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# Exploring Residence Life Needs of College Students with Autism Spectrum Disorder in Their Transition to College

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**EXPLORING RESIDENCE LIFE NEEDS OF COLLEGE STUDENTS WITH AUTISM  
SPECTRUM DISORDER IN THEIR TRANSITION TO COLLEGE**

A dissertation submitted to  
the Graduate College of  
Marshall University  
in partial fulfillment  
of the requirements  
for the degree of  
Doctor of Education

In  
Curriculum and Instruction  
by

Jaclyn Clark

Approved by

Dr. Edna Meisel, Committee Chairperson

Dr. Michael Cunningham


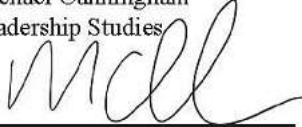
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December, 2018

APPROVAL OF DISSERTATION

We, the faculty supervising the work of **Jaclyn Clark**, affirm that the dissertation, *Exploring Residence Life Needs of College Students with Autism Spectrum Disorder in their Transition to College*, meets the high academic standards for original scholarship and creative work established by the EdD Program in **Curriculum and Instruction** and the College of Education and Professional Development. This work also conforms to the editorial standards of our discipline and the Graduate College of Marshall University. With our signatures, we approve the manuscript for publication.

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## **DEDICATION**

This dissertation is dedicated to my family; Willy, Penelope, and Oliver. You have all helped me to better understand hard work, resiliency, and love. Thank you for making me a stronger and better person, I love you!

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## ABSTRACT

The purpose of this study was to explore the housing and residential supports of first-year college students diagnosed with Autism Spectrum Disorder (ASD). Specifically, this study utilized a Delphi Survey method to reveal the necessary resident life needs, potential barriers, and effective supports for first-time college students with ASD. Professionals from the field of autism, housing and resident life departments, and individuals diagnosed with autism served as the panel of experts (n=14). Participants identified that effective supports should include the following areas: campus-based professional expertise, communication supports, day-to-day activity supports, organizational and executive function supports, and social interaction supports.

*The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD*

*Transitioning to College* was an outcome of the research and is proposed to be used as representative list of programmatic suggested supports within housing and resident life departments.

# CHAPTER 1

## INTRODUCTION

### **Background**

Students diagnosed with an Autism Spectrum Disorder (ASD) are enrolling in increasing numbers on college campuses. Combined with the increasing prevalence of persons diagnosed with an ASD, including those who have average or above intelligence, obtaining a post-secondary degree is becoming increasingly common (Centers for Disease Control and Prevention, 2014; Christensen et al., 2018; Jackson, Hart, & Volkmar, 2018) for this demographic. First-time college students diagnosed with an ASD who choose to live on campus are met with unique academic, social, and independent living barriers that directly relate to characteristics of the disorder. Transition supports that specifically address the distinctive needs of students with an ASD are essential components for a positive college experience. Whereas research on the academic and social needs for transitioning college students with ASD has been explored (Dillon, 2007; Graetz & Spampinato, 2008; VanBergeijk, Klin, & Volkmar, 2008; Brown, Wolf, King, & Bork, 2012; Ellison, Clark, Cunningham, & Hansen, 2012; Longtin, 2014; Garland, 2015) the unequivocal focus on resident life needs of this group is limited.

### **Statement of the Problem**

Empirical research with a focus on the residential needs of freshmen students diagnosed with an ASD has not yet been examined in the literature. Indeed, research that includes perspectives of experts within the field of autism, those who have worked in resident services, and most importantly, those diagnosed with an ASD has not yet been produced. It is crucial that the perspectives of adults with an ASD are included in this research. The tool of using self-

narrative and personal accounts can aid in the understanding of the unique needs and in the implementation of the appropriate supports on a college campus (Young & McKibban, 2013; Renn, 2000).

### **Purpose of the Study**

The current study proposes to research and explore the phenomenon of housing and residence hall-based supports for freshmen students with ASD. The research will be useful to college administrators in understanding as they seek to enhance the experience of first-year college students with ASD living in a residence hall. The study will provide insight into the perspectives of the necessary resident life needs and most successful supports as pulled from a panel of experts within the field of autism, the department of housing and resident life, and from those diagnosed with ASD. It is intended that a possible outcome of the research will be to produce *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College*.

### **Rationale of the Study**

This research will be useful to high-school teachers and support staff that help students with ASD and their families with the transition planning piece of the Individualized Education Plan (IEP). Transition planning for college living is important for high school students with ASD who are graduating so they may be better prepared for living on a college campus. Educator perceptions of supporting students with ASD in the transition plan process gained from this research could fill in gaps to the current body of scholarly literature. The information gathered from the research would also be valuable for university housing and residence life staff members to better understand and support college students with ASD living on a college campus.

In addition to university staff, the larger student resident population may also benefit from the research to allow for better understanding and greater awareness of living with peers with ASD. This research may be useful to professionals within the field of autism so they may successfully support students with ASD in their transition to adulthood. Finally, the research could benefit future college students who have a diagnosis of ASD in their transition to living on a college campus.

### **Research Questions**

The questions guiding the research are:

- 1) What are the specific housing and residence needs of students in the first-year transition to college?
- 2) How do specific housing and residence transition needs of students with ASD differ from neurotypical freshmen?
- 3) What supports, if any, are housing and residence life staff utilizing to provide effective supports, if any, for first-year college students with ASD?
- 4) What are reported barriers or challenges in providing effective housing and residence life supports for first-year college students with ASD?
- 5) How can housing and residence life staff provide support that adapt to the social and communication needs of first-year students with ASD?

### **Operational Definitions**

**Autism Spectrum Disorder.** Autism Spectrum Disorder (ASD) is a complex neuro-developmental disorder that is diagnosed through the observation of clinically significant impairments in social communication and social interaction, and rigid, repetitive patterns of

behavior. (American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) 2013). To meet diagnostic criteria, characteristics of the disorder must be present in early childhood. The diagnosis of an ASD is currently accompanied with one of three tiers that range in level of severity from: level 1 'requiring support,' level 2 'requiring substantial support,' to level 3 'requiring very substantial support' (APA, 2013).

**Autism Spectrum Disorder supports.** Refers to unique and individualized social communication and interaction, as well as behavioral interventions, needed for college students with ASD. Examples may include: visual schedules aiding in time management organization, and written scripts and role-playing activities aiding in the understanding of social competence (Dillon, 2007; Rochester Institute of Technology, 2014).

**Asperger's Disorder.** The condition called Asperger's Disorder, taking the name of Dr. Hans Asperger, became internationally known in the early 1980s through the work of Dr. Lorna Wing (Smith, 2007). First appearing in the 1994 DSM, under the classification of "Pervasive Developmental Disorder," the most current APA (DSM-5) involved the elimination of the diagnosis "Asperger's Disorder" and re-naming the diagnostic category "Autism Spectrum Disorder" ([APA], 2013). The distinctive feature that varied between an individual diagnosed with Autism Spectrum Disorder and an individual diagnosed with Asperger's Disorder was that there were no clinically significant delays in language development, cognitive development, or adaptive behavior in the first three years of life for individuals with Asperger's Disorder (APA, 2000).

**Barriers and Challenges.** Refers to the panel of experts' self-reported responses to an open-ended question on the Delphi survey, provided in the Appendix, describing the trials that

hinder college residence staff from providing the most effective supports for first-year residents with ASD.

**Neurotypical.** Term often used to describe individuals without a diagnosis of ASD (Jordan & Caldwell-Harris, 2012).

**Delphi Method.** The Delphi Method is a type of survey used in research that includes anonymous participants who hold expertise on a given topic (Brady, 2015). The procedure typically includes participants responding to several rounds of open-ended questions and/or Likert Scale items (Krell & Pérusse, 2012). Responses from each round are analyzed and are used in shaping the set of questions for the next round, until finally a consensus is reached (Delbecq, Van de Ven, & Gustafson, 1975).

### **Summary of Methods Used**

The research method for this study will be to use the Delphi Method (Delbecq et al., 1975) to design a survey to assess the specific needs and potential barriers in providing effective supports for first-year students with ASD in their transition to living on a college campus. The Delphi technique will be used in this research to seek out information and determine if there are emerging patterns or consensus on the experiences of first-year students with ASD living on a college campus. Through purposive sampling, proposed participants will have experience in: 1) freshmen housing and residence living, 2) supporting college students with ASD, and 3) college students with ASD. The Delphi method elicits feedback from a group of individuals who are selected based on their expertise on a topic (Brady, 2015). This research will purposively seek out approximately twenty individuals who have expertise in three distinct areas: 1) experience in working in a college freshmen housing and residence life department, 2) experience in working



with college students with ASD, and 3) adults with ASD who have lived in a college residential hall.

The Delphi method is appropriate with this type of study because the panel of experts will consist of participants who are located across the nation. Several email listservs, such as a housing and residence life list and a college support of students with ASD list, have been provided to the researcher that will be used in attempts to elicit participants. Electronic delivery of questionnaires can be readily disseminated. The Delphi process typically consists of three rounds of questions. Responses from each round are analyzed and are used in shaping the set of questions for the next round, until a consensus is reached (Delbecq, et al., 1975). Once a consensus is reached by the research and the participants, a possible goal is to produce a comprehensive tool that can be used for institutions of higher education in their support of residents with ASD. The title of the final product will be *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College*.

### **Assumptions of the Study**

The Delphi survey will be sent to a panel of experts within the field of autism, housing and resident life departments, and individuals with ASD. It is assumed that all participants will be chosen for their high-level of knowledge regarding the focus of the study in college-based resident life needs and supports for first-year residents with ASD. It is also assumed that all participants will provide honest and accurate responses to the questions of the survey.

### **Limitations and Delimitations of the Study**

Because the Delphi-survey will be sent to approximately twenty experts comprised of those within the field of autism, those within housing and resident life departments, and

individuals with ASD, the sample size is limited. The researcher will conduct an exhaustive participant search via email listservs through professional based autism networks and college-based residence life departments that have either had experience in supporting residents with ASD or anticipate will eventually have residents with ASD. The participants are planned to be included from various geographical regions across the nation. The Delphi method will have some wait time, due to the nature of rounds that are involved, where the preceding response data must be analyzed to form the next round of questions/scaled information (Brady, 2015). For this reason, the researcher plans to provide response deadlines with each round so that responses can be analyzed in an appropriate manner.

## **CHAPTER 2**

### **REVIEW OF LITERATURE**

#### **Introduction**

The transition from high school to college requires a great deal of independent social navigation of a new environment. First-time students living on a college campus must maneuver a different world with new complex procedures. Recognizing, understanding, and following these processes are integral to a successful transition. Failure to navigate these new surroundings may cause resident life staff, professors, and classmates to have a negative perception of a student. This transition can be daunting and carry a host of significant challenges. Freshmen college students leave the familiarity of their homes, families, and routines; often for the first time, to live in a completely foreign situation. Students must learn how to co-habitat with strangers, engage in mandatory meetings, make use of public restrooms, showers, and other necessary independent living facilities. This transition will be particularly challenging for those students who are diagnosed with an Autism Spectrum Disorder, whose chief struggles are within social communication and social interaction. This chapter will describe the evolution in the understanding of Autism Spectrum Disorder and explore the specific struggles that students with Autism Spectrum Disorder face when living on a college campus. The chapter will also address the information that exists for supporting college students diagnosed with an Autism Spectrum Disorder who are transitioning to living on a college campus.

#### **Autism Spectrum Disorder (ASD)**

Autism Spectrum Disorder (ASD) is a complex neuro-developmental disorder that is diagnosed through the observation of clinically significant impairments in social communication and social interaction, and rigid, repetitive patterns of behavior set by criteria defined in the

American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* (2013). Autism has evolved greatly since first described by American child psychologist Dr. Leo Kanner in 1943 (Taylor, 2005). Kanner described children with extreme inabilities to develop relationships, exhibited repetitive and stereotyped patterns of play, displayed abnormal fixations, and social communicative delays (Taylor, 2005). Unaware of Kanner's work, German Dr. Hans Asperger described cases of children with similar tendencies in 1944. Dr. Asperger's work was published during the time of World War II and was not widely read (Smith, 2007). The condition called Asperger's Disorder, taking the name of Dr. Hans Asperger, would not become internationally known until the early 1980s through the work of Dr. Lorna Wing (Smith, 2007). Wing's (1981) *Asperger's syndrome: a clinical account* discussed the observations of Asperger's 1944 work, as well as 34 case studies of individuals examined and diagnosed with Asperger's disorder by Wing (Wing, 1981). Wing (1981) suggested that Asperger's disorder, along with distinct clinical observations, should be diagnostically identified as its own entity (Wing, 1981). Asperger's disorder diagnostically first appeared in 1993 with other autism spectrum disorders in the DSM-IV/ICD-10 editions of the international classifications systems, under the heading "pervasive development disorder" (World Health Organisation, 1993; Wing, 2005). Describing and naming Asperger's disorder led to greater public understanding of the skills and challenges associated with the disorder, as well as access to specialized services and resources to individuals and their families (Wing, 2005).

