaylord-Harden, Gipson, Mance, & Grant, 2008) as the level of independence expected by others increases (Patterson & McCubbin, 1987) and the possible response to each stressor multiplies (Compas, Conner, Saltzman, Thomsen, & Wadsworth, 2001). Some researchers believe that increasing an adolescent's stress coping skills could be the most effective way to prevent problems during this developmental period (Sandler, Wolchik, MacKinnon, Ayers, & Roosa, 1997).

Similar to gender, there are unambiguous endogenous and inner conditioning factors with regard to age. Physical, emotional, and intellectual abilities differ depending on age. In contrast, the expectations of peers, teachers, and parents change toward an individual dependent on his or her age, and these exogenous and outer conditioning factors could likely contribute to the experience and perception of a stressor throughout

the life cycle.

Intelligence quotient. At its inception, the intelligence quotient (IQ) was often used as a sole measure of capacity for potential performance (Sternberg, 2003). Due to the identified bias inherent in this measure, intelligence quotient is no longer used in this way (Fagan & Holland, 2007; Share, & Silva, 2003). However, IQ measurement continues to be used in identifying the continuum of capacity for individuals within academic and enrichment settings (Pintrich & Schunk, 2002). For example, it has been suggested that individuals with high IQ scores, such as those categorized in school as gifted, are more reactive to stress than their typically developing peers (Silverman, 1993; Woodin, 1997). Intelligence quotient in the field of ASD is considered a central predictor in developmental course (Shea & Mesibov, 2005), stable throughout the lifespan (Nordin & Gillberg, 1998), and highly correlated with adult outcome (Barroff, 1999). Additionally, IQ is often a contributing factor in diagnosis and treatment for individuals on the spectrum. Those individuals with high IQs are usually diagnosed later than those with more severe cognitive impairments (Howlin & Asgharian, 1999). Intelligence quotient measures can differentially affect the stressors to which individuals on the spectrum are exposed. Specifically, individuals who are lower functioning (those with lower IQ scores) tend to be placed in more segregated special education classrooms as compared to their higher functioning (those with higher IQ scores) peers (White, Scahill, Klin, Koenig, & Volkmar, 2007). Further, it is evident that each setting offers distinct stressors to a student with ASD and ranges in the amount of social and academic demand.

As demonstrated through the research, IQ can be viewed as an unambiguous endogenous and inner conditioning factor. However, similar to age and gender, IQ may

interact with environment (such as classroom placement) which will inevitably contribute to the development of stress reactions.

Disability. Research indicates that individuals with disabilities experience higher levels of stress than the general population (Bellini, 2004; Groden et al., 2001). Additionally, research has documented that each member of the family and extended family of a person with a disability experiences higher levels of stress as well (Blacher & Baker, 2007; Mitchell & Hauser-Cram, 2008). Further, individuals working with those with disabilities often display high levels of stress and anxiety (Kelly, Carey, McCarthy, & Coyle, 2007; Lecavalier, Leone, & Wiltz, 2006). Consequently the individual with the disability is surrounded by others with high levels of stress, in turn adding to his or her general state of stress and anxiety.

Lazarus and Folkman (1984) suggest that individual perception plays a significant role in an individual's stress response. When an individual perceives a stressor as too demanding or beyond his or her capabilities, a high level of stress is likely to result. Individuals with disabilities are more likely to perceive stressors as too demanding or beyond their capabilities. Moreover, when compared to those who are typically developing, individuals with disabilities are more likely to have previous negative experiences when faced with stress, fewer environmental resources, and lower levels of personal confidence; each of these may contribute to an increased likelihood in the perception of the stressor by an individual with a disability as extremely negative (Lunksy & Bramtson, 2006). Research confirms the relationship between major stressors and mental health crisis in individuals with intellectual disability (Ghazziuddin, 1998; Hastings, Hatton, Taylor, & Maddison, 2004; Nadarajah, Roy, Harris, & Corbett, 1995).

Individuals with ASD also experience greater levels of stress and anxiety in their lives (Arick, Krug, Fullerton, Loos, & Falco, 2005; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000).

Disability is consistent with the other factors mentioned previously in that there are initial unavoidable endogenous or inner conditioning factors present. For some disabilities, such as Down syndrome, specific genetic markers indicate these differences. For other disabilities, such as ASD, research points to the strong genetic component in the development of the disorder. Nonetheless, disability can become an exogenous or outer conditioning factor as the individual moves through the world and develops relationships with those around them.

Stress, Anxiety, and Autism Spectrum Disorders

Researchers have found increased levels of anxiety in individuals with ASD as compared to the general population (Rescorla, 1986; Van der Gaag et al., 1995; Volkmar, Cohen, Hoshino, Rende, & Paul, 1988) and based on rates for psychiatric referrals (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). Gillott, Furniss, and Walter (2001) used a self-report measure (*The Spence Children's Anxiety Scale*; Spence, 1997) and parent report measure (*The Social Worries Questionnaire*; Spence, 1995) to compare anxiety and social anxiety in three groups of children between 8 and 12 years of age: children with autism, children with specific language impairment, and children developing typically. Results indicated the children with high functioning autism had considerably higher levels of anxiety and social anxiety than both comparison groups based on self- and parent report.

Kim et al. (2000) found significantly higher levels of anxiety and depression in children 4 to 6 years of age with PDD-NOS and AS when compared to the general population. Upon enrollment in the study, subjects were given a full psychometric evaluation, including two IQ tests and semi-structured parent interviews (the *Autism Diagnostic Interview*; Lord, Rutter, & LeCouteur, 1994). Six years later, anxiety and depression were measured through the use of a parent questionnaire (initially used in the Ontario Child Health Study (OCHS-R) and a revision of the *Child Behavior Checklist*; Achenbach, 1991) addressing the prevalence of psychiatric problems. Although unable to identify risk factors for anxiety and mood disorders, results indicated that a substantial portion of the subjects with high-functioning ASD scored at clinical levels of anxiety and depression. In the subjects with PDD-NOS and AS, there were high correlations between anxiety and mood problems and aggressive and oppositional behavior. Comparison of the two groups (PDD-NOS and AS) found no identifiable differences on anxiety measures.

In addition to finding higher reports of symptoms of anxiety, researchers also have found a high rate of comorbidity between Anxiety Disorders and ASD (De Bruin, Ferdinand, & Sijifra, 2007; Gadow, DeVincent, Pomeroy, & Azizian, 2004; Ghaziuddin, 2002; Tsankanikos, Sturmey, Costello, Holt, & Bouras, 2007). For example, 19 of 20 male adolescents with ASD demonstrated comorbidity on three or more anxiety symptoms as assessed using the *Isle of Wight Semistructured Interview* (Rutter & Graham, 1966) which solicits information regarding physical and psychiatric illness. Specific anxiety symptoms reported by individuals with ASD included worrying, hypocondriasis, nonsituational anxiety, panic, and specific fears (Green, Gilchrist, Burton, & Cox, 2000). The *Diagnostic Assessment for Severely Handicapped* (DASH-II:

Matson, 1995), which provides dimensions of frequency, severity, and duration of current behaviors, also has established comorbidity between Anxiety Disorders and ASD (Bradley, Summers, Wood, & Bryson, 2004; Hill & Furniss, 2006).

The presence of higher levels of anxiety in individuals with ASD may be explained by endogenous traits. Tantum (2000) states that high trait anxiety is a feature of many people with ASD, particularly when there is a family history of anxiety disorder. The resulting hereditary endowment may produce what Bellini (2006) describes as a biological predisposition to high physiological arousal. Ghaziuddin et al. (1998) suggested that possible contributing factors to increased anxiety and depression were vulnerability to affective disorder, family tension, higher than usual rate of adverse life events, and awareness of difference. Bellini (2006) noted that social withdrawal and social skills deficits, as well as repeated negative experiences with peers and adults, result in high levels of social anxiety.

In addition to the possibility of a biological predisposition to high physiological arousal, the higher rates of stress and anxiety in individuals with ASD may be unique to the disability. Characteristics of individuals on the spectrum may result in a special vulnerability to stressors (Groden, Cautela, Prince, & Berryman, 1994). Some of the internal characteristics that also can add stress to the lives of individuals with autism include communication deficits, deficits in social skills, mental retardation, low cognitive ability, heightened sensitivity in response to perceptual stimulation, the need to maintain sameness, and ritualistic behavior. These internal characteristics also impede development of the skills necessary to cope with stress. Some researchers are particularly

interested in this reciprocal relationship. Morgan (2006) has explored the question "Is autism a stress disorder?" She writes:

> Certainly what is known about the psychobiology of stress overlaps in interesting ways with what is known about the psychobiology of autism and suggests some provocative questions about those similarities . . . excessive stress or anxiety can alter the brain in ways that promote hypervigilance and abnormal behavior, exaggerate fearfulness, disturb sleep, impair memory, and cause shifts in attention – all characteristics of autism. These behaviors, in return, can exacerbate feelings of anxiety, so that the entire cascade becomes one of constant emotional distress and arousal spiraling out of control. Thus stress in a person who has difficulty moderating his or her emotional behavioral responses to stimulation can produce a situation that, because of its potential for bringing about permanent physiological change, is self-perpetuating. (p.159)

When compared to children with Down syndrome and those who are typically developing, children with ASD displayed anxieties and fears significantly different from the other two groups (Evans, Canavera, Kleinpeter, Maccubbin, & Taga, 2005). Children with ASD exhibited fewer fears and anxieties related to their own physical harm, but more fears and anxieties in all other areas. In comparison to children who were typically developing, participants with AS demonstrated significantly higher rates of anxiety on both parent and self report measures (Meyer, Mundy, Van Hecke, & Durocher, 2006). Statistical analysis indicated a strong correlation between inaccurate social perception and repeated negative social experiences and high levels of anxiety.

In summary, individuals with ASD are characterized by increased levels of anxiety and a higher likelihood of being diagnosed with an Anxiety Disorder (De Bruin et al., 2007; Kim et al., 2000). While it may be possible that this increased experience of anxiety is genetically determined, also it is possible that core characteristics of ASD add stress to those with this diagnosis. Additionally, the deficits experienced by those on the autism spectrum can make coping and self-management more difficult in stressful

situations. Due to the prevalence of anxiety in this population, it is essential for those serving these individuals to have resources with which to measure the extent and the nature of their anxiety.

Methods for Measuring Anxiety in Individuals with ASD

While there is clear evidence that individuals with ASD have higher rates of anxiety than typically developing individuals and individuals with some other disabilities, as well as an increased likelihood of being diagnosed with an Anxiety Disorder, a standardized way of demonstrating the presence of anxiety and stress in individuals with ASD has not yet been identified. Previous research acknowledges that differentiating between anxiety symptoms and behaviors specific to ASD is a difficult task (Bradly et al., 2004; Gillott et al., 2001; Green et al., 2000). Not only do individuals with ASD have limited verbal and possibly cognitive skills with which to express anxiety, but also it is difficult to identify whether behavioral symptoms (such as flapping or repeated questioning) occur as a function of anxiety or of the disorder. Tatum (2000) speculated that one diagnostic difficulty encountered when working with individuals with AS was that the increased anxiety may increase the severity of AS characteristics (for example, the increased need for and use of rituals). Researchers have attempted to quantify and measure stress and anxiety in one of three ways: physiological measures, self-report or other report measures, and by documenting stereotypical and aggressive behaviors displayed by individuals with ASD.

Physiological Measures. While there is a growing body of research employing physiological measures of stress and anxiety in individuals with ASD, this area of research is still in its infancy, and findings are inconsistent (Bernier, Dawson,

Panagiotides, & Webb, 2005; Goodwin et al., 2006). Some studies have found individuals with ASD demonstrate an increased heart rate as a response to stress. Goodwin et al. (2006) used heart rate to determine the response to stressors of individuals with ASD as compared to typically-developing individuals. Biological changes indicating stress (both movement data and heart rate data) were measured in reaction to 22% of the stressors for individuals with ASD as compared to 60% of the stressors for those who were developing. While individuals with ASD in this study demonstrated an increased heart rate as a response to stress they responded to fewer stressors than individuals who are typically developing. In contrast, several studies comparing adult and child participants with ASD to those who were developing typically noted that the individuals with ASD experienced decreased heart rates in response to stressors (Jansen et al., 2006). Bernier et al. (2005) investigated the fear potential startle response, as measured through eyeblink latency and magnitude using electromyographic (EEG) activity, in individuals with ASD and individuals developing typically. No significant differences were found between the two groups.

Baron et al. (2006) assert that physiological indicators can be more accurate in assessment of stress and anxiety due to the difficulty that individuals on the spectrum have with self-report. However, employment of such tools can be difficult for individuals to tolerate, costly, and provide more information than can be used in most settings (Groden et al., 2006). Many researchers believe that the most valid measurement of stress within this population would involve multiple measurements (direct observation, survey instruments, and physiological measure). Also, repeated assessment within various settings over time can aid in providing a more complete and accurate measurement (Tsai,

2006). An invaluable component of a multi-faceted assessment of anxiety and stress in individuals with ASD is self- or other report.

