NEEDS OF PARENTS OF UNIVERSITY STUDENTS
ON THE AUTISM SPECTRUM

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NEEDS OF PARENTS OF UNIVERSITY ASD STUDENTS

Abstract

As the number of students on the autism spectrum rises, educational services and social support for this population continue to develop and expand. Parents of those diagnosed with Autism Spectrum Disorders (ASD) receive information, guidance, and support as they work closely with K-12 teachers, therapists, medical professionals, and social service agencies to assist their children as they grow and progress to adolescence and young adulthood. These supports for parents typically end abruptly as their ASD children turn 18 and become legal adults. Many higher education institutions provide programming for ASD students to assist them academically and socially as they transition to and attend college. However, little to no information, guidance or support are provided by universities to parents of ASD college students. Further, limited research is available to determine the needs of parents during this transition.

Nine parents of new and continuing university ASD students were interviewed to ascertain parental needs during the transition process as their children enrolled in and attended college, and explored their perceptions of tools and programming colleges can provide to support them. Utilizing the lenses of Separation-Individuation Theory and Transactional Coping Theory, this project identified transitional and coping strategies utilized by parents of ASD students and ways to provide appropriate support for them. The following research questions were examined:

1. What are the experiences of parents of students on the autism spectrum as their children transition to and attend college?
2. What do parents of university ASD students report are systemic barriers which hinder them from coping with the transition and attendance of their child at college?
3. What supports might help parents of ASD students explore their new role and adjust effectively as their children transition to and attend college?
NEEDS OF PARENTS OF UNIVERSITY ASD STUDENTS

Results indicated the emergence of seven major themes, including the transition of ASD students to college as an emotional experience for parents, parental tendencies to hover over their adolescents, excessive use of “I” and “We” rather than “Him” or “He” when referring to their children, lack of communication for parents, students, high school guidance counselors and university faculty and staff with information pertaining to ASD college students, lack of timeliness and awareness of student and parental college needs, and parental solutions such as fixing communication and responding to parental wisdom. Further research with a broader parent population is needed to determine additional supports colleges can provide for parents of ASD college students during the transition of their children to college.
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To my Fall 2018 GSE co-hort...keep going...you got this. Your friendship, support and encouragement continue to inspire me. I will never forget our time together. As I reach this goal on my 60th birthday, it is never too late! Go for it, no matter your age!

WOO HOO!!
DEDICATION

To Justin

You are my hero, my superstar.

my son.

In the words of Princeton Professor John Nash
during his acceptance speech when receiving
the 1994 Nobel Prize in Economics,

Justin,

“I am only here because of you.

You are the reason I am. You are all my reasons”.

I LOVE YOU
NEEDS OF PARENTS OF UNIVERSITY ASD STUDENTS

TABLE OF CONTENTS

ABSTRACT ..............................................................................................................................iii

ACKNOWLEDGEMENTS ......................................................................................................v

DEDICATION .........................................................................................................................vi

TABLE OF CONTENTS ........................................................................................................vii

LIST OF TABLES ....................................................................................................................x

LIST OF FIGURES ..................................................................................................................x

I. INTRODUCTION .............................................................................................................1

i. FAMILY RESPONSE ...........................................................................................................2

ii. PARENTAL STRUGGLES AS THEIR ASD CHILDREN TRANSITION TO COLLEGE ................................................................. 3

iii. RESEARCH QUESTIONS ..................................................................................................5

II. LITERATURE REVIEW ..................................................................................................7

i. AUTISM SPECTRUM DISORDERS ..................................................................................7

ii. FAMILY EXPERIENCES WITH AN AUTISTIC CHILD ..................................................8

i.i. PARENTAL DISCORD ..................................................................................................10

ii.i. STRESS .......................................................................................................................10

iii.i PARENTAL ADVOCACY .............................................................................................11

iv.i HELICOPTER PARENTS ...............................................................................................12

iii. TRANSITION TO COLLEGE – ASD STUDENTS .........................................................13

iv. PARENTAL NEEDS AS THEIR ASD CHILDREN TRANSITION TO COLLEGE ..........15

v. HOW TO SUPPORT ASD STUDENTS AND THEIR PARENTS ..................................19

vi. COLLEGE SUPPORT PROGRAMS THAT INCLUDE PARENTS ................................20
NEEDS OF PARENTS OF UNIVERSITY ASD STUDENTS

vii. THEORETICAL FRAMEWORKS……………………………………………………………..21
  i.i. SEPARATION-INDIVIDUATION THEORY……..22
  ii.i TRANSACTIONAL MODEL OF STRESS AND COPING………………………………….24
  iii.i SUMMARY…………………………………………………………………………………24

viii. CONCLUSION…………………………………………………………………………………26

III. METHODOLOGY…………………………………………………………………………..………………..27
  i. SETTING AND SAMPLE……………………………………………………………………28
  ii. DATA COLLECTION………………………………………………………………………32
  iii. DATA ANALYSIS…………………………………………………………………………36
  iv. RESEARCHER ROLE AND POSITIONALITY………………………………………………….37
  v. VALIDITY……………………………………………………………………………………37