The most current APA (DSM-5) involved significant changes that included the elimination of the diagnosis "Asperger's Disorder" and re-naming the diagnostic category "Autism Spectrum Disorder" ([APA], 2013). The distinctive feature that varied between an

individual diagnosed with Autism Spectrum Disorder and an individual diagnosed with Asperger's Disorder was that there were no clinically significant delays in language development, cognitive development, or adaptive behavior in the first three years of life for individuals with Asperger's Disorder (APA, 2000). Although individuals with an autistic disorder may present with cognitive difficulties and other impairments, the majority of those diagnosed with Asperger's Disorder typically have IQs that are of normal to gifted levels (Graetz & Spampinato, 2008). Because an ASD diagnosis now falls on a continuum, symptoms are wide-ranging. The diagnosis of an ASD is currently accompanied with one of three tiers that range in level of severity from: level 1 'requiring support,' level 2 'requiring substantial support,' to level 3 'requiring very substantial support' (APA, 2013).

Individuals with ASD face lifelong challenges in the areas of social interaction and communication, in addition to demonstrating restricted and repetitive patterns of behaviors, interests, and activities (APA, 2013). The Center for Disease Control and Prevention (2018) reports the current prevalence of ASD as 1 in 59 children (Christensen, et al., 2018). Prevalence has increased dramatically during the last several decades, as what is understood to be 'autism' has evolved significantly. The ability to understand and better diagnose ASD, early intervention and treatment, as well as heightened public awareness have all been factors that have contributed to the increase in prevalence (Centers for Disease Control and Prevention, 2014). An ASD diagnosis was once associated with low-levels of cognitive ability, but current research shows that nearly 50% of individuals diagnosed with an ASD have average to above average intelligence (Adreon & Durocher, 2007; Centers for Disease Control and Prevention, 2014; and Cai & Richdale, 2016). Thus, more and more young adults with an ASD have the academic aptitude and intellect to successfully attend institutes of higher education.

Dr. Marc Ellison, director of the West Virginia Autism Training Center, (2012) spoke at the 42<sup>nd</sup> annual Autism Society of America national conference, describing his work with a college student with ASD. Ellison (2012) illustrates the social communication, social interaction, and behavioral challenges the student with autism faced when living on a college campus:

*“I received a call from the front-desk clerk at Holderby Hall, saying,*

*“John is playing pool in his underwear again.”*

*“Again?” I said.*

*“Yes, we were hoping that he would eventually realize that it was inappropriate, but he hasn’t caught on yet,” the front desk clerk answered.*

*Marc met with John to discuss the seriousness of what just transpired. When asked why John thought it was OK to play pool in the common shared space of a dorm in only his boxer shorts, John replied,*

*“Well, when I moved in the RD [Resident Director] told me to ‘make myself at home’ and at home, I have a pool table at my house that I play every evening in my boxer shorts.”*

Fortunately, this scenario was easily resolved with consistent communication about the situation as well as a visual tool that hung on the back of John’s dorm door that reminded him to wear appropriate clothing when leaving his room. Unfortunately, this is not the case for many with ASD. The instinctual nature of social interaction that includes the ability to relate to others and the understanding of how to best respond to both verbal and nonverbal communication is not formed the same for those with ASD (Pierangelo & Giuliani, 2008).

### **ASD and Higher Education**

“The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act ensures that any person with a disability will not be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity of a public entity”

(Garland, 2015, p. 57). This historic piece of legislation is the avenue for which college students with disabilities gain accessibility and accommodations. Many incoming college freshmen and their families who have guided the support services process, do not understand how the laws that govern the college experience will differ from their K-12 education. College students with a documented disability are now responsible for playing the lead role in accessing and advocating for their needed accommodations and resources. Students must self-disclose their disability to the appropriate office on campus, typically through the university disability office, in order to seek accommodations. This dramatic shift in responsibility can be problematic for college students with disabilities for a variety of reasons, such as: inexperience with self-advocacy, no current documentation of their disability, and no sound understanding of the functional limitations of their disability (Graetz & Spampinato, 2008; Brown, et al., 2012; Longtin, 2014; Garland, 2015).

Although ADA is supposed to provide accessibility and protection from discrimination, the language used within the law is general and subject to interpretation for college administration and support staff. For example, “reasonable accommodations” are generally designed to help students remove any barriers or limitations that would otherwise prevent the student from completing the task. A well-known and common academic accommodation for those with processing delays for example, would be extended time on an exam in an isolated environment with an assigned test proctor (Brown, et al., 2012). Although college students with ASD have the potential and academic intellect to perform well, needs of these students tend to go outside the scope of traditional academic accommodations. Challenges related to executive functions of planning, organizing and time management, as well as social communication difficulties directly related to the disorder, can become problematic during the college experience

(Dillon, 2007; Longtin, 2014). The everyday social demands of a college environment can be extremely overwhelming and anxiety producing for students with an ASD.

Dillon (2007) discussed the unique needs of students with ASD and how critical individualized support is for success. Challenges associated with ASD can manifest in areas of classroom behavior and expectations that can greatly affect students' reputations, such as talking too much in class or not speaking at all (Dillon, 2007). Students with ASD have deficits related to executive functioning; the cognitive process responsible for self-regulation and goal-directed activities that involve planning, organization, and time-management (Anderson & Butt, 2017). Common daily tasks like adhering to deadlines, punctuality to class, and flexibility with emotional impulse, can be extremely difficult for college students with ASD (Anderson & Butt, 2017; Dillon, 2007; VanBergeijk, et al., 2008). Social interaction, such as not understanding how to become engaged in campus-based involvement, is another barrier for college students with ASD. The social communication challenges that exist for college students with ASD, such as not understanding others' points of views and struggling to interact with peers and professors, can ultimately lead to problems within the classroom (Longtin, 2014; Cai & Richdale, 2016). Because of the diversity of issues for students with ASD, there is no single method of support (Dillon, 2007).

There has been some research that examines the needs of post-secondary students with ASD. Some of these studies have focused on the traditional academic needs of students with ASD within the classroom. The Organization for Autism Research developed *Understanding Asperger Syndrome: A College Professor's Guide*, an informational video piece that provides college educators strategies and advice in the preparation for instructing college students with Asperger's Syndrome (Organization for Autism Research, 2011). Items like providing clear



academic classroom expectations and being thoughtful of sensory overloads, such as florescent lighting, are suggestions that are made in the video for educators in higher education (Organization for Autism Research, 2011). Rochester Institute of Technology (2014) developed *Emerging Practices for Supporting Students on the Autism Spectrum in Higher Education: A Guide for Higher Education Professionals*, a manual proposed to help institutions of higher education be best prepared to work with students with ASD. The manual provides an overview of ASD, common challenges for college students, and then a proposed action plan of suggested supports, including a Support Model Planning Worksheet (Rochester Institute of Technology, 2014). Current research also suggests the use of peer mentors as beneficial for self-esteem, social anxiety, and social connectedness for young adults with ASD (Curtin, et al., 2016; Robledo & Donnellan, 2016).

Existing research that includes perspectives from interviews with students with ASD and in some cases, family members, share a common theme that identifies a greater focus on the social needs of students with ASD outside of the academic setting (Anderson & Butt, 2017; Cai & Richdale, 2016; Madriaga, 2010; and Mitchell & Beresford, 2014). Ellison, Clark, Cunningham, and Hansen developed *The Benchmarks of Effective Supports for College Students with Autism Spectrum Disorders*, a tool that is used to identify the readiness of an institution of higher education in its' academic, social, and independent living supports for students with ASD (Ellison, Clark, Cunningham, & Hansen, 2012). Although *The Benchmarks of Effective Supports for College Students with Autism Spectrum Disorders* is beneficial in recognizing if colleges have the most effective supports for students with ASD, there is not a specific component that addresses the transition to residence life in how to carry out the most effective supports for freshmen students living in residence halls. An existing tool that does focus on the needs of

resident staff in supporting students with ASD was created by psychology student, Tara D'Andrea. D'Andrea (2016) created the tutorial based on her research survey that quizzed resident staff on their knowledge of handling certain situations with residents with ASD (D'Andrea, 2016). Generally, there is a paucity of information and research that directly relates to the residential needs of first-year college students with ASD, and specifically including the perspectives of students with ASD.

### **Transition to College for Students with ASD**

Institutions of higher education have a strong focus on retaining students, as this is often used as an indicator of success for policy makers. Research has shown that the transition year, specifically the first few weeks on a college campus, is related to retention and ultimately graduation (Jacobs & Archie, 2008; Morrow & Ackermann, 2012; Tinto, 2001; Woosley, 2003). In the fall of 2015, according to The National Student Clearinghouse Research Center (2017), 26.6% of first-year college students did not return for their sophomore year (NSCRC, 2017). Although the number of college ready students with a diagnosis of ASD continues to grow, there is limited research on how to best support the transition to college for academic and social success.

Transitioning college freshmen often experience a dramatic shift where they are now expected to be personally responsible in all aspects of their academic and social lives (Chow & Healey, 2008). Students are expected to be an active participant in all realms of college life, from constructing knowledge within the classroom to involvement in campus-based organizations and activities outside of the classroom. This transition is even more daunting for those students with ASD who struggle greatly with the social and communicative demands of college life. The research of Valérie Hees, Tinneke Moyson, and Herbert Roeyers (2015)

focused on identifying the transition needs of college students with ASD through semi-structured interviews with over twenty students diagnosed with ASD. Transition needs of preparation for unexpected changes, new environments, social relationships, information processing, and issues related to disclosure were themes that emerged from the research (Hees, Moyson, & Roeyers, 2015; Anderson & Butt, 2017). The Stepped Transition in Education Program for Students with ASD (STEPS), described by White et al., (2017) is currently being evaluated in a randomized control trial. STEPS has a two-step curriculum that focuses on the transition into college for high-school students (step 1) and ongoing support for college students (step 2) with ASD (White, et al., 2017). The transition needs identified within the existing research are all related to core features of ASD that share common themes of needed supports beyond academic scopes. It is noted that transition needs for college students with ASD have clearly defined procedures, such as manuals, while simultaneously also allowing for personalization and flexibility based upon meeting students' varying needs (White, et al., 2017).

Traditionally, supports for college students with disabilities has primarily been focused on the academic needs of students, such as access to assistive technology, extended time on examinations, and note-taking. College places a heavy concentration on academic supports and often neglects the housing and residence life needs for students with varying disabilities (Davidson & Bauman, 2013). ASD is a lifelong developmental disorder that presents the individual challenges with social interactions and communication, in addition to demonstrating restricted and repetitive patterns of behaviors, interests, and activities (APA, 2013). ASD is often referred to as an “invisible disorder,” because individuals with ASD do not commonly require obvious environmental supports to move about the community. Because individuals with ASD experience severe challenges with everyday social interactions, the overall college

experience, and most notably living in a residence hall, may be overwhelming. It is proposed that the results of this research will enhance the experience of first-year college students with ASD living in a residence hall. Specifically, the research hopes to produce a comprehensive tool, using the Delphi Method, institutions of higher education may use to best support students with ASD in a residence hall setting.

### **Residence Hall and ASD**

The notion that the purpose of a residence hall is to support the holistic development of college students is not new. James A. Wallace's (1980) article, *The Philosophy of University Housing*, advocates for an environment that fosters a sense of community through the encouragement of students' personal, intellectual, and social growth. Wallace (1980) suggests those actions fit with the purpose of the university at large. Some research has shown that campuses that have residential components may have some positive outcomes in many facets of college life, such as residents with higher grade point averages, overall retention boost, and increases in student satisfaction reports (Shushok & Manz, 2012). Meeting the holistic needs of students with ASD in the college housing environment is something that is critical to the growing numbers of students with ASD transitioning to college. The supports that students with ASD need that fall into the realm of social interaction, communication, and executive dysfunction all are essential components in living independently on a college campus.