Self- or Other Report. Self-report measures are typically used to screen for anxiety in individuals without disabilities to determine need for further assessment (Hale, Raaijmakers, Muris, & Meeus, 2005). Individuals with ASD who are high-functioning and verbal may be able to report their experiences of stress and anxiety. Some of the self-report and other report measures utilized in this area of research are general child or adult anxiety measures, not specifically developed for individuals with ASD. Most require only a familiarity with the child (other report) and are designed to be used without formal training since perceptions are being solicited in lieu of behavioral documentation. While many different measures are employed, the most frequently used include the following:

The Diagnostic Interview Schedule for Children-Parent (DISC-IV). The DISC-IV (Schaffer, Fisher, & Lucas, 1998) provides information about the frequency, severity, and duration of the current behavior. The DISC-IV has both a parent version, appropriate for children ages 6-17, and a child version, appropriate for children ages 11-17. There are just fewer than 3,000 true/false questions on the interview: however, many of these are 'contingent' questions assessing the intensity, frequency, and duration of the behavior which are only asked if there is a positive response to that specific behavior. The instrument has demonstrated good test-retest reliability and interrater reliability and moderate to good reliability (Schaffer et al., 1996; Schaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000). De Bruin et al. (2007) used the DISC-IV to assess comorbid symptoms in children with PDD-NOS ages 6-12 years old. Based on the results of the DISC-IV, more than half of the individuals in the study met the criteria for an anxiety

disorder.

Diagnostic Assessment for the Severely Handicapped-II (DASH-II). The DASH-II (Matson, 1995) was designed for the purpose of assessing psychopathology in children with severe and profound intellectual disability. The 84 item assessment can be completed by parents or other caregivers and identifies problematic behaviors and psychiatric disorders including anxiety, depression, mania, Pervasive Developmental Disorder/ autism, schizophrenia, stereotypies, self-injury, elimination, eating, sleep, sexual, organic, and impulse. Each of the 13 subscales is scored on three dimensions: frequency within the last two weeks (zero, 1-10, or over 10 occurrences), duration of problematic behavior (less one 1 month, 1-12 months, or over 12 months), and severity within the last two weeks (cause no disruptions or damages, cause no damages but at least one disruption to others, or caused injury or property damage at least once). Inter-rater reliability ($r = 0.86$) and test-retest reliability ($r = 0.84$) are strong (Matson). Bradley et al. (2004) and Hill and Furniss (2006) used the DASH-II to evaluate a total of 82 children and young adults with severe intellectual disabilities and challenging behavior. When individuals with autism were compared to those without autism, significantly higher scores on the DASH-II subscales emerged (specifically organic disorder, anxiety, mania, PDD/autism, and stereotypies). Further, group effects were identified on the anxiety, mood, mania, PDD/autism, schizophrenia, and stereotypies subscales by group ASD severity (moderate, severe, nonautistic).

The Spence Children's Anxiety Scale (SCAS). The SCAS (Spence, 1997), a 45-item self-report measure of anxiety based upon DSM-IV criteria, provides a measure of overall anxiety as well as a measure for each of the six anxiety subscales. Item responses

are on a four-point severity scale. Reliability and validity measures have been strong (internal reliability=0.93, split-half reliability=0.92). Gillott et al. (2001) used the SCAS to compare the anxiety and social worries of individuals ages 8-12 with ASD, specific language impairment, and typically developing. The children with ASD demonstrated the highest levels of both anxiety and social worries as compared to the two control groups.

Screening for Childhood Anxiety and Related Emotional Disorders (SCARED). The SCARED (Birmharer et al., 1999) consists of 41 items that are answered by parents and children and takes approximately 15 minutes to complete. The 41 items are identical on each of the versions with the exception that the parents' version refers to "your child" while the children's version refers to "you." The statements relate to common children's anxieties and are rated on a three-point Likert scale with a rating of "0" indicating the descriptor is not true or seldom true, a "1" indicating the descriptor might be true, and a "2" indicating that the description is true or often true. The SCARED was designed for use with children 10-18 years of age and scoring results in a total score as well as domain scores in the areas of somatic/panic, generalized anxiety, separation anxiety, social phobia, and school phobia. The five-factor structure has been independently confirmed for diverse populations (Hale et al., 2005). Birmaher et al. (1997) found good internal consistency (alphas = .77 to .93) and test-retest reliability (.70 to .90) for the SCARED. Monga et al. (2000) reported good convergent and divergent validity when using the SCARED to screen children and adolescents for anxiety disorders.

The SCARED has been used with children and adolescents across income levels (Boyd, Ginsburg, Lambert, Cooley, & Campbell, 2003; Ginsburg & Drake, 2002; Sung, Puskar, & Sereika, 2006) and cultures (Essau, Muris, & Ederer, 2002; Hale et al., 2005;

Muris, Schmidt, Engelbrecht, & Perold, 2002; Su, Wang, Fan, Su, & Gao, 2008). The SCARED also has been used to predict trajectories of anxiety (Bar-Haim, Dan, Eshel, & Sagi-Schwartz, 2007; Hale, Raaijmakers, Muris, van Hoof, & Meeus, 2008; Muris et al., 2001). Specific to youth with ASD, Reaven et al. (2009) used the SCARED to assess the effects of a group cognitive behavioral therapy intervention for 8 -14 year old children functioning on the high end of the autism spectrum. Each of the 33 child participants and their parents completed the SCARED before and after the 12-week treatment program and the results indicated that the parents perceived the intervention to be more beneficial than their children.

Early Child Inventory-4 (EIC-4). The ECI-4 (Gadow & Sprafkin, 1997), a 108 item DSM-IV-referenced rating scale to assess psychiatric symptoms, has both a parent and teacher version. Inventory items are rated as "never," "sometimes," "often," or "very often" and provide both a categorical symptom count and symptom severity score. Specific symptoms assessed by the ECI-4 include: Attention Deficit Hyperactive Disorder, Oppositional Defiance Disorder, Conduct Disorder, Generalized Anxiety Disorder, Separation Anxiety Disorder, Social Phobia, Major Depressive Disorder, Dysthymic Disorder, PDD Symptoms, Posttraumatic Stress Disorder, sleep problems, feeding problems, reactive attachment disorder, simple phobia, obsessions, compulsions, and tics. Internal consistency, test-retest reliability, and convergent and divergent validity with other scales are satisfactory (Gadow, Sprafkin, & Nolan, 2001; Sprafkin, Volpe, Gadow, Nolan, & Kelly, 2002).

The ECI-4 has demonstrated that both preschool (Gadow, DeVincent, Pomeroy, & Azizian, 2004) and school-age (Gadow, Devincent, Pomeroy, & Azizian, 2005)

students with PDD-NOS have increased DSM-IV psychiatric symptoms, including anxiety and separation anxiety, when compared to students in general education settings as well as other various special education settings.

Stress Survey Schedule for Persons with Autism and Other Developmental Delays (SSS). The SSS (Groden et al., 2001) has recently been developed as a tool for assessing stress in individuals with ASD. While not yet standardized, the *Stress Survey Schedule for Persons with Autism and Other Developmental Delays* (SSS) is the first and only tool developed specifically to measure perceived stress in this population (Groden et al.). The SSS is a 49-item Stress Survey Schedule to collect information about the types of stress and stressors experienced by individuals on the autism spectrum. The types of stress are categorized in eight daily stress subscales of the SSS (Groden et al.). These include: (a) changes and threats (11 items), (b) anticipation/uncertainty (7 items), (c) unpleasant events (9 items), (d) pleasant events (8 items), (e) sensory/personal contact (4 items), (f) food related activity (3 items), (g) social and environmental interactions (3 items), and (h) ritual/related stress (4 items). Internal consistency for these categories ranges from .70 to .87. The behavioral items (performance rating) portion of the survey includes behavior statements rated for severity on a 5-point Likert scale (1 = None to Mild, 2 = Mild to Moderate, 3 = Moderate, 4 = Moderate to Severe, 5 = Severe).

In a recently published study using the SSS, Gilliott and Standen (2008) found adults on the autism spectrum almost three times more anxious than the comparison group (adults with intellectual disabilities). Additionally, high levels of anxiety experienced by those on the autism spectrum were correlated with specific stressors as identified by the SSS (change, anticipation, sensory stimuli, and unpleasant events).

Researchers also have used the stressors identified in the SSS when comparing physical arousal responses (heart rate) of individuals who are on the autism spectrum and those who are typically developing (Goodwin et al., 2006; Groden et al., 2005).

Self- and other- reports are frequently used to assess stress and anxiety, and some protocols use a combination of self- and other- reporting (e.g., ECI-4, SCARED). Self-reporting formats present certain challenges for individuals with ASD. For example, individuals with ASD who have cognitive impairments may need parents, caregivers, or teachers to complete the questionnaires to determine levels of stress and anxiety. Even individuals with ASD who can read the protocol may have difficulty understanding terminology or abstract concepts (Nikolaenko, 2004). However, relying on others to report on the individual's experience of stress and anxiety may result in inaccurate assessments. Wren, Bridge, and Birmaher (2004) discovered that the parents of typically-developing children tended to under estimate their children's stress and anxiety levels, particularly in the areas of somatic symptoms and separation anxiety. Using the SCARED, Wren et al. found that self-reports by the 236 children in their study provided more accurate indicators of stress and anxiety. In contrast, results of the Reaven et al. (2009) study indicated that the parents' reports of the 33 children and adolescents with high-functioning ASD were more sensitive to detecting change after the cognitive-behavioral intervention. In contrast to the significant reduction in anxiety based on the parents' reports, almost 25% of the children and adolescents reported an increase in anxiety after the treatment as measured by their self-report on the SCARED. Reaven et al. speculated that the children and adolescents probably under reported their stress and

anxiety during pre-treatment assessment because they were unable to identify their emotional, cognitive, and psychological responses to stressful stimuli.

Behavioral Observations. In addition to physiological measures and the use of self- and other-reporting, some researchers have focused on evaluating overt behaviors to document that individuals are experiencing stress. Anxiety may underlie participation in stereotypical behavior and increased compulsion with regard to routines and rituals. Additionally, research shows that stressful events occur as an antecedent to challenging behaviors for individuals with ASD (Groden et al., 1994). For many children with ASD, symptoms of anxiety may be a response to difficulty in understanding and negotiating the environment. Minor environmental changes or uncertainty within a given environment can lead to distress for children with autism (Groden et al.; Schopler & Mesibov, 1994). Reliance on behavioral observations may be necessary when dealing with lower functioning individuals with ASD who could be unable to provide the information required by self-report and who may not cooperate with the efforts to measure physiologic indicators.

Stereotypical behaviors are repetitive behaviors that appear to serve no function for the individual engaging in them and are set in appearance (Lawrence & Rushen, 1993). While still an area of continued debate, (Kennedy, Meyer, Knowles, & Shukla, 2000) some researchers hypothesize that individuals with ASD engage in stereotypical behaviors in response to stress (Militerni, Bravaccio, Falco, Fico, & Palermo, 2002) or to reduce stress (Berkson, 2002). Research demonstrates that stereotypical behaviors such as echolalia, twirling, hand flapping, and repetitive questioning increase when children with autism are distressed or anxious (Howlin, 1998; Thomas et al., 1998). Individuals with

PDD-NOS may participate in stereotypical behaviors and rituals as a mechanism for coping with fear and anxiety (Despart, 1965; Howlin, 1997, 1998). Further, impeding or disrupting ritualistic behaviors may result in increased anxiety (Groden et al., 1994; Rutter, 1985).

Self injurious behaviors (SIB) can include self-biting, eye-poking, pica, head-banging, excessive scratching, self-hitting, and hair-pulling (Reese, 1997). It is possible that like stereotypical behaviors, SIB occur in response to stress as well as to reduce stress for individuals on the autism spectrum (Morgan, 2006). O'Reilly, Sigafoos, Lancioni, Edrisinha, and Andrews (2005) implemented the use of an individualized schedule to reduce the levels of self-injury for a 12 year old boy with autism. The individualized schedule prepared the student for upcoming stressful occurrences and/or transitions, suggesting that stress was contributing to the high level of self-injury.

While most research continues to focus on how to reduce the frequency of stereotypical and SIB (Matson & Vullo, 2008), some diagnostic centers are using a behavioral measure as one component of a comprehensive assessment of stress for individuals on the spectrum. A multimodal approach to assessment includes functional assessment, scales or schedules, informant interviews, and physiological measures of the stress responses (Groden, Baron, & Groden, 2006). The functional assessment in identifying stressors includes a direct observation of behaviors, including description of the behavior, antecedents, setting events, consequences, and perceived functions.

Implications

The detrimental effects of stress and anxiety have been well documented (Arborelius et al., 1999). Some specific effects include decreased attention span, short

and long term memory problems, and fatigue. Additionally, when experiencing high levels of stress and anxiety, individuals are missing the opportunity to learn and develop. This is particularly important for individuals with ASD, as their willingness to engage with others in educational experiences are likely limited by high levels of stress. Furthermore, the biological repercussions of stress and anxiety have been determined to have lasting, long-term, and developmental implications (Kaufman et al., 2000). Additionally, while there are no well established pharmacological interventions to treat ASD, biologic therapies have been found to be successful in ameliorating the overt symptoms of Anxiety Disorders (De Bruin et al., 2007; Gadow et al., 2005). While each of these findings is important to those working in the field of autism, in combination they indicate the necessity of further focused research and overall understanding of the role that anxiety plays within ASD. The limits of this new knowledge underscore the significance of the understandings yet to be gained.

Those researching comorbidity between Anxiety Disorders and ASD suggest that increased understanding of the genetic or neurobiological correlates in this complex relationship will aid practitioners in ASD diagnosis, prognosis, medical and psychological assessment, treatment, educational programming, family intervention, and overall understanding of the subjective experience of individuals with ASD (De Bruin et al., 2007; Kim et al., 2001; Tantum, 2000). Clearly, increasing the knowledge of the relationship between anxiety and ASD as well as identifying and studying the efficacy of interventions effective in decreasing anxiety in individuals with ASD is relevant for medical and mental health practitioners, educators, family members, the individuals themselves, and others serving this population. Therefore, attention must be given to

integrating this knowledge in both education for new practitioners and continuing education for current professionals across the relevant fields of practice. Moreover interdisciplinary research and practice collaborations are necessary to move the field forward in this critical area.

