January 2016

School Experiences Of Middle School Adolescents With Autism Spectrum Disorder

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Recommended Citation

Grave, Shannon D., "School Experiences Of Middle School Adolescents With Autism Spectrum Disorder" (2016). *Theses and Dissertations*. 2021.
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SCHOOL EXPERIENCES OF MIDDLE SCHOOL ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

by

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A Dissertation

Submitted to the Graduate Faculty

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

Grand Forks, North Dakota

August
2016

This dissertation, submitted by Shannon Denise Grave in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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July 19, 2016
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PERMISSION

Title	School Experiences of Middle School Adolescents with Autism Spectrum Disorder
Department	Teaching and Learning
Degree	Doctor of Philosophy

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Shannon Grave
July 15, 2016

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ACKNOWLEDGMENTS

I would like to thank my advisor, Dr. Katherine Terras, for her guidance and support throughout my doctoral program at the University of North Dakota. She is an amazing mentor, confidante, and role model. I am grateful for the way she nudged me toward greatness and helped me establish myself as a researcher.

I would also like to thank my committee and the faculty members who gave of their time in assisting and teaching me during this process. I would especially like to thank Dr. Carol Johnson, Dr. Patti Mahar, Dr. Meghan Salyers for serving on my committee. I would also like to acknowledge Dr. Lynne Chalmers and Dr. Kari Chiasson for their guidance and feedback in the earlier phases of completing this dissertation.

I am eternally indebted to the brave adolescents who agreed to meet with me. Without them, this study would not have been possible.

Last, but not least, I would like to thank my family for supporting me in this venture. I would not have been able to accomplish this without the ability to focus for long periods of time in my home office. For the same reason, I am thankful to good friends who helped me with the day to day chores associated with being a parent. Thank you to my mom and dad for raising me to work hard and always believe in myself.

To my family.

Thank you for your support and patience.

Janessa and Carsen, you can accomplish anything.

Brian, I could not have done this without your help.

I love you.

ABSTRACT

This phenomenological study examined the school experiences of adolescents with high functioning Autism Spectrum Disorder (ASD) in sixth through eighth grade. Two research questions guided this study: what were the participants' day to day experiences and what were their perceptions of those experiences? The results of the study yielded three conclusions. First, school can be a confusing and unpredictable source of stress. This stress can be ameliorated through increased predictability in the classroom and through adaptations to materials based on individualized needs and preferences. Specific classroom based strategies were identified and discussed, with clear shared preferences emergent. Participants indicated preferences for specific traits in teachers. Second, friendships were desirable, but symptomology associated with ASD makes it difficult to establish and maintain them. Participants needed peers to remain quiet in the classroom so they could focus and pay attention. The issue of bullying emerged as a shared concern, likely related to difficulties in accurately reading peers' social cues. Third, individuals with ASD are capable of regulating emotions if they are taught how to identify early signs of dysregulation and are supported in using self-calming strategies. Great variability was demonstrated in the level of insight in identifying dysregulation and in using adaptive calming strategies across participants.

Keywords: Autism Spectrum Disorder, ASD, accommodations, bullying, emotional regulation, modifications, peer relationships

CHAPTER I

INTRODUCTION

At the start of this study, the diagnostic terminology used to describe Autism Spectrum Disorder (ASD) was in a state of transition. Prior to 2013, the American Psychiatric Association's Diagnostic and Statistical Manual – IV, Text Revision (DSM-IV-TR) used several diagnostic terms for what most professionals collectively referred to as Autism Spectrum Disorders. These included the diagnoses of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorders, Not Otherwise Specified under the broad diagnostic classification of Pervasive Developmental Disorders (American Psychiatric Association, 2000). These three diagnoses, usually diagnosed during childhood, described a pattern of varying levels of impairment in the ability of the person to: (a) engage in social interactions; (b) communicate effectively; and (c) demonstrate a pattern of restricted, repetitive, and stereotyped patterns of behavior (American Psychiatric Association, 2000).

In May 2013, a new diagnostic classification manual, Diagnostic and Statistical Manual - 5, was released using the more encompassing diagnostic term of Autism Spectrum Disorder to describe the previous diagnoses classified under Pervasive Developmental Disorders with this more inclusive diagnostic term (American Psychiatric Association, 2013). Instead of designated levels of severity or impairment by using different diagnostic terms, clinicians now determine levels of severity by designating the level of support required by the individual affected by ASD within the areas of social communication and restricted, repetitive behaviors (American Psychiatric Association, 2013). In keeping consistent with the most current terminology and shift in diagnostic criteria, the term Autism Spectrum Disorder or ASD will be used interchangeably throughout this document.

Individuals with ASD share a set of core deficit areas with great variability in the presentation of those deficits. This variability in the presentation of strengths and deficits is paramount to the disorder being considered a "spectrum disorder." The diagnostic criteria for Autism Spectrum Disorder as delineated in the current Diagnostic and Statistical Manual of Mental Disorders 5th Edition is as follows (American Psychiatric Association, 2013):

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):
    1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back and forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
    2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or

deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

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

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

excessing smelling or touching of objects, visual fascination with lights or movement).

For each of the criteria (A and B) above, the diagnostician notes a severity level of 1, 2, or 3, with a designation of 3 demonstrating the need for the most intensive level of supports. In order to meet the criteria for a clinical diagnosis of ASD, the symptoms must cause a "clinically significant impairment in social, occupational, or other important areas of current functioning" (American Psychiatric Association, 2013). For youth, the concept of occupation is interpreted as pertaining to school. A diagnosis of ASD represents a significant level of difficulty or impairment in the area of social communication and behavior.

Clinical diagnoses of ASD are determined by Licensed Mental Health Professionals or Medical Doctors. Within school systems, teams of professionals do not diagnose, but make determinations of eligibility for special education services under the Individuals with Disabilities Act (IDEA). The Individuals with Disabilities Act is the law that governs special education services in America. Under IDEA, youth between the ages of three years to graduation (up to age 22) are afforded a free and appropriate education in the list restrictive manner possible (IDEA, 2004). While the school based teams take into consideration a diagnosis of ASD from an appropriately credentialed professional, schools use different criteria to determine the need for special education services and accompanying supports within the school system. This process results in identification of eligibility for special education services under IDEA. The criteria under IDEA uses the term "autism" and specifies:

> Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences (IDEA, 2004).

States have the option to expand criteria, meaning they can use more inclusionary verbiage for determining eligibility for special education services in order to provide services to more youth than the law requires. As such, many states will use terms consistent with current DSM5 diagnostic criteria (see above) when determining the degree to which associated deficits negatively impact the student educationally.

While somewhat confusing, it is possible for a student to meet criteria for a diagnosis of ASD from a licensed clinician, yet not meet eligibility criteria in requiring special education within the public school setting, and vice versa. An example could include a youth diagnosed with ASD requiring minimal supports (Level 1), with above average intellectual functioning, and few behaviors that complicate academic performance. A youth with that description could potentially earn average grades in school and demonstrate a lack of troublesome or impairing behaviors. Such a student may be determined ineligible for requiring special education services within the school setting. In a similar manner, a youth may be found eligible for special education services within the school setting under the category of ASD/Autism, yet never see a licensed clinician for a formal diagnosis of ASD. Or if seen by a clinician, could be diagnosed with a range of diagnoses that frequently co-occur with ASD or diagnoses that describe aspects of ASD criteria. Unlike other medical diagnoses, ASD is diagnosed by applying observations and reports of behaviorally observable characteristics rather than through brain scans, blood work, or other medical diagnostic processes. All participants in the current study were sixth through eighth grade adolescents diagnosed with having Autism Spectrum Disorder and were currently receiving special education services within his or her public school at the time of participation in the study.

Based on data from 2012, current prevalence rates estimate 1 in 68 children are diagnosed with ASD (Christensen et al., 2016). In 2002, it was reported that 1 in 150 children were affected by ASD (Centers for Disease Control, 2016). This represents considerable increases in prevalence rates over the last decade. Of those children identified as having an ASD, only 31% have a co-occurring intellectual disability, defined as having an intelligence quotient (IQ) of less than or equal to 70 (Christensen et al., 2016). Lacking an intellectual disability is one of the most common criteria for a person being identified as having high functioning ASD (Attwood, 2006; Dritschel, Wisely, Goddard, Robinson, & Howlin, 2010; Sansosti & Sansosti, 2012). Although frequently assessed and referenced, the accuracy of measuring intelligent quotient (IQ) in individuals with ASD is indeed somewhat controversial when discussing the needs and abilities of this diverse group of people (Frith, 2003). Another way that practitioners and researchers categorize a person as being high functioning relates to language development, particularly being able to communicate using words (Atwood, 2006;

Sansosti & Sansosti, 2012). At the same time the United States is experiencing unprecedented growth in prevalence rates for children being diagnosed with ASD, and increasing numbers of students with ASD are being educated in classrooms with their typically developing peers (Sansosti & Sansosti, 2012). The practice of students with disabilities being placed in general education classrooms with their peers without disabilities is called *mainstreaming*. Educators in mainstream classes are not usually licensed special educators with specialized training in specific disabilities such as ASD.

Autism Spectrum Disorder is complex. This is exacerbated by the wide range of deficits and abilities seen across this extremely diverse group of individuals. This wide range of abilities and deficits contributes to reasons for it being considered a spectrum disorder. This is demonstrated through great variability across individuals with the same diagnosis, but also in the variations in presentation and severity that fluctuate over time within an individual person (American Psychiatric Association, 2013).

It is estimated that approximately 70% of individuals with ASD have a co-occurring mental health disorder, with 40% having more than one co-occurring mental health disorder; the most common co-occurring diagnoses being anxiety disorders, depressive disorders, and attention deficit hyperactivity disorder (American Psychiatric Association, 2013). Individuals with ASD often present symptomology of co-occurring diagnoses in ways that are not what is typically expected. Sixty-three percent of youth with ASD are purported to experience clinically significant levels of anxiety, yet they often do not present symptoms that fully align with the criteria set forth in the Diagnostic and Statistical Manual (Kerns et al., 2014). Medications commonly prescribed to individuals suffering from anxiety disorders do not always react the same way in people with ASD as they do in people without ASD (Vasa et al., 2014). Further, there is some evidence suggesting that medications commonly prescribed may react differently in males with ASD compared to females with ASD and that other, less conventional treatments such as deep pressure and neurofeedback may show promise in managing anxiety (Vasa et al., 2014).

Whereas individuals with ASD are frequently noted to have deficits in the area of attention, there is some evidence that sustaining attention is less impaired than the ability to maintain attention while switching between tasks (May, Rinehart, Wilding, & Cornish, 2013). Some practitioners conceptualize this by saying that people with ASD can focus on something just fine, but struggle in shifting or transitioning their attention to something new. Another way this difficulty in switching between tasks can be explained relates to differences in what are commonly referred to as executive functioning skills (May et al., 2013). Executive functioning is an "umbrella term that encompasses various higher-order cognitive processes considered to be necessary for preparing and performing complex goal-oriented behaviors in situations in which automatic (habitual) behaviors are not sufficient" (Blijd-Hoogewys, Bezemer, & van Geert, 2014, p. 3089). In simple terms, youth with ASD demonstrate deficits in executive functioning, making it difficult to start tasks, to plan and complete the steps needed to execute a multistep process, to remember important information, and to self-regulate emotions and actions (Blijd-Hoogewys et al., 2014). Within the school-based setting, the difficulties associated with impaired attentional capacities and differences in executive functioning significantly impacts the ability of youth with ASD within the school environment to complete the expectations placed upon them by teachers and peers. These differences are believed to be brain-based and can be assessed using standardized tools such as the Behavior Rating Inventory of Executive Functions (Blijd-Hoogewys, Bezemer, & van Geert, 2014).

In addition to brain-based deficits in the process of starting and completing work in school due to deficits in executive functioning, youth with ASD share differences in the manner in which they typically process information and make sense of interactions with others. There is some consensus rooted in what is commonly referred to as difficulties with having a "theory of mind" which is defined as the "ability to recognize and understand the thoughts, feelings, beliefs, and intentions of other people" (Constable, Grossi, Moniz, & Ryan, 2013, p. 7). Simon Baron-Cohen was the first to coin the term "mind blindness" which referred to impaired abilities in understanding others' mental states due to brain-based differences (Stone, Baron-Cohen, Knight, 1998). This is associated with the social communication deficits noted in the aforementioned diagnostic criteria, but provides a context with which to make sense of the deficits as being the result of brain-based differences. One manner in which this is demonstrated is through difficulties in understanding the perspective of others (Frith, 2006). In addition to difficulties in understanding the perspectives of others and anticipating what he or she is saying or thinking, individuals with ASD share deficits in what is known as having a "weak central coherence" which refers to the tendency for focusing on details rather than the larger picture or main point (Happe & Frith, 2006). In practical terms this means that a person with ASD may focus in-depth on the details of a topic when interacting with others, yet completely miss the main point within the communication. For example, when describing one’s car, a person with ASD may provide significant details about the color, the leather seats, or the tires, yet never say that they are describing his or her beloved vehicle. He or she may describe the leather as brown with small flecks of grey hidden in the details, or the way the sun glints off it when it is cleaned or buffed, or how every speck of dust or lint is visible in bright sunlight. The listener may hear significant details about the seats, yet never be told that they are describing the seats in a car. Further complicating the social interaction is that the entire discussion could have resulted from a comment about a friend who was in an automobile accident.

With the ability to recognize what is and is not important and the capacity for understanding others’ mental states impaired, it is little wonder why youth with ASD struggle in school and require additional supports through special education services under IDEA. Academically, this deficit could result in a student with ASD missing the main point of the conversation and instead providing answers that do not earn him or her a passing grade because, while rich in detail, they miss the main points required in the response. If the above example occurred between two youth, the peer without ASD may become annoyed at the level of detail provided without a context with which to fully understand what the other person was actually describing. Further, the youth with ASD may be viewed as having a lack of empathy which could have negative repercussions on friendships.

Similarly, the intense focus on specific topics of interest can be alienating as most adolescents have a wide range of interests and do not wish to discuss the same topic in great depth repeatedly. For example, if an adolescent with ASD had a perseverative interest in trains, he or she may have extensive knowledge on the topic and attempt to veer all conversations toward trains and railyards. This could result in others avoiding conversations and interactions with the adolescent with ASD because peers would grow weary of discussing the same topic over and over again. In addition to perseverative interests dominating conversations and interactions, individuals with ASD struggle with engaging in reciprocal interactions. This can result in conversations feeling one-sided, with the person with ASD doing the majority of the talking. With difficulties in understanding subtle social cues, he or she may continue to pursue the "conversation" with a peer who is clearly communicating disengagement through non-verbal signals. Academically, a student with ASD may seek to find a way to inject his or her topic of interest into every assignment. There are some who urge educators to use special interests as a way to academically and socially motivate individuals with ASD (Koegel, Kim, Koegel, & Schwartzman, 2013). Regardless of the perspective held in managing this difference, the core deficits associated with the diagnosis are far reaching. For individuals with ASD, the differences related to perspective taking and understanding the main point in communication has far reaching effects on both relationships with others, especially peers, and academic tasks.

Within schools, commonly implemented academic strategies revolve around making clear the content and expectations within the school environment to teach and support those with ASD (Fleury et al., 2014). In particular, reading comprehension is also negatively impacted, even though the ability to read fluently is typically not adversely affected by ASD (Carnahan & Williamson, 2013). Reading fluency, in fact, may be higher than what is commonly expected as compared to similar aged peers. In middle school, there is an increase in the level of importance placed on students independently reading materials to learn information. This demand of "reading to learn" (Carnahan & Williamson, 2013) becomes particularly problematic to adolescents in middle school with high functioning ASD. Individuals with ASD do not have any identifying facial or physical anomalies compared to peers; in addition they may have extensive vocabularies, and they often have average to above average intellect, all of which contribute to the aforementioned problems. Strategies to improve performance with written materials generally center on increasing the level of visually supported instruction and individualized learning support from a teacher (Knight & Sartini, 2015).

To focus purely on academic needs alone misses the needs described as core deficit areas shared by individuals with ASD. It is vital that youth with ASD are equipped both academically and socially as they transition toward adulthood. Youth with ASD experience the lowest rates of community involvement and participation in school-based activities when compared with similar aged peers who do not have disabilities (Test, Smith, & Carter, 2014). This is attributed to both social communication difficulties and differences in behavior that preclude them from involvement in activities with peers. With a strong propensity toward a narrow range of interests and limited capacity to understand the perspective of others, the number of meaningful opportunities for reciprocal interactions with others becomes quite limited without adult intervention (Lindsay, Proulx, Thomson, & Scott, 2013).

The regulation of behavior and emotions is yet another area that is negatively impacted in youth with ASD (Khor, Melvin, Reid, & Gray, 2014; Mazefsky et al., 2013; Samson et al., 2014). Unique stereotypic and repetitive behaviors (called *stereotypies*) such as hand flapping, rocking, repeating phrases from movies or other phrases heard, and even repetitive body movements are part of the diagnostic criteria, yet the difficulties in regulating body and emotions creates more insidious problems within the school environment. To lose control of one's emotions or completely disengage from interactions adds to the culmination of interpersonal issues felt by those with ASD, particularly in adolescents (Khor et al., 2014; Samson et al., 2014). The ability to manage one's emotions is referred to as *emotional regulation*. Although the study of regulating emotions is relatively new, particularly in adolescents with ASD, there appears to be clear evidence that indicates they have difficulty in regulating behavior and emotions as common within this population (Khor et al., 2014; Mazefsky et al., 2013; Samson et al., 2014). As an example, an adolescent with ASD may break down in tears while pacing and rocking when frustrated over something similarly aged peers may view as minor. Or, an adolescent with ASD who typically has a large vocabulary, could become unable to think of the words needed to effectively communicate what is wrong or to meaningfully engage in problem solving. Erratic or immature behavior could lead to negative responses by peers who may feel irritation, fear, or bewilderment over the behavior of the adolescent with ASD. At a time when other adolescents are beginning to seek greater conformity with peers, adolescents with ASD are demonstrating delayed and disordered responses to stimuli and emotional situations (Happé & Frith, 2014). There is also evidence indicating that externalizing behaviors in youth with ASD have negative effects on the quality of the student/teacher relationship (Eisenhower, Blacher, & Bush, 2015).

Most individuals with high functioning presentations of ASD attend public school in classes with their peers without disabilities (Newman, 2007). With increased overall prevalence rates, more students with ASD are attending regular classes with peers who do not have a disability (Sansosti & Sansosti, 2012). General education teachers are often at a loss as for how to support students with ASD who are increasingly being placed within their classrooms (Lindsay, Proulx, Thomson, & Scott, 2013; Morningstar, Shogren, Lee, & Born, 2015).

Statement of the Problem

There are countless publications and journal articles documenting a range of methods and practices as being efficacious with this population. In particular, there are two significant pieces of work that have determined levels of empirical evidence for strategies, methods, and treatments commonly used with school-aged individuals with ASD. The two most commonly referenced and respected publications are the *Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder* report (Wong et al., 2014) and the *Findings and Conclusions: National Standards Project, Phase 2* report (National Autism Center, 2015). Each of these publications represent the culmination of extensive literature reviews and analyses of the merits of the studies reviewed in order to determine the level of empirical evidence supporting the use of the specific practices with youth with ASD. Highly rigorous methods, including extensive inter-rater reliability, were employed by both groups to validate all results. The result of these extensive practices was the culmination of two separate documents that place commonly used practices into logical groupings with levels of empirical evidence noted for each practice. While there may be some differences in the manner in which the two groups of researchers conceptualized commonly used methods, the findings are remarkably similar. Both reports delineate levels of empirical support for specific practices commonly used to support and educate people with ASD from birth through graduation. Both emphasize the need for more research identifying evidence-based practices with adolescents as there are significantly fewer published articles for adolescents and young adults (National Autism Center, 2015; Wong et al., 2013).

Publications such as those produced by Wong et al. (2014) and the National Autism Center (2015) are excellent references on identifying evidence-based practices for use in supporting and teaching youth with ASD. However, there are few publications that have identified extensive evidence-based practices for supporting adolescents with ASD, and even fewer chronicling the perspectives of adolescents with ASD as to which practices they find most beneficial to them during their school experiences.

Under IDEA it is very common for students with disabilities to receive accommodations and modifications to the curriculum, particularly in the manner for which materials are presented and in the ways students demonstrate understanding through tests and assignments (Morningstar et al., 2015). Schools frequently have prescribed lists of commonly applied accommodations and modifications from which to choose while implementing appropriate adaptations to the curriculum. There is significantly less empirical guidance on the use of evidence-based academic accommodations and modifications with adolescents with ASD (National Autism Center, 2015; Wong et al., 2013). Within the field of special education, there is a lack of consensus on determining what is considered an accommodation versus what is considered a modification to curriculum. For this reason, the current study will use the term adaptation(s) to refer to both accommodations and modifications. The most commonly applied adaptations in schools alter the way materials are presented or the manner in which the individual with ASD completes work. This frequently involves increasing the use of visual supports and graphics (Morningstar et al., 2015), or through strategies that support reading (McMahon et al., 2016) and writing (Evmenova et al., 2016). In general, information on how to implement educational adaptations with adolescents with high functioning ASD is sparse, even though they are commonly employed throughout the K-12 school years extending into college experience (Barnhill, 2016). Also absent from the literature base are the perspectives of adolescents with ASD identifying which adaptations are believed to be the most beneficial to them.