The obstacles of living in a residence hall on campus can be extremely challenging. Students may have to share living spaces and bathrooms with strangers, attend required meetings, and adjust to changes in routines like random fire drills. To be successful, students must know when and how to self-advocate for their needs. This new lifestyle is riddled with "hidden" regulations that can be overwhelming for any student, but especially so for students

who have a diagnosis of ASD who experience major challenges with the social and organizational demands of college. As the autism spectrum has broadened and students with ASD have learned skills necessary to live more independently, the prevalence of ASD has also increased within higher education. Because college students with ASD represent a consistently growing population it is important for university faculty and staff to understand how to best support them in their college journey (Brown, et al., 2012; VanBergeijk, Klin, & Volkmar, 2008).

There is a dearth of research that has specifically addressed the needs of the growing population of college residents with ASD. Ackles, Fields, and Skinner (2013) proposed that purposeful collaboration of varying campus departments, specific training focused on ASD, early arrival and mentorship programs are needed components in successfully supporting student with ASD in a resident hall setting. In the proposed model by Ackles, et al., (2013) a certain level of disclosure by residents with ASD is needed for the components to be carried out. Disclosure is a very personal decision that is highly individualized and varies between each person. A typical question that many students face is whether a disclosure of a diagnosis of ASD is more beneficial or harmful to resident hall staff. Thus, research that focuses on housing and resident life staff's knowledge of ASD, perceptions of what is needed from those students with ASD and identifying possible barriers between the two is critical in understanding the most effective supports for new residents with ASD. Longtin (2014) also discusses the need for coordination and collaboration of campus-based resources and departments, including residence life, in supporting the needs of college students with ASD. Specifically, Longtin (2014) suggests that residence life and disability offices coordinate to address issues of needed accommodations for sensory overload, as well as social communication challenges that are typical for residents with ASD.

## **Disclosure and Impression of ASD**

Individuals living with an ASD face lifelong challenges that are related to social communication and interaction. To receive accommodations or related services as an adult with ASD, individuals must disclose their disability, self-advocate, and often provide disability documentation. The social communicative skills that are needed for this level of advocacy can be challenging for individuals with ASD. Stigmatization may also occur because the challenges associated with ASD often manifest themselves in behavior which sets those on the autism spectrum apart from others. Disclosure of their diagnosis is an important part of the lives of those with ASD and can ultimately also be a struggle in deciding who they should disclose to and when would be the optimal time.

Questions as to whether freshmen diagnosed with ASD should disclose their disorder are increasingly common in a college setting. Further, addressing who to specifically disclose to - such as professors, university staff, and peers - are integral to the preparation for college. Students with ASD who live in a residence hall question if they should share their diagnosis with their roommates, other peers living on their floor, and residence staff. According to ADA (1990), students with disabilities have equal access, but must disclose their diagnosis to gain the appropriate accommodations (Brown, et al., 2012). However, due to everyday struggles of social communication, students with ASD may not have the skill set to disclose and advocate for the accommodations they need.

The potential stigmatization that may accompany a disclosure of ASD has been explored. Existing research focused on the presence of increased stigma when examining the various labels and behaviors of ASD with and without a disclosure has produced varying results of stigmatization (Butler & Gillis, 2011; Kite, Gullifer, & Tyson, 2013; Ohan, Ellefson, &

Corrigan, 2015). The decision to disclose one's disability is deeply personal, and fear or concern of judgement or stereotyping is often enough to prevent one from sharing private information within a higher education environment. Research on "thin slice" judgements by Sasson, et al., (2017), found that observers' first impressions were rated as far less favorable for those participants with ASD when compared to first impressions of typically developing participants when engaging in real-world social behavior (Sasson et al., 2017).

A large and crucial component of college is a successful independent living experience within the resident hall setting. Regardless of diagnostic labels and whether a student discloses, the number of college students with an ASD is ever increasing. Because many individuals with an ASD struggle with something called, "Theory of Mind Deficit," substantial difficulty in developing an awareness of what's in the mind of another; misunderstanding and problematic interactions between fellow peers and staff within the residence halls is likely to occur (Pierangelo & Giuliani, 2008). The behaviors often associated with ASD may lead to significant problems simply due to a lack of understanding of the needs and most appropriate supports within a residence hall setting (Livingston, et al., 2013).

### **Benchmarks for Supporting Students with ASD in a Residence Hall Setting**

Identifying an expert-based criterion for supporting first-time college students with ASD in a resident hall setting is very important in higher education. It is clear from the literature review that the number of students diagnosed with an ASD who are transiting to college continues to be on the rise. Since an ASD is a lifelong developmental disorder that presents the individual not only challenges with social interactions and social communication, but a restrictive focus on fixed interests and topics, transition to essential adulthood items, such as post-secondary education, can be quite difficult (Graetz & Spampinato, 2008). Because the

unique needs of college students with ASD typically fall within the broad scope of social communication and social interaction, providing benchmarks of effective supports that fall within these categories is critical. Providing housing and resident life staff with the necessary tools that would aid in effectively supporting this unique population is essential for professional development. The proposed research will include the perspectives of experts who will identify the types of supports that are required for freshmen college students with ASD living on campus in the areas of social communication and social interaction, and restricted, repetitive patterns of behavior, interests or activities.

Research and anecdotal evidence suggest that although people with ASD experience diagnostic symptoms on an individual basis, each person must meet specific DSM-5 diagnostic criteria in the following areas: persistent deficits in social communication and social interaction, and restricted, repetitive patterns of behavior, interests or activities (APA, 2013; Rochester Institute of Technology, 2014; Anderson & Butt, 2017). According to the DSM-5 (2013), social communication and social interaction challenges can fall into the areas of social-emotional reciprocity, the understanding of relationship development, as well as the proper use of non-verbal communication used for social interaction, including verbal cues and facial gestures (APA, 2013). The inability to read social cues and the awareness of this social dilemma can create anxiety, as well as impact college students' confidence to socially engage. Research that includes interviews that highlight the perspectives of college students with ASD and their families, provided narratives that detailed difficulty in navigating and participating in social aspects of college life (Madriaga, 2010; Hees, Moyson, & Roeyers, 2015; Anderson & Butt, 2017). Participants described social dilemmas of not knowing when to ask questions in class or not understanding how to access social networks (Hees, Moyson, & Roeyers, 2015), anxieties



about entering public spaces to the ultimate point of exclusion (Madriaga, 2010), and not understanding the self-advocacy and initiation to receive appropriate accommodations (Anderson & Butt, 2017).

Restricted and repetitive types of pattern can include: insistence on sameness, highly fixated interests that are often abnormal in intensity, stereotyped patterns of behavior, object, or speech, and hyper or hypo sensitivity to the environment and its' surroundings (APA, 2013). This rigid way of thinking and inflexibility makes changes extremely difficult for students with ASD, thus it is not surprising that the transition to the new environment and way of living in college would be distressing. Research has demonstrated that students with ASD experienced a smoother transition when the change was planned during high-school, with a well-developed transition plan component of the Individualized Education Plan (IEP) that details appropriate supports at the college level and campus-based visits prior to attendance to adjust to the campus life (Holtz, Owings, & Ziegert, 2006; VanBergeijk, Klin, & Volkmar, 2008; Anderson & Butt 2017). Because many students with ASD have either hyper or hypo sensitive to sensory stimulation, the adjustment to a new environment can be extremely difficult. The research of Madriaga (2010) found that an awareness of one's hypersensitivities, such as sensitivity to noise and crowds, hindered students from participating in activities like orientation week's social outings, as well as the local hang-out spot, the 'pub' that would allow for social engagement within the college lifestyle.

### **Summary**

In the face of the burgeoning number of college bound and attending college students diagnosed with an ASD, best practice support research is limited. The research that does exist is limited, but limited existing and emerging research does share a common theme and suggests that necessary supports are well beyond the scope of academics and must be more holistic in

nature, including the social, communicative, and independent living needs (Anderson & Butt, 2017; Ellison, Clark, Cunningham, & Hansen, 2012; White, et al., 2017). Even more limited is research that has a focus on the needed supports for students with ASD who are making the transition to campus-based living in a residence hall. The social, communication, and independent living skills that are required for living in a residence hall are particularly challenging for students with a diagnosis of ASD. It is important that research efforts explore ways in which to enhance the first-year housing experience for college students with ASD. The benchmarks of best supports for campus-based living created from the perspectives of those with ASD, professionals working within residence life departments, and experts working in the field of autism is a possible outcome goal of this research.

## **CHAPTER 3**

### **METHODS**

The Center for Disease Control estimates currently 1 in 59 children in the United States live with an Autism Spectrum Disorder (ASD) diagnosis. Evidence suggests that nearly 50% of those diagnosed with an ASD have average to above average intelligence, making higher education a natural path for adults with ASD (Adreon & Durocher, 2007; Centers for Disease Control and Prevention, 2014; and Cai & Richdale, 2016). Although many first-time students with ASD have the academic intellect to enter college, many are unprepared for the social, emotional, and communication demands of living on a college campus. Current literature describes the common challenges faced for college students with ASD, as well as evidence based best practice supports (Anderson & Butt, 2017; Ellison, et al., 2012; White, et al., 2017). However, there is a dearth of information regarding the most effective living supports for first-time students with ASD who choose to live in a campus residence hall.

The purpose of this study is to explore the existing challenges and necessary elements in providing effective living supports to first-time college students with ASD living in campus residence halls. This chapter will describe the research design, the participants who were involved in the study, the research instrumentation used, the process of data collection, and the procedures used in the data analysis.

#### **Research Design**

The Delphi surveying method was used in this study to solicit information and gather insight from anonymous expert panel members (Brady, 2015) into the existing challenges and necessary living supports for first-time college students with ASD who reside on campus. The Delphi survey contains several rounds of open-ended questions and/or Likert scale items that are

sent in rounds until a consensus is reached (Delbecq, et al., 1975; Krell & Pérusse, 2012). The emergent data collected from each round then shapes the questions or scale ratings for the next round. The Delphi survey is appropriate for the research because it is designed to reach a population of experts with diverse backgrounds and extensive knowledge from various locations. One proposed product of the Delphi survey will be to produce a tool titled *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College* that will be used to train Residence Life staff in the support of first-time students with ASD living on a college campus.

### **Population and Sample**

Through purposive sampling, twenty-five experts were identified and invited to participate in an open-ended survey. The experts were selected based on their professional expertise within the field of autism, housing and residence services, and those diagnosed with autism. Participation was voluntary and participants in the study remained anonymous, identified in the study only as a number (Participant 1, Participant 2). The primary researcher invited panel members to participate via blind email on May 23<sup>rd</sup>, 2018 that contained the Institutional Review Board approval number and informed consent letter (Appendix A and B), as well as round 1 of the Delphi Survey (Appendix C). The informed consent letter detailed the purpose of research, the survey process, provided the known risks and benefits, freedom to leave the study at any point, as well as provided information about participation anonymity. The email asked for a participation reply of round 1 responses by May 31<sup>st</sup>, 2018. Fourteen of the twenty-five experts participated with round 1 responses by June 4<sup>th</sup>, 2018. The deadline was extended for a few experts who replied with an interest in participating but needed a few more days to respond.

## **Instrumentation**

The Delphi protocol was the instrumentation used in the research. The Delphi survey was designed to gather insight into the phenomenon of existing challenges and necessary supports for first-time college students with ASD living in a residence hall.

## **Data Collection**

The proposed outcome of the data will be to answer the research questions that seek to explore the phenomenon of effective living supports of first-year residents with ASD. The data will provide a possible product outcome, *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College*, a tool to be used in the training of college housing and residence life departments. The exchange of surveys and responses took place electronically via email and saved in multiple formats. The primary researcher provided panel members with specific dates for completion for each round of the Delphi survey.

## **Data Analysis**

The first round of questions that was sent to panel members were the research questions presented in Chapter 1:

- 1) What are the specific housing and residence needs of students in the first-year transition to college?
- 2) How do specific housing and residence transition needs of students with ASD differ than neurotypical freshmen?
- 3) What supports, if any, are housing and residence life staff utilizing to provide effective supports, if any, for first-year college students with ASD?

- 4) What are the reported barriers or challenges in providing effective housing and residence life supports for first-year college students with ASD?
- 5) How can housing and residence life staff provide support that adapt to the social and communication needs of first-year students with ASD?