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STRESS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS: EFFECTS OF AGE, GENDER, AND INTELLIGENCE QUOTIENT

Autism is a pervasive developmental disorder (PDD) that is diagnosed by direct observations of an individual's behavior (American Psychiatric Association [APA], 2000; Maurice, Green, & Luce, 1996). While the methods of diagnosis, manifestations of behavior, and effectiveness of educational programs continue to be explored and refined, some identified components of autism have remained consistent since the initial observations of children with autism. Kanner (1943) first identified the link between autism and anxiety, hypothesizing anxiety as the driving factor for the insistence on sameness and repertoire of fixed behaviors, routines, and obsessions commonly seen in individuals with the disability.

Anxiety is produced by exposure to stress, which is defined as an organism's physiological reaction to life's events and situations (Selye, 1956, 1974). Stress is "the pressure that life exerts on us *and* the way this pressure makes us feel" (McEwen, 2002, p. 3). While events may be positive or negative in nature, all require that the organism works to recreate the equilibrium which existed previously. Although stress is a protective force (i.e., the body's natural form of defense), chronic experiences of stress can lead to physical and emotional harm. Researchers have demonstrated that prolonged exposure to the stress response can be more damaging to the organism than the

actual stressor (Sapolsky, 2004). Over time, extended or intense stress can lead to increased anxiety as well as to irreversible physical, psychological, and developmental damage (Arborelius, Owens, Plotsky, & Nemeroff, 1999; Kaufman, Plotsky, Nemeroff, & Charney, 2000; Lazarus & Folkman, 1984). As the number and intensity of external stressors present in daily life continue to rise, it is increasingly important to understand the role of stress within individuals' daily lives.

INTRODUCTION

Individual Factors Influencing Stress and Anxiety

Researchers have found several individual factors to be important with regard to the experience of stress, including gender (Van Well, Kolk, & Klugkist, 2008), age (Baron, Lipsitt, & Goodwin, 2006), intelligence quotient (IQ; Shea & Mesibox, 2005), and disability (Bellini, 2004; Groden et al., 2001). With regard to gender, it is well accepted that different stressors may be uniquely related to being male versus being female; moreover, researchers also reveal that females demonstrate an increased heart rate in response to stressors (Schmaus, Laubmeier, Boquiren, Herzer, & Zakoski, 2008), report more overall stress (Allgood-Merten, Lewinsohn, & Hops, 1990; Davies & Windle, 1997), and are more likely to experience stressors as negative in nature when compared to matched males (Hankin, Mermelstein, & Roesch, 2007).

Chronological age can influence what is perceived as a stressor and the reaction to specific stressors. Even in utero, infants demonstrate biological reactions associated with stress (Murkoff, Eisenberg, & Hathaway, 2002.) What elicits a stress response varies by age. At each developmental stage, particular types of stress are introduced as individuals

face changing expectations and move through the critical tasks to be mastered (Erikson, 1963).

Finally, intelligence has been implicated in the perceptions of stress and stress responses. Individuals with high IQs, such as those categorized in academic settings as gifted, are more reactive to stress than their typically developing peers (Woodin, 1997). Researchers demonstrate a significant correlation between low IQ scores and impaired language skills (Tager-Flusberg, Paul, & Lord, 2005). Further, individuals with poor communication skills are likely to experience higher levels of frustration and stress than those with strong communication skills (Olive, Lang, & Davis, 2008). Finally, researchers indicate that individuals with disabilities experience higher levels of stress than the general population (Bellini, 2004; Groden et al., 2001). Interestingly, researchers have documented that each member of the family and extended family of a person with a disability experiences higher levels of stress as well (Blacher & Baker, 2007; Mitchell & Hauser-Cram, 2008), further exacerbating the experience of stress for the individual with a disability.

Anxiety in Individuals with ASD

Researchers have confirmed high levels of stress and anxiety in individuals with autism spectrum disorders (ASD; Gillott, Furniss, & Walter, 2001; Stavrakaki, 1999). Autobiographical accounts from individuals with ASD clearly depict individuals as stressed and anxious (Grandin & Scariano, 1986; Volkmar & Cohen, 1985). Additionally, researchers have established that when compared to the general population, individuals with ASD have higher rates of anxiety (Rescorla, 1986; Van der Gaag et al., 1995; Volkmar, Cohen, Hoshino, Rende, & Paul, 1988) and a greater likelihood of being

diagnosed with an Anxiety Disorder (De Bruin, Ferdinand, & Sijifra, 2007; Gadow, DeVincent, Pomeroy, & Azizian, 2004; Ghaziuddin, 2002; Tsankanikos, Sturmey, Costello, Holt, & Bouras, 2007). High levels of stress and anxiety have been attributed to poor outcomes and behavioral manifestations of ASD, such as increased participation in echolalia, twirling, hand flapping, and repetitive questioning as well as demonstration of other challenging behaviors frequently associated with this population (Despart, 1965; Evans, Canavera, Kleinpeter, Maccubbin, & Taga, 2005; Howlin, 1997; Groden, Cautela, Prince, & Berryman, 1994).

In the field of ASD, IQ is considered a central predictor in the developmental trajectory (Shea & Mesibov, 2005). Intelligence quotient is stable throughout the lifespan (Nordin & Gillberg, 1998) and highly correlated with adult outcomes (Barroff, 1999). Moreover, IQ can differentially affect the stressors to which individuals on the spectrum are exposed. Specifically, individuals who are lower functioning (i.e., those with lower IQ scores) tend to be placed in more segregated special education classrooms as compared to their higher functioning peers (i.e., those with higher IQ scores; White, Scahill, Klin, Koenig, & Volkmar, 2007). Further, it is evident that each academic setting ranges in the nature and amount of social and academic demand and thus offers distinct stressors to a student with ASD.

Measurement of Anxiety in Individuals with ASD

Three types of measures have been employed to quantify and measure stress and anxiety in individuals with ASD: physiological measures (Bernier, Dawson, Panagiotides, & Webb, 2005; Goodwin et al., 2006); observation of stereotypical and aggressive behaviors (Rutter, 1985; Thomas et al., 1998); and self-report or other-report

measures (Glenn, Bihm, & Lammers, 2003; Hill & Furness, 2006). While there is a growing body of research employing physiological measures of stress and anxiety in individuals with ASD, research in this area is still in its infancy, and findings are inconsistent (Bernier et al., 2005; Goodwin et al., 2006). While a physiological measure would certainly be most accurate, variable results, expensive materials, and intrusive procedures make this approach currently not easily employable for educators.

As an alternative measurement, since stress and anxiety may be related functionally to behavior, the characteristic and stereotypic behaviors displayed by individuals with ASD can be assessed (Groden et al., 1994). While there is strong evidence pointing to this link, further research is needed (Bradley, Summers, Wood, & Bryson, 2004; Green, Gilchrist, Burton, & Cox, 2000). Behavioral observations are a possible way for educators to assess anxiety in students; however, each individual on the autism spectrum must be assessed to determine the behavioral markers, and all other factors possibly correlated to these behaviors must be identified and controlled, both of which are difficult and time consuming tasks.

This leaves the option of reports to measure and quantify stress and anxiety. To date, self-report or other-report measures have been developed for populations with other disabilities and modified to assess students with ASD (Groden, Baron, & Groden, 2006). Clearly, self- and other-report measures have the potential to be the most useful for educators. The main advantages of self- or other-report measures are the ease and relatively low cost involved in administration. Also, these measures can be administered repeatedly to monitor intervention and treatment success (Caselman & Self, 2008). Most importantly, self- and other-report methods have been utilized successfully to measure

behavioral equivalents of anxiety (Gillott & Standen, 2007; Sullivan, Hooper, & Hatton, 2007). Researchers have explored the agreement (Macintosh & Dissanayake, 2006) and disagreement (Achenbach, McCohaughy, & Howell, 1987; De Los Reyes & Kazdin, 2005) found in ratings when individuals in distinct and varying roles (parent, teacher, clinician, etc.) complete other-report measure for individuals with disabilities. Whether reported differences are a result of differences in knowledge, in context, or in bias is unclear (Miner & Clarke-Stewart, 2008). Nonetheless, it is clear that each type of other-respondents can provide helpful, accurate information (Sullivan et al., 2007) and that the possibly differing perspectives offered by various reporters who know the individual with a disability is invaluable (Mattison, Carlson, Cantwell, & Asarnow, 2007).

Unfortunately, there are few self-report or other-report measures available for use with individuals with ASD, and a standardized way to measure the daily experience of stress in individuals with ASD needs to be developed (Groden et al., 2001). Such an assessment tool could have numerous applications in the field of ASD including: increasing the understanding of stress in individuals with ASD as well as across the specific ASD diagnoses; helping develop programs and specific coping mechanisms for individuals with ASD experiencing stress; and serving as a pre-post measure for assessing the effectiveness of interventions designed to decrease stress (Goodwin, Groden, Velicer, & Diller, 2007).

While not yet standardized, the *Stress Survey Schedule for Persons with Autism and Other Developmental Delays* (SSS) (see Appendix A) is the first and only tool developed specifically to measure perceived stress in individuals with ASD (Groden et al., 2001). In a recently published study in which clinicians completed the SSS (i.e.,

other-report measure), Gillott and Standen (2007) found adults with ASD almost three times more anxious than the comparison group (adults with intellectual disabilities). Additionally, high levels of anxiety experienced by those with ASD were correlated with specific stressors as identified by the SSS (change, anticipation, sensory stimuli, and unpleasant events). Another critical finding in this research was that the higher the level of anxiety reported by the individual on the spectrum, the less able he or she was to cope with the demands of the stressors outlined in the SSS. Researchers also have used the stressors identified in the SSS when comparing physical arousal responses (heart rate) of individuals with ASD and those who are typically developing (Goodwin et al., 2006; Groden et al., 2006). Missing from the previous research is an assessment of how characteristics such as age, gender, and intelligence may affect an individual's responses to specific stressors.

The Effects of Stress and Anxiety on Individuals with ASD

Stress can be debilitating to all individuals, but particularly so for individuals with ASD. Specifically, experiences others may find mildly frustrating, such as a change in the weekly routine, can be exceedingly stressful for individuals on the spectrum. Nevertheless, the research literature investigating stress in the lives of those with disabilities is scant (Groden et al., 2005).

Much of the life of individuals on the spectrum is spent in educational settings. In an educational setting, individuals with ASD learn the skills necessary to effectively function in society, but they also experience the stressors inherent in these settings. Almost all (92%) of the stressors identified on the SSS are experienced by individuals in educational settings (see Table 1).

Table 1. *Constructs of Stress, Associated Items, and Internal Validity for the SSS*

*Indicates stress item not experienced at school

Changes and Threats
Internal Validity alpha = 0.87

Item #	Label
7	Having a cold
10	Having a change in task to a new task with new directions
*11	Going to the store
13	Having a change in environment from comfortable to uncomfortable
15	Moving from one location to the next
17	Having a change in environment from familiar to unfamiliar
25	Transitioning from preferred to non-preferred activity
31	Having to engage in not-liked activity
33	Being unable to communicate needs
38	Needing to ask for help
39	Participating in a group activity

Anticipation/Uncertainty
Internal Validity alpha=0.81

Item #	Label
4	Having a change in schedule or plans
6	Waiting for preferred events
22	Having unstructured time
32	Waiting in line
35	Going home (from school, to visit parents)
*36	Waiting for transportation
47	Waiting for routine to begin

Unpleasant Events
Internal Validity alpha=0.85

Item #	Label
3	Waiting to talk about a desired topic
9	Having personal objects or materials missing
*21	Following a diet
24	Receiving a reprimand
26	Being told “no”
27	Receiving criticism
28	Having something marked incorrect

40	Having a change in staff, teacher or supervisor
41	Losing at a game

Pleasant Events
Internal Validity alpha=0.85

Item #	Label
*1	Receiving a present
16	Playing with others
18	Receiving activity reinforcement
19	Having something marked correct
23	Being allowed to attend a party or favored event
45	Receiving tangible reinforcement
48	Having a conversation
49	Receiving verbal reinforcement

Sensory/Personal Contact
Internal Validity alpha=0.73

Item #	Label
5	Being in the vicinity of noise or disruption by others
8	Being touched
30	Receiving hugs and affection
43	Feeling crowded

Food Related Activity
Internal Validity alpha=0.75

Item #	Label
*34	Waiting at a restaurant
42	Waiting for reinforcement
46	Waiting for food

Social/Environmental Interactions
Internal Validity alpha=0.70

Item #	Label
20	Being in the vicinity of bright lights
37	Being unable to assert oneself with others
44	Someone else making a mistake

Ritual Related Stress

Internal Validity alpha=0.87

Item #	Label
2	Having personal objects or materials out of order
12	Being prevented from completing a ritual
14	Being prevented from carrying out a ritual
29	Being interrupted while engaging in a ritual

Educators work to expand individual skills and competencies while adapting the environment to increase individuals' effectiveness and understanding. Therefore, it is important for educators to identify stressors for individuals with ASD to provide support and coping strategies. Additionally, identifying interactions and dynamics that contribute to the experience of stress and anxiety for those on the autism spectrum can guide educators in prevention and intervention. Developing expectations by age, gender, and intelligence for the SSS will provide educators a snapshot of stressors to be aware of when working with individuals with ASD. Determining which specific variables contribute most to stress for individuals on the autism spectrum could provide educators with critical information for use in planning educational setting environments and instructional curriculum.