Difficulties in the area of social relationships and communication are central to the difficulties shared by individuals with ASD, regardless of the level of functioning or abilities (American Psychiatric Association, 2013). The desire for relationships with peers represents a unique struggle for adolescents with ASD (Happé & Frith, 2014) and can create significant emotional distress (Holloway, 2013). Further, adolescents with ASD are often the target of bullying by peers, particularly when placed in the general education classroom with peers without disabilities (Hedges et al., 2014; Zablotsky, Bradshaw, Anderson, & Law, 2014). Again, few studies document the perspectives and lived experiences of adolescents with ASD around peer interactions, although there is limited empirical evidence supporting the assumption that it is indeed more difficult for adolescents with ASD than for their peers without disabilities (Happé & Frith, 2014).

Another area that is largely under-researched is related to emotional regulation (ER). Whereas the study of ER is fairly limited, empirical studies on this construct is almost non-existent for adolescents with ASD. Emotional regulation "relates to the ability to modulate experienced and expressed emotion" (White, et al., 2014, p. 1). It has been suggested that deficits in ER are part of the ASD presentation (Mazefsky et al., 2013; Robinson & Elliot, 2016; Samson et al., 2015; Weiss, 2014; White et al., 2014). Although it is generally accepted that individuals with ASD struggle with ER, little guidance exists on how to support ER, with even fewer guidelines on strategies to support adolescents with ASD. Once again, no studies could be located that presented the perspectives and experiences of adolescents with ASD relative to strategies employed to promote emotional regulation.

The theme of under-representation in the literature base is clear. The voice of individuals, particularly adolescents, with ASD is glaringly absent. Perhaps the most compelling argument for this study comes from adults affected by ASD in their demand for "nothing about us without us" in addressing the needs and perspectives of individuals with ASD (Autistic Self Advocacy Network, n.d.). The main point made by this advocacy group is that the voice of those affected by ASD needs to be heard across all settings. Other authors, including academics, call for increased attention to understanding the perspectives and lived experiences of those directly affected by their individual presentation of ASD (Milton, Mills, & Pellicano, 2014; Szatmari, 2004; van Roekel, Scholte, & Didden, 2010). Obtaining the views of a group of individuals, for whom social communication and regulation is paramount, requires significant planning and careful attention to be paid to the individualized supports necessary to facilitate meaningful interviews (Harrington et al., 2013; Preece & Jordan, 2009; Tozer, Atkin, & Wenham, 2013).

Purpose of the Study

The purpose of this phenomenological study was to examine the experiences and perspectives of adolescents with high functioning ASD presently in middle school. Numerous accounts of the lived experiences of parents and siblings of children with ASD can be found in both scholarly literature and popular culture (Cutler, 2004; Fish, 2006; Gill & Liamputton, 2009; Mori, Ujie, Smith, & Howlin, 2009; Smith et al., 2010; Smith & Elder, 2010). Such accounts document the struggles and triumphs in providing care to children, adolescents, and adult children with ASD. The perspectives of professionals working with people with ASD can be located and reviewed with relative ease as well (Dillenburger, et al., 2010; Szatmari, 2004). While there are numerous published accounts of living and working with children and adolescents with ASD from an outside perspective, the lived experience of adolescents with ASD remains glaringly absent.

The researcher is a professional trained in both social work and special education. At the core of those professions lies the ideal that people with disabilities have much to say and to contribute about the way in which they are treated. Put another way, the voice of those who are sometimes marginalized is one that should be illuminated and made public. Advocacy organizations such as Autism Speaks, Global and Regional Asperger Syndrome Partnership, and Autistic Self Advocacy Network all share the view that individuals affected by ASD must be given opportunities to have their experiences shared from their own perspective. This relates to the research paradigm of critical theory which offers the critique that certain groups have inherent privilege over other groups (Crotty, 2012). By virtue of not being adults yet (not of the age of majority) and having a disability, adolescents with ASD could indeed be considered part of a group of people who have less privilege and inherent rights than those without disabilities.

The underpinnings for this study note the current literature base documenting the perceptions of adolescents with ASD on practices considered to be evidence-based as insufficient in fully supporting this population. Teachers and practitioners can locate a plethora of research on the behavioral indicators of evidence-based practices related to specific intervention and support strategies; however, the perspective of how those individuals who are directly affected by ASD view and experience those supports and interventions is sorely lacking.

Semi-structured individual interviews were conducted in order to identify information deemed important to the participants about his or her school day, what was helpful to him/her, what he/she wished was different during the school day, and any information he/she were willing to provide about taking *breaks* during the school day in order to regulate themselves. The purpose was to identify the participants' shared experiences and their perceptions of those experiences in order to determine commonalities across the responses.

Research Questions

1. What were the experiences of adolescents with high functioning Autism Spectrum Disorder throughout their school day?
2. What were the perceptions of their experiences by adolescents with high functioning Autism Spectrum Disorder throughout their school day?

Delimitations of the Study

There were several delimitations regarding participants in this study. All participants were required to have a diagnosis of an ASD or be served through an Individualized Education Plan for Autism/Autism Spectrum Disorder. The age at which the participant was diagnosed or found eligible for special education services was not limited. All participants were to be regarded as having a *high functioning* ASD, meaning he or she was without a co-occurring diagnosis of intellectual disability and was able to use verbal speech to communicate, namely English. Participants needed to be aware that he or she had ASD. Participants were to be currently enrolled in the sixth through eighth grades in any school setting (e.g., home school, public school, private school).

Assumptions of the Study

The author theorized that learning the perspectives of those with ASD could inform practice through better understanding of shared needs and preferences, thus aiding in the development of a starting point from which methods for more effectively supporting adolescents with ASD during their school day could be identified. It was anticipated that the participants would have clear preferences for how they wanted to be supported in school. The participants exceeded this anticipation by openly sharing their personal experiences in school and their preferences for supports with the researcher. The researcher maintained the assumption that the participants held valuable information as to the manner in which they viewed supports and that they would have distinct preferences for some over others. There was an assumption that the use of breaks were helpful for regulation. It was also presumed that the participants would illuminate what they believed were the best practices for supporting them during the school day and that they would have much to teach the researcher when it came to educating and supporting them. It was anticipated that their responses may align with findings and conclusions outlined in the *National Standards Project* (National Autism Center, 2015) and the *Evidence Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder* reports (Wong et al., 2014.

Although this researcher had extensive experience working in a variety of settings with individuals with disabilities, including but not limited to ASD, knowledge of the evidence-based practices reports was set aside during the interview and analysis phases of the study. This was done to remain open to the potential that the participants may have opposing perceptions or experiences with methods purported as evidence-based for those adolescents with ASD. The only assumption held during the course of the study was that of recognizing the expertise of those being interviewed whilst striving to learn the essence of what they were communicating throughout the interview process.

Acronyms and Definitions of Terms

Accommodations: Changes made to the environment that allow equal access to materials and experiences (United States Department of Education, 2004).

Autistic Disorder: A diagnosis using the previous Diagnostic and Statistical Manual (DSM-IV-TR) marked by qualitative impairments in all three specific areas: (a) social interactions; (b) communication; and (c) behavior. Differences in behavior are described as restricted repetitive and stereotypical patterns of behavior, interests, and activities (American Psychiatric Association, 2000)

Autism Spectrum Disorder (ASD): Prior to DSM5's release, ASD included diagnoses of autistic disorder, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome. With the May 2013 publication of the new Diagnostic and Statistical Manual (DSM-5), these autism subtypes were merged into one umbrella diagnosis of ASD. Autism Spectrum Disorder is characterized, in varying degrees, by difficulties in social communication and social interaction, and restricted, patterns of behavior, interests, or activities (American Psychiatric Association, 2013).

Asperger's Disorder: A diagnosis using the previous Diagnostic and Statistical Manual (DSM-IV-TR) marked by qualitative impairments being present in two specific areas: Qualitative impairment in social interactions and restricted repetitive and stereotypical patterns of behavior, interests, and activities (American Psychiatric Association, 2000). Individuals with a "well documented diagnosis" of Asperger's

Disorder previously, are to be diagnosed currently with ASD (American Psychiatric Association, 2013).

Diagnosis of an Autism Spectrum Disorder: The documentation of applying diagnostic criteria by a licensed mental health professional or medical doctor, determining that a person demonstrates the specified number of criteria indicative of an Autism Spectrum Disorder (American Psychiatric Association, 2000).

Echolalia: the repetition of words or phrases used by another person (Buron & Wolfberg, 2014, p. 451).

Educational Classification: A child is determined to need special education and related services due to an assessed need because of a disability (United States Department of Education, 2004).

Emotional Regulation: Pertains to the ability of a person to modulate or alter his or her response or expressed emotion to a given situation (Mazefsky et al., 2013; White, et al., 2014).

Executive Functioning Skills: processes involved in preparing and performing complex, multi-step behaviors where rote responses are insufficient (Blijd-Hoogewys, Bezemer, & van Geert, 2014).

High Functioning Autism Spectrum Disorder: People with high functioning ASD are generally considered to have average to above average intelligence and are able to communicate using spoken language. (Sansosti & Sansosti, 2012). Currently defined as ASD Level 1 in DSM-5 (Buron & Wolfberg, 2014).

Individuals with Disabilities Education Act (IDEA): The legal statutes that guarantee a free and appropriate public education for youth with disabilities (United States Department of Education, 2004).

Individualized Education Program (IEP): a written document for a child with a disability that is developed, reviewed, and revised in a meeting in accordance with the laws governing special education (United States Department of Education, 2004).

Intellectual Disability: A disability characterized by significant deficits in mental abilities and impairment in everyday adaptive functioning. Generally defined as having intellectual quotient scores around or below 70 (American Psychiatric Association, 2013).

Mainstreaming: The practice of placing individuals with disabilities in the same classrooms as peers who do not have disabilities. This is sometimes referred to as "inclusion" or "inclusive educational practices" (Hall, 2013).

Mind Blindness: Difficulty inferring the perspective of another person (Buron & Wolfberg, 2014).

Modifications: Changes made to the academic expectations, curriculum, and/or instruction to meet the needs of a student with a disability (Buron & Wolfberg, 2014).

Pervasive Developmental Disorders: The related diagnoses in the previous Diagnostic and Statistical Manual (DSM-IV-TR) that include: (a) Autistic Disorder (b) Rett's Disorder (c) Childhood Disintegrative Disorder (d) Asperger's Disorder and (e) Pervasive Developmental Disorder, Not Otherwise Specified. (American Psychiatric Association, 2000). Individuals with a "well documented diagnosis" of Pervasive

Developmental Disorder previously, are to be diagnosed currently with ASD (American Psychiatric Association, 2013).

Pervasive Developmental Disorder, Not Otherwise Specified (PDDNOS): This diagnosis from the previous Diagnostic and Statistical Manual (DSM-IV-TR) was used when a severe and pervasive impairment in the development of reciprocal social interaction, communication, and behaviors consistent with a specific diagnosis of a Pervasive Developmental Disorder was present, but the criteria are not met for a specific diagnosis (American Psychiatric Association, 2000). Individuals with a "well documented diagnosis" of PDDNOS previously, are to be diagnosed currently with ASD (American Psychiatric Association, 2013).

Self-Regulation: "Self-regulation tasks involve the management of one's own behaviors in order to meet a goal" (National Autism Center, 2009, p. 37).

Special Education: individualized instruction designed to address the unique educational needs of a child due to his or her disability (United States Department of Education, 2004).

Special Interest Areas: Solitary pursuits in a particular area, subject, or activity that dominates a person's focus, attention, and time (Buron & Wolfberg); also referred to as repetitive and restricted areas of interest within the diagnostic criteria for ASD (American Psychiatric Association, 2013).

Theory of Mind: the ability to infer other people's mental states (Stone, Baron-Cohen, & Knight, 1998).

CHAPTER II

METHOD

The purpose of this phenomenological study was to examine the experiences of adolescents enrolled in sixth through eighth grade with ASD about their school day. Learning from the adolescents themselves, in their own words, was important. What they identified as important, helpful, supportive, or difficult throughout their current daily school experiences holds value. Through individual interviews, the researcher sought to understand how each participant viewed the use of various evidence-based practices commonly employed, how they perceived supports in the classroom, what they believed was helpful and/or not helpful, and if there were things with which they struggled during the school day. This study sought to learn which practices they believed were helpful and not helpful to them during their school day in order to develop emergent themes and assertions to form conclusions in order to guide future practice. The study was reviewed and approved through the University of North Dakota's Institutional Review Board. The study was approved as proposed with an approval number of IRB-201311-155.

Design

This study employed a phenomenological perspective using individual interviews in order to "understand the lived experience" and "the meaning of those experiences" (Seidman, 2006; Wertz, 2011). The experience studied was that of the day-to-day school experiences of adolescents with high functioning Autism Spectrum Disorder (ASD). An exploration of the experiences and phenomena of being an adolescent with high functioning ASD in middle school is best described by a person demonstrating all of those characteristics. Aligned with phenomenological perspectives, the participants were viewed as holding the expertise on the topic explored (Seidman, 2006; Stake, 2010). Interviews and observations were used to determine the essence of what participants communicated (Hycner, 1985).

Within a constructivist framework, which is where phenomenological studies lie, the belief is that the answers to questions, such as those proposed in this study, are socially constructed through the recollections and experiences of those who experience a specific phenomenon (Crotty, 2012). Individuals affected by ASD present with a unique set of needs to bear in mind when inquiring about experiences. Frith (2003) referred to the concept of a weak central coherence, or difficulty with understanding the gestalt (big picture) with regard to a scenario or experience. Because of the difficulties commonly experienced by people with ASD in making connections between pieces of information, the research questions were formed as two distinct but closely related questions. The two research questions guiding this study were:

- What were the experiences of adolescents with high functioning Autism Spectrum Disorder throughout their school day? This question elicited the actual lived experiences of the adolescents in describing the activities, supports, and routines experiences during their school day.
- What were the perceptions of their experiences by adolescents with high functioning Autism Spectrum Disorder throughout their school day? This

question explored what they thought about those experiences. This question sought to uncover any insights or opinions the participants held. At the close of each interview, participants were asked if he or she had any advice for teachers, professionals, or others working with people with ASD.

Theoretical Framework

At present, two significant publications delineate levels of evidence for various practices commonly used to support individuals with varying presentations and severity of ASD (National Autism Center, 2015; Wong et al., 2014). Reports such as the *National Standards Project* (National Autism Center, 2015) and the *Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder* (Wong et al., 2014) are two large studies categorizing levels of documented efficacy for various supports and interventions commonly used with people with ASD. They also provide a basis for conceptualizing the degree to which various supports and interventions commonly used with people with ASD are believed to be established interventions or *evidence-based*. For efficiency, the two reports will be referred to as the *Evidence Based Practices Reports* (EBP Reports).

The EBP Reports provided the framework for the development of this study. At the time of the study, increasing emphasis was being placed on the implementation of evidence-based practices with individuals with ASD. In conceptualizing the current study, this author projected that the participants would identify experiences in school that could, on some level, be related back to the EBP Reports. While it was anticipated that the participants would likely identify a range of supports and interventions used with them during the school day, and that many of them may align with those indicated within the EBP Reports, the levels of empirical support for various methods used was set aside until the results of this study were compiled.

In designing the study, the use of open-ended questions to elicit information about the school day was intentionally planned. By specifically asking what teachers and peers did that was helpful and not helpful, it was predicted that participants would provide details about his or her experiences and views on commonly employed strategies used in classrooms. Through responses to open-ended questions during the semi-structured interviews, it was anticipated that the participants would provide examples from the school day where specific methods or strategies were employed. This allowed for participants to independently identify what he or she believed was pertinent or significant to them.

Throughout the data analysis process the words spoken by the participants were used to the greatest degree possible. This was particularly important during the process of coding and the reduction of those meaning units into categories. As themes and assertions began to emerge, categories of methods and strategies identified within the two EBP Reports overlapped with those identified by the participant in the present study. Once the assertions and supporting themes were identified in the current study, they were compared to and contrasted with the findings from the two EBP Reports. These reports provided a framework for conceptualizing terms used in the findings of the present study in a way that aligned with the current literature base in order to contribute to the literature base in a more meaningful manner.

Participants and Setting

Seven adolescents, in grades six through eight, with a diagnosis of an Autism Spectrum Disorder (ASD) were recruited using purposeful and snowball sampling techniques. All participants lived within a 100 mile radius in the Upper Midwest. By parent report, each participant was formally diagnosed with an Autism Spectrum Disorder by a licensed mental health clinician or medical provider using criteria from the Diagnostic and Statistical Manual (DSM-TR-IV).

Because of the timing of the transition to an updated version of the Diagnostic and Statistical Manual (DSM5), participants held diagnoses of Asperger's Disorder and Pervasive Developmental Disorder, Not Otherwise Specified, which were used in the previous edition of the DSM (DSM-IV-TR). Current clinical guidelines for individuals with these documented diagnoses are to consider them as meeting criteria for the new, more encompassing diagnosis of Autism Spectrum Disorder (ASD) under the revised diagnostic manual (American Psychiatric Association, 2013). There were no limitations placed on the age at which a participant was identified as having ASD nor the date of the most current diagnostic assessment; this is because ASD is considered a life-long diagnosis with a waxing and waning of symptomology over time (American Psychiatric Association, 2013).

Each participant received special education services through an Individualized Education Program (IEP) due to his or her educational needs. Each one required special education support due to his or her unique learning challenges due to ASD. This was verified through parent report and during the interview process.

Participants were considered high functioning with regard to his or her presentation of ASD. For the purpose of this study, this means they were able to use language to communicate. Further, the parents concurred during the recruitment process the general belief that the participant did not have a co-occurring intellectual disability. All participants were aware of the diagnosis of ASD. All participants identified English as the primary language spoken in the home.

There were no limitations placed on whether the participant must be currently receiving special education services under an IEP, unless that was used as documentation of the participant's ASD. It was quite possible that a student could have a formal diagnosis of an Autism Spectrum Disorder using diagnostic criteria, but not meet criteria for needing special education services under the classification of ASD or Autism. It was also quite possible that a participant could be served under the educational classification of Autism or ASD (depending upon the state in which they resided) without having a documented clinical diagnosis from a licensed mental health provider or doctor who applied diagnostic criteria from the Diagnostic and Statistical Manual (Kanne, Randolph, & Farmer, 2008).

There were no requirements as to educational placement of the participant. The degree of support provided through special education was not prescribed. This meant that a participant could spend his or her entire school day in either a special education setting or potentially spend their entire school day in classes with their peers who did not have disabilities, or any combination thereof. In terms consistent with special education practices, there were no limitations placed on the degree to which the individual was mainstreamed with regard to educational placement or setting. Mainstreaming refers to the practice of students receiving special education services while placed with their peers who do not have disabilities in the general education classroom. All participants were mainstreamed for a portion of their day within a public middle school setting.

Participant Recruitment

Care providers and educators *(gatekeepers)* known to the researcher were approached about the study for the purpose of identifying potential participants. Initial contacts were made via private, text-based electronic correspondence with teachers and professionals working with potential participants, as well as parents with whom the researcher had a relationship. Parents/guardians were provided written information about the study (interview protocol and consent/assent forms) along with a request to ask their adolescent if he or she would consider consenting to an interview to talk about their school day. Parents/guardians were responsible for inquiring if his or her adolescent wished to consider participation. No direct contact was made between the researcher and the adolescent participants until the time of the interview. This was so as not to place undue pressure on vulnerable adolescents.

After indicating an understanding of the study and time commitments associated with participation, gatekeepers were asked to make an initial inquiry with the parents/guardians of potential participants. This ensured anonymity for potential participants until contact was initiated by the parent or guardian. For those willing to consider participation in the study, parents/guardians were given the contact information of the researcher. This ensured confidentiality and respected the vulnerable nature of the participants being minors with a disability. Further, it was believed this would be the least distressing to participants given the potential for anxiety associated with initiating contact with an unknown person. Approximately 70% of individuals with ASD have a comorbid mental health disorder, with anxiety being identified as a common concurrent diagnosis with ASD (American Psychiatric Association, 2013).

Consistent with snowball sampling procedures, the researcher asked the gatekeepers and families of potential participants to share information about the study and researcher's contact information with anyone else known by them to be a potential participant. This method of sampling is considered appropriate in a qualitative study using this methodological framework (Creswell, 2012; Seidman, 2006). The parents were encouraged to use any means they wished to contact the researcher. This included email, phone call, or text. No more than two unreciprocated attempts were made to contact potential participants.

Special Circumstances

Having identified an insufficient number of participants from the initial sampling methods, an addendum to the Institutional Review Board application process with a plan for collaborating with other agencies and gatekeepers was completed. A flyer was produced, submitted, and subsequently approved for use in recruiting additional participants (see Appendix A - Invitation to Participate in Study). The flyer was delivered in person to various gatekeepers. The flyers advertising the study were hung in mental health clinic offices where the researcher maintained an ongoing, consultative relationship as well as distributed to anyone known to the researcher who may have contact with individuals meeting criteria for participation. The approval process for distribution of the flyer in a large Upper Midwest school district was completed. Special education teachers were approached to share the flyer with parents of children meeting the criteria for the study. To maintain confidentiality, the researcher did not learn any names of potential participants until contact was initiated by the participant's parent or guardian.

Despite parenting a child with ASD and being involved in the provision of clinical and supportive services with individuals with ASD through several locations in the geographic region, gaining consent to interview participants was an unanticipated challenge. This was likely due to the level of distress experienced by the potential participants when asked to consider participation. The degree to which individuals with ASD suffer distress from changes in their routines and in engaging in social interactions with new people is well documented and is part of the core diagnostic criteria (American Psychiatric Association, 2013). In several instances, the researcher received a call from a gatekeeper indicating that a potential participant was identified and he or she had indicated interest in participating, yet no action was pursued by the potential participant. In each of the four separate instances, anxiety or distress was indicated as the cause for inaction. This was honored and no further attempts were made to contact those particular individuals.