Data received from round 1 was analyzed by two investigators. The primary researcher asked a colleague to be included in the research as a co-investigator. The co-investigator is a professional within the field of autism who has extensive experience in working with college students with ASD who reside on campus. The co-investigator also has knowledge and previous research experience in using the Delphi method. The primary researcher and the co-investigator independently analyzed each categorized response from each question from round 1. The responses from each question for round 1 were placed into categories in order from “most cited” to “least cited” according to the panel of experts, and the investigators compared answers to ensure a reliability.

The data from round 1 were then organized into emergent themes and placed into a matrix. The matrix was then emailed to the fourteen panel members on June 18, 2018 for round 2 (Appendix D) to either “agree” or “disagree,” as well as provide further explanation or new information when deemed necessary by the panel member. A deadline of June 25, 2018 was requested for completion of round 2. The fourteen panel members responded by June 27, 2018 to complete round 2. The primary investigator developed a table to track the fourteen responses according to “agree” “disagree” and “more information” based on each question and corresponding table from round 1. The research investigators determined at the start of round 2 that a consensus was reached when at least 12 of the 14 participants “agreed” with the research question and corresponding table from round 1. A consensus was reached for round 2 with only

two disagreements for question and table 1, one disagreement for question and tables 2, 3, and 4.

More detailed information about this analysis is provided in the next chapter.

## CHAPTER 4

### ANALYSIS OF FINDINGS

#### Introduction

This study sought to research and explore the phenomenon of housing and residence hall-based supports for freshmen students with Autism Spectrum Disorder (ASD). The study gained insight into the perspectives of the necessary resident life needs, successful supports, and potential barriers as pulled from a panel of experts within the field of autism, the department of housing and resident life, and from those diagnosed with ASD. It is intended that a possible outcome of the research will be to produce *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College*, a tool to be used in the training of Housing and Residence Life Staff. Findings are organized respectively: a) participants, b) data collection, c) data analysis, and d) summary of the findings.

#### Participants

A total of 25 professionals were initially sent an invitation via blind email to participate in the research, and a final number of 14 responded with agreement for participation. Participants were considered experts within 1 of 3 areas of professionalism: 1) the field of autism, 2) housing and residence services, and 3) those diagnosed with autism. The participants who have expertise in the field of ASD or Housing and Residence Life have provided supports for college students diagnosed with ASD living on a college campus through specialized support-based programs, academic settings, housing and residence life departments, or disability offices. Several of the participants who have a diagnosis of ASD have had notable professional experience in either public speaking, publications, and/or the experience of living on a college campus themselves. Many of those have also provided support to college students diagnosed



with ASD living on a college campus through speaking at national conferences and publications specifically related to ASD. The data describing the participants' area of expertise is in Table 1.

Table 1  
*Participants' Area of Expertise*

<u>Participant</u>	<u>Area of Expertise</u>
1	Field of ASD *
2	Field of ASD
3	Housing and Residence Life
4	Field of ASD
5	Diagnosed with ASD
6	Housing and Residence Life
7	Field of ASD
8	Housing and Residence Life
9	Field of ASD
10	Housing and Residence Life
11	Diagnosed with ASD
12	Diagnosed with ASD
13	Field of ASD
14	Diagnosed with ASD

\* Autism Spectrum Disorder (ASD)

The description of experts who were included in the Delphi survey are listed below:

Participant 1 Private consultant in the field of autism who has provided educational, employment, and residential services to children and adults with ASD.

Participant 2 Director of a university-based specialized support program for college students with learning differences, including ASD.

Participant 3 Interim Associate Dean of Students and Executive Director of Housing and Residential Education at a public university.

Participant 4 The director of a university-based program that specializes in supporting and educating individuals with ASD.

Participant 5 A university faculty member, author, and public speaker diagnosed with ASD.

Participant 6 Dean of Students and former Director of Housing and Residence Life at a public university.

Participant 7 Assistant Professor of Special Education at a public university and co-author of a book on the topic of ASD supports for educators.

Participant 8 Director of Housing and Residence Life Department at a public university.

Participant 9 Director of Disability Resources at a public university, former director of a university-based specialized support program for college students with ASD.

Participant 10 Director of Housing and Residence Life at a public university.

Participant 11 An author, Autism Advisory Board member, mother of child with ASD, and public speaker diagnosed with ASD.

Participant 12 College graduate and public-school teacher diagnosed with ASD.

Participant 13 Assistant Professor of Special Education, parent of child with ASD, and director of a university-based specialized support program for students with ASD.

Participant 14 Educator, author, and public speaker diagnosed with ASD.

### **Data Collection**

Professionals from the field of ASD, Housing and Residence Life departments, and individuals diagnosed with ASD were selected as expert panel members in a Delphi Survey to explore the phenomenon of housing and residence hall-based supports for freshmen students with ASD. A total of 25 experts were invited to participate in the survey via email request on May 23, 2018. The email contained the Institutional Review Board approval number and informed consent letter (Appendix A and B), as well as round 1 of the Delphi Survey (Appendix C).

The email asked for a participation reply of round 1 responses by May 31<sup>st</sup>, 2018; however, the deadline extended a few days for a few experts who asked for an extension. Of the 25 experts who were invited, a total of 14 participated with round 1 responses by June 4<sup>th</sup>, 2018.

## **Data Analysis**

### **Round 1**

The data analysis for round 1 was organized by each of the 5 research questions presented in chapter 1. Two investigators, the primary researcher and co-investigator, independently analyzed each question and categorized responses by code words and phrases. The categorized responses from the panel members were then ranked from “Most Cited” to “Least Cited” by the investigators and then compared outcomes to ensure a reliable interpretation of data. Once the code phrases and words were identified, the investigators came together, and an emergent category analysis was performed. The emergent categories that resulted were placed into matrix tables that were then used for round 2 of the Delphi Survey. The emergent categories of findings and the matrix tables per question for round 1 are:

#### **Question 1: What are the specific housing and residence *needs* of students in the first-year transition to college?**

Expert panel members suggested a variety of housing and residence needs that exist for first-year college freshmen. Types of needs that were identified by panel members, from most-to-least cited responses were: *roommate issues* (such as a need for learning how to co-habitat with a roommate), *independent living needs* (most notably privacy related issues related to the bathroom use), *campus-based orientation needs* (like interactions and utilizing administrative offices and staff), *organizational needs* (particularly regarding time management), *academic needs* (such as involvement in living learning communities), *communication needs*, *environmental needs* (sensory and space related needs), *safety needs*, and *social connections*.

The investigators had disagreement over the coded word of *social*. The primary investigator tended to code words and phrases under the social category for literal use of words and phrases from panel members, like *social skills* and *social events*, whereas the co-investigator coded more phrases under their interpretation of feeling socially connected. The investigators discussed these disagreements and due to the prevalence of the terms in the responses from panelists, however, a decision was reached to make *campus orientation support* a separate and distinct category that would include both social events, skills, and feeling socially connected. The investigators also felt it was important to note that 3 of the 14 participants described similar language in recognizing that first-year students living on a college campus must have a “*sense of belonging*.” Although 3 responses did not yield a standalone category, it is note-worthy that panel members feel it is especially vital for first-year students to feel valued and connected to their campus.

Themes that emerged from these responses indicate most first-year college students transitioning to living on campus will need: (1) Assistance with Living Arrangements, (2) Independent Living Needs, (3) Campus Orientation Support, (4) Non-Academic Organization, (5) Academic Support, (6), Communication Needs, and (7) Environmental Needs. See Table 2 that lists the emergent themes from round 1, question 1.

Table 2  
 Matrix for Round 1, Question 1

Participant	Assistance with Living Arrangements	Independent Living Needs	Campus Orientation Support	Non-Academic Organizational Needs	Academic Support Needs	Communication Needs	Environmental Needs
1	X						
2	X	X			X		
3			X		X		
4	X	X		X			
5	X	X	X				X
6	X	X	X				X
7		X	X	X		X	
8	X	X		X	X		
9		X	X	X	X	X	
10	X		X				
11	X						X
12			X	X	X	X	
13	X	X		X		X	
14		X					X

**Question 2: What are the unique housing and residence transition *needs* of students with Autism Spectrum Disorder?**

The housing and residence needs for first-year students diagnosed with ASD was asked of the panel members for question 2. The needs identified by the panel members in order of most cited to least cited were as follows: *roommate related issues* (understanding how to live with a roommate), *living environment preferences* (request for a single room or private bathroom), *training for residence staff that is specific to ASD*, *connections to ASD resources*, *early transitional planning and logistical practice for students with ASD*, *organizational and life skills needs* (such as time management, hygiene related issues, and navigation of campus), *self-advocacy needs*, *social communication needs* (especially in understanding and using the pragmatics of language), and *social support needs* (specifically in regard to community building).

The investigators discussed the results and felt that the 2 coded categories of *self-advocacy* and *social communication needs* ultimately were best combined because panel members echoed similar examples for what was coded under social communication, such as:

“Responding to pre-conceived notions/bias from others” from 1 participant and what was coded under self-advocacy, for example, “They sometimes need a script/social story on how to discuss specific concerns related to common issues (i.e. – sleep/study schedules, video game playing, use of personal property, etc.)” from another participant.

Themes that emerged from the responses for question 2 indicate most college students diagnosed with ASD will require the following housing and residence life needs: (1) Assistance with Living Arrangements, (2) ASD Specific Training, (3) Early Transitional Support, (4) Non-Academic Organizational Needs, and (5) Advocacy and Communication Needs. See table 3 that lists the emergent themes from round 1, question 2.

Table 3  
Matrix for Round 1, Question 2

Participant	Assistance with Living Arrangements	ASD Specific Training	Early Transitional Support	Non-Academic Organizational Needs	Advocacy and Communication Needs
1	X				
2	X	X	X	X	X
3	X	X			
4					
5	X	X	X		
6	X			X	
7			X		X
8	X		X	X	X
9	X		X	X	X
10	X	X			X
11		X	X		
12	X				
13	X	X		X	X
14	X	X		X	

**Question 3: What supports are housing and residence life staff using to provide effective supports, if any, for first-year college students with Autism Spectrum Disorder?**

Responses for question 3 of round 1 centered around what supports are currently in place for first-year college students with ASD. Responses from most cited to least cited were as follows: *planned social events* (such as floor events or college related events), *ASD specific expertise, training, or resources, mentor training and support, not aware of ASD specific*

*supports or minimal in place, campus-based connections, and room preferences (single room and choice of a roommate).*

The emergent themes indicated experts feel that: 1) Social Community Building, 2) On-Campus ASD Expertise and Training, 4) Campus-Based Collaborations, and 5) Specifically Designed Living Spaces are integral to effective supports for first-year students with ASD. Experts voiced that although they are aware of some effective supports in place in higher education, they also are unfamiliar or uncertain with supports specific to transitioning first-year students with ASD. The third most cited category theme was “minimal or no known supports in place.” For example, one participant voiced, *“I am not aware of any campus housing units that have incorporated ASD needs into their training, programming, and other strategies to better meet the needs of students with ASD.”* See table 4 that lists the emergent themes from round 1, question 3.

Table 4  
*Matrix for Round 1, Question 3*

Participant	Social Community Building	ASD Specific Training	Minimal or No Known Supports in Place	Campus Based Collaborations	Specifically Designed Living Space
1			X		
2	X	X			X
3			X		
4		X			
5			X		
6	X			X	X
7			X		
8	X	X		X	
9	X				
10	X	X		X	
11		X			
12	X		X		
13		X	X	X	X
14	X				

**Question 4: What barriers or challenges exist in providing effective housing and residence life supports for first-year college students with Autism Spectrum Disorder?**

Panel members expressed a variety of reasons that may prevent effective housing and residence life supports for first-year students with ASD. The investigators independently categorized a dozen code words and phrases. Responses from most-to-least cited were: *no ASD specific training or support, communication challenges, self-advocacy challenges, too many challenges, private room needed, roommate relations, social skill challenges, organizational challenges, community connection, joint or collaborative efforts, emotional and mental health needs, interactions with parents, and sensory challenges*. Investigators discussed and concluded that several of the common words and phrases would be combined into emergent themes. For example, the categories of *private room needed, roommate conflicts, and sensory challenges* all fit under the lack of appropriate living environment arrangements.