Purpose of This Research

The purpose of this study is to gain novel understanding of the stress experienced by individuals with ASD, with particular attention to the effects of age, gender, and intelligence quotient. Past research suggests these variables are important to explore because: (a) the course and characteristics of disabilities change throughout the life span (Volkmar, Paul, Klin, & Cohen, 2005); (b) gender is a variable relating to the severity and presence of disabilities; and (c) intelligence quotient is associated with distinct

behavioral profiles (Aman, 1991; Brown, Aman, & Havercamp, 2002). The greater the understanding of the effects of stress on individuals with ASD, the more effectively educators can anticipate the need for and provide intervention and treatment of the problematic levels of stress and anxiety.

Research Hypothesis and Questions

It is hypothesized that age, gender, and intelligence quotient will all have significant effects upon the experience of stress for individuals with ASD. Three specific research questions have been investigated:

1. What is the nature and degree of stress in students with ASD?

2. Which independent variable (gender, age, or intelligence quotient) is the best predictor of the different types of stress experienced by individuals with ASD?

3. What are normative scores for a sample of individuals with ASD with regard to age, gender, and intelligence quotient?

METHOD

Settings

Participants for this research were staff members and caregivers associated with a diagnostic and treatment facility located on either the east or west coast of the United States. Both centers (the Groden Network in Rhode Island and the M.I.N.D. Institute at the University of California-Davis in California) provide comprehensive services for individuals with developmental disorders, including assessment, diagnosis, and treatment. Two centers were chosen to provide a more representative sample than a sample drawn from only one treatment facility or from two centers in one geographic location. Targeting centers on each US coast allowed for diversity across age, geographic, and

socioeconomic variables. Furthermore, due to the variety of services offered at each site, the individuals with an ASD diagnosis span all ages, abilities, and profiles of the autism spectrum. Brief descriptions of the two centers follow.

Groden Center. Initially established in 1976 by Drs. June and Gerald Groden, the Groden Center programs serve children, teens, and adults with disabilities in two locations. The Groden Center programs include a school and residential treatment center for youth with autism, behavioral disorders, and developmental disabilities; instructional, vocational, and residential programs for adults over 21 with developmental disabilities, autism, mental retardation, behavioral disorders, emotional disturbances, learning disabilities, and mental health disorders in Rhode Island and Massachusetts respectively; and a Charter School in Rhode Island.

UC Davis M.I.N.D. Institute. The M.I.N.D. Institute offers educational, assessment, diagnostic, and treatment opportunities for children and adults with developmental disorders. The M.I.N.D. Institute is devoted to extending the knowledge and training of those treating neurodevelopmental disorders. Some of the current projects include ongoing multi-disciplinary research, a postdoctoral training program, and a collaborative effort with the St. HOPE Public Schools.

Participating Respondents

Groden Center. In their professional roles, Groden Center staff members are committed to the generation of knowledge and subsequently provide consent to participate in research. All staff members working with individuals with ASD at the time of the data collection were given the opportunity to participate in this study. Eighty-six staff in the Groden Center (22 males, 64 females) completed the SSS for a client with

whom they worked. Age range for the participating staff was 20 to 52 years (M = 27.2) and these individuals had one to 20 years (M = 5.4) of work experience at the Groden Center. Each staff person completed one to four (M = 2.6) surveys. Staff education ranged from high school diploma to a Master's degree and they worked in one of the following programs: community-based, therapeutic, or educational. Participating respondents must have been involved in a working/treatment relationship with the individual with an ASD diagnosis for at least one month prior to completing the survey.

UC Davis M.I.N.D. Institute. All of the parents serving as participating respondents provided consent to participate in this research. The parents completed the forms under the guidance of trained Research Assistants. No additional information was collected about the M.I.N.D. Institute participant respondents.

The investigator did not have direct contact with the participants. Participants completed the SSS for 313 individuals ages 3-41 years with an ASD diagnosis. Formal clinical diagnoses included Asperger's Disorder, Autistic Disorder, or Pervasive Developmental Disorder- Not Otherwise Specified (consistent with the current diagnoses categories outlined in the *DSM-IV-TR* [APA, 2000]). Each individual's diagnosis had been confirmed by qualified staff at the centers using one of the following standard assessment tools: Autism Diagnostic Interview (ADI) (Lord, Rutter, & Le Couteur, 1994; Lord, Storoschuk, Rutter, & Pickles, 1993), Childhood Autism Rating Scale (CARS) (Schopler, Reichler, & Renner, 1986), or Gilliam Asperger's Scale (Gilliam, 2001).

Individuals with Autism in this Sample. Mean age for this sample was 13 years (*M* = 157.98 months; *SD* = 109.95) with a range from 3 to 41 years old. Mean total IQ for this sample was 75 (*SD* = 21). Based on IQ, the sample was divided into two categories,

high functioning and low functioning. This distinction was created to allow comparison of the relevant stressors for individuals functioning on the high end of the autism spectrum and those functioning on the low end of the autism spectrum. The cut-off used for grouping was an IQ of 70. Those classified in the low functioning group had IQs less than or equal to 70. Those classified in the high functioning group had IQs greater than 70. The mean IQ score for the group that was low functioning was 55 (*SD* = 8); for the group that was high functioning the mean IQ score was 91 (*SD* = 13) (see Table 2).

When comparing the individuals with ASD who were classified as low functioning to those who were classified as high functioning, mean age remained consistent for each group. The mean age of the individuals with ASD who were low functioning was 13 years old (*M* = 150.79 months; *SD* = 105.17) with a range from 3 to 35 years old. The mean age of the individuals with ASD who were high functioning was 14 years old (*M* = 163.30 months; *SD* = 113.35) with a range from 3 to 41 years old. T-test analyses indicated that there was no significant difference between groups for age (*t* = .995, *p* = .320).

The majority of the individuals with ASD in the total sample were male (82.70%). This sample presents a male:female ratio for individuals on the spectrum as 4.8:1. A higher ratio of males to females is to be expected as there is a larger overall proportion of males diagnosed with ASD in the general PDD population (APA, 2000; Croen, Grether, Hoogstrate, & Selvin, 2002; Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001; Volkmar, Webb, Lobo, Hervas, Scourfield, & Fraser, 1997). Comprehensive epidemiological review suggests that the mean male:female ratio for individuals on the spectrum is 4.3:1 (Fombonne, 2005). In this study, the gender breakdown was consistent

between groups: individuals with ASD who were low functioning (79.7% males) and those who were high functioning (85% males). T-test analyses indicated that there were no significant differences between groups for gender (t = -1.226, p = .221), or ethnicity (t = -1.135, p = .257). As expected, there was a significant difference between groups for IQ (t = 27.153, p = .000). The demographics of the individuals with ASD are presented in Table 2.

Table 2. *Characteristics of Individuals with ASD*

	Total Sample (n=313)	Low Functioning Sample (n=133)	High Functioning Sample (n=180)
Gender (%)			
Male	82.70	79.70	85.00
Female	17.30	20.30	15.00
Age (in Months)			
Mean	157.98	150.79	163.30
SD	109.95	105.17	113.35
Range	36 – 492	36 – 420	36 – 492
IQ			
Mean	75	55	91
SD	21	8	13
Range	40 – 138	40 – 70	71 – 138

Between Site Differences. Statistical analyses were conducted to identify differences between the two locations relative to the samples and source of information (i.e., clinician reports from the Groden Center versus parent reports from the M.I.N.D. Institute). Both gender and age were determined to be statistically different for the two locations. The individuals with autism spectrum disorders were older in the Groden Sample (M = 17.4 years) than in the M.I.N.D. Institute sample (M = 7.4 years). Difference in IQ means between the two locations was not statistically significant. However, statistically significant differences were found with regard to three of eight

SSS scale scores (when gender and age were held constant). Table 3 presents the similarities and differences between these groups.

Table 3. *Characteristics of Individuals with ASD based upon type of other-report*

	Clinician-Report (n=180)	Parent-Report (n=133)	$F_{(1, 311)}$
Gender (%)			4.45 *
Male	78.89	87.97	
Female	21.11	12.03	
Age (in Months)			129.93**
Mean	209.21	88.66	
SD	117.63	37.29	
Range	36 – 492	47 – 209	
IQ			1.24
Mean	76.58	73.91	
SD	20.56	21.42	
Range	40.36 –109.75	40.00 – 138	
Scale			
Changes/threats	27.14	30.81	.01
Anticipation/uncertainty	15.06	17.30	1.00
Unpleasant events	20.80	23.68	22.45**
Pleasant events	12.35	14.85	9.31**
Sensory/personal	8.99	9.30	.19
Food related activity	6.34	7.55	.37
Social/environmental	4.68	6.70	7.60**
Ritual/related stress	10.04	12.43	1.82

*p <.05, **p <.01

Independent and Dependent Variables

Independent variables. The independent variables examined in this investigation were characteristics of the individual with ASD including (a) age, (b) gender, and (c) intelligence quotient. Age of individual was defined by the number of years the individual had lived at the time of the administration of the survey (Wolery et al., 1993). Gender was defined as male or female. Intelligence Quotient (IQ) was based on the most recent standardized scores available and used to provide information regarding individual

participant level of cognitive functioning. Although there are limitations related to using IQ as an accurate indication of cognitive level of individuals with ASD, this measure is typically utilized to assess individual cognitive level and is consistently employed in research and educational programming (Ben-Itzchak & Zachor, 2007; Cederlund, Hagber, Billstedt, Gillberg, & Gillberg, 2008; Coolican, Bryson, & Zwaigenbaum, 2008). Cognitive functioning was assessed using one of the following standardized measures: Standford-Binet Fourth Edition, Wechsler scales (WISC-III, WAIS-III), Leiter International Performance Scale, Baylay Scales of Infant Development, and the Comprehensive Tests of Non-Verbal Intelligence (C-TONI).

Neither current diagnosis nor verbal ability of the individuals in the sample was selected as an independent variable in this study. Although all persons for whom the survey was completed were confirmed to be individuals with ASD, each individual's current specific diagnosis of Asperger's Disorder, Autistic Disorder, or Pervasive Developmental Disorder–Not Otherwise Specified (consistent with the current diagnostic categories outlined in the *DSM-IV-TR*) was frequently missing. Therefore, because these data were frequently missing, the individuals' current specific diagnosis was not selected as an independent variable. Data also had been collected regarding individuals' verbal ability. Individuals were determined to be either verbal or nonverbal by the persons completing the SSS. However, no criteria for this assessment had been provided to those completing the survey and therefore the respondents' determination was highly subjective. For this reason, verbal ability was not included as an independent variable in this research.

Dependent variables. The dependent variables were the 49 Stress Scale Score items across eight daily stress scales of the SSS (Groden et al., 2001). Previous research involving the SSS identified eight constructs of stress. These include: (a) changes and threats (11 items), (b) anticipation/uncertainty (7 items), (c) unpleasant events (9 items), (d) pleasant events (8 items), (e) sensory/personal contact (4 items), (f) food related activity (3 items), (g) social and environmental interactions (3 items), and (h) ritual/related stress (4 items). Internal consistency for these categories ranges from .70 to .87. See Table 1 for a complete listing of items per category and internal validity per category.

The SSS can be self-administered by the individual, completed in an interview style with the individual, or completed by a third party who knows the individual well. To control for varying cognitive and communication abilities, all surveys used in this study were completed by a third party (participating respondents). Use of one type of reporting (3rd party) eliminated possible variation due to type of report (self versus other).

Materials

This study used the 49-item Stress Survey Schedule to collect information about the types of stress and stressors experienced by individuals on the autism spectrum. Participants were asked to complete one SSS (see Appendix A) for each individual with ASD. For the purposes of this research, each SSS had two sections: demographic information and behavioral items.

Participants completed the first page of the survey, demographic information, to document personal characteristics of the individual who was the subject of the survey including (a) intelligence quotient, (b) age, (c) gender, (d) race, (e) classroom placement,

(f) most recent diagnosis, and (g) verbal ability. The behavioral items (performance rating) portion of the survey included 49 behavior statements rated for severity on a 5-point Likert scale (1 = None to Mild, 2 = Mild to Moderate, 3 = Moderate, 4 = Moderate to Severe, 5 = Severe). Each survey was scored by a trained research associate in each location. A calculator was used to determine total figures for each category. Scores were rechecked for accuracy. To ensure accuracy, a Research Assistant at the Groden Network verified 20% of the paper survey scores (randomly selected) with the database. The agreement was 92%. To ensure accuracy, The M.I.N.D. Institute created a scoring algorithm via Micorsoft Excel. Scores entered into the database were compared to the paper copy and 100% were confirmed for accuracy by a second rater.

No documents with identifying information were shared with the investigator. This ensured the confidentiality and anonymity of both the participants and the individuals for whom they completed the SSS. Identifying information was stored by Matthew Goodwin at the Groden Center in compliance with ethical guidelines and standards required by the Institutional Research Board.

Database

Data for this study were collected by the Groden Center and the M.I.N.D. Institute during 2006-2007 for the purpose of analyzing individual responses to the SSS. Given that the data had not yet been analyzed for the purposes relevant to this study, access to the data was granted (see Appendix B). A database created at the Groden Center was emailed directly to the investigator and stored under a password protected file on the investigator's personal computer. All identifying personal information was removed from the database prior to sending it to the investigator.

In the database received, individuals with an ASD diagnosis were assigned numerical identifiers. Data were downloaded directly into Microsoft Excel. Prior to analyses, a second person not affiliated with the study compared the data downloaded into Excel with a hard copy of the database emailed to ensure that all data were downloaded without error. No errors were found. Data were entered into SPSS 15.0 for Windows (Apache Software, 2006) as applicable to the analyses conducted (see data analysis section below).