Setting

After coordinating verbal consent and assent to participate in the study, an interview was scheduled in a location of the family's choosing. This included the family home or a public location such as a library or restaurant chosen by the participant. Three interviews were held in public locations at the request of the participant and his or her parent. Four were held in the family home. In every situation, parents remained within earshot or visual line of sight.

Data Collection

Interview Protocol

All interviews with participants were audiotaped using a digital recording device to allow for verbatim transcription. Prior to each interview, the digital recorder was tested and freshly charged batteries were used. Contingency plans for device failure included a fully charged mobile phone with a built-in digital recording application along with spare batteries for the digital recording device. Copious notes of all observations of subtle non-verbal and para-communication were recorded during and immediately following each interview. The procedure and interview protocol along with the consent/assent forms were reviewed. Consent and assent were obtained prior to interview commencing. All participants and parents or guardians were provided copies of the consent and assent forms for their records. From this point forward, parents/guardians will be shortened to read as *parents* with the implication this includes any legal guardians.

Difficulties with maintaining attention and regulation during social interactions are well documented in the literature on working effectively with people with ASD (Hall, 2013; Marans, Rubin, & Laurent, 2006; Prizant, Wetherby, Rubin, & Laurent, 2007). To accommodate for this difference, plans included the possibility to interview participants up to a maximum of three times. Having the flexibility to interview more than one time also allowed for the possibility of following up on any questions that may have lingered after the initial interview (Seidman, 2006). Each participant was interviewed only once.

Immediately following the consent and assent processes, copies were given to the participant and her/his parent. Parents were asked to remain either in direct line of sight or within earshot of the interview at all times. This served to protect both the researcher and the participant. It also functioned as a safety precaution in case the participant became agitated or dysregulated during the interview; the parent could be in close proximity to help calm or redirect the participant if needed.

The interview began with the interviewer and the participant developing a written schedule of his or her school day. The use of visual supports, particularly written schedules, is considered a research supported best practice with people with ASD (Hall, 2013; Hodgdon, 1995; National Autism Center, 2009, 2015; Wong et al., 2014). The visual support of the daily school schedule guided the interview process, provided support for sequencing the day, and served as a visual support to the participant as to how much longer the interview would last. It is believed that visual supports assist self-regulation in people with ASD by communicating what is expected and how long an activity will last (Hall, 2013; Hodgdon, 1995).

The need for brief breaks is common in people with ASD and could be conceptualized as an environmental modification of task demands, which is considered a behaviorally based intervention (National Autism Center, 2015). When participants appeared to begin to experience dysregulation demonstrated through increased stammering or facial flushing, a short break was offered. No participants required any breaks from the interview and all were able to complete the full interview by addressing all of the questions within the interview protocol.

Although Seidman (2006) advises that all interview questions be completely open-ended, this population of participants needed somewhat more directive and focused queries based on their differences in understanding verbal questions (Hall, 2013). In following the daily schedule co-constructed by the researcher and participant, each class period or block of time was addressed in a linear manner from start to finish. Participants were asked about their perception of each individual block of time. This provided information about the types of methods, supports, and interventions used across their school day. Insights as to his or her experiences and perceptions of those experiences across the entire school day were gleaned from the conversation.

Sciutto et al. (2012) surveyed parents of children with ASD on challenges faced by their children in school. Specifically, the parents were asked how characteristics of ASD affected school experiences, how teachers impacted the adolescent's experience, and how the school experience was affected. This research was invaluable in forming the interview protocol (see Appendix B – Interview Protocol).

In following the order of the daily school schedule for classes, participants were asked to describe each class. After providing a description of the class period/subject, the researcher gestured to the interview protocol and asked the first question: "Is there anything the teacher does that you think is helpful or not helpful? Let's start with what they do that you think is helpful." Once the participant had completed his or her response, they were asked a similar question about what the teacher does that is not helpful or if there was anything they wish the teacher did differently in that particular class. Upon completion of the response, the participant was asked the same series of questions about peers. Follow-up questions were posed to gain deeper insight into the participant's experience. This process was followed for each class period in a sequential manner.

After asking what each teacher and peers did that was helpful or not helpful for every class period across the school day, participants were asked about the use of breaks. Participants were asked if she or he ever took breaks when others were working during class. Follow-up questions included asking how this was indicated, what was done during the break, and if or how the break helped. The final question in the interview protocol sought responses relating to the participant's advice on what others should know, or advice he or she had for others working with "kids with ASD." The interviews ranged in duration from 28 minutes to 70 minutes.

Record Review

The use of record review as a form of data triangulation is one way to increase the validity and trustworthiness of findings in a qualitative study (Creswell, 2012; Maxwell, 2005). Parents were asked to share any pertinent records or documents about the participants' educational needs and experiences. Three parents allowed review of Individualized Educational Plans (IEPs). The researcher photocopied and redacted identifying information for later use. In each case, the researcher made notes of pertinent information to facilitate triangulation of data. Following the completion of data analysis, the researcher referred back to the records provided by the parents to compare the accommodations listed in the IEP against those identified as "helpful" by the participants. The IEP documents provided greater insight into the needs and level of assistance provided to the participant during his or her school day. All records were kept in a locked storage cabinet with all identifying information removed.

Transcription Process

After each interview, the digital recording was assigned a coded name and uploaded to the researcher's password protected computer and a password protected cloud storage system called OneDrive. Once uploaded to both locations, the digital recording was deleted from the recording device.

Interviews were transcribed verbatim with all personally identifying information removed. A free computerized program obtained from the Internet was used to transcribe the interviews. The program, Express Scribe, allows one to stop, start, rewind, fast forward, slow down, and speed up digital recordings for the purpose of transcription. To further ensure participant confidentiality, the digital recording did not include the participant's name, age, or location. The file was saved as the date of the interview and a shortened version of the "fake name" assigned to the participant. One file was uploaded at a time and was deleted upon completion of the transcription. The transcriptionist then used a word processing program on a password protected computer to type the written transcript. At no time was the participant's actual name used in storing or sharing files. The entire process was completed on a password protected computer.

The researcher transcribed one and one-half interviews before employing three contracted laborers. The remainder of the interviews were transcribed by paid individuals. The individuals paid to transcribe the remaining interviews included two high school students and one adult friend of the researcher. Great care was taken by the researcher to ensure that the participant would be unknown by the transcriptionist in case the voice was familiar. Confidentiality was addressed with each transcriptionist. Each agreed to maintain the confidentiality of the participants and any information they gleaned through the process. The two high school students hired for transcription indicated understanding of the importance in maintaining confidentiality of participants in the research process. In both cases, the students hired to transcribe interview data had parents employed in the field of special education at the University level. The adult friend of the researcher had experience in working as a paraprofessional in the field of Special Education and agreed to the same terms with regard to maintaining the confidentiality of the participants. Depending on the length of the interview, each transcriptionist was paid between $50.00 and $100.00 per interview transcribed.

The digital recording of the interview was shared one at a time using a link to the researcher's password protected OneDrive online storage. The transcriptionist then downloaded the transcript with the coded name to her individual, password protected personal computer. Each used Microsoft Word and Express Scribe during the transcription process.

After each transcript was completed, the researcher reviewed each typed transcript for accuracy and to re-acquaint herself with the data. At the time of reviewing the recording with the transcript, the notes taken earlier during and immediately following the interview were added to the transcript to facilitate a more complete picture of the participant responses during the data analysis process (Hycner, 1985). Pertinent background information on each participant was also added to the beginning of the word processed transcript.

Data Analysis

A thematic analysis congruent with a phenomenological approach was employed. The sequential, reductive analysis techniques used were consistent with those commonly used by other qualitative researchers (Hycner, 1985; Seidman, 2006; Smith, 2011). Each transcript was reviewed in its entirety before moving on to the next transcript. Reflective and descriptive comments coinciding with sections of each transcript were noted within the transcript. Each transcript was reviewed and analyzed line by line. This aligns with a common practice for documenting observations and reflections (Creswell, 2012; Hycner, 1985; Smith, 2011). This yielded an identification of both significant statements and smaller units of meaning. These smaller units of meaning are sometimes referred to as *meaning units* (Wertz, 2011). Going line by line and paragraph by paragraph, meaning units were noted as comments within the Microsoft Word document. Significant statements made by the participants were recorded and identified as such in the same manner. By engaging in systematic data reduction, the amount of information was reduced to increasingly smaller units of analysis with each subsequent step.

Following this reduction in data, the meaning units and significant statements were printed using the Microsoft Word feature called *list all markups*. The meaning units were then placed into several tables correlating directly with the interview protocol. A separate document recorded all potentially significant statements. The tables produced grouped the meaning units in the following manner:

- What teachers do that is helpful or not helpful
- What peers do that is helpful or not helpful
- Information related to taking breaks during the school day
- Differences noted in communication patterns
- Special notes about each participant

After each line within the transcript was analyzed, data analysis tables were developed to group the meaning units into a logical manner. Each table listed the meaning units into one column, followed immediately to the right of that column an identification of the emerging patterns noted.

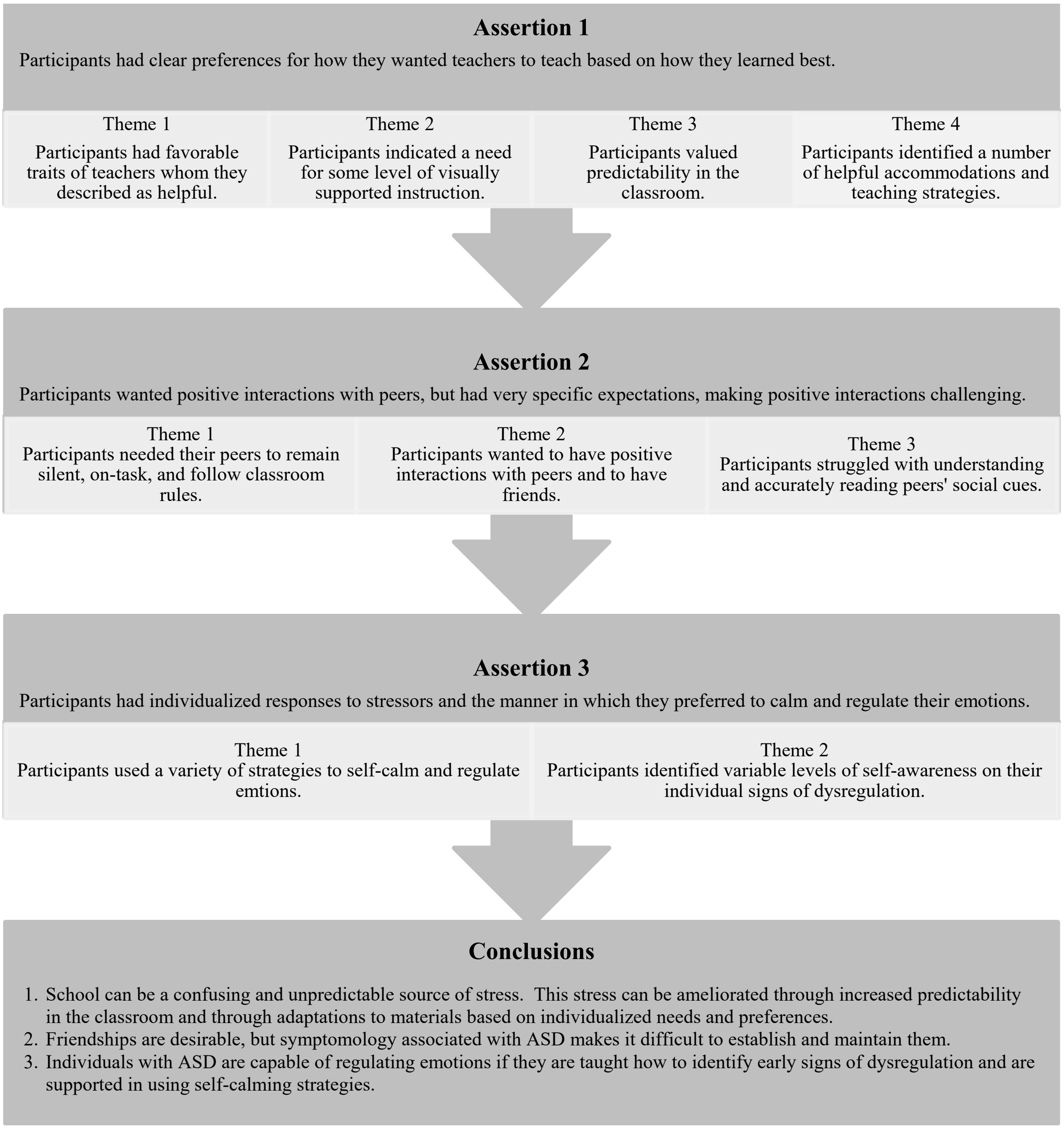
Aligning with the interview protocol, the first table represented a grouping of all meaning units associated with what the participants indicated was helpful and not helpful by their teachers. The second table represented a grouping of all meaning units associated with what participants indicated was helpful and not helpful with regard to peers in class. The third table grouped meaning units related to the use of breaks. All meaning units relative to breaks were placed into one of the following three columns: communicating needs for breaks, activities done during a break, and descriptions of the participants' understanding of the purpose for their breaks. The final tables simply listed meaning units related to noted differences in communication patterns and miscellaneous notes that did not fit best in another table. This process was done to completion for each participant.

Table 1. Sample Data Analysis of Questions One and Two of the Interview Protocol.

List of Meaning Units related to what teachers/peers did that was helpful	Patterns and Emerging Categories (helpful)	List of Meaning Units related to what teachers/peers did that was not helpful	Patterns and Emerging Categories (not helpful)
Participant 1			
Participant 2			
Participant 3 . . .			

After all meaning units were addressed and grouped into the respective tables, the groups of meaning units were analyzed for emerging patterns. Those emerging patterns formed the categories, and subsequently the themes, and later the assertions and conclusions.

The categories identified were the result of meaning units that were seen repeated throughout the analysis in relation to the main questions from the interview protocol (Hycner, 1985). The ensuing categories represented patterns in responses reflecting the essence of the experiences and perceptions of the participants.



Assertion 1

Participants had clear preferences for how they wanted teachers to teach based on how they learned best.

Theme 1
Participants had favorable traits of teachers whom they described as helpful.

Theme 2
Participants indicated a need for some level of visually supported instruction.

Theme 3
Participants valued predictability in the classroom.

Theme 4
Participants identified a number of helpful accommodations and teaching strategies.

Assertion 2

Participants wanted positive interactions with peers, but had very specific expectations, making positive interactions challenging.

Theme 1
Participants needed their peers to remain silent, on-task, and follow classroom rules.

Theme 2
Participants wanted to have positive interactions with peers and to have friends.

Theme 3
Participants struggled with understanding and accurately reading peers' social cues.

Assertion 3

Participants had individualized responses to stressors and the manner in which they preferred to calm and regulate their emotions.

Theme 1
Participants used a variety of strategies to self-calm and regulate emtions.

Theme 2
Participants identified variable levels of self-awareness on their individual signs of dysregulation.

Conclusions

1. School can be a confusing and unpredictable source of stress. This stress can be ameliorated through increased predictability in the classroom and through adaptations to materials based on individualized needs and preferences.
2. Friendships are desirable, but symptomology associated with ASD makes it difficult to establish and maintain them.
3. Individuals with ASD are capable of regulating emotions if they are taught how to identify early signs of dysregulation and are supported in using self-calming strategies.

Figure 1. Analytic Schema depicting summary of results. Three separate assertions with supporting themes combined to form three final conclusions.

This process was completed for each participant in the same manner as referenced above. The emerging patterns of the grouped codes were then copy and pasted into a new table so only the reduced data were being analyzed and referenced at any given time. Once the large list of meaning units had been further reduced into categories, themes emerged. These themes were then grouped together to form larger themes, resulting in three assertions. Assertion one had four supporting themes, assertion two had three supporting themes, and the third assertion had two supporting themes. The three themes resulted in three conclusions. A detailed data trail has been retained documenting the entire process from start to finish.

Validation Strategies/Trustworthiness

In the past, qualitative researchers attempted to use terms aligned with those used by quantitative researchers. At present, the term *validation strategies* is not commonly used in describing qualitative research. Rather, *trustworthiness* is currently the preferred term when describing the degree to which findings are considered credible (Marshall & Rossman, 2011). Each of the strategies used in establishing trustworthiness in this study have been well documented in textbooks on research using qualitative methods (Creswell, 2012; Marshall & Rossman, 2011; Stake, 2010). The follow strategies were employed throughout this study:

- Member checking: Typically, researchers provide participants with transcripts of the interviews to review after the interview is transcribed. Because of the difficulties commonly experienced with people with ASD relative to reading comprehension, regardless of cognitive ability and ability to read fluently (Frith, 2003), member checking was conducted slightly differently during this research. Throughout the interview, the researcher used paraphrasing to clarify and confirm what the participant said. This was done to ensure that the response was understood correctly.

Another technique employed by the researcher was the use of narrated descriptions of the participant's body language and mannerisms along with a possible interpretation of the meaning. For example, when the participant rolled his or her eyes or their face began to flush, the researcher used reflective listening techniques garnered from extensive experience in providing mental health services to note the emotion expressed (e.g., I can tell by your face getting red that it seemed like it bothered you). Participants indicated either agreement or disagreement with the researcher's reflective statement and demonstrated the ability to indicate both agreement and disagreement with the researcher's reflection.

- Data triangulation: Three participants provided educational records to review. In all seven interviews, parents confirmed that participants received special education services due to ASD and met all parameters for participation. During every interview, at least one parent remained physically present. If participants said something that was incorrect, parents were able to interject into the conversation or comment after the interview to make any corrections. No parent felt it necessary to make amendments to what the participants reported. Record review further corroborated information shared during the interview process for three participants. Records reviewed provided information on the supports and accommodations used in the school setting with the participant as well as the types of goals addressed within the Individual Education Plan.

- Searching for discrepant evidence: The manner in which the interview was structured provided numerous response opportunities to similar questions in order to demonstrate consistency in reporting by the participants. For example, participants were asked what his or her teacher did that was helpful and not helpful for every class period identified throughout the school day. The same was done relative to his or her peers in each and every class period across the school day. This allowed for the demonstration of consistent responses to the same question across multiple settings. Any discrepancies in the reporting by the participant would be documented within the transcripts.
- External audit: An analysis of the data was completed on three interviews to determine emerging themes and to ensure the researcher was adhering to the essential principles associated with qualitative data analysis. This analysis was reviewed in detail by the Chair of the dissertation committee. Finding no flaws in the analysis technique and agreeing with the overall emerging themes identified at that point, the analysis was set aside in order to analyze the remainder of the interview transcripts. Upon completion of analysis of all seven interview transcripts, a *white board session* with a colleague experienced in qualitative analysis was conducted. Finding no fault with the processes used in the analysis, the researcher proceeded in compiling and reporting on the results.

Researcher Reflexivity

As a parent of a child who shares many of the same characteristics as the participants in the study, the potential for bias in interpretation remained an ever present reminder to set aside preconceived notions in order to “enter the world of the unique individual who was interviewed” (Hycner, 1985). The potential for overestimating or misinterpreting the strengths and insights by the participants was a valid concern. It is very common for individuals with high functioning ASD to frequently underestimate their level of impairment relative to social deficits (Cederlund, Hagberg, & Gilberg, 2010). Without carefully adhering to the data, it was very possible for the researcher to also over-estimate participants’ competency concerning insights relative to social situations. By using external audit and data triangulation, this potential for bias was further mitigated.

Due to the nature of consultative roles in neighboring geographic regions, the research had some prior knowledge of two of the participants. Having prior knowledge of a participant could potentially bias the analysis and subsequent findings. By using member checks, triangulation, and external audits, the researcher reduced the potential for bias resulting from previous encounters with those participants. Further, by using only the data acquired through this study (record review and interviews) the possibility of prior knowledge tainting interpretation of the data was greatly reduced. This process of setting aside previous knowledge is sometimes called *bracketing* of prior knowledge (Wertz, 2011).

Another assumption to *bracket* included prior knowledge of the literature involving evidence based practices with individuals with ASD in the school setting. Even though there is a growing body of research documenting the efficacy of various supports with adolescents with ASD, it cannot be assumed that those supports were consistently implemented throughout the school day. Nor could it be assumed that they were not. Given the communication difficulties inherent in adolescents with ASD, it was important for the researcher to listen carefully and ask follow up questions to fully determine both the supports provided and the adolescent's perceptions of those particular methods being employed or not. Ultimately, this required remaining cognizant of relying only on the data from the transcripts and documented observations to formulate meaning units, categories, themes, and ultimately assertions. Prior clinical and educational experiences of the researcher were bracketed for the time being during the data collection and analysis phases of the study.

CHAPTER III

RESULTS

"I don't think that you should be rushing kids with ASD. I think that you should give them their time, you know. Because if you're rushing them, and what I mean by rushing is, like, rushing them on homework assignments, you know. You really want them to do their best. And, it's like, if you're rushing them, then you're stressing them out which will cause, you know, your brain to jam." (Ryan)

The purpose of this study was to examine the experiences of adolescents with Autism Spectrum Disorder (ASD) and explore their perceptions of those experiences. Face-to-face interviews were conducted with seven adolescents. All participants were currently enrolled in sixth through eighth grade, received special education services, and were enrolled in a public middle school. Each had a diagnosis of an ASD from a licensed mental health provider, as confirmed by their parent/guardian. All participants lived within 120 miles from the researcher's home located in a Midwestern city with a population of roughly 100,000 people. Three of the participants identified their preference for the pseudoname/fake name to be used in the study. Where applicable, this is indicated in the brief description that follows.