Six dominant themes emerged from the responses by participants. Experts strongly voiced the lack of ASD specific training and on-campus knowledgeable staff who could serve as resources as top barriers in providing effective supports. Due to either ineffective communication between staff and students and/or the symptoms associated with the disorder, primarily based in social communication and interaction challenges, along with difficulty understanding when and how to advocate for personal needs, were cited by experts as barriers to carrying out effective supports. Experts also echoed similar responses that cited the barriers or challenges to providing effective housing and residence supports were extreme and overwhelming. One participant said, “*Due to the lack of special services for most kids on the spectrum that are in college, the barriers are many.*” Experts also voiced potential barriers in having appropriate living arrangements, such as enough single residence hall rooms as an option for students with ASD. Although there were less cited responses for the themes of parent



challenges and behavior and mental health challenges, the investigators felt it still needed to be included as significant in providing effective supports. See table 5 that lists the emergent themes from round 1, question 4.

Table 5  
*Matrix for Round 1, Question 4*

Participant	Advocacy and Communication Challenges	Lack of ASD Specific Training or Expertise	Barriers are Great	Lack of Appropriate Living Arrangements	Parent Challenges	Behavioral and Mental Health Challenges
1		X	X			
2	X		X	X		
3		X				
4	X			X		
5	X	X	X	X		X
6	X				X	X
7		X		X		
8	X	X				
9	X	X		X		X
10	X		X		X	X
11				X		
12						
13	X	X	X		X	
14	X		X		X	

**Question 5: How can housing and residence life staff provide support that adapt to the social and communication needs of first-year students with Autism Spectrum Disorder?**

The final question for round 1 asked experts to provide ways in which housing and residence staff could adapt to meet the social and communication needs of first-year college students with ASD. This question resulted in the most unanimous of categories for common themes and words among the panel members. Categories cited from most-to-least included: *ASD training and support, community building activities, programming that address the needs of students with ASD, proactive planning and anticipating the needs of students with ASD early, early arrival options, collaborative campus efforts, and identifying safety and mental health needs.*

After discussion, the investigators found that several of the categories could be combined such as: *the programming that addresses the needs of students with ASD, proactive planning and*

anticipating the needs of students with ASD early, as well as early arrival options into one single theme of “early arrival programming.” Investigators concluded with 4 emergent themes: 1) ASD Specific Training, 2) Community Building Activities, 3) Early Arrival Programming, and 4) Collaborative Campus Connections. See table 6 that lists the emergent themes from round 1, question 5.

Table 6  
Matrix for Round 1 Question 5

Participant	ASD Specific Training	Community Building Activities	Early Arrival Programming	Collaborative Campus Connections
1			X	X
2	X		X	
3	X	X	X	X
4	X			
5			X	
6	X	X	X	
7	X	X	X	
8	X		X	
9	X	X		X
10	X	X		X
11		X		
12		X		
13	X	X		X
14	X		X	

## Round 2

Once themes were categorized, and matrix tables for each question from round 1 were developed to illustrate how individual responses from panelists fit themes that emerged from the group, round 2 of the Delphi Survey was then sent to panel members on June 18, 2018 via blind carbon copy email. round 2 of the survey (Appendix D) provided expert panel members with a brief analysis of the initial findings, the matrix table for each corresponding question from Round 1, and asked panel members to “agree” or “disagree” with the results and provided each an opportunity to add or clarify information. All 14 participants from round 1 provided responses for round 2, by June 25, 2018. It was determined prior to sending round 2 to experts,

that a consensus for round 2 would be deemed so long as at least 12 of the 14 participants selected “agree” with the results from round 1.

The primary investigator organized the responses for round 2 into a table that corresponds with each matrix table from round 1. The table included each participant as a row with either “agree,” “disagree,” and “missing” as columns. Once the table was complete, the investigators met to discuss the results. The investigators conclude that a consensus was reached for round 2, according to the guidelines initially set and that a third round was not necessary.

The following results were found according to each question:

**Question 1: What are the specific housing and residence *needs* of students in the first-year transition to college?**

Panel members were asked if they agreed or disagreed and were asked to add any missing or additional information with the matrix table 1 for question 1. 12 of the 14 members selected “agree” for round 1, question 1 table data. Participant 3 and participant 12 were two of the fourteen participants who selected “disagree.” Participant 3 placed the following in the “missing” portion of survey, *“I would take the point of view that in their transition to their first year of college, independent living needs and campus support and orientation are critical to help these students with adjusting and acclimating to college life.”* The investigators interpreted the expert’s response that although both “independent living needs” and “campus support and orientation” were included in the table, the expert felt they should have been included in the table as most cited, as opposed to 2<sup>nd</sup> and 3<sup>rd</sup>, as they were placed in the matrix table. While participant 12 reported, *“I believe that students not on the Autism Spectrum, do not necessarily need assistance in Living arrangements or independent living needs. Although I do agree that Orientation support and academic support are most needed for student resident needs.”* The investigators interpreted the expert’s response as the belief that support for orientation (ranked

3<sup>rd</sup> cited) and academic supports (ranked 5<sup>th</sup> cited) were more critical types of supports to first-time freshmen transitioning to campus living.

Half of the experts added responses to the missing or additional information section of the survey for question 1. Many of those who added missing or additional information still marked “agree” with the table but felt that areas of support might need to be ranked differently. For example, expert 14 agreed with the table but felt that *environmental* (ranked 6<sup>th</sup> cited) and *communication needs* (ranked 7<sup>th</sup> cited) “...are instrumental in bringing everything together.” Contrastingly, expert 1 felt that *environmental* and *communication needs* were important to students with ASD, but not as important for first-time freshmen without ASD. Expert 4 felt that a missing category of *medical support* should have been included as a standalone category. However, no mention of medical information was provided by experts for question 1 and investigators felt that if there was a response within this area, it most likely would fit best into the *independent living needs* (ranked 2<sup>nd</sup>) category. See table 7 that lists the results of round 2, question 1.

Table 7  
 Matrix for Round 2, Question 1

Participant	Agree	Disagree	Missing
1	X		
2	X		For most first-year students transitioning to college, I don't see communication or environmental needs as large concerns. However, I do see those as needs for most students with ASD.
3		X	I would take the point of view that in their transition to their first year of college, independent living needs and campus support and orientation are critical to help these students with adjusting and acclimating to college life.
4	X		I wonder whether medical should be its own category—help with making appointments, filling out forms, having insurance card, filling prescriptions, describing symptoms, etc.
5	X		
6	X		
7	X		Students with ASD need social support in this area
8	X		
9	X		
10	X		
11	X		
12		X	I believe that students not on the Autism Spectrum, do not necessarily need assistance in Living arrangements or independent living needs. Although I do agree that Orientation support and academic support are most needed for student resident needs
13	X		
14	X		I agree with most of the responses, with that being said, communication and environmental needs are instrumental in bringing everything together.

**Question 2: What are the unique housing and residence transition *needs* of students with Autism Spectrum Disorder?**

For question 2, round 2, 13 of the 14 experts agreed with the matrix table 2 from round 1 data. Participant 3 was the only expert who marked “disagree,” citing “*I think the biggest need here is transitional support and campus support for student needs, as their living arrangements will have already been determined by this point.*” It should be noted that expert 3 has had many years of experience as a director of housing and residence life departments and is extremely

familiar with the process of providing living assignments prior to student arrival. However, the investigators included responses in this category that went beyond just a room assignment. For example, items that included living in a sensory friendly environment with appropriate space, any roommate and/or co-resident relational issues were also placed into the category of *assistance with living arrangements*.

Four of the 14 experts provided missing or additional information for the table data for question 2. Aside from participant 3 who marked “disagree,” experts 2, 4, and 9 marked “agreed” but also provided details in the missing or additional information section. Expert 2 cited feeling there needed to be a category of environmental needs, such as: “...*knowing that they need ear plugs if they decide to attend a large group event...*.” Expert 4 included in the missing or additional information section: “*Integration with roommates or suitemates.*” The investigators noted items, such as those noted by expert 2 and 4, related to sensory needs, functional living space, or proximity locations, and roommate issues all under the *assistance with living arrangements* category. Expert 9 responded with confusion over the category of *ASD specific training* (2<sup>nd</sup> cited), but an overall agreement with examples that do relate to ASD training for housing and resident life staff. See table 8 that lists the results of round 2, question 2.

Table 8  
*Matrix for Round 2, Question 2*

<u>Participant</u>	<u>Agree</u>	<u>Disagree</u>	<u>Missing</u>
1	X		
2	X		As mentioned in Question 1, I do think that there are environmental needs of this population. By that, I mean that they may need to have help in finding their classrooms ahead of time (and possibly getting to each one the first week or so), knowing that they need ear plugs if they decide to attend a large group event, how to get across campus without being in the midst of a large group of other students, when some good times are to go to the cafeteria that there are not huge crowds there, and other similar needs.
3		X	I think the biggest need here is transitional support and campus support for student needs, as their living arrangements will have already been determined by this point.
4	X		Integration with roommates or suitemates
5	X		
6	X		
7	X		
8	X		
9	X		I'm not quite sure what ASD specific training means in relation to the unique housing/res transition needs of students with ASD, but in general, I agree with the panelists. The areas are broad so they can encompass many components (e.g., Advocacy and Communication needs could mean communication with roommates, advocating for needs with roommates, communicating needs with RA/res life staff/disability resources, etc.).
10	X		
11	X		
12	X		
13	X		
14	X		

**Question 3: What supports are housing and residence life staff *using* to provide effective supports, if any, for first-year college students with Autism Spectrum Disorder?**

Thirteen of the 14 panelists agreed with question 3, table 3 data from round 1. Expert 12 cited, “*Although I mostly agree, I feel like “No Support or Little support” isn’t necessarily [necessarily] true for students on the Autism Spectrum. While some colleges do not give much support, there is still much support out there.*” Investigators felt that although this expert marked “disagree” his response indicated an overall agreement, except for feeling that the category of *minimal or no known supports in place* (3<sup>rd</sup> cited) perhaps should be placed as a lower cited category.

Including expert 12’s response above, a total of 6 experts provided missing or additional information. Expert 2 felt that a private room was “...*essential for almost all our students who have ASD.*” Expert 12 was curious what institutions of higher education had specifically designed spaces for students with ASD. Investigators included under the category of *specifically designed living space* (5<sup>th</sup> cited) items: private rooms, specialized, thoughtfully designed living communities, such as a Gaming Living Learning Community, and assistance with assigned roommates. Expert 9 noted that, “*I don’t see a large number of community building opportunities that are specifically geared towards students with ASD in Res Life.*” This comment and similar phrases cited by several experts in round 1 were what inspired the investigators to create the *minimal or no known supports in place* category. Expert 11 provided a suggestion for how they felt that Housing and Resident Life staff could provide supports “...*beyond training...*” for freshmen students with ASD that requires rapport building and deeper connections. This comment was significant to investigators and it was determined that it best fit with additional information for question 5. See table 9 that lists the results from round 2, question 3.



Table 9  
*Matrix for Round 2, Question 3*

<u>Participant</u>	<u>Agree</u>	<u>Disagree</u>	<u>Missing</u>
1	X		
2	X		If some college have specifically designed living spaces for this population, I would love for them to share with the rest of us! Also, we are allowed to request private rooms for this population as an accommodation based on their disabilities. I think this is essential for almost all of our students who have ASD.
3	X		
4	X		
5	X		
6	X		
7	X		
8	X		
9	X		A large number of individuals on the panel included social community building – I agree that this is an effective support from Res Life, but some of the activities/engagement opportunities don't consider the unique needs of students on the spectrum – this question makes it a little difficult for me to answer because it asks specifically for ASD and I don't see a large number of community building opportunities that are specifically geared towards students with ASD in Res Life.
10	X		
11	X		It needs to be beyond training. They need to hang out, party (in a good way), and really genuinely get to know autistic students. Often the RAs are uneasy even after training. Immersion in the only way that shifts.
12		X	Although I mostly agree, I feel like “No Support or Little support” isn't necessarily true for students on the Autism Spectrum. While some colleges do not give much support, there is still much support out there
13	X		
14	X		support, as I said cannot be overstated. For a student with autism the additional support will more likely breed success

**Question 4: What barriers or challenges exist in providing effective housing and residence life supports for first-year college students with Autism Spectrum Disorder?**

Thirteen of the 14 experts marked “agree” for table 4, question 4 from round 1 data. Panel member 2 marked “disagree” and noted that: “...*I also think that behavioral and mental health challenges are a much larger concern than was indicated by just four participants noting that as a challenge.*” Expert 8 also provided a similar response concerning the frequency of mental health challenges. Investigators agreed with these panel members regarding a need for a focus on the mental health supports for students with ASD. Current literature has shown that college students with ASD report higher rates of loneliness, anxiety, depression, and suicidal behaviors when compared to their neuro-typical peers (Gelbar, Smith, & Reichow, 2014; Jackson, Hart, Brown, & Volkmar, 2018).