Data were not edited in any way. Data were reduced as an aggregate based on the specific subcategories used for individual analyses. These data were used to compare differences within SSS for individuals on the autism spectrum according to the variables identified by the investigator as having the potential to influential.

Research Design

This investigation used a correlational research design to assess the relationship between stress scores of individuals with ASD with their age, gender, and intelligence quotient. This design was necessary because the investigator had control over neither the independent variables (age, gender, and intelligence quotient) nor dependent variables (Stress Scores) being studied. A limitation of correlation research is that while the relationships between variables are explored, no causal conclusions can be found (Alberto & Troutman, 2009). In addition, the direction of the relationship cannot be determined and outside influences cannot be controlled (Mash & Krahn, 2000). Despite these limitations, this study extends previous research on individual factors meditating the experience of stress for individuals with ASD. Findings will enable clinicians,

educators, parents, and caregivers to more effectively interpret individual ratings on the SSS.

Data Analysis

To provide adequate power for valid statistical analysis, 313 completed surveys for individuals with an ASD diagnosis were included in this research. Data were entered into SPSS for analysis. The following analyses were conducted to answer the three research questions identified above. To answer the questions with regard to the nature and degree of stress in individuals with ASD as well as determining which independent variable (gender, age, or intelligence quotient) is the best predictor of the different types of stress experienced by individuals with ASD, the data from both site locations were combined and analyzed as an aggregate. Using both locations provided a larger number of participants, which was necessary in these analyses. Additionally, research questions one and two ideally encompass the types of stress experienced by those on the autism spectrum spanning all environments, not isolated to home or clinic settings. Due to the differences in age, gender, and response to some items found between the two groups (parents and clinicians), the answer to research question three required analysis of the two groups separately and provided normative scores based upon both parent and clinician report. Additionally, normative data were calculated for the whole sample, including both parent- and clinician-report SSS results.

Multiple Regressions. To learn more about the relationships between independent and dependent variables, multiple regression equations were used. This statistical technique allowed for the modeling and analysis of numerical data representing the independent and dependent variables. The use of multiple regressions also allowed for

the analysis of continuous independent variables (such as IQ and age), which enabled the investigator to build one or more linear functions of the stress scale variables to maximally discriminate among the different individual characteristic variables.

One multiple regression analysis was conducted to determine how each of the SSS scales related to the total Stress Score. The eight scales were used as the predictor variables, and the Total Stress Scores were used as the outcome variable. To determine how age, gender, and IQ relate to each of these scales, multiple regression analyses were conducted with age, gender, and IQ entered as the first step of the regression analysis. The result of these eight analyses determined the influence of each independent variable on the scale under investigation. To determine how age, gender, and IQ related specifically to the scales in the SSS, three additional regression analyses of all combinations of independent variables were conducted for each of the eight scales. During these analyses, the independent variable that was not being considered was held constant. Regression analyses conducted were:

1.) Age and Gender with IQ held constant

2.) Age and IQ with Gender held constant

3.) Gender and IQ with Age held constant

To determine how the three independent variables interact with each other on the scale scores, a multivariate analysis of variance (MANOVA) was conducted. Each scale was analyzed as a function of gender (2 levels, male and female), IQ (2 levels, high functioning and low functioning), and age (4 levels, 3-11 years, 12-20 years, 21-30 years, and 31-41 years). These age classifications are comparable to childhood, adolescence,

young adult, and adult and parallel those used in previous SSS research (Goodwin et al., 2007).

In order to establish norms for the SSS in a representative sample of persons with ASD, descriptive statistics, specifically means and standard deviations, were calculated for all independent variables (age, gender, and IQ).

Stress Scale Reliability

To ensure that the scales on the SSS were applicable to this specific sample, internal reliability was calculated for each of the eight stress scales using this sample. The reliability ranged from $\alpha = .501$ to $\alpha = .898$. Table 4 provides the internal reliability previously calculated for each scale in the development and validation studies of the SSS (Groden et al., 2001; Goodwin et al., 2007) as well as internal reliabilities found in the current study (Hess).

Table 4. *Internal Validity Scores for SSS scales*

Scale	Author		
	Groden et al. (2001)	Goodwin et al. (2007)	Hess
Changes/threats: 11 items (α)	.88	.89	.88
Anticipation/uncertainty: 7 items (α)	.90	.83	.81
Unpleasant events: 9 items (α)	.78	.85	.83
Pleasant events: 8 items (α)	.74	.87	.85
Sensory/personal: 4 items (α)	.73	.76	.71
Food related activity: 3 items (α)	.63	.80	.72
Social/environmental: 3 items (α)	.56	.57	.50
Ritual/related stress: 4 items (α)	.49	.91	.90

Clearly, internal validity measures are strong for this sample, and consistent with the findings of previous studies, therefore, it is safe to assume the SSS is an adequate tool to use to measure stress for this sample.

RESULTS

A total of 313 surveys were completed for analysis. To be included as a respondent in this study, the survey needed to include data on the individual with ASD's age, gender, IQ score, and diagnosis of an ASD. Visual inspection of the data enabled the investigator to ensure that each respondent was qualified to participate in the study and that the individuals being assessed had an ASD. All of the surveys met these criteria and therefore no surveys were excluded.

Multiple Regressions

Total Stress and Scales. The sample multiple correlation coefficient was 1.0, suggesting that 100% of the variance of the Total Stress Score Index can be accounted for by combining each of these stress measures. Table 5 presents the means and standard deviations for each scale as well as the standardized coefficients, R^2, and the correlations between each scale.

Two scales *Changes and Threats* and *Unpleasant Events* were the greatest contributors to the Total Stress Score, together accounting for 12% of the Total Stress Score. Two other scales (*Social/Environment Interactions* and *Food-Related Activity*) contributed the least to the Total Stress Score, together accounting for only 1.4% of the Total Stress Score. However, the scales themselves are correlated (ranging from .32 to .74); thus it is difficult to reach conclusions about the relative importance of the scales as predictors of the Total Stress Score.

Table 5. *Multiple Regression for Scales and Correlations between each Scale*

Scale	Mean	Standard Deviation	Standardized Coefficients	R^2	Correlation							
					1	2	3	4	5	6	7	8
1. Changes and threats	28.55	8.69	.27	.07	-	.74	.64	.57	.57	.68	.51	.54
2.Anticipation/ Uncertainty	15.90	5.68	.18	.03		-	.60	.57	.50	.72	.42	.52
3. Unpleasant events	21.79	7.45	.23	.05			-	.56	.47	.45	.52	.57
4. Pleasant events	13.33	5.69	.18	.03				-	.48	.53	.53	.37
5. Sensory/ personal	9.08	3.58	.11	.01					-	.41	.39	.32
6. Food related activity	6.78	2.95	.09	.01						-	.38	.36
7. Social/ environmental	5.53	2.43	.08	.01							-	.37
8. Ritual/ related	10.98	4.81	.15	.02								-

Age, Gender, IQ, and Scales. The regression equation with all three variables (age, gender, and IQ) revealed significant correlations with *Sensory/Personal Contact* and *Anticipation/Uncertainty* (see Table 6). Table 7 presents indices to indicate the relative strength of the individual predictors by scale. As would be expected, correlations between age, gender, and IQ were both positive and negative. Six of the twenty-four indices were statistically significant ($p < .05$ or greater).

Table 6. *Age, Gender, and IQ entered as the first step of the regression analysis for each Scale*

	R^2	Adjusted R^2	$F_{(3, 309)}$	*P*
Changes/threats	.01	.00	1.15	.33
Anticipation/uncertainty	.03	.02	3.08	.03*
Unpleasant events	.02	.01	2.36	.07
Pleasant events	.01	.00	1.43	.23
Sensory/personal	.08	.07	9.17	.00***
Food related activity	.03	.02	3.21	.02
Social/environmental	.01	-.01	.50	.68
Ritual/related stress	.01	.00	1.31	.27

*$p < .05$ ** $p < .01$ *** $p < .001$

Gender and Age. Eight multiple regression analyses were performed to predict how the combination of gender and age contributed to each stress score scale. The linear combination of gender and age measures was statistically significantly related to *Sensory/Personal Contact*, $F_{(2, 310)} = 13.09$, $p < .01$ and *Unpleasant Events*, $F_{(2, 310)} = 3.54$, $p < .05$. Age and gender measures did not demonstrate significance with regard to the remaining scales, *Changes and Threats*, $F_{(2, 310)} = .12$, $p = .89$;

Table 7. *Age, Gender, and IQ by Each Scale*

Scale	Correlation predictor and stress scale			Correlation controlling for all other predictors		
	Age	Gender	IQ	Age	Gender	IQ
Changes/threats	-.01	-.03	-.10	.00	-.04	-.10
Anticipation/uncertainty	.11*	-.05	-.11*	.12	-.07	-.12
Unpleasant events	.12*	-.07	.01	.13	-.08	-.01
Pleasant events	.02	-.11*	-.03	.03	-.11	-.04
Sensory/personal	.28**	-.01	-.05	.28	-.04	-.06
Food related activity	-.02	-.08	-.151**	-.00	-.09	-.16
Social/environmental	-.01	-.06	.04	-.01	-.05	.04
Ritual/related stress	.04	-.07	-.07	.05	-.08	-.08

*p <.05, **p <.01

Anticipation/Uncertainty $F_{(2, 310)} = 2.41$, $p = .09$; *Pleasant Events*, $F_{(2, 310)} = 1.89$, $p = .15$; *Food-Related Activity*, $F_{(2, 310)} = .91$, $p = .40$; *Social/Environmental Interactions*, $F_{(2, 310)} = .52$, $p = .59$; and *Ritual-Related Stress*, $F_{(2, 310)} = 1.03$, $p = .36$. Table 8 presents R^2 and adjusted R^2 as well as relative strength of the individual predictors per scale.

Age and IQ. Eight multiple regression analyses were performed to predict how age and IQ contributed to each stress score scale. The linear combination of age and IQ measures was significant related to the *Sensory/Personal Contact* scale, $F_{(2, 310)} = 13.54$, $p < .01$. Both the *Anticipation/Uncertainty* scale, $F_{(2, 310)} = 3.85$, and the *Food-Related Activity* scale, $F_{(2, 310)} = 3.62$, were significant at the $p < .05$ level. Five scales did not demonstrate significance: *Changes and Threats*, $F_{(2, 310)} = 1.54$, $p = .22$;

Table 8. *Gender and Age: R^2 and Adjusted R^2, Bivariate and Partial Correlations of the Predictors with Scale*

Scale	R^2	Adjusted R^2	Correlation predictor and stress scale		Correlation controlling for all other predictors	
			Age	Gender	Age	Gender
Changes/threats	.00	-.01	-.01	-.03	-.00	-.03
Anticipation/ Uncertainty	.02	.01	.11	-.05	.11	-.06
Unpleasant events	.02	.02	.12	-.07	.13	-.08
Pleasant events	.01	.01	.02	-.11	.03	-.11
Sensory/personal	.08	.07	.28	-.01	.28	-.03
Food related activity	.01	-.00	-.02	-.08	-.01	-.07
Social/environmental	.00	-.00	-.01	-.06	-.01	-.06
Ritual/related stress	.01	.00	.04	-.07	.04	-.07

Unpleasant Events, $F_{(2, 310)}$ =2.44, p = .09; *Pleasant Events* $F_{(2, 310)}$ = .25, p = .78; *Social/Environmental Interactions*, $F_{(2, 310)}$ = .30, p = .74; and *Ritual-Related Stress* $F_{(2, 310)}$ = .98, p = .27. The Table 9 presents R^2 and adjusted R^2 as well as the relative strength of the individual predictors per scale.

Table 9. *Age and IQ: R^2 and Adjusted R^2, Bivariate and Partial Correlations of the Predictors with Scale*

Scale	R^2	Adjusted R^2	Correlation predictor and stress scale		Correlation controlling for all other predictors	
			Age	IQ	Age	IQ
Changes/threats	.01	.00	-.01	-.10	-.00	-.10
Anticipation/ Uncertainty	.02	.02	.11	-.11	.11	-.11
Unpleasant events	.02	.01	.12	.01	.12	.00
Pleasant events	.00	-.01	.02	-.03	.03	-.03
Sensory/personal	.08	.07	.28	-.05	.28	-.06
Food related activity	.02	.02	-.02	-.15	-.01	-.15
Social/environmental	.00	-.00	-.01	.04	-.02	.04
Ritual/related stress	.01	.000	.04	-.07	.04	-.07

Gender and IQ. Eight multiple regression analyses were performed to predict how gender and IQ contributed to each stress score scale (see Table 10). The *Food-Related Activity* scale was significant at the $p < .01$ level, $F_{(2, 310)} = 4.84$. The seven remaining scales did not demonstrate significance (*Changes and Threats*, $F_{(2, 310)} = 1.74$, $p = .18$; *Anticipation/ Uncertainty* scale, $F_{(2, 310)} = 2.33$, $p = .10$; *Pleasant Events*, $F_{(2, 310)} = 1.97$, $p = .14$; *Ritual-Related Stress*, $F_{(2, 310)} = 1.65$, $p = .19$; *Sensory/Personal Contact*, $F_{(2, 310)} = .35$, $p = .70$; and *Social/Environmental Interactions*, $F_{(2, 310)} = .73$, $p = .48$; *Unpleasant Events* $F_{(2, 310)} = .82$, $p = .44$).