Participants

Introduction of the Participants

Karen. "Karen" was a seventh grade girl. She resided in a predominantly urban community approximately 80 miles from the researcher. Her mother contacted the researcher by phone and the 34-minute interview was conducted over ice-cream, Karen's favorite treat, in a fast food restaurant of her choosing. At the time of the interview, she received most of her instruction in the mainstream classroom with her peers who did not have disabilities with minimal supports provided by the Special Education teacher.

Becky. "Becky" was a sixth grade girl. She resided in a predominantly rural community approximately 100 miles from the researcher's home. The 35-minute interview was conducted in her home. At the time of the interview, she received most of her instruction in the mainstream classroom with additional supports and some instruction provided in the Special Education room.

Jay. "Jay" was a seventh grade boy. He resided in a predominantly urban community shared by the researcher. He and his mother chose to meet the researcher in the public library of their home town. His interview was 29 minutes in length. At the time of the interview, he received most of his instruction in the mainstream classroom with the support of a Special Education para-professional in some of his classes.

Mark. "Mark" was a seventh grade boy. He resided in a predominantly urban community approximately 80 miles from the researcher's home. He and his mother choose to meet in a fast food restaurant while Mark ate supper during the interview. His interview was 44 minutes in length. At the time of the interview, Mark received most of his instruction in the mainstream classroom with minimal supports from the Special Education team.

James Bond1. "James Bond1" was a seventh grade boy. He wanted to choose his own "fake name" for the study. He and his brother both shared an affinity for this pseudoname so they agreed to be designated as #1 and #2 in the results. He resided in the same community as the researcher. The 28-minute interview was conducted in his home. At the time of the interview, he received most of his instruction in a Special Education room with other individuals with disabilities.

James Bond2. “James Bond2” was an eighth grade boy. He wanted to choose his own “fake name” for the study. He and his brother both wanted the same “fake name” so they agreed to be designated as #1 and #2 in the results. He resided in the same community as the researcher. The 53-minute interview was conducted in his home. At the time of the interview, he received most of his instruction in a Special Education room with other individuals with disabilities.

Ryan. “Ryan” was a sixth grade boy. Ryan wanted to choose his own “fake name” for the study. He chose this name because it was his middle name and therefore made the most sense to him. He resided in the same community as the researcher. The 70-minute interview was conducted in his home. At the time of the interview, he received most of his instruction in mainstream classes with minimal para-professional support.

Presentation of Findings

Three overarching themes emerged during the analysis of the data. The overarching themes resulted in three broad assertions. The three assertions were related to learning practices, interactions with peers, and regulation of emotion. Several themes emerged under each assertion, with patterns of participant responses further supporting each. The three assertions with the supporting themes are summarized here:

1. Participants had clear preferences for how they wanted teachers to teach based on how they learned best. Four themes emerged and are delineated below.
    a. Participants had specific, favorable traits of teachers whom they described as helpful.
    b. Participants indicated a need for some level of visually supported instruction.
    c. Participants valued predictability in the classroom.
    d. Participants identified a number of helpful accommodations and teaching strategies.
2. Participants wanted positive interactions with peers, but had very specific expectations of their peers, making positive interactions challenging. Three themes emerged and are delineated below.
    a. Participants needed their peers to remain silent, on-task, and follow classroom rules.
    b. Participants wanted to have positive interactions with peers and to have friends.
    c. Participants struggled with understanding and accurately reading peers' social cues.
3. Participants had individualized responses to stressors and the manner in which they preferred to calm and regulate their emotions.
    a. Participants used a variety of strategies to self-calm and regulate emotions.

b. Participants identified variable levels of self-awareness on their individual signs of dysregulation.

This chapter will present the results of the study in a linear manner, beginning with the first assertion, followed by the second, and concluding with the third. Each theme will be addressed in the same order presented above with the supporting patterns located within the corresponding section of this chapter.

Supporting evidence will include results from published studies intermixed with participant responses from the interviews. The author attempted to report participant responses exactly as they were spoken, in that the author did not alter or fix communication errors made by the participants nor those made by the author. Given that people with ASD have clear differences in the use and understanding of social communication (American Psychiatric Association, 2013), it was determined that pronoun reversals, stammering, stuttering, and unique descriptions were important in understanding the perspective and experiences of the participants.

On several occasions, participants were asked to rate the degree to which actions by others was either “helpful” or “not helpful” to them. One manner that is commonly used with individuals with ASD, is the use a *Five Point Scale* (Buron & Curtis, 2012; Buron & Wolfberg, 2014). This is a strategy intended to be used to help people with ASD more effectively communicate degrees of a situation or scenario and to facilitate self-regulation (Buron & Curtis, 2012). The scale places a rating of 5 as the highest level and a rating of 1 at the lowest end.

The use of a 5-point scale was employed during this study to provide greater insight into the participant experience. When participants in this study appeared to have strong feelings about a situation, or when they had shared similar examples or responses to interview questions repeatedly, they were asked to provide a rating as to how helpful or unhelpful something was. A rating of 1 indicated it was *not at all helpful*, while a rating of 5 indicated it was *very helpful or super-duper helpful*. Variations of this included gesture and demonstration by the researcher to create an impromptu visual during the conversation. In each case, the participants were able to use this simple support to indicate degrees about a particular experience or belief. Some of the participant quotes include some manner of scaling their experiences and perceptions.

Assertion One

Participants had clear preferences for how they wanted teachers to teach and how they learned best. Within this assertion, four themes emerged.

Theme 1

Participants verbalized specific, favorable traits of teachers whom they described as helpful. Four patterns supported this finding. The first pattern was that participants preferred teachers who were fair and consistent with enforcing classroom rules. Three participants indicated that they felt it was “unfair” when teachers punished the whole class because of the misbehavior of some individuals. In particular, they were bothered when they believed their teachers withheld much needed academic help because the rest of the class was “not listening” or was otherwise misbehaving. Jay explained, with a scowl on his face as he shook his head and rolled his eyes:

> But now that everyone won’t shut up, we have to make our own notes from scratch, from-from, lined pieces of paper. . . . There is usually a review game but since people weren’t being quiet, we’re not doing that anymore either.

Mark was more forceful in proclaiming his dislike for teachers acting in an unfair manner as he exclaimed, “one student does something bad she’ll [the teacher] give the punishment to the whole class. I really hate that so much.” The way that teachers responded to misbehavior in class impacted the relationship that participants described with those teachers. The need for positive relationships between teachers and students has been well documented as a predictor of student success (Burchinal, Peisner-Feinberg, Pianta, & Howes, 2002; Hughes et al., 2012). This was substantiated and evident in the data from this study.

The participants in this study indicated a need for having consistent rules so they knew what was expected of them in school. Universally, they did not want to “get into trouble” with their teachers at school. James Bond2 rated inconsistent rules as causing a moderate level of difficulty. In a specific example, he stated:

> You see, the reason I say a 3 [on a 5 point scale] is ‘cuz – also – they don’t want me running in the halls, but the teachers upstairs don’t care if I run down the hall – then back [coupled with sarcastic voice tone but with furrowed eyebrows and a shoulder shrug]. On the third floor they don’t care. It’s like, okay run kid run! It’s like bad for me.

Hedges et al. (2014) asserts that when classroom rules are inconsistent, they are not only viewed as unfair, but are potentially confusing to individuals with ASD. This is likely related to the struggle experienced by people with ASD in understanding subtle nuances within communicative intent (Happé & Frith, 2006) and the strong need for sameness that is part of the diagnostic criteria for ASD (American Psychiatric Association, 2013).

The second pattern was that participants preferred teachers to communicate in ways that were calm, quiet, direct, and clear. Several participants described their teachers as “yelling” or “screaming” in class, particularly when trying to maintain order in the classroom. Mark described how he felt when a teacher “yelled” saying, “It’s not very cool to do that to someone. … I really don’t like that. Even if there was a … even if you could scream at the teacher, which you can’t … I wouldn’t.” When clarification was sought whether it was bothersome because the volume was too loud or if it was hurtful inside or to his feelings, he indicated it was “hurtful inside” to feel that a teacher was “yelling” at him. Karen stated she did not like it when teachers “talked loud” or “yell[ed]” in class. She pointed to one teacher in particular whom she described as “nice” because “she never gets mad” and speaks “softly.” James Bond1 and Becky both described teachers who raised their voices as “mean.” Ryan did not describe teachers as mean but did point to one of his favorite teachers as “kind and nice” because she “doesn’t get angry at us when we mess up.” Karen provided an excellent description of what her teacher does that is helpful to her in saying, “she’s a nice teacher, she never yells, never gets mad … talks softly.” Additional descriptors used by participants to describe unhelpful teacher actions included talking too fast and using words they did not understand.

Individuals with ASD struggle with making sense of emotions in others, regardless of her or his intellectual functioning (Uljarevic & Hamilton, 2013). This, combined with the social communicative deficits associated with having a diagnosis of ASD (American Psychiatric Association, 2013) make it challenging to understand the intent of the person with whom they are interacting. Further, it is estimated that 63% of youth with ASD have impairing levels of anxiety, even though symptoms may not always present in a manner consistent with diagnostic criteria for an anxiety disorder (Kerns et al., 2014). Social anxiety disorders are known to peak in adolescence (Happé & Frith, 2014). Whether due to social communication deficits or anxiety driven fear, the participants' perceptions of their teachers speaking with raised voices to correct behavior, even of others in class, or to gain the attention of the class was perceived as "yelling." There is also some evidence that these actions potentially hurt the participants' feelings, thereby negatively impacting the student/teacher relationship.

The third pattern was that participants placed value on the teacher being organized, maintaining order in the classroom, and being ready to help when needed. The reasons provided and context with which the participants placed value on these provided a deeper understanding as to the reason why these were important to them. While the majority of participants said they felt comfortable raising their hands to ask the teacher for help when they had a question, several participants indicated it was important for the teacher to be able to notice when they needed help on school work. Becky explained “so like if I need help, he’ll [the teacher] just come to me.” She did not always raise her hand to ask for help and assumed the teacher “knew” when she had a question. James Bond2 valued teachers who helped him when he had a question, but stated that he sometimes “does not have the courage” to ask the teacher for clarification when he is confused. This response has been substantiated in school settings, where individuals with ASD did not always ask for help when they needed it from the teacher (Constable, Grossi, Moniz, & Ryan, 2013). The precise reason for this is unclear, but the fore mentioned authors point to deficits in the ability to understand the perspective of others as a contributing factor. The ideals of the teacher being organized, maintaining order in the classroom, and being ready to help when needed align with recommendations for effective teaching practices throughout the literature base (Diehl & McFarland, 2012; Emmer & Stough, 2001; Gordon, 1997; Kounin & Sherman, 1979).

Every participant indicated a need for the teacher to maintain order in the classroom so that peers were not disrupting the class, making it difficult for them to pay attention. Participants shared a common sentiment and explanation for why it was important to them that their teachers maintained order. Universally, they reported they “could not pay attention” or “could not focus” when peers were talking while the teacher was talking or during silent work time. James Bond2 pronounced that disruptions from other students impacted him so significantly that it influenced his request for classroom placement. He concluded his explanation with “…and that is why I didn’t want to be in that advisory [a homeroom type class] this year.” In addition to the disruption to his focus, he also brought up concerns about “bullying” by peers in certain school-based settings more than others.

Bullying was a concern shared by several participants. While Becky denied being bullied herself, she did express concerns about it occurring in locations such as the playground. She viewed the teacher as playing a role in ensuring that people “didn’t bully.” James Bond1 shared similar concerns over bullying with James Bond2. James Bond1 explained that it was particularly frustrating when bullying resulted in the “wrong person getting into trouble.” He believed that his teacher did not always pay attention to what was happening in the classroom and offered this explanation:

> Well, we talk about bullying and that but she [pronoun error made by participant] doesn’t really care about bullying obviously because he doesn’t stop the bully.

Yoon and Bauman (2014) examined the importance of the teacher’s role on classroom bullying, specifically the leadership role teachers have in setting the stage for expectations, responses, and modeling of appropriate and respectful behavior. When the teacher does not exhibit organization and maintain order, one unintended consequence can be increased bullying.

The fourth pattern was that participants indicated that having a relationship with their teacher mattered to them. Participants indicated a desire to have a positive relationship with their teachers. Ways in which they thought this was demonstrated was through shared jokes about their special interest areas, if the teacher helped them when they needed help, and if the teacher was able to respond to them in a way that was calming and reassuring. Jay valued a postcard from his teacher saying that he was "doing extremely good" in class so much that he brought it up twice during the interview. Both Karen and Ryan spoke fondly of teachers with whom they had positive relationships, calling them "nice." Ryan expanded on this, calling one teacher in particular "nice" and "supportive." When asked if there was anything she wished her teacher did differently or anything that was not helpful, Karen was reluctant to say anything. After she was reassured that her teacher would never hear the interview or know it was her, she provided examples of things she wished were different with her teachers. James Bond1 demonstrated a negative affect through his voice tone and rolling his eyes when describing a specific teacher for whom he had numerous examples of things the teacher did that was "not helpful." Also, most participants indicated a desire to be viewed as smart by their teacher.

Every participant demonstrated a strong inclination to view their teachers as either "helpful" or "not helpful." Specifically, when participants provided examples of things a particular teacher did that was helpful they did not have any examples of things that the same teacher did that was not helpful or that they "wished the teacher did different" and vice versa. Every participant followed this pattern in describing his or her teachers for every class throughout the school day. Every participant described each teacher as doing things in class that were helpful or not helpful or described a teacher as either "kind/nice" or "mean." Individuals with ASD frequently have what is known as "black and white thinking" (Gobbo & Shmulsky, 2014) which coincides with diagnostic criteria for ASD (American Psychiatric Association, 2013). The view of a teacher being categorized as "helpful" or "not helpful" without elements of both being present is an example of black and white thinking.

Experiencing conflict in the teacher/student relationship was stressful to the participants. Jay described one teacher as "usually not helpful" because she "doesn't help me in that class." He said "everything" was hard about the class and had nothing to add that the teacher did that was helpful. Ryan provided an example of when his relationship with his teacher was stressful until his academic team met to discuss his needs and openly address the perceived conflict. He explained:

> Well, she was definitely a lot more kind to me, you know. She is definitely kinder. Is kinder a word? … [After being asked "What changed?"] … Her point of view about autism … she understood what I was going through. … And, you know, that changed how she saw autism. It was like a new dimension of autism for her, you know. And, um, I think that really helped other kids in the class, too.

Difficulty in the development of a positive teacher/student relationship is purported to be influenced by a lack of knowledge, preparation, and support to general education classroom teachers (Lindsay et al., 2013). Most of the participants spent the majority of their school day in general education classrooms.

One aspect of positive student/teacher relationships that emerged was the sharing of the participant's special interest, especially when combined with humor. Mark relayed the following example while laughing and appearing to replay the interaction through pantomime about a teacher whom he described as "nice:"

> …there was a NASCAR race that was postponed that they had to do on Monday…and I told [teacher's name], like, what are you gonna take when we get [go] to the library? … Just left turns? … All left turns?

James Bond2 also enjoyed teachers who made jokes related to the subject matter. Ryan shared this sentiment as he relayed a story about a teacher whom he found "amusing" and called a "joker," saying, "she loves to joke with kids and is very, she's very fun." The examples provided by participants incorporated either the subject in the classroom or an event in the classroom. Sometimes, the jokes related to the participant's special interest. Special interests are sometimes referred to as *perseverative interests* (Carnett et al., 2014) and are thought to be part of the diagnostic criteria for ASD (American Psychiatric Association, 2013).

Oftentimes, it is challenging for teachers to develop a warm teacher/student relationship with individuals with ASD (Blacher et. al., 2014; Eisenhower, Blacher, & Bush, 2015; Lindsay, Proulx, Thomson, & Scott, 2013). Teacher/student relationships with students with ASD have been characterized by less closeness and more conflict compared to students with intellectual disabilities and those without any disabilities (Blacher et al., 2014). The importance of relationships between teacher and students has been well documented (Blacher et al., 2014; Burchinal et al., 2002; Hughes et al., 2012; Ruzek et al., 2016; Wang, Brinkworth, & Eccles, 2013). The responses from participants in this study align with those findings.

Theme 2

Participants indicated a need for some level of visually supported instruction. Three patterns support this finding. The first pattern was that participants needed teachers to write down instructions, write down notes, and refer to written materials when providing an explanation. Every participant in this study addressed support for this in some manner by indicating a desire or need for these supports. Visually supported instruction, including the use of written schedules, is well documented as an evidence based practice for individuals with ASD (Hall, 2013; Knight, Sartini, & Spriggs, 2015; National Autism Center, 2015; Wong et al., 2013).

Participants each identified things that the teacher did that were *helpful* and *not helpful* (or things they wish the teacher did differently) in each class over the course of his or her school day. Consistent across all participants over the course of every single class during their school day, every one of them indicated that it was helpful for the teacher to write the schedule on the board every day. The participants also needed their teachers to write down instructions and notes so they knew what to do. Specifically, participants needed their teachers to write page numbers for assignments, write instructions for assignments, and list what to do along with the order in which the assignments should be completed. Difficulties with planning and organizing are thought to be related to deficits in executive functioning, which are quite common in individuals with ASD (Blijd-Hoogewys, Bezemer, & van Geert, 2014; Endedijk, Denessen, & Hendriks, 2011; Robinson et al., 2009). Even with no intellectual disability present, individuals with ASD frequently struggle with executive functioning (Robinson et al., 2009). Regardless of the level of cognitive functioning, individuals with ASD share executive functioning deficits specifically in the areas of planning and organizing, initiating, working memory, and monitoring (Blijd-Hoogewys et al., 2014).

Further substantiating this need were the observations of the participants throughout the interviews. Every participant closely referenced the co-constructed written schedule guiding the interview protocol. When asked how helpful the written interview schedule and protocol were, participants indicated they were moderately to extremely helpful (rating between 3 and 5 on a 5-point scale). More telling was that each participant monitored the written interview schedule closely, often needing to cross off items as they were completed during the interview. When the researcher did not cross off an item on the schedule during the interview, two participants indicated the need for items to be crossed off with Jay prompting, “aren’t we going to cross these off?” The participants also used the interview schedule to guide their discussions and the timing for when they opted to discuss certain aspects of their day and when they were done talking about subjects that were more stressful to them.

The second pattern was that participants sometimes needed teachers to use a visual to support an explanation, specifically by providing a visual model or demonstration. The participants in this study identified specific preferences and needs relative to the use of visually supported instruction. Karen found it helpful when her teacher modeled a demonstration projected from the computer onto the wall. When asked which he finds more helpful, Ryan responded, “the visual presentation.” Becky stated it was helpful to her when her teacher worked math problems on the board. James

Bond1 indicated a preference for a live model by his teacher as opposed to a recorded or video model. He explained how he preferred a demonstration by his teacher in music class. Regarding the use of a live model, “it is actually real music… you can actually hear the real sound of it, like the full sound,” he explained. James Bond2, who shared a number of classes with James Bond1, had clear preferences for live modeling for social skills instruction for completely different reasons. He indicated that the video model examples were “boring.” Upon further examination, it became apparent that the videos used in his eighth grade social skills class were intended for a much younger audience. While modeling is considered an evidence-based strategy (National Autism Center, 2015; Wong et al., 2014), Marshall and Tragni (2015, p. 59) advised, “it is important that we make scenarios as real and age appropriate as possible in order to equip our youth to be truly socially prepared for any social interaction.” Whether due to lack of knowledge, preparation, or support (Hedges et. al., 2014), it is a frequently occurring issue that teachers are not implementing evidence-based practices with fidelity (Stahmer et al., 2015).

Most of the participants were able to catch on very quickly to the use of number-based scales to communicate the degree to which they perceived an experience. In particular, the use of a *5-point scale* (Buron & Curtis, 2012) was used to ask participants about their perceptions and experiences of various phenomena during the interview. Not only did participants use the scale to communicate perceptions, but each indicated how having things written down for them was moderately to very helpful. This was demonstrated by ratings between 3 and 5. The descriptions provided to participants by the researcher were 1 to 5, with 1 being *not at all helpful* and 5 being *super-duper helpful/very helpful*. Other variations of this were noted when the researcher used hand gestures to indicate a range, and some participants responded by pointing to the researcher's hand that symbolized his or her range of responses.

The participants demonstrated individualized methods for visualizing and expressing their thoughts. James Bond2 frequently looked to a blank wall when describing experiences. This was often coupled with pantomime and gestures consistent with describing a mental image of what had occurred. This was verified by directly asking him to verify or refute the accuracy of the researcher's observation. Ryan described how he mentally visualizes what he is reading:

> See like, I was reading *The Giver* today and, um, it was talking about, like, the area that he was in. … And……hmh - I couldn't imagine that if I was reading, but since I was listening to my audiobook and following along I could definitely see the grass waving by the wind and the sun blasting down. You know. It's, it was very, it was very cool because I've never really connected like that with a book before. So this audiobook is really helping me out.

This is a phenomenon that is frequently but not universally described by others affected by ASD (Grandin, 1995; Kunda & Goel, 2011).