Three of the panel members cited in question 4 some confusion with the term *barriers are great* as a singular response category. The meaning of this category is that the barriers are significant and pervasive. This category emerged because several participants responded with items such as, “*The barriers are many.*” And “*Some students need more support than can be provided.*” And “*The barriers are significant.*” Investigators believed that these descriptors of barriers to providing support were noteworthy and felt that this needed to be a category. Expert 8 also noted some confusion in interpreting the category of *lack of appropriate living arrangements*. Investigators included in this category panel members’ responses, for items like, not having enough private rooms in first-year halls to accommodate students with ASD, or not having the appropriate sensory environment, such as lighting or noise reduction spaces, to accommodate students with ASD. See table 10 that lists the results from round 2, question 4.

Table 10  
*Matrix for Round 2, Question 4*

<u>Participant</u>	<u>Agree</u>	<u>Disagree</u>	<u>Missing</u>
1	X		
2		X	I don't know that I don't agree. I just don't know what "Barriers are Great" means. I think very few barriers are "great." I agree with the other barriers/challenges listed. I also think that behavioral and mental health challenges are a much larger concern than was indicated by just four participants noting that as a challenge.
3	X		
4	X		
5	X		
6	X		
7	X		I would change or delete the statement "Barriers are great" since it is a nonspecific answer.
8	X		I'd be curious to learn more about what is meant by "lack of appropriate living arrangements." I would also add that Mental health challenges are becoming more prevalent.
9	X		I'm confused by the Barriers are Great answers, what that means, and how it relates to this question asking about what barriers exist. I think context for a number of these questions could improve understanding.
10	X		
11	X		
12	X		
13	X		
14	X		

**Question 5: How can housing and residence life staff provide support that adapt to the social and communication needs of first-year students with Autism Spectrum Disorder?**

All 14 panel members agreed with table 5, question 5 data from round 1. There were 2 experts who provided additional or missing information. Expert 6 felt that ASD specific training needed to be extended beyond just housing and resident life departments, but to various faculty,

staff, and departments across college campuses. Expert 14 noted that, in addition to training of housing and residence staff, there should also be programming that is specifically designed to integrate students with ASD into housing communities on campus, but also cited that there needs to be a shift in “...*positive attitudes towards them* [students with ASD]” from the campus community at large. Investigators ultimately agree with these remarks from experts and feel that a well-informed campus community is essential for success for students with ASD. See table 11 that lists the results of round 2, question 5.

Table 11  
*Matrix for Round 2, Question 5*

<u>Participant</u>	<u>Agree</u>	<u>Disagree</u>	<u>Missing</u>
1	X		
2	X		
3	X		
4	X		
5	X		
6	X		I would make sure that training is all inclusive. Meaning for student staff (RAs), professional staff (academic advisors), faculty and front office staff. I have found that we train our housing staff, but we are lacking in training with faculty and other staff.
7	X		
8	X		
9	X		
10	X		
11	X		
12	X		
13	X		
14	X		There needs to be training and programs to help students with autism integrate into the dorm life and help students become aware of students and to promote positive attitudes towards them.

## Summary of Analysis

This chapter described the data collection, analysis, and findings of the study to explore the phenomenon of housing and residence life supports for transitioning freshmen with ASD. A Delphi Survey method was used with a panel member of experts who had professional expertise in either: 1) the field of ASD, 2) housing and residence life, and 3) individuals diagnosed with ASD. Round 1 of the Delphi Survey asked participants to answer the 5 research questions, first introduced in chapter 1. Two investigators independently coded and themed the responses from round 1, then met to ensure reliability of the results, developing matrix tables for each question based upon the emergent themes. Round 2 included each matrix table from round 1, and asked experts to either agree or disagree with the results, as well as provided an opportunity to add missing information. After analyzation of round 2 data, investigators concluded that a consensus had been reached.

The major findings from the Delphi Survey showed the following: There is a need for *ASD specific training* for housing and residence life staff. Panel members reported that there is a dearth of ASD specific supports in college housing and residence life settings. Responses from experts frequently addressed the need for ASD specific training for housing and residence life staff or a collaborative campus partner with ASD expertise. Some mention of specific ASD training was cited in all research questions from round 1, aside from question 1, which did not specify the needs for first-year students with ASD.

The panel of expert members revealed that professional staff who can provide *social communication* and *advocacy supports* is needed for freshmen students with ASD. Experts cited that professional support that could improve communication dynamics between residents, staff, and others on campus is an essential need for freshmen students with ASD. Also included are

professional staff who can provide *organizational support*, especially with the development of routines and day-to-day lists of activities, is needed for freshmen students with ASD.

There is a need for assistance with, and *pre-planning for appropriate living arrangements*, specifically in the need for private rooms, selection of roommates, continued support in roommate interactions, and thoughtfully designed living communities for freshmen students with ASD. *Early arrival programming* designed to meet the needs of freshmen students with ASD living in the residence halls may be helpful for transition. Panel expert members suggested that early arrival transitional programming that is designed to help students adjust to campus-based living prior to academic start of the year may be beneficial for first-year students with ASD. *Community building*, such as consistent and pre-planned activities, may be helpful for freshmen students with ASD. *Collaborative campus community partners* are essential in the support of freshmen students with ASD living in the residence halls. Having a well-informed campus, including various departments across campus that are working together to ensure students with ASD feel a sense of belonging is critical during the first-year transition.

## CHAPTER 5

### CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

#### Introduction

This chapter includes the purpose, methods, and findings of the study. The conclusions are organized by the five research questions, in accordance with the two rounds of the Delphi Survey. The chapter ends with a description of implications and recommendations for further research.

#### Purpose of the Study

The purpose of this study was to explore the existing challenges and necessary elements in providing effective living supports to first-time college students with Autism Spectrum Disorder (ASD) living in campus residence halls. The study revealed the necessary resident life needs, successful supports, and potential barriers as pulled from a panel of diverse experts. The research questions that guided the study were:

- 1) What are the specific housing and residence needs of students in the first-year transition to college?
- 2) How do specific housing and residence transition needs of students with ASD differ from neurotypical freshmen?
- 3) What supports, if any, are housing and residence life staff utilizing to provide effective supports, if any, for first-year college students with ASD?
- 4) What are reported barriers or challenges in providing effective housing and residence life supports for first-year college students with ASD?
- 5) How can housing and residence life staff provide support that adapt to the social and communication needs of first-year students with ASD?

## Methods

This study was completed using qualitative methods and utilized, specifically, the Delphi Survey Method. Through purposeful sampling, fourteen experts were included and were from one of three areas: 1) professionals in the field of ASD (n=6), 2) professionals in housing and resident life (n=4), and 3) individuals with ASD (n=4). The survey was conducted electronically via email exchange between the participants and the primary investigator through two rounds. Round 1 of the survey asked the panel of experts for responses to the five research questions listed. The responses from round 1 were independently analyzed by the primary investigator and a co-investigator who categorized words and phrases, and then collaborated to discuss emergent themes. The emergent themes were placed into matrix tables according to each question and were then sent as round 2 of the survey. Round 2 asked experts to either “agree,” “disagree,” and add any missing or new information to each matrix table developed from round 1 results. A consensus was reached at round 2, with at least 12 of the 14 experts agreeing with each of the 5 research question results and coordinating matrix tables.

## Summary of Findings

### Round 1

Round 1 asked panel members to respond to the five research questions and the findings will be summarized based on each question:

#### **Question 1: What are the specific housing and residence *needs* of students in the first-year transition to college?**

Emergent themes from the panel of experts indicated that most first-year college students transitioning to living on campus will need: (1) Assistance with Living Arrangements, (2) Independent Living Needs, (3) Campus Orientation Support, (4) Non-Academic Organization, (5) Academic Support, (6) Communication Needs, and (7) Environmental Needs.



**Question 2: What are the unique housing and residence transition *needs* of students with Autism Spectrum Disorder?**

Panel members stated that most college students diagnosed with ASD will require the following housing and residence life needs: (1) assistance with living arrangements, (2) ASD specific training, (3) early transitional support, (4) non-academic organizational needs, and (5) advocacy and communication needs.

**Question 3: What supports are housing and residence life staff *using* to provide effective supports, if any, for first-year college students with Autism Spectrum Disorder?**

This question probed experts into responding with what known supports were already in place for freshmen college residents with ASD. One recurrent theme, the third-most-cited category, was that experts responded that they were either unfamiliar or unaware of supports that existed for housing and resident life departments that were ASD specific. Experts' unawareness of what ASD specific support exists is a critical piece in the research because it shows the need for ASD training. The emergent themes indicated experts believe that: 1) social community building, 2) on-campus ASD expertise and training, 3) minimal or no known supports in place, 4) campus-based collaborations, and 5) specifically designed living spaces are integral to effective supports for first-year students with ASD.

**Question 4: What barriers or challenges exist in providing effective housing and residence life supports for first-year college students with Autism Spectrum Disorder?**

Panel members provided a wide array of possible barriers or challenges in housing and residence life staff support for first-year students with ASD. The emergent themes in order were: 1) advocacy and communication challenges, 2) lack of ASD specific training or expertise, 3) barriers are great (meaning that challenges were significant and pervasive), 4) lack of appropriate living arrangements, 4) parent challenges, and 5) behavioral and mental health challenges.

**Question 5: How can housing and residence life staff provide support that adapt to the social and communication needs of first-year students with Autism Spectrum Disorder?**

Panel members concluded round 1 with addressing the question about possible suggestions or ways in which housing and resident life could provide effective supports to first-year students with ASD. The 4 emergent themes that developed were: 1) ASD specific training, 2) community building activities, 3) early arrival programming, and 4) collaborative campus connections.

**Round 2**

Round 2 provided panel members with the matrix tables that were developed after round 1 results (reference Chapter 4). Panel members were asked to either “agree,” or “disagree,” with the table, and included a place for panel members to provide any additional or missing information. It was decided between the two investigators, prior to round 2, that a consensus meeting would be met when at least 12 of the 14 participants selected “agree” for each question and corresponding matrix table. Overall, a consensus was reached and there was not a need for a third round of the Delphi Survey.

Round 2, question 1 and corresponding table, 12 of the 14 participants agreed with the results. Six of the 14 experts provided additional or missing information with varying thoughts on how the categories should be ranked. It is noted that there was not a general agreement on these comments; one expert felt environmental, specifically sensory, needs should be greater, whereas another expert felt independent living needs should be greater.

Thirteen of the 14 experts agreed with round 2, question 2 and the corresponding table. Four of the 14 participants provided additional or missing information that cited specific examples of needs for freshmen residents with ASD, that were ultimately included in the broader categories of the table.

For round 2, question 3 and corresponding table, 13 of the 14 participants agreed with the results. Six of the 14 experts provided additional or missing information that focused on a need for community building that is specific for residents with ASD.

Thirteen of the 14 participants agreed with round 2, question 4 and corresponding table. A total of 4 experts included additional or missing information which generally noted confusion of the category name “barriers are great.” It was intended that this category means barriers to providing support for residents with ASD is pervasive and significant. Two of the experts also included that the mental health needs for residents with ASD was critical and should be ranked higher on the table.

Round 2, question 5 and corresponding table had a unanimous result with all participants agreeing with the results. Two experts included additional or missing information that spoke of a type of early arrival programming specific to meet the needs of freshmen residents with ASD.

## **Conclusions**

Investigators analyzed the responses from the panel of experts from rounds 1 and 2, and several overall conclusions were identified. The most cited response from the panel of experts was the *need for ASD training* for housing and resident life staff. Panel members reported this a critical need in all questions that addressed residents with ASD. The unique needs of residents with ASD, those that fall in the realms of social communication and interaction, are typically outside the scope of traditional housing and resident staff trainings. Specifically, experts cited that providing support so that communication dynamics between residents, staff, and others on campus could be improved, especially regarding *advocacy support* is needed for freshmen residents with ASD. *Organizational support*, such as providing specific day-to-day lists of activities and help with routine planning, was another large component of support that was cited

by experts as a need for freshmen students with ASD. *Pre-planned appropriate living arrangements*, such as access to a private room, specifically designed living communities, or selection and continued support of roommates and co-living conditions is critical for freshmen students with ASD. The panel of experts also cited that *early arrival programing* that aids in the transition and navigation of campus before all students arrive, may be best for freshmen residents with ASD, and continued *community building with collaboration of campus partners and departments* is essential in supporting students living on campus with ASD.