Table 10. *Gender and IQ: R^2 and Adjusted R^2, Bivariate and Partial Correlations of the Predictors with Scale*

Scale	R^2	Adjusted R^2	Correlation predictor and stress scale		Correlation controlling for all other predictors	
			IQ	Gender	IQ	Gender
Changes/threats	.01	.01	-.10	-.03	-.10	-.04
Anticipation/uncertainty	.02	.01	-.11	-.05	-.11	-.06
Unpleasant events	.01	-.00	.01	-.07	.00	-.07
Pleasant events	.01	.01	-.03	-.11	-.04	-.11
Sensory/personal	.00	-.00	-.05	-.01	-.05	-.01
Food related activity	.03	.02	-.15	-.08	-.16	-.09
Social/environmental	.01	-.00	.04	-.06	.04	-.05
Ritual/related stress	.01	.00	-.07	-.07	-.08	-.08

Multivariate Analysis of Variances

Age, Gender, IQ, and Scales. MANOVA was utilized to analyze the effects of individual participant characteristics (age, gender, and IQ) on the scale scores. A three-way model was used and each scale was analyzed as a function of gender (2 levels, male and female), IQ (2 levels, high functioning and low functioning), and age (4 levels, 3-11 years, 12-20 years, 21-30 years, and 31-41 years). To correct for different sample sizes, the least squares means option was utilized (type III analysis). Significant differences were found with regard to age, Wilks's $\Lambda = .02$, $F_{(24, 842)} = 1.67$, $p < .05$. The multivariate $\eta^2 = .04$, (based on Wilks's Λ) indicated 4.4% of multivariate variance of the dependent variables is associated with the age factor. Significant differences were found with regard

to age by IQ, Wilks's $\Lambda = .85$, $F_{(24, 842)} = 2.03$, $p < .01$. The multivariate $\eta^2 = .05$, (based on Wilks's Λ) indicated 5.3% of multivariate variance of the dependent variables is associated with the age by IQ factor.

Table 11 shows the scale scores and standard deviations by gender. One significant main effect was found for gender, *Pleasant Events*. Pairwise Comparisons were completed to gain more information about the nature of the differences between males and females. On the *Pleasant Events* scale, males reported significantly more stress when compared to females. Additionally, there were non-significant trends for females to score lower than males on all scales.

Table 11. *Summary for the Main Effect of Gender*

Scales	Gender				$F_{(1, 135)}$
	Male (n=259)		Female (n=54)		
	Mean	SD	Mean	SD	
Changes/threats	28.66	8.76	28.03	8.44	.09
Anticipation/uncertainty	16.03	5.64	15.26	5.87	1.89
Unpleasant events	22.03	7.43	20.60	7.50	2.45
Pleasant events	13.599	5.719	12.019	5.399	4.20*
Sensory/personal	9.10	3.64	9.00	3.29	.64
Food related activity	6.88	2.99	6.30	2.68	2.14
Social/environmental	5.59	2.47	5.22	2.22	.19
Ritual/related stress	11.14	4.75	10.24	5.08	2.016

* $p < .05$

Scale scores and standard deviations for IQ are presented in Table 12. Two significant main effects were found for IQ, *Changes and Threats* and *Unpleasant Events*.

Pairwise Comparisons indicate that individuals with a lower IQ report significantly higher levels of stress on both scales (*Changes and Threats* and *Unpleasant Events)* than those who have a higher IQ.

Table 12: *Summary for the Main Effect of IQ*

Scales	IQ				$F_{(1, 294)}$
	High Functioning (n=180)		Low Functioning (n=133)		
	Mean	SD	Mean	SD	
Changes/threats	27.64	9.36	29.79	7.56	3.85*
Anticipation/uncertainty	15.40	6.22	16.56	4.77	2.55
Unpleasant events	21.53	7.57	22.14	7.30	5.71*
Pleasant events	13.35	5.99	13.29	5.28	.00
Sensory/personal	8.97	3.74	9.24	3.35	.20
Food related activity	6.41	3.01	7.29	2.79	.42
Social/environmental	5.59	2.60	5.44	2.19	.01
Ritual/related stress	10.72	4.81	11.34	4.81	2.30

* $p < .05$

One significant main effect was found for age, *Sensory/Personal Contact*, $F_{(3, 35)} = 2.96$, $p = .03$. With regard to the *Sensory/Personal Contact* Scale, Pairwise Comparisons show that individuals 3-11 in age were reported to have significantly higher levels of stress than those ages 21-30 or 31-41. Scale scores and standard deviations for age are presented in Table 13.

Table 13. *Summary of Results for the Main Effect of Age*

Scale	Age in Years								F
	3-11		12-20		21-30		31-41		
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Changes/threats	28.68	8.05	28.50	10.16	26.89	9.65	30.44	7.71	1.72
Anticipation/uncertainty	15.63	5.43	15.81	6.00	15.61	5.81	18.54	6.12	2.17
Unpleasant events	21.28	7.13	21.82	7.23	22.82	9.41	23.78	6.62	1.71
Pleasant events	13.55	5.68	12.63	5.24	12.78	6.13	14.26	6.17	1.13
Sensory/personal	8.40	3.08	9.53	3.68	10.15	4.65	11.28	3.49	2.96*
Food related activity	6.87	2.73	6.85	3.44	5.78	2.68	7.60	3.28	1.47
Social/environmental	5.60	2.46	5.50	2.49	5.32	2.43	5.40	2.20	.44
Ritual/related stress	10.89	4.68	10.63	4.92	11.46	5.20	11.76	4.96	1.25

* $p < .05$

A significant interaction effect was found between gender and age for *Changes and Threats*, $F_{(3, 188)} = 2.56$, $p = .06$. A significant interaction was found between IQ and age for both *Unpleasant Events*, $F_{(3, 326)} = 6.35$, $p = .00$, and *Sensory/Personal Contact*, $F_{(3, 39)} = 3.24$, $p = .02$. No significant interaction effects were found for gender and IQ or gender, IQ, and age.

Normative Scores

The means and standard deviations (using both Groden and M.I.N.D. data) for all scales by age, gender, and IQ are presented in Table 14. Table 15 presents the clinician-reported normative scores and standard deviations by age, gender, and IQ. Table 16 presents the parent-reported normative scores and standard deviations by age, gender, and IQ. Due to the limited number of individuals with ASD in the older age groups and for all

female groups except for the 3-11 age group in the M.I.N.D. sample (parent report), norms are not reported for these individuals. Based on the M.I.N.D. sample, norms are reported only for males (ages 3-11 years and 12-20 years) and females (ages 3-11 years).

Table 14: *Parent- and Clinician-Report (includes Groden Center and UC Davis M.I.N.D. Institute sites): SSS scale scores by age, gender, and IQ*

Gender /Age	n	Changes				Anticipation				Unpleasant				Pleasant			
		<70		>70		<70		>70		<70		>70		<70		>70	
		M	*Sd*	*M*	*Sd*	*M*	*Sd*	*M*	*sd*	*M*	*Sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*
Males																	
3-11	155	30.09	7.41	27.84	8.45	16.55	4.59	15.20	5.82	20.63	6.01	22.60	7.94	13.61	5.60	13.89	5.83
12-20	53	31.05	8.77	28.53	11.03	17.62	5.70	15.47	6.27	24.71	7.89	20.94	6.59	13.43	4.97	12.78	5.93
21-30	33	29.54	8.65	23.95	10.44	15.92	5.17	15.15	6.91	25.31	8.98	19.25	8.84	15.92	6.25	12.05	6.43
31-41	18	28.33	7.99	29.83	7.02	20.67	4.89	17.29	5.48	26.50	8.31	22.63	4.36	15.33	4.89	13.04	5.07
Females																	
3-11	30	26.43	5.84	29.50	9.46	13.86	2.88	15.81	7.49	17.07	5.38	20.25	6.51	11.07	3.97	13.63	6.30
12-20	9	28.20	5.67	15.25	2.50	15.40	4.77	9.50	1.29	21.20	5.89	14.50	3.79	10.40	1.52	10.00	2.31
21-30	8	30.58	8.18	28.00	8.18	17.33	3.98	13.00	2.83	31.75	5.36	15.50	4.95	9.83	2.14	8.50	.71
31-41	7	36.00	4.24	31.60	4.24	17.50	4.95	19.4	9.66	20.00	2.83	24.80	9.93	11.50	2.12	17.00	10.37

Gender /Age	n	Sensory/personal				Food related activity				Social				Ritual/related stress			
		<70		>70		<70		>70		<70		>70		<70		>70	
		M	*Sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*	*M*	*sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*
Males																	
3-11	155	8.83	3.17	8.19	3.11	7.71	2.65	6.37	2.81	5.39	2.27	5.87	2.69	11.05	4.57	11.01	4.70
12-20	53	9.95	3.68	9.44	4.06	7.76	3.69	6.72	3.39	6.23	2.16	5.31	2.74	12.57	4.87	10.19	4.76
21-30	33	10.92	4.44	9.25	5.05	7.00	2.71	5.20	2.88	5.62	2.69	5.00	2.66	12.00	5.23	10.55	5.18
31-41	18	8.67	1.75	12.92	2.81	7.33	2.34	7.50	3.21	4.83	1.17	5.25	1.22	14.00	5.29	1.050	4.42
Females																	
3-11	30	7.93	2.20	8.19	3.29	6.29	1.73	6.69	2.70	4.50	1.83	5.94	2.17	8.93	4.48	10.75	5.26
12-20	9	9.00	2.45	8.75	2.22	6.00	3.54	4.25	.96	4.40	1.34	3.50	1.00	8.60	4.04	6.50	4.36
21-30	8	12.00	4.00	8.50	3.54	5.17	1.60	5.50	.71	5.50	1.38	6.00	1.41	14.17	4.83	9.00	7.07
31-41	7	7.50	2.12	12.00	4.53	6.50	3.54	8.60	4.93	6.00	2.83	6.20	4.44	11.00	7.07	12.40	5.77

Table 15: *Clinician-Report: SSS scale scores by age, gender, and IQ*

Gender /Age	n	Changes				Anticipation				Unpleasant				Pleasant			
		<70		>70		<70		>70		<70		>70		<70		>70	
		M	*sd*	*M*	*Sd*	*M*	*Sd*	*M*	*sd*	*M*	*Sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*
Males																	
3-11	155	26.95	1.85	24.94	1.50	15.71	1.23	13.09	.99	21.33	1.53	18.69	1.24	14.14	1.21	10.83	.98
12-20	53	30.10	2.69	28.39	1.61	17.20	1.78	15.39	1.06	24.90	2.22	20.14	1.33	13.60	1.76	12.43	1.05
21-30	33	29.54	2.36	23.95	1.90	15.92	1.56	15.15	1.26	25.31	1.95	19.25	1.57	15.92	1.54	12.05	1.24
31-41	18	28.83	3.47	29.83	2.45	20.67	2.29	17.29	1.62	26.50	2.87	22.63	2.03	15.33	2.27	13.04	1.61
Females																	
3-11	30	24.83	3.47	31.25	3.00	13.67	2.29	15.75	1.99	16.33	2.87	20.00	2.48	9.67	2.27	12.50	1.97
12-20	9	28.20	3.80	15.25	24.25	15.40	2.51	9.50	2.80	21.20	3.14	14.50	3.51	10.40	2.49	10.00	2.78
21-30	8	30.58	3.47	28.00	6.00	17.33	2.29	13.00	3.97	31.75	2.87	15.50	4.96	9.83	2.27	8.50	3.93
31-41	7	36.00	6.00	31.60	3.80	17.50	3.97	19.40	2.51	20.00	4.96	24.80	3.14	11.50	3.93	17.00	2.49

Gender /Age	n	Sensory/personal				Food related activity				Social				Ritual/related stress			
		<70		>70		<70		>70		<70		>70		<70		>70	
		M	*Sd*	*M*	*sd*	*M*	*Sd*	*M*	*Sd*	*M*	*sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*
Males																	
3-11	155	8.86	.76	7.91	.61	7.29	.62	5.03	.51	4.95	.50	4.00	.40	9.00	1.03	9.44	.84
12-20	53	11.20	1.10	9.18	.66	8.30	.90	6.68	.54	5.50	.72	4.86	.43	12.40	1.49	9.82	.89
21-30	33	10.92	.96	9.25	.78	7.00	.79	5.20	.64	5.62	.63	5.00	.51	12.00	1.31	10.55	1.06
31-41	18	8.67	1.42	12.92	1.00	7.33	1.19	7.50	.83	4.83	.93	5.25	.66	14.00	1.93	10.50	1.36
Females																	
3-11	30	7.67	1.42	8.13	1.23	5.50	1.69	6.63	1.01	3.67	.93	5.75	.81	8.50	1.92	9.63	1.67
12-20	9	9.00	1.55	8.75	1.73	6.00	1.28	4.25	1.43	4.40	1.02	3.50	1.14	8.60	2.11	6.50	2.36
21-30	8	12.00	1.42	8.50	2.45	5.17	1.17	5.50	2.02	5.50	.93	6.00	1.61	14.17	1.93	9.00	3.34
31-41	7	7.50	2.45	12.00	1.55	6.50	2.02	8.60	1.28	6.00	1.61	6.20	1.02	11.00	3.34	12.40	2.11

Table 16: *Parent-Report: SSS scale scores by age, gender, and IQ*

Gender /Age	n	Changes				Anticipation				Unpleasant				Pleasant			
		<70		>70		<70		>70		<70		>70		<70		>70	
		M	*sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*	*M*	*Sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*
Males																	
3-11	155	31.56	1.27	29.47	1.13	16.93	.84	16.39	.744	20.31	1.05	24.78	.93	13.36	15.25	15.61	.74
12-20	53	31.91	2.56	29.50	4.25	18.00	1.69	16.00	2.81	24.55	2.12	26.50	3.51	13.27	1.68	15.25	2.78
Females																	
3-11	30	27.63	3.00	27.75	3.00	14.00	1.99	15.88	1.99	17.63	2.48	20.50	2.48	12.13	1.97	14.75	1.97

Gender /Age	n	Sensory/personal				Food related activity				Social				Ritual/related stress			
		<70		>70		<70		>70		<70		>70		<70		>70	
		M	*Sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*	*M*	*sd*	*M*	*Sd*	*M*	*sd*	*M*	*sd*
Males																	
3-11	155	8.82	.52	8.35	.46	7.91	.43	7.12	.38	5.60	.34	6.91	.30	12.00	.71	12.04	.63
12-20	53	8.82	1.05	11.25	1.73	7.27	.86	7.00	1.43	7.27	.69	8.50	1.14	12.73	1.43	12.75	2.36
Females																	
3-11	30	8.13	1.23	8.25	1.23	6.88	1.01	6.75	1.01	5.13	.81	6.23	.81	9.25	1.67	11.88	1.67

DISCUSSION

Quality of life and availability for learning are affected by stress and anxiety. Professionals who can identify and predict what individuals with ASD find stressful will be better prepared to create supportive environments conducive to learning. This study was designed to investigate the following three research questions:

1. What is the nature and degree of stress in individuals with ASD?

2. Do individual characteristics (age, gender, and intelligence quotient) affect the type of stress experienced by individuals with ASD and, if so, in what ways?