The third pattern was that participants needed to be *shown* what to do, rather than just being *told* what to do. Each of the participants specified a clear preference for being shown what to do by their teacher, compared to only being told what to do. Specifically, they each indicated that having the teacher write clear instructions on the board, working problems on the board or smart board, and providing a demonstration were helpful strategies to them. Jay provided an example of something that he still does not understand. His teacher only provided spoken information and did not use any visuals to support the explanation. James Bond1 found it helpful when his teacher "tells us and shows us, um, she like tells us about the rules and then shows us." He further explained his teacher was "helpful with projects, they show it on the board - how we do it." Karen reported it was helpful to see demonstrations by her teacher, but sometimes could not see the demonstration because of her seat placement and she did not always feel comfortable asking to move.

The participants specifically identified being able to see and hear the teacher providing the model or visually supported explanation as a need. Competing noises were another issue that caused difficulty for all participants. Ryan, who has no problems with hearing acuity, explained:

> … I have some hearing issues, you know. Um, but it's not too bad, um, it's just when there's other noises going on, like loud noises - it's hard for me to hear people. Like even when someone else is talking over there - it's hard for me to hear you. … Because I'm trying to, like, listen to that person and listen to you at the same time … so like half of my brain is on that person and the other half is on you.

Elwin et al. (2013) found that individuals with ASD were unable to focus when more than one conversation was occurring because of problems with knowing where to direct attention. This coincides with research demonstrating that individuals with ASD have atypical processing when presented with both auditory and visual input, but less difficulty when presented with visual input only (Stevenson et al., 2014).

Theme 3

Participants valued predictability in the classroom. Specifically, participants needed to know what was going to happen each day in class. Three patterns emerged in the manner in which they stated this should be accomplished. The first pattern was that participants valued a predictable routine in class every day. All of the participants demonstrated this through a strong preference for teachers to have predictable routines in the classroom. Each identified having predictable routines in class as helpful. Examples provided by the participants included having the same sequence of activities every day in class, having the schedule written on the board every day, and being given a warning when the schedule was going to change. Every participant indicated in some manner that this was something the teacher did that was helpful. This need for sameness is well documented in individuals with ASD (American Psychiatric Association, 2013).

The second pattern was that participants preferred teachers to write the schedule on the board each day in class. All of the participants in this study indicated strong preferences for the schedule to be written on the board every day in each class. Karen demonstrated just how important it was for the teacher to either have a predictable schedule or to write the schedule on the board by indicating that it was a 5 on the 5-point scale (with 5 being *very helpful*). Other participants had clear preferences in needing the schedule or instructions written on the board every day in class, especially when there was going to be a change in the routine. Mark described his teacher as "nice" when she wrote the schedule with the date on the board every day.

The third pattern was that participants indicated a need to be informed of any upcoming schedule changes. Participants indicated a written schedule was more necessary on days where the schedule was changing. James Bond2 rated the importance of having a written schedule as more important when there was going to be a change such as a field trip by saying, "if we go on a bunch of field trips and all that, whew! That's gonna be something." Becky rated the need for being informed of upcoming schedule changes as a 5 on a 5-point scale. Ryan was very bothered when he felt teachers "sprang changes on him" and found a way to work the following statement into the interview protocol by physically adding it to the written schedule/interview protocol:

> Now there's something I really wanna talk about, something that I wanna get off my chest…instead of taking away our [school specific study hall name], because I don't think that-that's fair to take away our time. …
> Then I would be able to plan, you know. Then, then I would know, okay, so, I can't use [school specific study hall name] as a time for homework. Usually I just get my homework done, um, after school, because I don't rely on [school specific study hall] because at home I have all the time I need.

Ryan, Karen, and Becky placed a high degree of importance on knowing what to expect and what to rely on every day in class. Ryan expanded on this, explaining that he found it “very stressful” when he felt that schedule changes occurred without warning. Abrupt or unplanned schedule changes were difficult for the participants.

The use of written and visual schedules to increase predictability in the classroom is not always considered a necessary support for middle school aged adolescents with high functioning ASD (National Autism Center, 2015). Other researchers, however, place visual schedules under the broader category of visual supports which have been classified as evidence based for adolescents with ASD (Wong et al., 2014). Although there is some discrepancy in the level of evidence necessitating this type of support for adolescents, the participants in the current study universally rated the use of visual schedules in class as “helpful” to “very helpful.”

Theme 4

Participants identified a number of helpful accommodations and teaching strategies. Six patterns support this finding. The first pattern was that most participants indicated that homework was stress inducing. Mark indicated that homework caused him worry and Ryan declared homework was “very stressful.” Ryan stated:

> Um, homework is very stressful on me. Like, if they pile up a lot of homework then, um, let’s say I have an anx- … an anxiety level from scale 1 to 10. Um, if they pile up a bunch of homework on me, then my anxiety level would probably be a 9 or a 10. Because then I’m super stressed. [Researcher clarified that 10 was the highest] …Yeah. Well, actually, it’d be an 8.

Individuals with ASD experience difficulties in inhibition, emotional control, initiation, working memory, planning and organizing, and monitoring (Blijd-Hoogewys et. al., 2014). Those with ASD also exert considerably more effort in the physical aspects of completing homework, namely handwriting (Fuentes, Mostofsky, & Bastian, 2009; Fuentes, Mostofsky, & Bastian, 2010). Many times, individuals with disabilities need specific accommodations in classes to perform to the utmost of their abilities. Accommodations are specific legal protections afforded to individuals with disabilities under the law (Individuals with Disabilities Education Act, 2004). The participants in this study identified five specific strategies, or accommodations, their teachers did to help them with homework.

Teachers allowed extra time to complete assignments. Several participants shared frustrations in feeling as though he or she worked “slower” than their peers. James Bond2 and Karen indicated that writing fast was a challenge for them and slowed them down in getting homework completed. When comparing himself to his peers, Ryan summed up his experience well in exclaiming, “I can’t finish this whole mathematics project in 30 minutes…it’ll take me an hour.” Mark “wish[ed] the teacher would give us more time to do things…so we could finish all, finish it all without being worried.”

Teachers reduced the number of problems required to demonstrate understanding. Participants said it was very stressful to them when they had “a lot of homework” that was all due within a short time frame. Ryan explained a time when he was overwhelmed by the number of assignments given at one time by multiple teachers and how he solved it by telling his teacher, “I can’t finish all this, like I have homework in science, I got reading in language arts, I've got all this, whole spiral packet in mathematics. I don't know if I can do this all in one night." Jay describes homework as "very stressful" and it was noted in his Individualized Education Plan that his teachers can reduce the number of problems he is required to do. In the same document, it was noted that he has moments of "tearing up" when he feels "overwhelmed" by his homework. At one point during the interview, Jay's eyes teared up when talking about needing more help in class than he received. Ryan explained that it was helpful when his teacher checked in with him after class to ensure that he could manage the number of problems assigned. He concluded with saying: "she'll always make sure that I'm comfortable with the amount of work that I have." In another example, he shared that even though he has permission to do less problems than his peers, he strives to do all of the work. Karen, Ryan, and Jay were each motivated by not disappointing their teachers. While accommodations related to reducing the workload was viewed as helpful by participants, the implementation of this accommodation may be potentially complicated by the documented difficulties frequently faced by individuals with ASD in asking for help from their teachers (Constable et al., 2013).

The school day was structured to provide a study hall or work time during the school day. The reason for viewing study hall as a support were two-fold. They wanted to be able to seek extra help from their teacher during a study hall or work time in class and they wanted to avoid having homework to complete at home. Jay, Ryan, and Mark reported that homework was stressful to them so having time to work during the school day reduced their stress level. Karen reported that she usually tries "to finish up as much homework" as she can during her study hall with her special education teacher so she does not have to work on it at home. Unlike their peers without ASD, the participants viewed work time during the school day as a time to do work and get help from the teacher. Ryan wanted to be able to consistently count on time during study hall to get homework done and expressed frustration when peers used study hall as "social hour."

Teachers allowed the use of a scribe. A scribe is someone who performs the duties of writing for another person. Karen described that writing in class "makes her hand hurt" and James Bond2 believed he "writes slower" than his peers. Ryan thought it was more important to have the ability to use a scribe when he had "a lot of homework" or when he was "stressed." There is some empirical evidence that has indicated that writing is somewhat more laborious for individuals with ASD (Fuentes et al., 2009).

Teachers allowed the participants to relate an assignment to his or her special interest. Participants did not state that this was a need, but clearly attributed positive affiliation with classes and teachers when they were allowed to relate an assignment to his or her special interest. Becky spoke in longer phrases when talking about a class where she was doing school work that was related to horses, her area of special interest at the time of the interview. She indicated a strong preference for reading books related to her special interest areas, adding that she was a "good reader." James Bond2 shared how his teacher allowed him to relate an assignment to the Civil War, even though the rest of the class had moved on to a new topic. He spoke at great length and with pride about that particular assignment when discussing what his teacher did that was "helpful" in class. Jay also indicated that it was helpful when he could relate an assignment to a topic he really likes. The integration of special interests in academics has been demonstrated to be particularly motivating to individuals with ASD (Carnahan, Williamson, & Christman, 2011; Gobbo & Shmulsky, 2014).

The second pattern was that participants viewed technology as helpful in completing school work. There were four specific uses of technology identified by participants. The first manner in which participants described technology as helpful to them related to the organization of class materials. Both Mark and Karen found it helpful when their teachers shared resources and information digitally using a computer. Karen, noted that she finds the digital organization of class materials more efficient and effective for her, adding, "I wouldn't have to dig out for anything. It's just right there on the screen." She also preferred cloud-based document sharing with her teachers saying that she sometimes "used to lose" important papers. Organization of materials and working memory are known deficits for individuals with ASD (Blijd-Hoogewys et al., 2014).

Several participants expressed strong dislike for handwriting. This applied to note-taking as well as completion of homework. There are multiple methods to compensate for the need to write during the school day. The participants identified two distinct ways to reduce the difficulties they experience with handwriting. Karen and Jay both preferred to type assignments and notes. Jay identified a preference for typing his work, saying, "I like computer drafts… you gotta write it [notes in class] down. You have to write down five sentences per question…I don't like to write." While typing can be a helpful accommodation for some, it can create barriers for others. For Ryan, typing poses challenges because he believed he types slower than his peers. Becky preferred voice to text software. When asked to rate on a scale of 1 to 5 how helpful this form of technology was for her, she gave it a rating of 5 (*very helpful/super-duper helpful*) because she "hates writing." Fuentes et al. (2010) advised teaching individuals with ASD to overcome or compensate for difficulties in handwriting due to motor control deficits.

Ryan advised that teachers should allow audio books because "with an audio book, reading is at a stress level of 3 and without the audio book, it is a 9, easily." He repeated himself, stressing, "now, without the audiobook, I'd be like. This - This would be a 9. Easily." Becky indicated that it was helpful when her teacher reads to her because she can determine the answer to questions more easily. It is generally agreed upon by professionals and researchers that individuals with ASD share in their struggles with reading comprehension (Carnahan & Williamson, 2013; Fluery et al., 2014). Reading difficulties shared by individuals with ASD are not necessarily coupled with difficulties in reading fluency (Carnahan & Williamson, 2013).

The third pattern was that participants identified specific teaching strategies and supports they believed were helpful. There were a total of 10 specific strategies and academic supports identified by participants as being helpful to them.

Teachers broke content down into smaller learning units. Participants explained that it was helpful when their teachers broke concepts down so they were more understandable. Becky, James Bond1, and James Bond2 each found it helpful to get extra help from their special education teacher when they did not understand a concept. Karen provided an example of a specific practice done by one of her teachers that she thought was particularly helpful. Her teacher folded a large piece of paper and wrote notes in certain locations on the paper to illuminate the relationships between the content. This method of making connections visually clear is supported by Carnahan and Williamson (2013) who recommended using strategies such as Venn Diagrams to show patterns in written text. Direct systematic instruction has been identified as a common practice for explaining concepts that are otherwise difficult to understand by students receiving Special Education services (Donaldson & Zager, 2010).

Participants were supplied written copies of notes or outlines. This included both copies of teacher notes and outlines as well as the use of peers' notes. Jay described writing as "tons of work." He said his teacher used to provide him with copies of notes but does not do so any longer because of peers' behaviors. He expressed great frustration over this and did not believe it was "fair." James Bond2 appreciated when peers shared notes with him, explaining, "depending on if they write faster, then I just bum and let them write…so then I can just copy it down. Cuz, some kids – I just cannot keep up with." Note taking in class is frequently difficult for individuals with ASD both due to the motoric demands associated with writing (Fleury et al., 2014) as well as the difficulties experienced in identifying what is important to write down due to a weak central coherence (Happé & Frith, 2006).

Teachers identified what was important to know. Specific strategies participants identified as helpful to them included study guides, practice tests, and review sessions during class. James Bond1 explained that his teacher was helpful when "she helps us like, with practice, and the like, tutorial, like helps us set up questions." This view was shared by Jay who said it was helpful when his teacher did review games and provided review sheets before tests. Without them, he was worried about what was important to study. Becky reported it was helpful to her when her teacher read content aloud so she could figure out the answers more easily. Determining what is important, or the main point, is difficult for individuals with ASD (Frith, 2003; Gobbo & Shmulsky, 2014; Happé & Frith, 2006; Knight & Sartini, 2015, Williamson, Carnahan, Birri, & Swoboda, 2015). This is generally believed to be the result of weak central coherence (Happé & Frith, 2006). Individuals with ASD need explicit instruction in order to learn new skills (Fluery et al., 2014).

Teachers gave hints and helped participants get started on work. Mark found it helpful when his math teacher provided “hints” on how to do problems. He explained that his teacher did problems “on the board. She’ll give us like work and then she’ll take it down to the last step and then we’ll be able to figure out the answer easier.” He expanded on this by saying he likes when his teacher “gives us… like if we’re doing like some tools online, he’ll get us there. He’ll give us the websites to do, then he’ll give us all the basic things that we need to do - so we know how to do it.” Becky appreciated her teacher helping her if she “got stuck on it [a problem/assignment], the teacher will help you.” Individuals with ASD often need supports and scaffolding in order to get started and make sense of school work (Williamson et al., 2015). Because of deficits in executive functioning, individuals with ASD frequently struggle with starting tasks (Blijd-Hoogewys et al., 2014).

Teachers used multiple ways and easier language to explain concepts. Karen wished that her teachers would “slow down” when explaining certain concepts in class. Ryan described how he sometimes needed his teachers to explain concepts “multiple times” before he understood. Like other participants, he did not always feel comfortable asking his teacher for help, especially if it required several explanations. Ryan contended that it can be helpful when teachers explain a difficult concept in a “common sense” way. He provided an example of a situation where he did not understand the concept of kinetic energy in Science class: “with kinetic energy, she’d be like, um, ‘so with the particles did they get faster or did they get slower?’ and I’d be like – oh, that’s an easier one. They get faster if they’re heating up.” James Bond1 indicated a strong preference for the use of more “hands on” learning activities. The use of hands on, concrete teaching techniques is empirically supported for individuals with ASD (Bouck, Satsangi, Doughty, & Courtney, 2014). Social communication deficits are a core deficit area for individuals with ASD (American Psychiatric Association, 2013). This makes it challenging for people with ASD to fully and consistently understand what is being communicated to them by others. This is true for all individuals with ASD, regardless of his or her level of impairment or intellectual functioning.

Teachers provided clear instructions. Several participants demonstrated very literal interpretations of questions and comments posed to them during the interview. For example, when setting up the interview protocol and constructing a schedule of her school day, Becky responded in a very literal manner to a question posed to her. After listing each class period in order, she was asked, “where is lunch in there?” while the researcher pointed to the co-constructed schedule. “In the lunch room,” she responded quite seriously. Mark relayed an experience where he needed much more explicit instruction than his teacher had assumed he required. He explained that when working on the dissection of a frog, he led his group because he was the only one willing to touch the frog. He found all but one structure in the frog, the brain. He explained the brain was not explicitly covered by his teacher or found on the study guide his teacher distributed. Individuals with ASD need explicit instruction (Fluery et al., 2014) and the participants in this study stated and indicated that they needed to know exactly what to do.

Teachers offered feedback and the opportunity to fix mistakes on assignments. Mark believed it would be helpful to him if his teachers allowed him to fix his mistakes after he had received feedback. He expressed concern over getting a bad grade because he did an assignment wrong. Several participants provided responses throughout their interviews that, at first blush, could seem tangential. Only at the end of his or her long monologue was the main point of the example being provided made clear. Other times, participants provided significant levels of detail in a response that did not fully address the question. Individuals with ASD, frequently struggle with identifying the “main point” (Barnes & Baron-Cohen, 2012; Gobbo & Shmulsky, 2014). The apparently tangential responses to questions posed provided evidence for how the participants could spend considerable effort and time on an assignment yet miss the main points sought by the teacher, subsequently earning a poor grade.

Teachers incorporated internet based resources for review outside of class. Mark found it helpful when his teacher directed him to content such as videos and other materials online to aid understanding. Several participants described computer programs and applications used to aid studying. They did not necessarily view those programs and applications as particularly helpful. There was some evidence that the teacher's role as helper and educator was diminished when there was extensive use of such programs and applications. James Bond1, James Bond2, and Becky did not identify anything their teacher did that was helpful when the majority of instruction, review for tests, and assignments were completed using digital media. In some instances, they could not provide any examples of things the teacher did that was helpful. There is growing evidence for the use of *flipped designs* for classroom instruction in middle and high school (Cargile & Harkness, 2015). A flipped design is one in which content is viewed independently by a student so that time spent in the classroom focuses on individualized support from the teacher. Similar to the findings by Cargile and Harkness (2015), not all of the participants' teachers were reported as implementing the method of with fidelity.

Para professional support was available for additional help in the classroom. From the perspective of the participants in this study, paraprofessionals were important to them so they could easily access adult support and feel successful in the classroom. Without this support in place, Jay illuminated his frustration by saying the "teacher's not usually helpful… sometimes I gotta do the work and [paraprofessional's name] doesn't help me in that class." He added that "everything" is "hard" about that class in particular. Ryan needed the paraprofessional to read aloud with his small group so he could keep up with his peers in reading assignments. He also wished there was paraprofessional support in each of his classes, adding, "cause I kinda need a teacher helper just in case, like, things get rough, you know. And then, um, the teacher could continue on teaching…or if I just plain out need help and the teacher's far away." Teaching individuals with ASD is not easy. One way that schools support students with ASD in mainstream classrooms with their peers is to place educational assistants, or paraprofessional educators, in the classroom along with a licensed teacher. This support is believed to be integral in supporting individuals with ASD, especially those with high functioning ASD, in the mainstream classroom (Lindsay, Proulx, Thomson, & Scott, 2013). A mainstream classroom is one in which the class is intended for and populated primarily by students without disabilities. It is generally taught by a licensed teacher rather than a licensed special education teacher.

When requiring group work, the teacher placed students in specifically chosen work groups. When discussing group work, several participants reported they preferred to work alone. The reasons the participants in this study provided included not wanting to be paired with bullies, not wanting to be paired with people who do not do their share of the work, and preferring to do the work the way they think it should be done to earn a good grade. Mark summed up his views on group work by saying:

> I get paired with bullies and they don't know. All they do is just go to netbook and play games. It's so…. [frustrated voice tone and sounds] I would wish that we could do our activities by ourselves…. cause they don't have to get a, I don't care if they don't get it right, I don't care if they do back on em…. Cuz they're not going to help…and that's not fair.

> … I think my teacher thinks it’s a bad thing if you have to start over by yourself, but I think that would be a good thing for me.

James Bond2 preferred to work alone because he “just want[s] to get it all…good and situated.” Jay stated that group work was distracting and preferred to work alone, even when his teachers thought it was more work for him to do so. “We’re working in groups now. And that, um, they [peers] distract me,” he declared. He shared this view with several participants. Regardless of the reason provided by participants, it remained clear that they preferred to work alone instead of in groups with peers. Adults with ASD in college settings share this sentiment as they also appear to prefer to work alone instead of in groups (Gobbo & Shmulsky, 2014). Social interactions between adolescents are difficult to navigate even for those without any form of disability, but for those with ASD, the complexities of group interactions are multiplied (Happé & Frith, 2014).

The fourth pattern was that preferential seating assigned by the teacher was identified as helpful. Several elements were thought to contribute to the efficacy of this practice. Participants identified four specific strategies that their teachers did that they considered helpful.

Seated in a location where it is easy for the teacher to help them. Becky and Ryan indicated a clear preference for sitting in a location where the teacher was close to them. This usually meant being seated at the front of the class. Another placement indicated as helpful was being seated at the end of a row of desks. Participants indicated various reasons as to why they found it helpful, but each indicated it was helpful that their teacher could easily come to help them if they had questions. Jay indicated he needed the additional support of having a paraprofessional available in each classroom to help him. Becky thought it was helpful that she was placed in a seat next to the teacher, but did not fully realize the intentionality of her seat placement by that teacher. When asked why the teacher put her in the front row, she responded, “because that was the only desk that was open.” Becky, James Bond1, and James Bond2 each spent time in a small group setting in the Special Education room for instruction and to receive additional academic supports. While Karen indicated she was comfortable raising their hand to obtain help, Becky believed her teacher could tell she needed help without her saying anything. Many students with ASD do not ask for help consistently when they need it (Constable et al., 2013).

Seated in a location to better see and hear the instruction and demonstrations by the teacher. Although she felt it was important to be able to see and hear the teacher, Karen stated that she did not feel comfortable asking her teacher if she could switch seats in order to see the teacher demonstrate a concept. Ryan was the most direct in identifying his specific needs relative to seat placement. He indicated he needed to sit up front because he had “more focus, that way I can hear the teacher…and see her.” Mark said it was helpful to be seated up front because he “can see better.” Individuals with ASD frequently have difficulties in maintaining attention and focus in the classroom setting, particularly when it is necessary to multi-task (Elwin et al., 2013).