IV. RESULTS……………………………………………………………………………………………………………………39
  i. RESEARCH QUESTION 1…………………………………………………………………………………39
     i.i. THEME 1 – EMOTIONAL EXPERIENCE………………………………………………………..39
     ii.i THEME 2 – ACT AS HELICOPTER PARENT…………………………………………………..43
     iii.i THEME 3 – USE OF “WE” AND “I”……………………………………………………………..45
  ii. RESEARCH QUESTION 2…………………………………………………………………………………47
     i.i. THEME 4 – LACK OF COMMUNICATION…………………………………………………….48
     ii.i THEME 5 – TIMELINESS AND AWARENESS OF STUDENT AND PARENTAL NEEDS………………….51
  iii. RESEARCH QUESTION 3…………………………………………………………………………………59
     i.i. THEME 6 – FIXING COMMUNICATION………………………………………………………61
     ii.i THEME 7 – RESPONDING TO PARENTAL WISDOM……………………………………..65
NEEDS OF PARENTS OF UNIVERSITY ASD STUDENTS

V. DISCUSSION

i. RESEARCH QUESTION ONE – PARENTAL EXPERIENCES

ii. RESEARCH QUESTION TWO – SYSTEMIC BARRIERS

iii. RESEARCH QUESTION THREE – FIXING COMMUNICATION AND RESPONDING TO PARENTAL WISDOM

iv. ADDITIONAL FINDINGS

v. LIMITATIONS

vi. RECOMMENDATIONS FOR FURTHER STUDY

VI. REFERENCES

VII. APPENDICES

i. APPENDIX A: LETTER OF CONSENT FROM THE CSP PROGRAM COORDINATOR

ii. APPENDIX B: INITIAL EMAIL SENT BY THE CSP PROGRAM COORDINATOR

iii. APPENDIX C: INTERVIEW CONSENT FORM

iv. APPENDIX D: ADDENDUM: CONSENT TO AUDIO/VISUALLY RECORD OR PHOTOGRAPH SUBJECTS

v. APPENDIX E: DEMOGRAPHIC QUESTIONNAIRE

vi. APPENDIX F: PERSONAL DATA SHEET

vii. APPENDIX G: INTERVIEW PROTOCOL

viii. APPENDIX H: DATA ANALYSIS
LIST OF TABLES

TABLE 1: PARTICIPANT/STUDENT CONNECTION ................................................................. 30
TABLE 2: PARTICIPANT DEMOGRAPHIC INFORMATION .................................................... 31
TABLE 3: RESEARCH QUESTIONS AND DATA COLLECTION METHODS ....................... 34
TABLE 4: STUDY TIMELINE ............................................................................................. 38
TABLE 5: REPORTED EXPERIENCES OF PARENTS .......................................................... 39
TABLE 6: SYSTEMATIC BARRIERS REPORTED BY PARENTS OF ASD STUDENTS ......... 48
TABLE 7: PARENTAL SOLUTIONS ....................................................................................... 60

LIST OF FIGURES

FIGURE 1: RELATIONSHIP BETWEEN GOALS, RESEARCH QUESTIONS, AND CONCEPTUAL FRAMEWORK ................................................................. 27
Chapter 1 - Introduction

Autism Spectrum Disorders (ASD) are a group of neurodevelopmental conditions characterized by difficulties with communication and interactions with others. ASD encompasses a wide range of symptoms and may include restrictive interests and repetitive behaviors. Further, ASD individuals struggle with identifying and responding appropriately to social cues, and are challenged to cope with external stimuli (American Psychiatric Association, 2013; Mayo Clinic, 2018; National Institute of Health, 2018). ASD symptoms are typically recognized in the first few years of life, with early detection relying on observations of children and parental reporting (Wiggins et al., 2019).

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), published by the American Psychiatric Association (APA, 2013), details criteria for a diagnosis of ASD, including: (a) deficits in social communication and interaction, (b) repetitive behavior, (c) difficulty adjusting to a change in routine, (d) struggling when responding appropriately to sensory stimuli, (e) problems transitioning to new situations, and (f) stress when experiencing a change in routine. Furthermore, severity of presenting symptoms is divided into three levels: (a) requiring support, (b) requiring substantial support, and (c) requiring very substantial support. The United States Centers for Disease Control and Prevention’s (CDC) recent estimates place the number of ASD children at one in 54 (CDC, 2020a). New Jersey reported the highest number of cases, with approximately 1 in 32 students receiving an ASD diagnosis (CDC, 2020b).

ASD can negatively impact academic performance. Likewise, ASD individuals, regardless of age, experience significant emotional and behavioral shortfalls, social challenges, and heightened anxiety in school both within and outside the classroom. According to Simpson, de Boer-Ott and Smith-Myles (2003), ASD students often struggle with communication, relating
to others, following a standard school curriculum, and adapting to change. Likewise, ASD students vary in their academic abilities and manner in which they process information.

Furthermore, ASD students struggle with transitions to new situations, communicating effectively with teachers and peers, dealing with heightened stress and anxiety, emotional difficulties and, quite often, behaving in an appropriate manner. These students process information in a different manner than their classmates, may lack empathy toward others, and struggle when asked to participate in group projects or organizing large pieces of information. These differences challenge students to adapt to the school environment, and drive teachers and other educational professionals to provide adequate services.