3. What are normative scores for a sample of individuals with ASD with regard to age, gender, and intelligence quotient?

Nature and Degree of Stress

The first research question addresses the nature and degree of stress in individuals with ASD. When possible, it is important to identify the most stressful areas of daily living for those on the autism spectrum because, the greater their stress and anxiety, the less likely they are to successfully cope and function (Gillot & Standen, 2007). Determination of high and low stress demands can help practitioners working with individuals on the spectrum to develop and practice effective coping strategies. Individuals with ASD in this sample experienced the greatest stress in the area of *Changes and Threats*. Specific items included in this scale are changing tasks or environments, specifically from preferred or familiar to non-preferred or novel, as well as items concerning an individual's need to request help and communicate needs. This finding is consistent with what is known about this population of individuals (i.e.,

changes and transitions, specifically away from preferred activities, can be extremely challenging and frustrating; Banda & Grimmett, 2008; Sterling-Turner & Jordan, 2007).

The other three scales highly predictive of the individuals' overall experience of stress were *Unpleasant Events* (including items related to being told no, being reprimanded, and losing personal objects), *Anticipation/Uncertainty* (items such as waiting and having unstructured time), and *Pleasant Events* (items such as having a conversation and playing with others). In previous research using the SSS, Gillott and Standen (2007) found adults with ASD were reported to have the highest levels of stress on the *Changes and Threats, Anticipation/Uncertainty, Unpleasant Events,* and *Sensory/Personal Contact* scales. These findings are similar to the findings reported here, specifically with regard to the relatively greater impact of the types of stressors found on the *Changes and Threats Anticipation/Uncertainty*, and *Unpleasant Events* scales. It is possible that the *Sensory/Personal Contact* scale was determined to be more stressful in this research due to the wider age range considered (ages 3-41 years) as compared to the adult population surveyed by Gillott and Standen (ages 18-57 years).

One surprising finding is that the lowest predictor of overall stress in this population was the *Social/Environmental Interactions* scale. Since a deficit in social interactions is a fundamental characteristic of autism, it would be expected that this scale would be the one on which higher levels of stress were reported for individuals with ASD. However, it is possible that the lack of understanding of social and environmental rules of individuals with ASD allows them to avoid the stress which might otherwise be experienced. Some researchers have speculated that individuals who are higher functioning (those with higher intelligence quotients) often experience greater social

stress because they have greater understanding of the social world around them and the nuanced or hidden rules and rituals (Bellini, 2004, 2006). While the results followed this pattern here, no significance was found to support this hypothesis.

When examining the *Social/Environmental Interactions* scale closely, several observations may be relevant to interpreting the study findings. First, this scale has only three items (being in the vicinity of bright light, being unable to assert oneself with others, and someone else making a mistake); this may contribute to its lower predictive nature. Also, lower internal validity of this skill may warrant additional attention to creating a stronger measure of the *Social/Environmental Interactions* construct and scale. It appears that some important items that relate to social/environment interactions have been included in the *Pleasant Events* scale, specifically having a conversation and playing with others.

In the development of the SSS, five of the stress scales (*Changes and Threats, Anticipation/Uncertainty*, *Unpleasant Events, Pleasant Event,* and *Ritual-Related Stress*) consistently emerged as dimensions of stress in each of the three preliminary studies (Groden et al., 2001). The other three scales (*Social/Environmental Interactions, Sensory/Personal Contact,* and *Food-Related Activity*) were less stable, emerging as dimensions in only one or two of the three total studies. Internal validity results calculated in this study are consistent with the results found by Groden et al. (2001). Internal validity scores for the five stress scales that proved to be more stable ranged from .81 to .90. The three scales which were less stable showed lower internal reliability ranging from .50 -.71.

When compared to other scales, the *Ritual-Related Stress* scale had less of an impact on the individuals' total stress score than might be expected. This indicates the need for researchers to further examine and clarify the relationship between engagement in rituals and the occurrence of stress and anxiety in individuals with ASD. However, it is important to note that, for this sample, the survey was completed by third party respondents, not by the individuals themselves. Therefore this finding provides limited insight into the direct relationship between the subjective experience of individuals with ASD and overt ritual-related behavior.

Effects of Gender, IQ, and Age on Stress Scores

The second research question is: Do individual characteristics (age, gender, and intelligence quotient) affect the type of stress experienced by individuals with ASD, and, if so, in what ways? The findings with regard to each of these characteristics are discussed below.

Gender. Based on the MANOVA, although male mean scores were higher on all eight stress scales, indicating higher levels of stress across all domains for males in this sample, gender was determined to have a significant main effect only on the *Pleasant Events* scale score. Therefore, based on the statistical analysis for the other seven scales, reported differences by gender could have occurred by chance. These findings are consistent with those found in the previous study using the SSS (Goodwin et al., 2007) which found no significant differences related to stress between genders. However, these findings are inconsistent with previous research with regard to stress in typically developing populations (Van Well et al., 2008), that found gender to be an important individual factor. Moreover, the overall finding of higher stress for males on all scales is

also inconsistent with findings regarding stress and gender in the general population (i.e., that females report more overall stress; Allgood-Merten et al., 1990; Davies & Windle, 1997). Additionally, the significant main effect on the *Pleasant Events* scale score contradicts previous research, specifically, that females are more likely to experience stressors as negative in nature when compared to matched males (Hankin et al., 2007). Since the current study and the study by Goodwin et al. (2007) included only individuals with ASD, it is possible that the presence of disability is a stronger contributor to stress than is gender. It also is possible that the findings are an artifact of the SSS. The isolated effects of gender on stress for individuals on the autism spectrum remain unclear.

When gender as an individual factor was combined with other individual factors (age and IQ), multiple regression analysis showed that gender interacts as a predictor for three of the Stress Survey Schedule scales. When combined with age, gender contributed to the prediction of two scale scores at a statistically significant level: *Sensory/Personal Contact* and *Unpleasant Events*. When combined with IQ, statistical analysis demonstrated that gender significantly contributed to the *Food-Related Stress* scale. Despite the limited statistically significant findings regarding the contribution of gender alone to the stress scale scores (i.e., significant differences only for *Pleasant Events*), it is important to recognize that when joined with both age and IQ, gender does play a role in stress as measured by three of the Stress Survey Schedule scales. Thus while gender alone may not be a predictor of the type or severity of stress experienced by and individual on the spectrum, it must be considered as a critical piece of the puzzle, that bears attention when it interacts with other factors.

Intelligence quotient. Significant intelligence quotient effects were observed on the *Changes and Threats* and *Unpleasant Events* scales. In both instances, the mean scores were higher for individuals who were lower functioning, indicating higher levels of stress. Further, in four additional areas (*Anticipation/Uncertainty*, *Pleasant Events*, *Food-Related Activity*, and *Ritual-Related Stress*), individuals who were lower functioning had higher stress scores. Conversely, individuals who were higher functioning were reported to have more stress in the areas of *Sensory/Personal Contact* and *Social/Environment Interactions*. When combined with other individual factors (age and gender) IQ consistently contributed to the prediction of the *Food-Related Activity* scale score. Together IQ and age predicted *Sensory/Personal Contact* and *Anticipation/Uncertainty* scales. Previous research has suggested that individuals with higher IQ scores may be more reactive to stress than their typically developing matched peers (Silverman, 1993; Woodin, 1997). On the whole, the findings presented here did not support previous research, as on six of the eight scales, individuals with lower IQ scores reported more stress. Further research is required to determine which types of stress are related to IQ for individuals with ASD.

Age. Age produced significant effects on two scales: *Anticipation/Uncertainty* and *Sensory/Personal Contact.* In both scales, individuals 3-11 years in age experienced more stress than those ages 31-41. Additionally, on the *Anticipation/Uncertainty* scale individuals ages 12-20 experienced more stress than those ages 31-41. Results suggest that on some scales, the younger population of individuals with ASD may demonstrate higher levels of stress than their older counterparts. These results are consistent with

personal accounts in which individuals with ASD describe extremely high levels of stress in the early years (Grandin & Scariano, 1986).

Additionally, chronological age can influence what is perceived as a stressor and the reaction to specific stressors. For many individuals with ASD, puberty is a time of extreme stress and anxiety (Grandin, 2006). While many adults on the spectrum experience high levels of both stress and anxiety (Gillott & Standen, 2007), it is possible that some older adults on the spectrum develop more efficient coping strategies over time, or that medication is being utilized to minimize some types of anxiety and stress in adults.

When combined with the other individual factors (age and gender), age consistently contributed to the prediction of the *Sensory/Personal Contact* scale score. MANOVA results indicated significant differences with regard to age independently and age by IQ. Further exploration into the contributing factor of age in the types and levels of stress experienced by those on the autism spectrum is an important area for further research. Increased knowledge about the relationship between age of individuals with ASD and stress is particularly important for teachers and could aid in the effective reduction of stress for this population.

Normative Scores

Normative Scores provide the "normal" or "average" scores on a scale across various independent variables. Normative Scores provide a way to interpret and compare the scores of one individual on the SSS to another, or to the larger population (here the larger population is individuals with ASD). In order to determine the normative score for an individual on the spectrum, one would look up the appropriate age, gender, and IQ

(ranges for age and IQ are listed on table 14). The mean score would be determined based on these variables. Additionally, a standard deviation is provided to indicate what would be an average range above or below the mean score. In general, one standard deviation above or below the mean is considered within the normal range and two or more standard deviations above or below the mean considered atypical (Minium, Clarke & Coladarci, 1999). These preliminary normative scores can be helpful in determining whether the stress experienced by an individual with ASD is fairly typical, higher than average, or lower than average.

Also reported in this document are normative scores based upon clinician report (Table 15) and parent report (Table 16). Since the SSS is relatively new, differences and/or similarities in parent versus clinician report have not yet been explored. Thus far, researchers have published findings using both types of report (parent and clinician) but have not compared or contrasted the two. It may be useful to explore this area in future research. At this time, it is unclear if normative results can be presented as an aggregate or whether separate normative tables need to be developed. The results presented here serve as a preliminary step in the process of developing norms for the SSS. Further research is needed to confirm norms for this population and to assess the stability of the results found here.

Educational Implications

Educators can apply these findings daily through identifying and predicting what students with ASD find stressful and modifying the environment to reduce this stress. Through this process, educators can enhance students' success. As previously mentioned, the typical school day requires individuals with ASD to transition through many

environments and activities as well as to communicate their needs and ask for help. Further, the school day is comprised of both pleasant and unpleasant events, and there are many opportunities for individuals on the spectrum to anticipate what happens next. High stress experienced during transitions, as well as pleasant and unpleasant events, is likely to present significant challenges for both students and teachers. This stress could undermine students' comfort, engagement, and progress. The more prepared individuals with ASD are to cope with such stressors, the more successful they can be. Educators are responsible to provide supports that directly respond to what is known about the strengths and challenges of this unique population.

These results suggest the importance of the continued use of several currently accepted practices, including group and individual schedules to help with predictability, preparation for changes in routine, and overall consistency. Individuals on the spectrum need support during transitions. These include transitions within the educational environment (i.e., from the music room back to the classroom or from work time to break time), transitions between environments (i.e., from home to school or from school to the bus), and more comprehensive transitions, such as those from elementary to middle school and from high school to college. Specific strategies such as visual supports, priming, timers, Social Stories^{TM}, and so forth can prepare these students for perceived changes and threats in their lives and help minimize the level of uncertainty they experience (Marks et al., 2003).

As one of the first studies in this area, the results provide foundational information about the types of stress experienced by those on the autism spectrum. Therefore, these findings allow educators, teacher trainers, clinicians, and researchers to

have a starting place to explore interventions and strategies to help individuals with ASD experience success in all environments.

Based on the results of this research, educators, clinicians, and researchers may find it beneficial to target stress reduction strategies and interventions on younger children with ASD, a group for whom overall levels of stress may be greater. It is possible that effective coping strategies learned at an early age could have profound effects on the stress experienced by individuals with ASD throughout their lives. The critical need for working with young children with ASD to reduce stress can be understood best through the work of Morgan (2006), who has noted that:

> Excessive stress or anxiety can alter the brain in ways that promote hypervigilance and abnormal behavior, exaggerate fearfulness, disturb sleep, impair memory, and cause shifts in attention – all characteristics of autism. These behaviors, in return, can exacerbate feelings of anxiety, so that the entire cascade becomes one of constant emotional distress and arousal spiraling out of control. (p. 159)

The result of this for the individual is permanent physiological change. If stress and anxiety reduction interventions, treatments, and strategies can be explored with young children, perhaps some of the long-term negative effects of stress and anxiety can be altered or avoided.