Seated in a location away from “bullies,” those who were not following the rules, and/or those who were talking in class. All of the participants indicated that they could not focus when others around them were off-task. James Bond1, James Bond2, and Mark were particularly concerned and bothered by bullying that occurred in the classroom. Most of the bullying was relational in nature and involved name-calling and teasing. The other manner bullying was described was by Mark, who indicated he was forced by a bully to do “all the work” in a group project. Each participant who had concerns over bullying believed the teacher had failed to structure the classroom environment to mitigate the effects of bullying behaviors. Individuals with ASD struggle greatly with reading the intentions of others (Colle, Baron-Cohen, & Hill, 2007). This specific social deficit is believed to increase the risk of bullying by peers (Schroeder et al., 2014).

Seated next to a supportive peer. Participants reported value in being placed next to a peer who could provide support. Karen noted, “if I don’t remember [the instructions from the teacher], I’ll ask a classmate that’s next to me.” Mark explained that if he misses part of the instructions he could ask a peer and “they’ll tell me what to do…what the expectations are.” He also explained how he relies on watching peers so that he knows what to do, particularly in gym class. Ryan indicated there are two peers seated by him who can help him because “they are smart.” Most of the participants shared similar experiences in seeking assistance and clarification from peers in class. It was equally important to participants that they were perceived as capable and smart. Participants pointed out times when they were the one helping someone else in class or times where they were “good at” the subject or task. James Bond2 ensured that the researcher knew he was the best at math in his class compared to his classmates in the special education classroom. Becky talked about a peer who had significant academic needs as she explained: “There’s this one other kid in our class that like - she’s like one of those people that like - she barely, like she’s like a special ed person…like she can barely talk and stuff. I help her a lot.”

The fifth pattern was that participants preferred silence in the classroom when they were working. Every participant found quiet work spaces less distracting. Several indicated they “could not focus” when the classroom was loud. Mark had a very clear preference for silence stating that “if they [peers in class] get too loud and they’re not working, she’ll [the teacher] give a strike…when they reach the third strike, it’s dead silence.” While clarifying that three strikes from the teacher meant that everyone needed to be silent, he smiled. The researcher reflected back to him that it did not seem like he viewed this as a punishment because he was smiling. He responded, “No, I think it’s better that it’s silent.” At the close of his interview, Jay’s final piece of advice to those working with individuals with ASD was, “I think people should be quiet. And it should be peaceful and not violence. ...That’s all, and that’s all I know.”

Assertion Two

Participants wanted positive interactions with peers, but had very specific expectations of their peers, making it challenging. Within this assertion, three themes emerged.

Theme 1

Participants needed their peers to remain silent, on-task, and follow classroom rules. Four patterns support this finding. The first pattern was that participants needed their peers to be quiet when they were trying to work because it was distracting and made it hard for them to listen, focus, and concentrate. All seven participants reported difficulties in paying attention and focusing when peers were talking during class. This was demonstrated through numerous accounts of how peers were *helpful* in class by “being quiet” or “silent all the time.” James Bond1 believed that his peers “don’t really help, they just like be silent and do their work too. Because then I can concentrate when I work.”

This was corroborated by the participants’ reports of what peers did that was *not helpful* in class. Ryan explained:

> Some of those kids get so bad because like, kids are like, talking all the time in that class. It bugs me, it bugs her [the teacher], it bugs lots of kids that are trying to learn the music and trying to practice…And I’ll be trying to hear when they’re like, you know, dis - tracting me. You know, they’re distracting me and I’ll be trying to hear what they’re saying.

Karen echoed this sentiment saying, “I just can’t get my work done” when peers are talking in class because she “can’t focus.” She expanded further by stating that her peers “talk and scream. They’ll usually - when my teacher gives out the demo they’ll usually constantly talk and I can’t hear that well.” In comparing what participants said was helpful and not helpful, they were consistent in voicing their need for quiet in order to focus and hear instructions in the classroom. The ability to filter out stimuli in order to focus is a struggle shared by many individuals with ASD (Elwin et al., 2013).

The second pattern was that participants wanted peers to talk in a quiet voice tone because loud talking was perceived as “screaming” or “yelling.” Karen used the word "screaming" to describe her peers talking in class. With increases noted in her stuttering, Becky indicated that her peers "scream too loud where I can't concentrate." Mark, more emphatic in his description, said that his peers "talk like the people do in lunch. They scream! [spoken with a loud voice] - like the people do in the lunch (*sic*)." Individuals with ASD frequently experience hyper- or hypo-reactivity to sensory input (American Psychiatric Association, 2013). One common presentation of this symptom in ASD is hypersensitivity to loud noises (Kirby, Dickie, & Baranek, 2015). Combining the difficulties in accurately reading and interpreting social interactions (American Psychiatric Association, 2013) with the sensory processing based differences commonly experienced by individuals with ASD (Kirby, Dickie, & Baranek, 2015) can intensify the difficulties experienced.

The third pattern was that participants wanted peers to follow the classroom rules and not talk when the teacher was talking because they perceived it as rude and distracting. Karen had many comments throughout her interview about peers talking in class when she was asked if there was anything peers did that was not helpful or that she wishes were different. She expanded, saying her peers "talk and scream. They'll [peers in class] usually, when my teacher gives out the demo, they'll usually constantly talk and I can't hear that well." Jay was especially troubled by his peers not following the rules and being disrespectful to teachers. He voiced his frustration by saying:

> They [peers] don't do anything helpful…they just keep yapping and yapping and yapping…The noises they make and mostly talk about other stuff and not, their lives… It's cause you're not supposed to talk during

> the teacher - while the teacher's talking. That's inappropriate. That's offensive. That's, that's not responsible.

Ryan and Mark both described situations where they thought it was sometimes humorous when peers were doing funny acts of misbehavior in class, even though they said they were "annoyed" by their peers' actions. Mark was particularly irritated when peers were "breaking the rules." He expounded saying, "Sometimes they [peers] run around and do what they're not supposed to…It's pretty funny. Sometimes, they do stuff that's funny." Regardless, it bothered him when people didn't get in trouble for breaking the rules. "It bugs me when they don't get into trouble. It's annoying!" he exclaimed. The increasing demands for adolescents seeking conformity with peers can certainly conflict with their rigid adherence to rules (Happé & Frith, 2014).

The fourth pattern was that participants wanted peers to stay on task in class. All of the participants indicated a preference for peers to do what they were supposed to be doing. They did not like it when peers asked irrelevant or inappropriate questions in class. Ryan explained that some girls in his class will ask questions that do not have anything to do with the subject matter. He noted his conflict by saying, "They're two very…chatty…girls." He said they are "actually kind of funny" but finds them "annoying" when he is "really focusing." He added, "But like when I'm not working, they, they're actually hilarious." Other forms of off-task behaviors brought up by the participants included acting silly, giggling, acting disrespectful or like "thugs," and "blurting." Again, the struggles of adolescence in balancing the desire to fit in with peers and the need for adherence to rules comes into play. This, coupled with the deficits in central coherence shared by individuals with ASD, can contribute to difficulties in knowing what is relevant in an interaction between people (Happé & Frith, 2006; Southall & Campbell, 2015). This is further complicated by the evidence of diminished focusing abilities in people with ASD when presented with irrelevant stimuli (Elwin et al., 2013).

The fifth pattern was that participants perceived the noise levels in the lunchroom as a barrier to social interactions with peers. Participants in this study did not attribute their dislike for the lunchroom to sensitivity to smells or avoidance of certain foods, although two of them went into lengthy monologues about their favorite and least favorite foods when asked more questions about lunchtime and the lunchroom. The majority of participants indicated that the volume in the lunchroom was a big issue. When James Bond2 described lunch he had an interesting way of portraying how he perceived lunch in school with his peers: "and a lot of kids start coming down – yeah, it's like a bunch of birds and that…coming to a pole or something. …Yes, it gets loud, very little at a time. It's pretty original." Ryan revealed that at the start of middle school, he felt a fear response initially because of the volume in the lunchroom. He expanded:

> So, the first thing I wanna mention is, I brung this up before… The noise… At lunchtime... You know, it's, it's very [long pause] it's SO LOUD! [emphasis through louder volume and gestures]. You know, on the first day of school I was actually afraid of going to the lunchroom. I didn't want to go down to the lunchroom. But now I kinda zone out the lunchroom.

Jay expressed a similar view of the lunchroom saying, “And that’s why I don’t go there [lunchroom]. Lots of people. They keep talking and it just drives me insane.” Many individuals with ASD suffer from hyper- and/or hypo-reactivity to sensory stimuli (American Psychiatric Association, 2013; Elwin et al., 2013; Kirby et al., 2015; Luisier et al., 2015). There was some evidence that the volume in the lunchroom was a stressor for the participants in this study and was not supporting the social opportunities with peers as expected.

Theme 2

Participants wanted to have positive interactions with peers and to have friends. Three patterns support this finding. The first pattern was that participants wanted to feel comfortable asking peers for help in class, but two expressed worry about “bullying.” Karen, Mark, and Ryan indicated that peers helped them by repeating instructions given by the teacher, by sharing written notes with them, and by answering questions on assignments. James Bond1 and James Bond2 both expressed concerns over certain peers “laughing at them” or “bullying” them if they asked them for help in class. Although the participants viewed peers as having a role in supporting them academically in the classroom, adult supervision and support was needed to ensure that participants felt safe in seeking help from their peers in class. Using peers to support academic and social gains is frequently used in schools, and is considered to be an evidence based practice for use with adolescents with ASD in middle school (National Autism Center, 2015; Wong et al., 2014). While peers can be a source of support to individuals with ASD in the mainstream classroom, great care must be taken to ensure the proper supports are in place for efficacy (Lindsay et al., 2013).

The second pattern was that participants placed value on interactions with friends during the school day. Participants did not use the word "friend" frequently during the interviews, and when they did, it appeared significant to them. Ryan and Jay both pointed out that they interacted with a "best friend" in either a class or during lunch. Even though participants found the noise levels in the lunchroom troublesome, they valued the time spent sitting with their friends during lunch. For Karen, lunchtime was the only time she mentioned sitting by a friend. James Bond2 expressed sadness over having to eat breakfast in the special education room away from his peers due to a negative situation that had occurred with another peer. He concluded by saying, "I cannot be down there on my own now. But it makes me feel undependent (*sic*) of myself." This desire for companionship, a need for having people to "hang out with," is frequently demonstrated through a desire to have someone to sit next to for lunch (Sedgewick et al., 2016). Despite difficulties with initiating and maintaining social interactions, people with ASD do indeed want to have friends (Bottema-Beutel et al., 2016; Hochman et al., 2015).

The third pattern was that participants wanted reciprocal relationships with peers. The participants needed to feel that they were viewed as smart, capable, and independent. Jay was sure to point out that he was "doing great in gym." He admitted that he was "not very good at throwing" in dodgeball, but was very good at "dodging" which helped his team win. He added, "I just wanna, just wanna dodge. I just wanna show off." Others provided examples placing them in a helping role to another student struggling with a concept in class. To be viewed by their peers as incapable was hurtful and upsetting. Mark provided the following illustration from physical education/gym class:

> Mark: I'm like [a peer's name who struggles academically], I'm like the person who's like the big loner out there. …they're all ball hogs! … Yeah. Yeah. Sometimes they're really about to pass to me then one of my teammates steals it from me. If I could push someone, I would literally, literally push them, if you could do that.
>
> Researcher: I can tell this makes you angry. I can tell, I can tell your face is looking a little red like it's bugging you.
>
> Mark: Yeah

James Bond2 provided several examples of times when he was at the "top" of his class in the special education room. He indicated great frustration over feeling "undependent (*sic*)." Both Ryan and Becky provided specific examples of individuals who perform lower than they do in certain classes. In each case, they presented ways in which they outperformed the person academically. They also presented it in a way that indicated they were able to somehow "help" that peer. Other authors have reported similar findings where individuals with ASD differentiated their level of disability from others having the same diagnosis who were "more disabled" than they (Huws & Jones, 2015). Like their peers, adolescents with ASD prefer naturally occurring interactions with peers and share concerns over the potential stigma of needing help (Bottema-Beutel et al., 2016). The participants in this study provided responses that align with those findings.

Theme 3

Participants struggled with understanding and accurately reading peers' social cues. Three patterns support this finding. The first pattern was that participants stated they were not always sure why peers were talking and laughing. Jay was unsure how to read his peer's actions and did not understand why they did the things they did. He added, "It's like they don't care. They don't have a care in the world." Mark quipped, "I don't even know what he's doin[g]," when disclosing an interaction that was confusing to him. Mark provided a specific example of a time when his peers in class were laughing and talking loudly. He did not understand what was happening because the teacher was talking. He had experienced distress over the manner in which his classmates were acting in school saying, "They'll sometimes talk…they'll sometimes jump on…jump on top, jump over their desks…they're like wild animals." Karen spoke of her peers laughing and joking, but stated she was "unsure why" they would be laughing and joking in that scenario. James Bond2 had concerns about bullying, but also admitted that "sometimes" he might misinterpret the intent of his peers. Peer interactions require extensive mental energy and are baffling to individuals with ASD (Bottema-Beutel, 2016; Holloway, 2013). Difficulty fitting in with peers is a common struggle of adolescence, but for those with ASD, the pressures and difficulties are multiplied (Happé & Frith, 2014; Hedges et al., 2014; Sedgewick et al., 2016).

The second pattern was that participants were not always sure of what was happening around them because they were focused on other things. Most participants described difficulties in focusing when there were competing noises. James Bond2 provided an example from an assembly where he had completely missed what was happening with a peer who was misbehaving and only figured out what was happening when the speaker confronted the peer who was being disruptive. Mark provided two examples of times when he was very confused and worried by the actions of a peer. One of the examples was more extreme. He described how his peer “actually got mad at [someone else] so he threw his tray on the floor like full speed. Yeah, he just threw his chair against the table. I’ve never seen a kid get that mad before…he had to go to the library because of it.” Mark was truly perplexed over what had happened. Further, he did not view being sent to the library as a punishment. Paying attention in school requires significant mental effort for individuals with ASD (Blijd-Hoogewys et al., 2014; Happé & Frith, 2006). This coupled with persistent deficits in social communication skills and social interaction skills are thought to drive up the anxieties experienced by individuals with ASD (Frith, 2013; Happé & Frith, 2014).

The third pattern was that participants indicated it takes a great deal of work to interact with peers. James Bond1 directly stated, “People get on my nerves.” While the other participants were not so blunt in communicating this, each demonstrated some accordance with this pattern by indicating a desire to work alone and for peers to maintain silence in class. James Bond1, even though he sat by friends in class, indicated a preference for others to remain quiet saying, “Some are chatty, but my table’s not chatty, which helps.” The amount of effort required to interact with others is significant. Becky was notably fatigued from the half-hour interview. She indicated that she was “done” with the interview by yawning, looking at the clock and the interview protocol, and through increasingly shorter responses toward the end of the interview. The most common word participants used to describe the difficulties they experienced in peer interactions was “annoying.” In another published study, an adult with ASD summed it up best, stating, “Social interaction requires a lot of emotional energy I don’t always have” (Bottema-Beutel et al., 2016, p. 201).

Assertion Three

Participants had individualized responses to stressors and the manner in which they preferred to calm and regulate their emotions. Within this assertion, two themes emerged.

Theme 1

Participants used a variety of strategies to self-calm and regulate emotions. The term *emotional regulation* is one that is frequently used to describe the ability to which a person is able to “regulate emotions appropriately and effectively” (Samson et al., 2014, p.1766). The participants in this study demonstrated varying levels of insight regarding emotional regulation, yet several of them were able to identify specific strategies they independently used to calm, or self-regulate. In this study, this was conceptualized as the *use of breaks* during the school day. Some of the words participants used to describe breaks were “brain break,” “mental break,” and “reset.” Mark denied taking breaks of any sort, indicating worry over getting into trouble with the teacher. Jay reported that he did not need breaks in elementary school, even though they were allowed, but felt he needed them now in middle school. Five of the participants reported taking breaks during school in order to calm or regain focus. The use of short breaks from work is a commonly employed strategy used by individuals with ASD to promote self-regulation (Kreibich, Chen, & Reichle, 2015). While not considered an evidence-based strategy per se, it can be conceptualized as part of the evidence-based practice of self-management. Self-management involves teaching the individual to regulate his or her own behavior and is considered an evidence-based practice for adolescents with ASD (Wong et al., 2013).

The participants reported that in most cases they were able to stay in the classroom and take a "break" by focusing their attention on something different until they were ready to work again. Karen reported "zoning out" in order to take a break from a task so she could then refocus on the teacher or schoolwork a bit later. Other times, participants reported doing specific activities to regain their focus. The participants reported a range of helpful activities. The activities in which the participants reported engaging were:

- looking things up using technology
- playing solitary games using technology
- counting to ten
- listening to music
- sitting in silence
- watching cartoons
- getting a drink

In some cases, they identified that it was necessary for them to leave the room in order to calm themselves. Ryan explained that leaving the classroom for a break "gives me the time to recoup instead of just like staying in the classroom, trying to hold in all my emotions." Without being able to leave the room, he said the feelings would "actually burst." When needing to leave the room, most participants retreated to a separate room staffed by a special educator. Participants reported that it took them between five and 20 minutes to calm when they needed to leave the room. Disengagement from a task is a commonly employed strategy used by individuals with ASD to cope with stressors (Khor, Melvin, Reid, & Gray, 2014).

Becky explained, "sometimes I just sit there and like…let my mind go… and then I get back to work." She reported thinking about horses and living on a farm, which related to her current special interest area. Jay, while discussing a beloved teacher who had cancer, began to make slapping sounds with his hands in the air and started flicking his fingers in the air in a repetitive manner. This likely was evidence of mild emotional dysregulation from discussing an emotionally difficult subject. He then abruptly switched the topic of conversation to his current special interest area. He proceeded to engage in a monologue describing YouTube videos related to his special interest. When the researcher attempted to engage in dialogue about the special interest topic with him, he dropped eye contact and began to make a few nonsense noises again. The researcher honored his communication by becoming silent and breaking eye contact, allowing him to redirect the interview. Within five minutes he had concluded his monologue and resumed full engagement in the interview process to the level he had demonstrated up to that point. The use of monologue on his restricted, special interest appeared to promote self-regulation in Jay. There is a growing body of evidence linking emotional dysregulation with repetitive and restricted symptomology in individuals with ASD (Samson et al., 2014). Samson et al. (2015, p. 909) hypothesized that "repetitive behaviors might be one way to gain control over an environment that otherwise seems confusing, and might therefore be a pathway for individuals with ASD to deal with overwhelming emotions." While it is known that individuals with ASD who demonstrate repetitive and restricted behaviors are more likely to experience dysregulation, the cause and effect relationship between such behaviors and regulation is unclear (Samson et al., 2014).

James Bond1, James Bond2, Jay, and Ryan used the interview schedule and protocol to self-regulate by controlling the pace of the interview. Specifically, when talking about something that was perceived as stressful to them, a brief answer was followed with a directive by the participant to move on to the next item on the schedule/interview protocol. Ryan redirected the conversation from an emotional topic in the following manner:

> No, they [peers and teachers] are respectful of it [taking breaks], because they know that I have special needs, you know. That I have autism. And, and I think that they know that I'm very fragile, like I'm a very fragile person, too. You know. Um. So, do you wanna go to social studies?

Similar examples occurred with James Bond1, James Bond2, and Jay. Each time participants directed "moving on" to the next part of the interview, the researcher honored this as a need in the participants.

Individuals with ASD struggle with using effective and appropriate strategies to manage feelings of anger and anxiety in particular (Samson et al., 2015). There is some evidence that "individuals with ASD generally lack the emotional insight needed for effective emotional regulation" (Mazefsky et al., 2013, p.683), yet regulation of emotion remains poorly understood in people with ASD (Mazefsky et al., 2013; Samson et al., 2014). While it is generally agreed that emotional regulation is a common problem for individuals with ASD, there is little empirically supported guidance on how to teach and support the acquisition of requisite skills for promoting emotional regulation with this population.

Theme 2

Participants identified variable levels of self-awareness on their individual signs of dysregulation. Participants were asked specifically if they ever take "breaks" during class when others were working. Karen denied needing breaks, yet provided examples of things she does to take a brief "mental break" when she "just needs enough time to…like settle down and stop thinking." Jay indicated that although he did not need breaks when he was younger, he does feel like he needs them now that he is in middle school. Becky believed that her teachers "know when I have a break…. Because I am just sitting there." Mark was very concerned about staying out of trouble with his teacher and stated he "never [takes breaks] when the teacher's talking."

James Bond1, James Bond2, and Ryan demonstrated the most insight into their emotions and regulatory needs through their responses during the interviews. James Bond1 stated that he recognized that he needed to take a break when his "heart beats fast," when "voice tone becomes an issue," and when "the swear words just start coming out." He identified a range of strategies he employs to calm and believed that it was "most helpful" when he "can take a break right away." He added that sometimes teachers don't allow him to take a break but "if you're getting angry, you can ask, they'll let you or they'll let you take a break in that room." James Bond2 viewed "breaks" as "something you do when your work is done." He preferred the term "reset." Like Becky, he believed his teachers "know when I do [need to reset]. They can tell by my face. They can tell I'm not tuned in today." The things he does to calm vary, but all of his calming activities involve some level of disengagement from others. Most of the time he reported staying at his desk. When taking a break or recovering from a frustrating situation, he explained, "I just keep going through my head and just keep working and just go… [while pantomiming typing on a computer keyboard] just put an end, put it in a file."