### **Implications**

Research has shown that transitioning first-time college students with ASD typically will need the most support in non-academic areas (Jackson, Hart, & Volkmar, 2018). The lifestyle that living on campus within a residence hall brings is majorly based within social communication and interaction, thus providing housing and resident life staff with the necessary tools that would aide in effectively supporting this unique population is essential. It was intended that a possible outcome of the research was to produce *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College*, a representative list of programmatic suggested supports. The list was intended to mirror the research of Ellison, Clark, Cunningham, and Hansen (2012) *The Benchmarks for Effective College Supports for Students with ASD*, a tool used to identify the readiness of an institution of higher education in academic, social, and independent living supports for students with ASD (Ellison, Clark, Cunningham, & Hansen, 2012).

The recommendations from the panel of experts were overwhelming in the need for: ASD specific training for housing and residence life staff, early arrival programing, social communication and interaction support, independent living with organizational supports, and

community building with campus partners that are specially designed to meet the needs of freshmen residents with ASD. The vision for *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College* will be a representative list of suggested programmatic supports that will be useful for housing and resident life staff to identify what resource they have in place, partially in place, or not in place at all in broad areas of: campus-based professional expertise, communication support, day-to-day activity support, organizational and executive function support, and social interaction support.

***The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD  
Transitioning to College***

The current study sought to understand the phenomenon of first-year college students with ASD transitioning to living on campus. Specifically, the study asked a panel of experts for their perspectives on the needed supports, known barriers, and recommendations for effective supports for residents with ASD within college residence halls. Although residence staff are expected to provide communal supports in varying ways (Davidson & Bauman, 2013), evidence-based programing specifically designed for first-year residents with ASD has not yet been developed. The development of *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College* (Table 6) is proposed to be used as a representative list of programmatic suggested supports that could be useful not only for housing and residence life departments, but also for prospective college students and their families when visiting potential college campuses to ensure if appropriate supports within the residence life department are in place.

*The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College* echoed the expert perspectives included in the Delphi Survey on the

necessary supports for first-time college students with ASD living on a college campus. The Housing and Residence Life effective services that were identified from the experts include: campus-based professional expertise, communication supports, day-to-day activity supports, organizational and executive function supports, and social interaction supports. Participating Housing and Residence Life departments would use *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College* to identify if their existing supports are: not available, partially available, or fully in place. There is also a designated place to list the appropriate items or needs that would help make the supports fully in place.

The effective support for “campus-based professional expertise” is a stand-alone rated category because this was the most cited item in both rounds of the Delphi Survey. The need for ASD training for professional staff within the Housing and Residence Life department is believed to be the most critical need and most effective support, according to the panel of experts. Existing research has also agreed with the need for professional training of staff for appropriate supports for college students with ASD (Ackles, Fields, & Skinner, 2013; Corona, Christodulu, & Rinaldi, 2017; Hamilton, Stevens, & Girdler, 2016).

The effective support for “communication supports” is strongly suggested by the panel of experts and is directly tied to social communication challenges that are symptomatic of ASD (APA, 2013). The three measures of support listed within the category are all connected to the need of available staff who can assist students with ASD in the skill development of social communication and self-advocacy. Social communication challenges are common for students with ASD and often create or lead to misunderstandings, problems with relationships, and may impede students’ ability to participate in events (Cai & Richdale, 2016). In the college setting, disclosure is imperative for those who are seeking accommodations. However, the

characteristics associated with ASD make the process of disclosure extremely difficult (Hees, Moyson, & Roeyers, 2015). Available staff who can assist with gaining the appropriate living accommodations, access to pre-arranged ideal living spaces, and communication dynamics between students and appropriate staff is critical for support.

The category of “day-to-day activity supports” includes panel members’ recommendations for assistance with the independent living needs and the importance of access to mental health for first-time freshmen with ASD. First-time freshmen who choose to live on campus are faced with a new-found level of responsibility and independence. Individuals with ASD tend to face even more challenges with this new lifestyle due to struggles with daily living skills like: personal hygiene, financial management, and nutrition (Adreon & Durocher 2007; Bal, Kim, Cheong, & Lord, 2015; Elias & White, 2018). Expert panel members also cited a need for a focus on the mental health supports for students with ASD. Indeed, this support is a necessity since college students with ASD report higher rates of loneliness, anxiety, depression, and suicidal behaviors when compared to their neuro-typical peers (Gelbar, Smith, & Reichow, 2014; Jackson, Hart, Brown, & Volkmar, 2018).

Expert panel members suggested that an integral support within housing and residence life would be in the category of “organizational and executive function supports.” Research has shown that college students with ASD will likely struggle with the executive function aspect associated with college life, such as: planning, scheduling, organization, and time management (Anderson & Butt, 2017; Dillon, 2007; VanBergeijk, et al., 2008). Available staff who can assist students with ASD in the areas of scheduling, time management, prioritization, and personal organization of living space is a suggested effective support.

The category of “social interactions supports” is also of no surprise, since this is a challenge that is characteristic for those with ASD (APA, 2013). Social involvement is a large component of the college life and can often be daunting for those with ASD who struggle with social interaction. Expert panel members voiced the need for campus partners who could aid in providing support to students with ASD in identifying various resources available on campus. Also, including students with ASD in the development and suggestion of campus-based activities is a recommendation of the panel members. If the recommendation comes from students with ASD, the likelihood of attendance is increased. A suggested effective support within this category is identifying upperclassmen who could serve as peer mentors for students with ASD. Research has shown that the peer-mentor relationship is effective for college students with ASD (Curtin, et al., 2016; Hamilton, et al., 2016; Roberts & Birmingham, 2017; Lucas & James, 2018). By creating mentors on a college campus, you are not only aiding in the support for students with ASD, but you are also creating autism awareness campus-wide. The draft of *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College* is shown in Table 12.



Table 12

*The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College*

<b><u>Campus-Based Professional Expertise</u></b>	<b><u>Supports N/A to My Needs</u></b>	<b><u>Supports N/A</u></b>	<b><u>Supports Partially Available</u></b>	<b><u>Supports Fully in Place</u></b>	<b><u>Specific Items or Needs to Make Supports Fully Available</u></b>
<p>Effective Services May Include:</p> <p>Campus-based, professional staff with ASD knowledge and experience to provide general autism-specific training and technical assistance to housing and residence staff.</p>					
<b><u>Communication Supports</u></b>	<b><u>Supports N/A to My Needs</u></b>	<b><u>Supports N/A</u></b>	<b><u>Supports Partially Available</u></b>	<b><u>Supports Fully in Place</u></b>	<b><u>Specific Items or Needs to Make Supports Fully Available</u></b>
<p>Effective Services May Include:</p> <p>Staff available to assist students with ASD in the recognition for the need and appropriate implementation of self-advocacy</p> <p>Access to pre-planned appropriate living conditions (single room, sensory-friendly room, living learning communities specifically designed for students with ASD, etc.)</p> <p>Staff available who have expertise in understanding effective and appropriate communication of procedures for mediation between a student with ASD and their roommates and/or suitemates.</p>					

<b><u>Day-to-Day Activity</u></b> <b><u>Supports</u></b>	<b><u>Supports</u></b> <b><u>N/A to</u></b> <b><u>My</u></b> <b><u>Needs</u></b>	<b><u>Supports</u></b> <b><u>N/A</u></b>	<b><u>Supports</u></b> <b><u>Partially</u></b> <b><u>Available</u></b>	<b><u>Supports</u></b> <b><u>Fully in</u></b> <b><u>Place</u></b>	<b><u>Specific Items or Needs to Make Supports</u></b> <b><u>Fully Available</u></b>
Effective Services May Include:  Staff available to assist students with ASD in the recognition and importance of independent living skills (daily hygiene habits, laundry, access to healthy eating on campus, access to financial assistance, etc.).					

Mental Health professionals with ASD knowledge and expertise available to provide therapeutic support to students with ASD.

<b><u>Organizational &amp; Executive Function</u></b> <b><u>Supports</u></b>	<b><u>Supports</u></b> <b><u>N/A to</u></b> <b><u>My</u></b> <b><u>Needs</u></b>	<b><u>Supports</u></b> <b><u>N/A</u></b>	<b><u>Supports</u></b> <b><u>Partially</u></b> <b><u>Available</u></b>	<b><u>Supports</u></b> <b><u>Fully in</u></b> <b><u>Place</u></b>	<b><u>Specific Items or Needs to Make Supports</u></b> <b><u>Fully Available</u></b>
Effective Services May Include:  Campus-based staff designated to aid, mentor, and support students with ASD in the development of skills related to cognitive organization, such as: planning, prioritization, time management, check-lists, self-regulation, etc.					
Staff available to assist students with ASD in the organization and maintenance of a clean-living space (step-by-step instructions for laundry services, weekly organizational charts for room cleaning, etc.).					

<b><u>Social Interaction Supports</u></b>	<b><u>Supports N/A to My Needs</u></b>	<b><u>Supports N/A</u></b>	<b><u>Supports Partially Available</u></b>	<b><u>Supports Fully in Place</u></b>	<b><u>Specific Items or Needs to Make Supports Fully Available</u></b>
Effective Services May Include:  Campus-based partners who can mentor students with ASD to the available peripheral supports on campus (academic tutoring, campus events and activities, campus clubs and organizations, etc.).					
Staff that works with students with ASD in the development of social activities that are specifically suggested and designed by students with ASD.					
Identified upperclassmen residents who could work as peer mentors in social skill development for students with ASD.					

## **Recommendations**

The current study utilized the Delphi Survey to better understand the phenomenon of first-year college students with ASD transitioning to living on campus. The following recommendations for further research would be beneficial to add to the study and guide future development of the training and early arrival programming for first-year residents with ASD:

- 1) This study provides a preliminary start for the development of a housing and resident life training that is tailored to supporting first-time residents with ASD. It is recommended that a curriculum for training be created that is geared toward staff's knowledge and confidence in supporting residents with ASD.
- 2) The panel of experts overwhelmingly cited a need for development of a pre-arrival program that is geared toward first-time students with ASD who are transitioning to

living on a college campus. The research of Elias and White (2018) also recommended a distinct type of early arrival program that focuses on the need of social interaction and independent living training for students with ASD. It is recommended that *The Benchmarks of Effective Residential Supports for Students Diagnosed with ASD Transitioning to College* be used as a catalyst for the research and development of a pre-arrival program.

- 3) The current study included a sample size of 14. It recommended that a larger sample size be conducted for further research. Although the 14 experts have extensive knowledge within their own expert fields, it would be a recommendation that a wider range of experts be included to compare the results and validity of this study.
- 4) It is noted that individuals with ASD be included in any further research that explores the necessary components of a successful transition to living on a college campus. Housing and Residence Life departments would benefit greatly from hearing first-hand about the transition and needs of first-time residents with ASD.

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**APPENDIX A  
INSTITUTIONAL REVIEW BOARD APPROVAL LETTER**



**Office of Research Integrity**  
Institutional Review Board  
One John Marshall Drive  
Huntington, WV 25755

FWA 00002704

IRB1 #00002205  
IRB2 #00003206

May 21, 2018

Edna Meisel, Ed.D.  
Elementary and Secondary Education, MUGC

RE: IRBNet ID# 1248238-1

At: Marshall University Institutional Review Board #2 (Social/Behavioral)

Dear Dr. Meisel:

**Protocol Title:** [1248238-1] Exploring Residence Life Needs of College Students with Autism Spectrum Disorder In Their Transition To College

**Site Location:** MUGC

**Submission Type:** New Project **APPROVED**

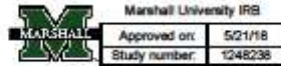
**Review Type:** Exempt Review

In accordance with 45CFR46.101(b)(2), the above study was granted Exempted approval today by the Marshall University Institutional Review Board #2 (Social/Behavioral) Designee. No further submission (or closure) is required for an Exempt study unless there is an amendment to the study. All amendments (including the addition of research staff) must be submitted and approved by the IRB Chair/Designee.

This study is for student Jadlyn Clark.