Future Directions for Research

These results both confirm findings of previous research and raise interesting questions for future research. This study was the first to look at such a large group of individuals with ASD to assess the types of stress they experience. These results also have implications for additional research questions regarding the way stress is defined, experienced, and reported by this population. Additional scrutiny at the types of stress experienced by those with ASD is necessary. Further, analysis of the different methods

for report (i.e., self-report versus other report) needs to be factored into this complex picture. What can be learned from each type of measure and how do these measures complement one another and contribute to creating a holistic picture of stress for this unique population of individuals? Additional research with large populations of individuals with ASD would be most beneficial in finding the answers to these specific questions.

Individual factors contributing to or protecting individuals from the experience of stress warrant further investigation. The individual factors explored in this research (age, IQ, and gender) need continued research to better identify the relationships between and among these factors and stress for individuals with ASD. Additional factors such as specific diagnosis, type of educational placement, and communication skills would be important to investigate. The SSS can also be useful in understanding behaviors believed to be related to stress in this population such as ritualistic behavior, stereotypies, and self-injurious behaviors.

There are many important research agendas associated with the SSS as a pre- and post-measure for examining the effectiveness of specific coping strategies and of medication to address stress and anxiety within this population. Another possible focus might be linking specific effective classroom strategies to reducing different types of stress. For example, what would be some of the most effective strategies for minimizing the stress associated with *Changes and Threats* within the school environment*?* What might this look like across age groups and grades, specifically elementary, middle, and high school settings?

Study Limitations

Several limitations of this study must be noted. The first concerns the use of a survey instrument still early in its development. To strengthen this very promising but not yet standardized measure, repeated studies will be required of the validity, reliability, and application of the survey instrument with varying populations of individuals on the autism spectrum. A second limitation concerns the exclusion of each individual's current specific diagnosis (i.e., Asperger's Disorder, Autistic Disorder, or Pervasive Developmental Disorder–Not Otherwise) from the independent variables studied. Although in the database this information was frequently missing, in future studies the inclusion of current specific diagnosis as an independent variable may help explain variation and provide further clarification in the study findings.

As indicated previously, although the relationships between variables can be explored in correlation research, no causal conclusions can be found (Alberto & Troutman, 2009). In addition, when using a correlational design, the direction of the relationships found cannot be determined and outside influences cannot be controlled (Mash & Krahn, 2000).

The method of data collection, other-report, also contributes to the study's limitations. While the inclusion of other-report, in the form of parent and clinician respondents, can be useful in creating a more comprehensive picture of the type of stress experienced by individuals on the autism spectrum, it also adds a limitation to the study. As explained by Groden et al. (2001), the SSS developers:

> There is always a tension between generating an adequate sample for the analysis and having a 'pure' sample. There is always as question about whether inclusion of one or more different sources could have changed the results. (pg. 216)

Future studies can replicate this study with a "pure" sample (based upon one type of report) and a sufficiently large sample of individuals with ASD. The SSS can be self-administered by an individual or completed in an interview style with the individual. The addition of self-report concerning anxiety by those with ASD either through self-administration or interviews would have provided further validity and reliability of the data for those individuals for whom self-report would have been possible. Inclusion of this additional data source might have influenced the findings. It should be noted, however, that the inclusion of the very young (preschool) and lower-functioning individuals in the sample would have complicated, if not precluded, this option with this specific sample.

Finally, the use of one or more additional method(s) of data collection, such as the use of physiological measures (Bernier et al., 2005; Goodwin et al., 2006) and/or observation of behaviors (Rutter, 1985; Thomas et al., 1998), might have yielded greater reliability and validity in the measurement of the reported anxiety of the individuals with ASD in this sample. However, as noted previously, the use of physiological measures of stress and anxiety in individuals with ASD is still in its infancy (Bradley et al., 2004; Green et al., 2000); findings are inconsistent (Bernier et al., 2005; Goodwin et al., 2006); and this approach is not easily employable in many settings. Behavioral observations of the individuals in the sample would have required the assessment of each individual with ASD to determine behavioral markers of anxiety; all other factors possibly correlated to these behaviors would have necessarily been identified and controlled. Each of these would be difficult and time consuming tasks.

Despite these limitations, the findings of this study extend previous research on individual factors meditating the experience of stress for individuals with ASD. Age, gender, and IQ correlated significantly with stressors measured in the scales related to *Sensory/Personal Contact*, *Anticipation/Uncertainty*, *Food-Related Activity*, and *Unpleasant Events*. Results suggest that younger individuals with ASD may experience more stress than their older counterparts. Although higher levels of stress were reported for males across all eight scales, gender was determined to have a significant main effect only with *Pleasant Events* ($F_{(1, 135)} = 4.20$, $p < .05$). On six of the eight scales, individuals with lower IQ scores were reported to be more stressed. Educators, clinicians, researchers, parents, and caregivers can use these findings as they attempt to more effectively interpret individual ratings on the SSS. These findings also raise important questions for future research concerning the experiences of anxiety for individuals on the autism spectrum.

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APPENDIXES

Appendix A

Stress Survey Schedule for Individuals with Autism Spectrum Disorders

The Stress Survey Schedule for Individuals with Autism and Other Pervasive Developmental Disabilities

The Groden Center, Inc.
86 Mount Hope Avenue
Providence, RI 02906
(401) 274-6310
(401) 421-3280 (fax)
www.grodencenter.org

June Groden, Ph.D.
Joseph R. Cautela, Ph.D.
Amy Diller, M.S.
Wayne Velicer, Ph.D.
Gregory Norman, Ph.D.

Enter Site Code and Survey ID Below and repeat on all 6 pages:

Example: XX1001

07-Feb-2005

3623321460

THE STRESS SURVEY SCHEDULE FOR PERSONS WITH AUTISM AND DEVELOPMENTAL DISABILITIES

The Groden Center, Inc.

Today's Date: ☐☐ / ☐☐ / ☐☐

Shade circles like this: ●
Not like this: ⊘ ◌

Your Name:

Name of individual who is the subject of the survey:

Most Recent Test Used:

Individual's most recent IQ Score: ☐☐☐

- ○ Stanford-Binet
- ○ Wechsler scales WISC-III
- ○ Wechsler scales WAIS-III
- ○ Leiter International Performance Scale
- ○ Bayley Scales of Infant Development
- ○ Comprehensive Tests of Non-Verbal Intelligence (C-TONI)
- ○ Other _____

Individual's most recent diagnosis:
(Check all that apply)

- ○ Autism
- ○ PDD (PDD-NOS)
- ○ Asperger's Syndrome
- ○ Mild MR
- ○ Moderate MR
- ○ Severe MR
- ○ Profound MR
- ○ Other:

_____

Individual's Date of Birth: ☐☐ / ☐☐ / ☐☐

Sex: Female ○ Male ○

Verbal Ability:
1 2 3 4 5 6 7
Non Verbal ○○○○○○○ Typical Speech

Race:

- ○ Caucasion
- ○ African American
- ○ Asian Pacific
- ○ Hispanic
- ○ Other:

_____

Diagnostic test used:

Score: ☐☐☐

- ○ ADI-R
- ○ ADOS
- ○ CARS
- ○ Other

Specify: _____

Your relationship to the individual:

- ○ Mother
- ○ Father
- ○ Other relative
- ○ Teacher
- ○ Caregiver
- ○ Staff
- ○ Friend
- ○ Other:

_____

Please mark all those which apply:

Placement:

- ○ Regular Education (Public)
- ○ Regular Education (Private)
- ○ Special Education (Public)
- ○ Special Education (Private)
- ○ Vocational
- ○ Employed
- ○ Other: _____

The individual lives:

- ○ at home
- ○ independently
- ○ in a group residence
- ○ other

_____

The individual lives with:
(Check all that apply)

- ○ mother
- ○ father
- ○ brother(s)
- ○ sister(s)
- ○ other

_____

☐☐☐☐☐☐

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THE STRESS SURVEY SCHEDULE FOR PERSONS WITH AUTISM AND DEVELOPMENTAL DISABILITIES
The Groden Center, Inc.

Please rate the intensity of the stress reaction to the following events by filling in the appropriate circle:

	None to Mild	Mild to Moderate	Moderate	Moderate to Severe	Severe
1. Receiving a present	1	2	3	4	5
2. Having personal objects or materials out of order	1	2	3	4	5
3. Waiting to talk about desired topic	1	2	3	4	5
4. Having a change in schedule or plans	1	2	3	4	5
5. Being in the vicinity of noise or disruption by others	1	2	3	4	5
6. Waiting for preferred events	1	2	3	4	5
7. Having a cold	1	2	3	4	5
8. Being touched	1	2	3	4	5
9. Having personal objects or materials missing	1	2	3	4	5
10. Having a change in task to a new task with new directions	1	2	3	4	5
11. Going to the store	1	2	3	4	5
12. Being prevented from completing a ritual	1	2	3	4	5
13. Having a change in environment from comfortable to uncomfortable	1	2	3	4	5
14. Being prevented from carrying out a ritual	1	2	3	4	5
15. Moving from one location to the next	1	2	3	4	5
16. Playing with others	1	2	3	4	5
17. Having a change in environment from familiar to unfamiliar	1	2	3	4	5
18. Receiving activity reinforcement	1	2	3	4	5
19. Having something marked as correct	1	2	3	4	5
20. Being in the vicinity of bright lights	1	2	3	4	5
21. Following a diet	1	2	3	4	5
22. Having unstructured time	1	2	3	4	5
23. Being allowed to attend a party or favored event	1	2	3	4	5

THE STRESS SURVEY SCHEDULE **The Groden Center, Inc**

Please rate the intensity of the stress reaction to the following events by filling in the appropriate circle:

	None to Mild	Mild to Moderate	Moderate	Moderate to Severe	Severe
24. Receiving a reprimand	1	2	3	4	5
25. Transitioning from preferred to non-preferred activity	1	2	3	4	5
26. Being told "no"	1	2	3	4	5
27. Receiving criticism	1	2	3	4	5
28. Having something marked incorrect	1	2	3	4	5
29. Being interrupted while engaging in a ritual	1	2	3	4	5
30. Receiving hugs and affection	1	2	3	4	5
31. Having to engage in not-liked activity	1	2	3	4	5
32. Waiting in line	1	2	3	4	5
33. Being unable to communicate needs	1	2	3	4	5
34. Waiting at a restaurant	1	2	3	4	5
35. Going home (from school, to visit parents)	1	2	3	4	5
36. Waiting for transportation	1	2	3	4	5
37. Being unable to assert oneself with others	1	2	3	4	5
38. Needing to ask for help	1	2	3	4	5
39. Participating in group activity	1	2	3	4	5
40. Having a change in staff, teacher or supervisor	1	2	3	4	5
41. Losing at a game	1	2	3	4	5
42. Waiting for reinforcement	1	2	3	4	5
43. Feeling crowded	1	2	3	4	5
44. Someone else making a mistake	1	2	3	4	5
45. Receiving tangible reinforcement	1	2	3	4	5
46. Waiting for food	1	2	3	4	5
47. Waiting for routine to begin	1	2	3	4	5
48. Having a conversation	1	2	3	4	5
49. Receiving verbal reinforcement	1	2	3	4	5

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THE STRESS SURVEY SCHEDULE **The Groden Center, Inc.**

Please rate the intensity of the stress reaction to the following events by filling in the appropriate circle:

	None to Mild	Mild to Moderate	Moderate	Moderate to Severe	Severe
FEARS					
1. Fear of animals	①	②	③	④	⑤
2. Fear of water (pool, lake, ocean, etc)	①	②	③	④	⑤
3. Fear of crowds	①	②	③	④	⑤
4. Fear of closed spaces	①	②	③	④	⑤
5. Fear of the dark	①	②	③	④	⑤
6. Fear of being left alone	①	②	③	④	⑤
LIFE STRESSORS					
1. Going to the doctor or dentist	①	②	③	④	⑤
2. Having seizures	①	②	③	④	⑤
3. Having a new sibling	①	②	③	④	⑤
4. Moving to a new house	①	②	③	④	⑤
5. Moving to a new school	①	②	③	④	⑤
6. Having parents get divorced	①	②	③	④	⑤
7. Having a parent re-marry	①	②	③	④	⑤

Please list any other stressors on the lines below

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THE STRESS SURVEY SCHEDULE The Groden Center, Inc.

Which do you consider the most significant stressors of those you have identified? Why?

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Appendix B

Mail Message

Reply Read Later

Mail Properties

From: Matthew Goodwin <msgoodwin@earthlink.net> Monday - March 24, 2008 1:58 PM
To: Kristen Hess <ecekhh@langate..gsu.edu>
CC: Juane Heflin <speljh@langate.gsu.edu>
Subject: Release of Data

Attachments: Mime.822 (4384 bytes) [View] [Save As]

Hi Kristen.

Please accept this email as confirmation of the following: I grant you access to a database consisting of 313 Stress Survey Schedules completed for individuals with ASD. When I send the data, all identifying personal information with regard to the individuals with ASD will be de-identified.

I'm grateful for your interest in this dataset and look forward to working with you on this project.

Best.

Matthew

_____

Matthew S. Goodwin, Ph.D candidate
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