Ryan indicated there were times he did not take a needed break because, like Mark, he did not want to "get into trouble" with the teacher. Other times, he did not want to stand out with peers. Ryan expressed concern over what his teacher and peers would think of him when he became dysregulated and conveyed the following example:

> Well the teacher is very kind. You know, and, she's, she's always, like, like, if-one time I didn't get my homework assignment done. And, I, I didn't have any, um, um, um, homework, um, homework passes with me, so, um, like. I ran out of the room crying, because I was so scared and sad, you know. And, um, Mrs. P, um, um, like, came out there too and I, I

> kinda felt like I was making a scene. And I thought that all the other kids would, you know, be mean to me after that and bully me and stuff and that all the kids would think I'm like a wimp or something. But, um, they really don't, they don't talk about it today or anything. They probably thought that I was just having a bad day, because that, that was at the beginning of the school year, I wasn't taking my pills [for anxiety] or anything.

Ryan used the term "brain jam" to describe his experience of becoming emotionally dysregulated. He described a brain jam as "kind of like, fog hits your brain and you can't see much things. And you can't really focus on the road down ahead." Put another way, he added that "a brain jam is usually like, not being able to focus because you're zoned out and you're focused on something else that's really bothering you….My brain was jammed because I was so stressed out." He provided the following scenario for what it felt like to be dysregulated in school.

> Like, when I was like, when I was going out of the classroom in that story, um, I – I asked um, can I talk to you? And my voice was, like, qu-qu-quay-vering (*sic*), or, you know. And then, um, I started walking and then my face just got red and I knew that the tears were coming. …. And so I just like, speed walked to the door, trying to shield my face from the other kids…you know. …It was hard. I wanted to just go home."

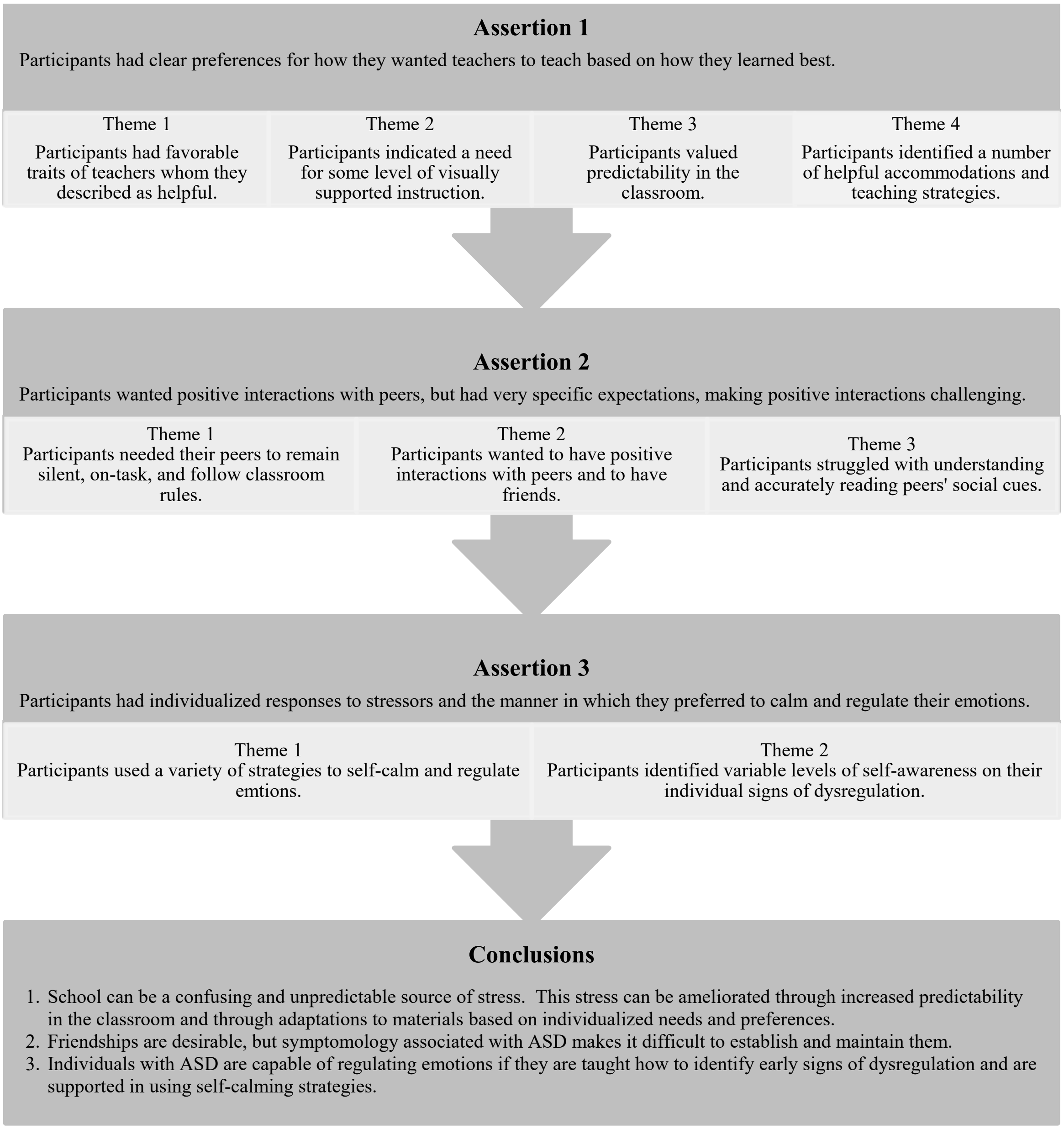
The other participants did not elaborate to the degree that Ryan did on their feelings, but his example certainly provides a glimpse into what it might feel like for someone to become dysregulated while at school.

Although the participants demonstrated varying levels of individualized capacity for emotional regulation, each implemented strategies in order to attempt to self-regulate. It is unclear why some individuals demonstrated greater levels of insight than others. Boys with high functioning ASD tend to present with higher levels of irritability than those without ASD (Mikita et al., 2015), and young children with ASD have been known to rely more on avoidance and venting as a way to manage difficult situations (Jahromi, Meek, & Ober-Reynolds, 2012) but little is known about the manner in which adolescents manage stressful situations in school. Most adolescents work very hard to suppress emotions in school, although there is evidence that they may be willing to accept support from a teacher with whom they already have a close relationship (Horner, Wallace, & Bundick, 2015).

CHAPTER IV

DISCUSSION

The purpose of this study was to examine the lived school experiences and perspectives of adolescents with high functioning Autism Spectrum Disorder (ASD) presently in middle school. Individual interviews were conducted in order identify what was important to them and what they wished was different during the school day. Two research questions guided this study. What were the day-to-day experiences of adolescents with high functioning Autism Spectrum Disorder (ASD) throughout their school day?; and What were their perceptions of those experiences? The author theorized that learning the perspectives of those with ASD could inform practice through better understanding of individual needs and preferences, thus aiding in the development of a starting point for determining more effective supports for adolescents with ASD during their school day. It was anticipated that the participants in this study would have clear preferences for how they wanted to be supported in school. The participants exceeded this anticipation by openly sharing their personal experiences and needs and preferences regarding both teachers and peers in school. The following analytic schema describes the analysis process, delineating subsequent themes and assertions resulting in three overarching conclusions.



Assertion 1

Participants had clear preferences for how they wanted teachers to teach based on how they learned best.

Theme 1
Participants had favorable traits of teachers whom they described as helpful.

Theme 2
Participants indicated a need for some level of visually supported instruction.

Theme 3
Participants valued predictability in the classroom.

Theme 4
Participants identified a number of helpful accommodations and teaching strategies.

Assertion 2

Participants wanted positive interactions with peers, but had very specific expectations, making positive interactions challenging.

Theme 1
Participants needed their peers to remain silent, on-task, and follow classroom rules.

Theme 2
Participants wanted to have positive interactions with peers and to have friends.

Theme 3
Participants struggled with understanding and accurately reading peers' social cues.

Assertion 3

Participants had individualized responses to stressors and the manner in which they preferred to calm and regulate their emotions.

Theme 1
Participants used a variety of strategies to self-calm and regulate emtions.

Theme 2
Participants identified variable levels of self-awareness on their individual signs of dysregulation.

Conclusions

1. School can be a confusing and unpredictable source of stress. This stress can be ameliorated through increased predictability in the classroom and through adaptations to materials based on individualized needs and preferences.
2. Friendships are desirable, but symptomology associated with ASD makes it difficult to establish and maintain them.
3. Individuals with ASD are capable of regulating emotions if they are taught how to identify early signs of dysregulation and are supported in using self-calming strategies.

Figure 2. Analytic Schema depicting summary of results. Three separate assertions with supporting themes combined to form three final conclusions.

Conclusions

Conclusion One

School can be a confusing and unpredictable source of stress. This stress can be ameliorated through increased predictability in the classroom and through adaptions to materials based on individualized needs and preferences. The assertion that school experiences are confusing and stressful to individuals with ASD is not a new concept. Published transcripts from verbatim recollections by an adult with autism revealed that childhood experiences “could be summarized as consisting of two predominant experiential states: confusion and terror” (Bemporad, 1979, as cited in Frith, 2003, p. 169). Current literature documents increased rates of anxiety in youth with ASD (Kerns et al., 2014; Vasa et al., 2014), yet explanations for this phenomenon are vast and varied. Commonly purported theories point to deficits related to social interactions (Happé & Frith, 2014), deficits in emotional regulation (O’Connor, Staiger, Kambouropoulos, & Smillie, 2014), and hypersensitivity to sensory input (Howe & Stagg, 2016) as contributing factors explaining increased rates of anxiety in youth with ASD. There is also some evidence documenting biologically based differences in children with ASD who also struggle with anxiety explained through atypical biomarkers within the parasympathetic nervous system (Guy et al., 2014). Regardless of the theoretical perspective held or mitigating factors noted, current research hypothesizes that multiple subtypes of anxiety may be present in this population and that individuals with ASD are indeed at greater risk for suffering from anxiety disorders (Kerns et al., 2014). Anxiety disorders are characterized by and commonly described as experiencing excessive fear, anxiety, and worry (American Psychiatric Association, 2013).

Participants in the current study specifically used words such as fear, anxious, stress, and worry to describe individual internal states throughout his or her school day. These undesirable states related to unpredictability in the school environment, insecurities within the teacher/student relationship, and academic struggles. Each participant in the current study described specific strategies they believed were helpful to them. The most prevalent forms of supports identified related to increasing predictability. Reductions in stress and anxiety levels were attributed to knowing what to expect along with clear instructions, explanations, and requirements. Increasing predictability in the classroom through the use of visual supports and schedules has been well established as an evidence based practice for individuals with ASD (National Autism Center, 2015; Wong et al., 2014). As indicated in the current study, the manner best implemented for adolescents can be quite variable and dependent upon personal preferences. Results from the current study indicated a strong preference for established classroom routines and for class schedules to be written on the board each day, particularly when a change in the anticipated routine was expected. This fits with current, well established paradigms of “best practice” in working effectively with individuals with ASD. The results of the current study illuminated the significant impact predictability, routine, and written schedules had on the school environment for the participants, yet there is very little emphasis on the importance of this practice remaining necessary for adolescents with high functioning ASD.

There has been considerable sustained attention paid to the importance of effectively reinforcing individuals with ASD to acquire and demonstrate new skills (Hall, 2013), however the participants in this study referenced few examples of reinforcement as being particularly relevant or important to them. They did, however, provide numerous accounts of specific strategies within the classroom environment that they did find helpful. Universally, they indicated they needed to know exactly what to do and how to do it, and they needed support from their teachers in order to successfully accomplish the targeted skills. This does not imply that reinforcement is not important, rather this aligns with perspectives that place more significant weight on antecedent based interventions such as altering the environment and providing explanations and supports to individuals with ASD so they can learn and generalize new skills (Aspy & Grossman, 2012). Participants in the current study provided a range of specific strategies deemed helpful to them. The overarching theme emphasized the use of commonly applied accommodations, modifications, and teaching strategies in an individualized manner based on the person's strengths, needs, and preferences as being the most helpful to them. Within the current study, strategies such as accommodations and modifications are referred to as *adaptations* as this term is the most descriptive and encompassing. Tailoring those strategies and supports to the individual's interests and unique personalities (Lanou, Hough, & Powell, 2012) and specific preferences for certain strategies over others (Nelson, Jayanthi, Epstein, & Bursick, 2000) was identified as important.

Adaptations to schoolwork and instructional methods are routinely used with individuals with disabilities, and are afforded by legal protections under the Individuals with Disabilities Education Act (Barnhill, 2016; Harrison, Bunford, Evans, & Owens, 2013; Nelson et al., 2000). In the current study, these were conceptualized as adaptations and teaching strategies. Common adaptations within the classroom included changes in the presentation of materials, environmental adjustments, altered adult responses to behaviors, and reductions in cognitive demands (Morningstar, Shogren, Lee, & Born, 2015). Numerous studies have documented the levels of efficacy of implementing a range of specific supports in the classroom (Barnhill, 2016; Buzick & Stone, 2014; Evmenova, et al., 2016; McMahon et al., 2016; Schneider, Codding, & Tryon, 2013; Smith & Riccomini, 2013). While a variety of methods have been identified as effective or evidence-based by researchers and practitioners, few studies to date have documented the preferences for specific supports over other supports with this population.

While not specific to ASD, evidence exists that students with disabilities prefer certain adaptations over others. Nelson et al. (2000) surveyed middle school students in general education classrooms, and the "most liked" adaptations reported were having more time to complete work, working in a group, having open book tests, and being provided practice test questions. Responses from participants in the current study independently aligned with these findings with the exception of working in groups. They indicated a strong dislike for group work in general. This is likely attributed to the social deficits inherent in having ASD and has been substantiated by studies involving college students (Gobbo & Shmulsky, 2014). In Nelson et al. (2000), the *least liked* adaptations included those that interfered with their personal learning style, particularly having tests read to them. This differed somewhat from the present study where the participants indicated a preference to have materials read to them, whether in real time or via technology. This is likely related to deficits in reading comprehension that are commonly shared by individuals with ASD (Carnahan &Williamson, 2013; Frith, 2003).

The findings from Nelson et al. (2000) indicated that concerns over *fairness* negatively impacted the desire for receiving adaptations such as shortened assignments or tests. Participants in the current study also expressed a strong preference for things to be "fair." Scanlon and Baker (2012) reported evidence that secondary teachers were somewhat resistant to the implementation of highly individualized accommodations and modifications in the general education class, instead preferring general accommodations for everyone in the classroom (Scanlon & Baker, 2012). Making general adaptations within the standard curriculum is sometimes referred to as implementing principles of universal design (Harrison et al., 2013). With a shift in focus to high stakes testing, some critics express concerns over adaptations such as materials being read aloud as placing students with disabilities at an unfair advantage (Buzick & Stone, 2014). Such viewpoints often miss the level of impact the deficits associated with having an ASD have on learning and school performance, particularly for those with high functioning presentations of ASD. It is common for teachers and others interacting with this population to overestimate their capacities due to average or above average intellect and expressive verbal skills (Aspy & Grossman, 2012). It is generally believed in the field of special education that adaptations such as those identified in the current study allow for students with disabilities to demonstrate their true capacities by reducing unnecessary barriers that do not affect demonstration of understanding or knowledge by the student. Regardless of personally held beliefs by teachers, accommodations and modifications are legal rights granted to individuals with disabilities and are mandated under the law (IDEA, 2004).

Conclusion Two

Friendships are desirable, but symptomology associated with ASD makes it difficult to establish and maintain them. The participants in the current study indicated feeling baffled by peers. One troubling outcome of their difficulties in reading and responding to others' communicative intent arose concerns over bullying. Most of the concerns over bullying were raised by the boys in the current study and were described in terms that were overt. When compared to those both with and without disabilities, it has been reported that the most likely group to be bullied by peers were middle school age adolescents with ASD (Zablotsky, Bradshaw, Anderson, & Law, 2014). Further, they found that individuals with high functioning presentations of ASD were more than twice as likely to be victimized as compared to those with more classic presentations. Among those most likely to be victimized were those who spent the most time in fully inclusive classrooms. In addition to being bullied, both males and females with ASD have been reported to be social excluded more often than their peers without ASD (Dean et al., 2014). Males were found to be more likely to be socially excluded whereas females with ASD tended to be overlooked, rather than excluded or rejected by their peers. A contributing factor to consider is that peers may not fully understand those with high functioning ASD. Middle school students reportedly hold many misconceptions about ASD and do not fully recognize the seriousness of the diagnosis or the range of symptomology expressed across the whole spectrum (Campbell, Morton, Roulston, & Barger, 2011). In particular, Campbell et al. (2011) found that middle school students did not understand the nature of the core difficulties associated with ASD and were often basing their viewpoints on faulty information.

Coupled with the inherent social deficits associated with ASD (Doi et al., 2013; Happé & Frith, 2014; O'Hearn, Schroer, Minshew, & Luna, 2010) are behavioral patterns of ineffective coping strategies in managing friendships and interpersonal conflicts (Bitsika & Sharpley, 2014). Doi et al. (2013) reported significant difficulties in adult males with high functioning ASD in determining and responding quickly to others' emotions based on facial expressions and voice tone. Others have substantiated disruptions in the processing of complex visual stimuli in adolescents with ASD (O'Hearn et al., 2010). Evidence suggests that the ability of adolescents with ASD to demonstrate capacities in effectively reading and responding to subtle social cues from peers is inherently faulty and impaired, regardless of the level of apparent cognitive functioning otherwise. The assertion that many males with ASD develop ineffective coping strategies to perceived bullying should come as no surprise. Bitsika and Sharpley (2014) found that males with ASD who believed they were being bullied responded by seeking ways to stay home to avoid school. The males in the current study indicated a desire to remove themselves from situations where they believed they were being treated badly by their peers. However, none of them reported staying home excessively, although a pattern of avoidance was evident.

Results from the current study indicated that participants placed value on being able to seek help from friends in class when they had a question, but there was evidence of a desire to have some degree of reciprocity in the exchange. Developing friendships is important to adolescents, both those with and without disabilities (Happé & Frith, 2014; Koegel et al., 2013; Laugeson et al., 2014). The participants in the current study demonstrated responses that placed importance on having friendships in school despite rarely reporting interactions with friends during the school day. The use of peer mediated interventions and supports is considered an evidence-based practice (National Autism Center, 2015; Wong et al., 2014) and there is emergent evidence that peer mediated interventions and adult supported group activities with peers can yield increased friendships (Collet-Klingenberg, Neitzel, & LaBerge, 2012; Gardner et al., 2014; Koegel et al., 2013; Laugeson et al., 2014).

Peer mediated interventions are believed to fulfill two purposes: supporting academic instruction and increasing friendships. The key elements identified for effective implementation include educating peers about ASD and teaching ways to effectively support their new friends (Collet-Klingenberg et al., 2012). Specifically, peers who are aware of the core deficits associated with ASD and what it means to the person with ASD are in a better position to guide and support social interactions. When peers are taught that certain behaviors are intrinsic to ASD and that the adolescent with ASD is not intending to be rude or self-centered, a change in perceptions can occur. If, for example, peers without ASD were taught that one-sided monologues by a person with ASD was a manifestation of the disorder and were taught how to redirect him or her, the individual with ASD could experience growth and a reciprocal interaction could be fostered. Another example would be to teach peers about sensory processing-based differences in order to provide insight and empathy for situations where the peer with ASD experienced sensory overload. A final example would be to help peers understand that adolescents with ASD may have significant academic abilities or giftedness in some subjects areas where the answer can be learned in a rote manner, such as math, but need more help in areas that require other skills such as taking the perspective of others or in comprehending a long written passage. Others urge using naturally occurring events around common interests to increase friendships and positive peer to peer interactions (Koegel et al., 2013; Laugeson et al., 2014). Several of the participants in this study identified specific areas of interest. Becky, for example, had a strong interest in horses. Her special interest could include horses or be expanded to other animals. For Becky, her participation in activities such as 4H with a central theme of animal care if supported could increase peer interactions and foster authentic friendships centered on a shared interest. She could then be supported to meet peers who share her interest in animals, irrespective of any disability. The academic possibilities include naturally motivating opportunities to relate the interest to specific assignments.

In addition to the obvious social benefits of developing meaningful friendships around mutual interests, there is evidence suggesting that friendships may also support emotional regulation strategies, particularly in situations evoking anger and fear (Reindl, Gniewosz, & Reinders, 2016). Another method proposed for increasing and supporting peer interactions is the introduction of paraprofessionals within the mainstream classroom (Koegel, Kim, & Koegel, 2014). In addition to prepping the person with ASD on the expected response academically, paraprofessionals can serve as a mediator within peer relationships. Theoretically, a paraprofessional with the same training as peers on core features associated with ASD, could provide support prior to, during, and immediately following social interactions to facilitate social learning for an individual with ASD. Specifically, a paraprofessional could support the individual with ASD in managing what is commonly called the *hidden curriculum*. The *hidden curriculum* refers to the unspoken social rules or customs that most people learn without being explicitly taught (Buron & Wolfberg, 2014). The concept of hidden curriculum proposes that individuals with ASD must be intentionally taught the hidden social curriculum because it is not learned through experiences alone. The results of the current study found that paraprofessional support was primarily viewed by participants as playing a role in supporting academics rather than in supporting social interactions. Koegel et al. (2014) asserted that with minimal training, paraprofessionals can play an important role in improving socialization in students with ASD.