If you have any questions, please contact the Marshall University Institutional Review Board #2 (Social/Behavioral) Coordinator Bruce Day, ThD, CIP at 304-696-4303 or day50@marshall.edu. Please include your study title and reference number in all correspondence with this office.

## APPENDIX B INSTITUTIONAL REVIEW BOARD CONSENT LETTER



### Letter of Consent

You have been identified as an individual with expertise in the effective support of college students diagnosed with Autism Spectrum Disorder. In that role you are invited to participate in a research project entitled *Exploring Residence Life Needs of College Students with Autism Spectrum Disorder In Their Transition To Colleges* designed to explore the phenomenon of housing and resident life based supports for freshmen students with Autism Spectrum Disorder. The study is being conducted by Dr. Edna Meisel and Jaclyn Clark and Dr. Marc Ellison from Marshall University. This research is being conducted as part of the dissertation requirements for Jaclyn Clark.

A Delphi survey comprised of several rounds is being conducted to gather information on this topic. The first round of the survey is attached, and consists of five qualitative questions; subsequent rounds will be developed based on themes found in your Round 1 responses.

There are no known risks involved with this study. Participation is completely voluntary and there will be no penalty or loss of benefits if you choose to not participate in this research study or to withdraw. If you choose not to participate simply respond to this email with your decline.

If you have any questions about the study you may contact Dr. Edna Meisel at 304-746-8983 or Jaclyn Clark at 304-696-3881. If you have any questions concerning your rights as a research participant, you may contact the Marshall University Office of Research Integrity at (304) 696-4303.

By completing this survey and returning it you are also confirming you are 18 years of age or older.

Please keep this page for your records.

Thank you for your attention and your help with this study. My hope is the information gathered will serve a practical purpose and help improve the college experience of students on the autism spectrum.

Sincerely,

Edna Meisel  
Jaclyn Clark

**APPENDIX C**  
**DELPHI SURVEY ROUND 1**

**Exploring Residence Life Needs of College Students with Autism Spectrum Disorder  
In Their Transition To College**

Round 1

*Thank you for taking time to complete this qualitative survey. Your knowledge and expertise on the subject of supporting college students with Autism Spectrum Disorder in the residence hall is recognized and valued and will be helpful in determining the direction of Jaclyn Clark's doctoral research on this topic.*

*This questionnaire serves as the initial round of a Delphi survey. Subsequent rounds developed by the answers you provide will be sent to you electronically during the next several weeks.*

*The five questions that make up this survey will take approximately 15 minutes to complete. Please answer in detail; then, email the completed survey as an attachment to Jaclyn Clark. Her email address is [luton1@marshall.edu](mailto:luton1@marshall.edu). Please return your response as soon as possible, but no later than May 31, 2018.*

What are the specific housing and residence *needs* of students in the first-year transition to college?

What are the unique housing and residence transition *needs* of students with Autism Spectrum Disorder?

What supports are housing and residence life staff *using* to provide effective supports, if any, for first-year college students with Autism Spectrum Disorder?

What barriers or challenges exist in providing effective housing and residence life supports for first-year college students with Autism Spectrum Disorder?

How can housing and residence life staff provide support that adapt to the social and communication needs of first-year students with Autism Spectrum Disorder?

**APPENDIX D  
DELPHI SURVEY ROUND 2**

**Exploring Residence Life Needs of College Students with Autism Spectrum Disorder  
In Their Transition To College**

Round 2

The five questions from Round 1 of the Delphi survey serve as section headlines below. If you agree with the expert panelist opinions documented in the Response Matrix under the question heading, simply check off “I agree with the panelist on this topic.” If you disagree with their responses, or recognize something is missing from that section, please write in your response in the space provided. Please email your responses (by pasting them into an email or by attaching this document to an email) to Jackie Clark, [luton1@marshall.edu](mailto:luton1@marshall.edu) before **June 25, 2018**. Thank you for your participation and your expertise.

**Question 1: What are the specific housing and residence *needs* of students in the first-year transition to college?**

\_\_\_\_\_ I agree with the panelist comments found in the Response Matrix for Question 1

\_\_\_\_\_ I don't agree with the panelists comments found in the Response Matrix for Question 1. I don't agree because:

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\_\_\_\_\_ There is something missing, or something I'd like to add to this section of the Response Matrix for Question 1. I'd like to add:

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**Question 2: What are the unique housing and residence transition *needs* of students with Autism Spectrum Disorder?**

\_\_\_\_\_ I agree with the panelists comments found in the Response Matrix for Question 2

\_\_\_\_\_ I don't agree with the panelists comments found in the Response Matrix for Question 2. I don't agree because:

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\_\_\_\_\_ There is something missing, or something I'd like to add to this section of the Response Matrix for Question 2. I'd like to add:

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**Question 3: What supports are housing and residence life staff *using* to provide effective supports, if any, for first-year college students with Autism Spectrum Disorder?**

\_\_\_\_\_ I agree with the panelist comments found in the Response Matrix for Question 3

\_\_\_\_\_ I don't agree with the panelists comments found in the Response Matrix for Question 3. I don't agree because:

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\_\_\_\_\_ There is something missing, or something I'd like to add to this section of the Response Matrix for Question 3. I'd like to add:

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**Question 4: What barriers or challenges exist in providing effective housing and residence life supports for first-year college students with Autism Spectrum Disorder?**

\_\_\_\_\_ I agree with the panelist comments found in the Response Matrix for Question 4.

\_\_\_\_\_ I don't agree with the panelists comments found in the Response Matrix for Question 4. I don't agree because:

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\_\_\_\_\_ There is something missing, or something I'd like to add to this section of the Response Matrix for Question 4. I'd like to add:

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**Question 5: How can housing and residence life staff provide support that adapt to the social and communication needs of first-year students with Autism Spectrum Disorder?**

\_\_\_\_\_ I agree with the panelist comments found in the Response Matrix for Question 5.

\_\_\_\_\_ I don't agree with the panelists comments found in the Response Matrix for Question 5. I don't agree because:

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\_\_\_\_\_ There is something missing, or something I'd like to add to this section of the Response Matrix for Question 5. I'd like to add:

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## **APPENDIX E VITA**

Jaclyn Clark  
Luton1@marshall.edu

### **Education**

#### **Bachelor of Art, History**

Marshall University, Huntington (2002-2006)

- Major: History
- Minor: Spanish

#### **Master of Art in Teaching (M.A.T.)**

Marshall University, Huntington (2007-2009)

- Specialization in Social Studies, Grades 5-Adult

#### **Doctor of Education (Ed.D.)**

Marshall University Graduate School, Charleston (Currently enrolled)

- Curriculum and Instruction

### **Employment History**

**Coordinator**, College Program for Students with Autism Spectrum Disorder, Marshall University  
(March 2018- Present)

- Aid in the development of second College Program for Students with Autism Spectrum Disorder at Concord University in Athens, WV
- Oversee one supervisor and one graduate assistant at Concord University
- UNI 100 facilitator for incoming freshmen students
- Collaboration with team members in management of program budget
- Committee member of several campus-based interviews
- Manage online graduate assistant employment process through Marshall's HR People Admin site
- Interview and select team of graduate assistants each semester
- Conduct annual HR evaluations for employees
- Develop and implement Summer Employment Preparedness Workshop that targets the employment readiness skills of adults with Autism Spectrum Disorder
- Collaborate with team members in the development and implementation of Summer Leadership Institute that targets the leadership skill development of adults with Autism Spectrum Disorder
- Aid in management of four supervisors who work directly with students in The College Program
- Oversee a team of eighteen graduate assistants who serve as mentors for students with Autism
- Consultation with universities from across the nation in providing best practice supports for students with Autism Spectrum Disorder

- Provide training to professors, housing and resident life staff, administrators, and students in the best practices for supporting students with ASD
- Provide Allies Supporting Autism Spectrum Diversity Training to various universities, places of employment, and various community partners
- Review applicant materials, interview prospective students, and facilitate admissions process for incoming freshmen, transfer, and graduate students
- Collaboration with students and their families throughout the semester in development of team-based supports
- Lead monthly individual and group staff meetings
- Communication and collaboration with various administrative, professional, and staff members of Marshall University
- Collect, analyze, and present data at national conferences regarding best support practices at the college level for individuals on the Autism Spectrum

**Assistant Coordinator**, College Program for Students with Autism Spectrum Disorder, Marshall University (January 2013 – March 2018)

- Aid in management of five supervisors who work directly with students in The College Program
- Oversee a team of eighteen graduate assistants who serve as mentors for students with Autism
- Lead staff meetings consisting of full-time and graduate assistant staff once per month
- Arrange transportation and housing/resident hall accommodations for students during semester breaks and holidays
- Compose and respond to e-mails that include: professors, administrative office representatives, parents, students, and staff of The College Program for Students with Autism Spectrum Disorder on a daily basis
- Provide group training sessions to various administrative offices and academic departments on supporting students on the Autism Spectrum
- Collect, analyze, and present data at national conferences regarding best support practices at the college level for individuals on the Autism Spectrum
- Communicate with prospective students and their families who are interested in applying to The College Program for Students with Autism Spectrum Disorder
- Review applicant materials, interview prospective students, and facilitate admissions process for incoming freshmen and transfer students
- Aid in the development of The Junior Experience; a five-week, high school summer program focused on the transition from high-school to college
- Act as a liaison/consultant to individuals and universities seeking information on providing support to college students on the Autism Spectrum

**Transition Specialist**, College Program for Students with Autism Spectrum Disorder, Marshall University (September 2010 – December 2012)

- Plan and implement organizational strategies for twelve students each week, including: medication reminders, class meeting times, connecting with tutors and counselors, managing due dates, study time, hygiene needs, social outings, and extracurricular events
- Communicate with professors and various administrative offices via e-mail, office hours, and scheduled meetings
- Work with the community in planning for and obtaining work experience internships for upper-class students
- Focus on the transition period for those students who will be graduating from college and moving into the work force or facilitate the admissions process for graduate programs
- Advise students on course selection and class registration
- Provide continued communication and support to students who have graduated from The College Program for Students with Autism Spectrum Disorder
- Plan and lead Discovery Group; a skill building group that covers topics that are directly related to employment and college-based student experiences, once per week

**Part Time Instructor and English/ Math Tutor**, Mountwest Community and Technical College, Huntington (August 2007- January 2013)

- Teach courses in College Study Skills and University Studies
- Tutor and mentor students in the Academic Skills Center in the following subject areas: English, Math, Sociology, Psychology, Computer IT, Study Skills, and History.
- Proctor exams and collect testing data.

**Student and Substitute Teacher**, (August 2009-October 2009)

- Teacher licenser and certification in West Virginia.
- Worked as a substitute teacher in Cabell and Wayne counties. Taught in the following content areas: Social Studies, Math, Language Arts, Science, Special Education, Physical Education, and Reading.

## **Professional Presentations and Publications**

- **SRCEA Round Table Presentation**, September 2012 - Dr. Cunningham, Rebecca Hansen: “Academic and Campus Accommodations that Foster Success for College Students with Asperger’s Disorder”
- **SRCEA Yearbook Publication**, October 2013 – Dr. Cunningham, Dr. Marc Ellison, and Rebecca Hansen: “Understanding the Role of Classroom and Campus Accommodations in the Effective Education of College Students with Asperger’s Disorder”
- **Co-teaching EDF 711**, Summer 2013 – *Survey Research* with Dr. Michael Cunningham
- **Publication in *Journal of Autism and Developmental Disorders*, Volume 43 Number 8**: Clark, J. (2013). [Review of the book *The Parent’s Guide to College For Student’s on the Autism Spectrum. AAPC Publication, Shawnee Mission, Kansas (2012)*. doi: 10.1007/s10803-013-1872-1.

- **43<sup>rd</sup> and 45<sup>th</sup> Autism Society of America National Conferences**, July 2012 and 2014 Pre-conference Workshop, Panel Discussions and Session Presentations
- **Children with Exceptionalities Conference**, November 2016 “Preparing for the Transition from College to Career”
- **1<sup>st</sup> West Virginia Autism Training Center Lifespan Conference**, September 2017, “Creating Connections” Professor/Student Panel
- **1<sup>st</sup> College STAR Summit**, October 2017, Break-Out Presentation on Benchmarks of Effective Supports for Students with Autism Spectrum Disorder and attendee
- **Independence Educational Consultation Association Conference**, November 2018, Break-Out “College Support Programs in Transition”