Conclusion Three

Individuals with ASD are capable of regulating emotions if they are taught how to identify early signs of dysregulation and are supported in using self-calming strategies. Within the current study, great variability existed in the level of participants' insight in identifying useful and adaptive calming strategies despite the fact that each shared the same diagnosis and were of similar ages. This level of variability is supported within the current literature base (Samson et al., 2015) and aligns with evidence for the implication of ASD as a spectrum disorder. Some authors have hypothesized that individuals with ASD are not capable of regulating their emotions (Mazefsky et al., 2013), yet research evaluating and seeking to understand the construct of emotional regulation (ER) in individuals with ASD is quite sparse (Hirschler-Guttenberg, Golan, Ostfeld-Etzion, & Feldman, 2015; Mazefsky, 2015; White et al., 2014). White et al. (2014, p. 31) described "deficits in ER as intrinsic to ASD, such that ASD itself affects mechanisms that give rise to ER impairments." Explained more simply, it is difficult to ascertain which condition is causing or complicating the other. They concluded by making a connection between deficits in ER and the risk for experiencing anxiety. It has been posited that difficulties in ER are a separate, yet related set of difficulties not always present in those diagnosed with ASD (Mazefsky, 2015). It is generally agreed upon by professionals that individuals with ASD have difficulties in recognizing emotions both in themselves and in others which further contributes to deficits in emotional regulation (Robinson & Elliot, 2016).

Emerging evidence has suggested that over-responsivity to sensory stimulation, particularly noise, can have detrimental effects on the regulatory capacities of adolescents with ASD (Howe & Stagg, 2016). Mazurek and Petroski (2015) reported evidence of a potential link between sensory over-responsivity and anxiety while Mazefsky et al. (2013) also questioned "idiosyncratic emotional triggers" as playing a role in dysregulation in ASD. Like the participants in the current study, experts in the field are struggling to fully grasp contributing factors, risk factors beyond having ASD, and strategies to adequately support individuals in the pursuit of emotional regulation. It appears that adolescents who rely on fewer emotional regulation strategies have more problems with depression, general anxiety, and social anxiety (Lougheed & Hollenstein, 2012).

Weiss (2014) proposed a “transdiagnostic approach” to understanding ER in youth with ASD. He advised drawing from other clinical perspectives as a starting point in planning supports and interventions for youth with ASD, citing there is slightly more research on ER when scouring the literature base applicable to younger age groups and those with other disabilities. In young children with ASD, parents greatly scaffold a child’s emotional regulation through practices such as using distraction, reassurance, encouragement/praise, guidance/problem solving, following/elaborating, and through control of the experiences (Weiss, 2014). Others have conceptualized this scaffolding of interactions as “mutual regulation” (Prizant et al., 2006). Prizant et al. (2006, volume 1, p. 63) described mutual regulation as relating to the “partner’s ability to read a child’s emotional signals of dysregulation and respond appropriately.” Hirschler-Guttenberg et al. (2015) described parents of young children with ASD physically soothing, verbally comforting their child, and diverting the child’s attention to something else to promote emotional regulation. Increasing the level of predictability through the use of schedules and visual supports has also been surmised as playing a role in setting the environment to support emotional regulation for individuals with ASD (Sansosti, 2012). Mazefsky et al. (2013) asserted that a psychoeducational approach where the individual is supported in developing awareness of internal states to prepare them for difficult situations whilst using his or her unique strengths should be considered for implementation. This involves adult assessment, which includes observation, for potential triggers followed by working with the individual to help them identify situations when a specific strategy should be used.

There is emergent evidence suggesting that repetitive behaviors and restricted areas of interest might be indicative of an attempt to regulate emotions in individuals with ASD (Samson et al., 2014; Samson et al., 2015). In the current study, it was hypothesized that participants attempted to regulate their emotions in this manner when discussing something that was stressful. While this can be effective, there have been concerns raised whether this is maladaptive in the long term (Samson et al., 2015). It has been hypothesized that "repetitive behaviors may be a way to gain control over an environment that otherwise seems confusing, and might therefore be a pathway for individuals with ASD to deal with overwhelming emotions" (Samson et al., 2015, p. 909). Samson et al. (2015) posited 10 categories of responses employed by individuals with ASD to regulate: problem solving, seeking support, cognitive reappraisal, distraction, acceptance, relaxation, exercise, relaxation, exercise, avoidance, suppression, and repetitive behaviors. The concern raised relates to the individual lacking a range of emotional regulatory strategies. To merely avoid difficult emotions does little to create opportunities for emotional growth or the acquisition of varied problem solving skills.

Another strategy rooted in self-monitoring which is considered an evidence based practice for individuals with ASD (National Autism Center, 2015; Wong et al., 2014), is to encourage individuals with ASD to take a *break* when becoming stressed or distressed in order to self-calm (Sansosti, 2012). The key elements of the intervention proposed by Sansosti (2012) was that the individual was told what to do, why it was pertinent to them, was explicitly taught the skills, and was reinforced adequately. Presently, there are no definitive answers as to the best course of action in promoting emotional regulation in individuals with ASD. There is some consensus that it should be rooted in evidence based practices, even if they are not practices necessarily considered evidence-based yet for adolescents with ASD (Weiss, 2014).

Implications

Adolescence is a turbulent period for everyone, but it is particularly difficult for those with ASD. At a time when social and academic demands are being increased, supports are frequently being decreased in efforts to promote independence in those both with and without disabilities. Unfortunately, social emotional development – particularly skills related to social interaction, executive functioning, and the ability to regulate emotions – remains delayed in those with ASD compared to their peers who are typically developing. Especially problematic is the uneven developmental profile exhibited by those with ASD as they frequently present as functioning much higher than they actually are and tend to look similar to their peers without disabilities. Adolescents with high functioning ASD frequently have robust vocabularies, yet struggle with accurately interpreting what others are communicating. When presented with emotionally difficult or stressful situations, they lack capacities in implementing strategies to self-calm on their own. Like a younger child, they may need the support of an adult to facilitate calming or to help them problem solve. Academically, they are likely to have average or even above average intellectual capacities and vocabulary, yet struggle greatly with organizing their thoughts, making sense of instruction, and starting on a task. Seeing the big picture, the gestalt, is a common struggle. Overall, they are indeed misunderstood.

The results of this study illuminated the preferences for how the participants needed and wanted to be supported within the school environment. Specifically, participants indicated they needed more supports than teachers may be presuming they require. They struggled between wanting to experience increased independence and needing specific, individualized supports within the classroom. They provided valuable lists of supports and adaptations they believed were helpful to them. They did not always communicate awareness or insight into why they preferred certain supports over others or why they found certain activities calming or frustrating to them.

This study provided a glimpse into the experiences and perceptions of those interviewed. It serves as a starting point in seeking to understand the preferences and inner thoughts of middle schoolers affected by high functioning ASD. Just as there are recommendations for teaching peers how to interact with individuals with ASD, this author proposes that similar, instructional needs occur directly with those individuals diagnosed with having ASD. It is well documented that individuals with ASD need to have explicit, clear instruction in order to experience success. In practice, this has seemingly been forgotten as professionals across disciplines have placed significant effort in addressing and publishing curricula on teaching social skills and modifying problematic behaviors while largely neglecting development of tools and curricula designed to increase insight relative to individual needs and the possible reasons for specific preferences in meeting the individual's academic, social, and regulatory needs. It is important that adolescents with ASD understand why certain strategies are used with them and why certain ones may be more preferred by them. It is equally important for practitioners to learn what adolescents with ASD think about the practices employed with them so that interventions and supports can be tailored and individualized based on needs, strengths, and individual preferences.

Recommendations

Recommendations for Teachers

A positive teacher/student relationship is valued. This group of participants wanted to have positive relationships with their teachers. Jokes relating to the academic content in a specific class or those related to the adolescent's special interest were particularly meaningful. This means that teachers needed to seek to identify the adolescent's special interests and then educate themselves on the topic to facilitate meaningful dialogue and jokes relative to that interest. Getting into trouble at school was something that incited worry with some evidence of fear have been experienced. The fear of getting into trouble with the teacher, making the teacher angry, or hurting the teacher's feelings was suspected as contributing to reduced instances of self-advocacy in class.

Recognize that individuals with ASD have a different way of communicating and seek out and implement individualized ways to support interactions. At times adolescents with ASD can be very blunt and precise in their interactions. They may need guidance on how to elaborate to explain something in greater detail. Their blunt communication of telling the truth is a communication style common with this group of individuals. It is important to avoid making the mistaken assumption that he or she is attempting to be rude or disrespectful. Another difference in communication patterns relates to being unsure what is relevant in a response so he or she may provide a substantial amount of detail while missing the main point. Remaining patient until the person gets to the end of his or her explanation is sometimes necessary since an explanation may otherwise seem tangential on the surface.

It may be necessary for teachers to make communicative intentions more clear than would ordinarily be expected for a person of comparable age. Accurately interpreting communication with others is a core deficit area of the disability. This can be particularly difficult for others to understand since individuals with ASD often have extensive vocabularies. Teachers may note incongruence among body language, gestures used, and what is said. This applies to both the use of expressive as well as receptive communication. This study revealed a tendency for participants to respond in a very literal manner to questions posed. In practice, it is important to remember this style of communication when providing instructions or directions on how to complete an assignment. There was an overarching need to be shown rather than simply told what to do, and some participants expressed not feeling completely comfortable in self-advocating to have this need met. Because of the need to see, rather than just listen to explanations, seat placement can play an important role in the classroom. Methods of instruction that can be described as more "concrete," explained in common sense terms, or experiential were viewed as helpful and preferred by the participants in this study.

Implement a range of adaptations and other supportive strategies within the classroom. While not universal, it is generally advised that the best place to start when seeking to implement evidence-based supports is to increase the use of visually supported instruction. The results of this study completely support this assertion. Increasing the use of visual supports can reduce some of the communicative difficulties experienced by individuals with ASD by making everything much clearer for them. This may take the form of visual schedules, schedules written on the board, providing examples of work, using study guides, and using graphic organizers. By taking into consideration the difficulties commonly shared by individuals with ASD in reading comprehension, this author suggests that practitioners consider drawing from the research supported strategies for individuals with specific learning disabilities. Many of the strategies identified by participants in this study coincided with recommendations for supporting individuals with learning disabilities in reading or math. It is important to remember that individuals with ASD frequently struggle with reading comprehension, even though they may have no difficulties in reading fluency. Awareness of what is considered evidence-based is but a portion of the process. It is important to enlist the input of the adolescent on what they prefer while helping them understand the purpose and rationale for each strategy chosen. Without understanding this, future aspirations of increased independence and self-advocacy are likely to be diminished.

Create opportunities for encouraging friendships between the adolescents with ASD and his or her similar aged peers around shared interests. The relationships need to be reciprocal with both partners benefitting from the relationship. It can be demoralizing to be paired with someone who is merely assigned to interact as a peer mentor for academic help. Because individuals with ASD are prone to restricted areas of interest, this author recommends determining the interests of the adolescent with ASD to serve as the basis for creating more natural interaction opportunities. Before pairing peers with an adolescent with ASD, it is advised that accurate information be provided to the peers without disabilities before any introductions. Specifically, the peers need to know basic facts about ASD and ways to support their friend. This author suggests consideration of integrating age appropriate books about people with ASD representing the entire spectrum into the general curriculum.

Be aware of early signs of potential dysregulation and intervene early through redirection or by suggesting calming strategies. It was common for the participants in this study to believe that others knew what they were thinking or feeling. Sometimes, they demonstrated difficulty in finding the words for feelings and may not have even been fully aware how their mannerisms were likely early indicators of mild dysregulation. They demonstrated a variety of early indicators of potential dysregulation when discussing topics or situations they recalled as stressful, not helpful, or things they wished were different in school. Increases in the following behavioral indicators were noted when discussing something stressful such bullying or describing situations where they experienced frustration:

- Sighing, stammering, stuttering, and making more language errors such as pronoun reversals;

- Fidgeting, flicking fingers in the air, making slapping sounds with hands, and making repetitive noises which are sometimes described as stereotypies; and
- Using an improbable example that seems nonsensical.

Recognize and honor attempts by the person to emotionally regulate. While highly individualized, the strategies used by the participants provide a starting point for consideration by others interacting with this population. To honor those attempts at communication means to allow them to do what is needed and preferred by the individual in order to calm, focus, and return to a state where he or she is ready to re-engage socially. It may mean altering a time line, reducing communicative demands, increasing the structure, providing choices, or allowing the person to engage in a preferred regulatory activity that may seem atypical or unexpected based on the age of the individual. In the present study, there were indicators of a preference for disengaging from interactions with others in an attempt to self-calm. Some of the participants indicated they preferred to have silence when becoming frustrated. This was accomplished by taking a quick mental break, sometimes to another room, and other times staying where they were and simply shifting his or her attention to something else for a brief time before resuming a task. Some reported that it was helpful to divert their attention to other things such as focusing on an area of special interest, watching cartoons, or playing games on a cellphone. It was important to them to be able to implement a calming strategy right away before things escalated further and they lost emotional control. The author urges that the preferences for calming activities are highly variable necessitating that the adolescent be involved in identifying calming preferences at a time when he or she is well regulated. Honoring the attempts at self-regulation means granting access right away, or as soon as possible, to the strategies indicated as calming by the individual with ASD. This also means respecting individual differences in what others may view as calming or regulating. Sometimes, individuals with ASD may find activities calming that others of similar age without ASD do not understand. For example, a person with ASD may find staring at a fish tank, swinging, rocking, or sitting in complete silence calming. As James Bond1 eluded in his interview, honoring his need to attempt to self-calm when first requested may reduce the risk of advanced dysregulation and angry outbursts.

Recommendations for Peers

It is important to become educated on the core symptoms of ASD. There are many misconceptions about ASD. Just like any other person, those affected by ASD are individuals with unique abilities, strengths, needs, and interests. One of the main struggles shared by people with ASD are difficulties in communicating with others, even if they have a huge vocabulary. It is helpful to give them extra time to process what they hear and then be patient with them when they try to explain something. Sometimes, they may seem to visualize something in their head while describing it and do not always recognize or get to the main point of what they are saying quickly. Talking with teachers and other professionals with expertise about ASD is the best way to learn more and to determine what is important to know. One way to learn more is to locate both fiction and non-fiction books and materials about people with ASD. It is important to obtain a list of credible materials from someone who has expertise in ASD since there is an abundance of misinformation readily available.

People with ASD struggle with managing their emotions, but they are not by their nature violent people. Sometimes, when emotions overtake them they may cry or do things that make them look younger than they are. It is embarrassing to them to lose control of their emotions in front of others. Some people with ASD call these experiences meltdowns, but the terms people use are highly individualized. If they are having a meltdown, many prefer to have quiet and to be left alone. Sometimes, it can be calming to take a break alone or to focus on something that is of great interest to them. This author recommends learning how to help them by talking with them when they are calm, and determining what helps them when they are starting to feel frustrated.

Even though it may not always seem like it, people with ASD want friends. They are not always sure how to go about meeting people, striking up a conversation, or how to keep a conversation going. People with ASD frequently have a communication style that can be described as blunt. Most do not intend to be mean to others when they state something that they believe is true or obvious to them. Another area affecting people with ASD to some extent are repetitive behaviors, rigid adherence to rules, and having restricted interests. Examples of repetitive behaviors commonly seen include flicking their fingers, flapping their hands, or making nonsense noises. It is important to not draw significant attention to these things. Also, they may seem inflexible because of a rigid adherence to rules, but when viewed as a strength, it can be reframed that the person will likely be an honest and loyal friend. Finding a common interest can be helpful since people with ASD often have significant passion for a narrow range of subjects. Some of the interest areas are similar to those of other adolescents, while others may be very unique to the individual or even what would be more typical of a younger child. If the friendship is cultivated from a shared hobby, pastime, or interest there is research supporting that it will feel more natural and may result in an enduring friendship for everyone involved.

Recommendations for Researchers

The results of the current study emphasized the significant impact that predictability, routine, and written schedules had on the school environment for the participants. There is less research on the importance of this practice remaining necessary for adolescents with high functioning ASD. Increasing predictability through routines and schedules is commonly accepted as empirically supported, few studies specifically examine the perceptions of adolescents on how they prefer their teachers implement these practices. The same is true with regard to the use of accommodations and modifications within the classroom. Lists of commonly applied accommodations, modifications, and strategies to support individuals with disabilities can be located via empirical literature, internet searches, and within school based record systems, although there is scant empirical information on the efficacy of them with adolescents with high functioning ASD. More information is needed on how to determine which strategy to use, why it is helpful, and the preferences of the individuals with whom they are used with adolescents with ASD.

Peer mediated interventions are also considered an evidence based strategy for use with individuals with ASD, yet there is great variability in the levels of success documented. At present, most research has focused on contrived situations or the practice of peers without disabilities somehow helping his or her peer with ASD. Studies focusing on the implementation of more naturalistic interactions rooted in common interests are believed by this author to be a promising direction for future inquiry. It is hypothesized such interactions would exhibit greater social reciprocity through sharing interests and expertise. This line of research could further contribute to greater understanding in way to reduce the effects of pervasive bullying experienced by this population.

Significantly more research is needed on understanding and promoting emotional regulation in adolescents with ASD. The mechanism by which adolescents with ASD exhibit varying levels of insight into their regulatory needs remains a mystery. It is unclear which factors contribute to some individuals with ASD demonstrating greater emotional regulatory capacity than others. Further, there is a complete lack of research to guide professionals on ways to best support regulation in adolescents with high functioning ASD. It is this author's contention that the best source of acquiring this information is by asking those affected directly in order to gain insight into their preferences and why they think certain activities are helpful or not.

Limitations

Study limitations are primarily related to the nature of completing an independent, self-funded, qualitative research study coupled with the barriers associated in studying a population known to find social interactions taxing. The resulting small sample size within a relatively limited geographic region produced a pool of participants that may not be a representative cross section of adolescents with high functioning ASD. The use of snowball sampling, although an accepted research practice, does result in a lack of stratified sampling. This is further complicated by the number of potential participants identified who did not elect to pursue inclusion in the study due to anxiety over needing to meet with a person with whom they did not know well.

Despite the limitations identified, this study does give voice to an under-represented group whose perspective is largely absent from the current literature base. To address the limitations in future studies, the author recommends consideration of multiple methods for collecting data. This could include the use of an online survey with short answers or remaining open to completing interviews using typed interactions similar to text over social media as this is currently a popular communication technique with adolescents in general. Enlisting additional researchers in other locations could produce a larger, more representative group of participants. Irrespective of the limitations presented, this study identified numerous shared experiences and common perceptions across the participants' school days. The study provided a meaningful glimpse into their collective experiences, what they needed, and how they wished to be supported in school. This information, coupled with what is known about evidence based practices, can serve as a starting point for engaging other adolescents with ASD on what is likely to be helpful to them with the result being more effective, targeted supports and interventions.

APPENDICES

Appendix A
Invitation to Participate in Study

Do you have a child with high functioning Autism Spectrum Disorder (ASD) who is in Middle School?

If so, I want to visit with them about their experiences in school.

I am conducting a study with middle school age kids who have high functioning ASD in order to learn about their school experiences. I believe that kids with ASD have a lot of important things to say, yet no published research has done this yet.

<u>Frequently Asked Questions:</u>

- How long is this going to take? About an hour
- Where do we meet? Anywhere, as long as a parent is close by
- Who can participate? Anyone in 6th, 7th, or 8th grade who has an ASD
- Do participants have to be on an IEP? No. Some kids with ASD need that and some don't
- Does it matter what type of school the child attends? No. Participants can be homeschooled, in private school, or in a public school setting

If you are willing to consider allowing your child to participate in this study, please contact me at:

Shannon Grave
701-200-5421 cellular phone
shannon.grave@und.edu

"School Experiences of Adolescents with Autism Spectrum Disorders"
University of North Dakota IRB-201311-155

Appendix B
Interview Protocol

Parents will be asked to stay in earshot or direct line of sight. Parents will be asked to provide any copies of records they think would be helpful. This could include a copy of the child's IEP, past assessments, or any other records that may provide more information or insights to make the interview more meaningful.

Review consent process. Obtain signed consent and assent forms before beginning.

Structure of Interview

I am wanting to hear about your experiences during a typical school day. To help keep us focused, I would like to make a written schedule of a typical school day for you. This will help us remember to talk about all the parts of your day. I am going to be asking you about your experiences across the whole day. I want to know if there are things that teachers and others do that is helpful as well as those things that may be hard or frustrating for you.

1. Work on developing written schedule of a typical school day with the participant.
2. After the schedule is developed, begin at the beginning and work in a linear sequential manner until the end of the day is reached. Adjust accordingly if the participant wants to skip to different parts of the schedule in order to keep her/him engaged in conversation.

Interview Questions:

1. Tell me what this class period is like for you.

2. I want to hear about the things the teacher does that is helpful and maybe not so helpful.
    a. Are there things that the teacher does that is helpful? If so, can you give me some examples?
    b. Are there things the teacher does that is frustrating for you or that make it hard for you? If so, can you give me some examples?
3. What about the other students in the class?
    a. Are there things that they do that help you? If so, can you give me some examples?
    b. Are there things other students do that annoy you? If so, can you give me some examples?
4. Do you ever take breaks during school when everyone else is still working or listening to the teacher? What is that like?
    a. How do you know when you need a break?
    b. How do you go about getting a break? How does it work?
    c. Are they helpful? Why do you think they are helpful?
    d. Is there something people could do to make it more helpful? If so, can you give me some examples?
5. At very end of interview: If there is anything else you think that people should know about working with kids with ASD, please tell me.

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