**Family Response**

Parenting an ASD child is not a small task, requires parents to change their lifestyle, and adapt to the needs of their son or daughter as the child moves through developmental stages. Early on, parents realize the main burden of caring for their ASD child is on the family. Parents and other primary caregivers act as advocates and service coordinators (Brown & DiGaldo, 2011). When a child is diagnosed with an ASD, families must make significant adjustments to stabilize their parental ability to cope with day-to-day tasks, as well as the children’s inability to follow social norms (Altiere & von Klug, 2009). Families, in an effort to learn about ASD and strategies to work with their ASD children, are challenged to discover appropriate resources, such as who to contact for support, and how to formulate proper questions for healthcare and other professionals. The goal is to cooperate together as a connected unit to create a positive environment and outlook for their children and themselves. Parents take the lead in making accommodations and changing the familial lifestyle in order to best serve the needs of all family members (Bayat, 2007; Brobst, Clopton, & Hendrick, 2009).
Naturally, from this level of adjustment and commitment, some parents of ASD children become protective and overly invested, making it difficult to overcome the urge to over-parent as their ASD children grow older. This is particularly difficult as their children transition to college. After changing their own lives to adapt to the needs of their children for many years, it is challenging for parents to allow their now adolescents to make their own decisions, and parents are likely to struggle to assist them in learning to be independent. It is not uncommon, nor unexpected, for some parents to feel uncertain, overprotective, and persist in their efforts to maintain a certain level of control over the activities of their children (Van Hees, Roeyers, & De Mol, 2018). These parental strategies, while designed to protect children from potentially negative outcomes and ensure success, often lead to child dependence on the parent, children not learning to advocate for themselves, make their own decisions, or assume personal responsibility (Segrin et al., 2012; Bradley-Geist & Olson-Buchanan, 2014; Montgomery, 2010).

**Parental Struggles as ASD Children Transition to College**

Unfortunately, there is limited research regarding support for parents as their ASD children transition to college. It is not surprising that, during this time, ASD students encounter many of the same challenges as their typically developing peers (e.g., navigating the campus, adjusting to a roommate, developing study routines, making new friends, and homesickness) (Hewitt, 2011). Also, not surprisingly, some researchers assert ASD college students face unique and complex adjustment challenges as a result of distress, loneliness, isolation, depression, and anxiety which they may experience transitioning from a structured school environment and familiar family routines to the freedom and new experiences presented on a college campus (Gelbar, Smith, & Reichow, 2014; Glennon, 2010). To address this potentially troublesome transition for ASD adolescents, some colleges and universities provide resources and support
systems, including a specialized orientation program, peer mentors, group activities, and counseling services.

In addition, each ASD student may exhibit unique behaviors and thought processes which can challenge college programming to not become stuck in a “one size fits all” approach. According to Dymond, Meadan, and Pickens (2017), many ASD college students are academically capable of completing college degrees with proper resources and accommodations. However, the range of support services needed are not readily available at many colleges and universities.

At a time when the expectation is for parents to allow their children to gain independence, they may recognize the new struggles their children are facing. Parents play a critical role in the lives of ASD adolescents in the post-high school transition and beyond (Smith & Anderson, 2014). However, they report higher levels of parenting stress and higher rates of mental health issues (Montes & Halterman, 2006). Many parents are unclear on how to reconcile the expectations and their own needs, as little research is available to guide them in this endeavor (Cheak-Zamora, Teti, & First, 2015). Parents report few outlets to discuss their own issues and receive assistance, and have described the need for more information about their children’s transition (Cheak-Zamora et al., 2015). Often both students and their parents struggle to find the balance between maintaining a close relationship and allowing each other the freedom and space which hopefully leads to the smooth and healthy transition of the student from adolescence to adulthood.

Unlike their children, who have potential supports in place, little to no parental support systems are in place at universities. Parents must navigate the tasks of offering support and encouragement to their children, while trying to back away and allow their young adult space to become independent. There is a fine line between offering appropriate support and over-
parenting, and it is often blurred by parents' own emotions and needs. This lack of knowledge suggests a need for interventions from colleges to support and foster positive parent expectations and parental supports to promote developmental autonomy for students.

I must situate myself in the importance of this research. As the parent of an ASD adolescent, a friend to ASD parents, a college transfer counselor, academic advisor, and college instructor, and an advocate for my son and my college students, my varied and vast experiences directed me to investigate the importance of colleges providing support, not only for ASD students, but their parents. When investigating the impact of having an ASD child has on parents, my personal experiences mirror in many ways research findings regarding parental thoughts, feelings, and behaviors. As the parent of an ASD child, I have worked with teachers, child study teams, doctors, and therapists, developing and implementing strategies to support my son and other family members. My varied roles working at a university motivated me to explore ways to provide additional assistance to ASD students and their parents. While my son is still in high school, my hope is that this project will provide information which will help him, other ASD college students, and fellow parents as our ASD children transition to and attend college.

Research Questions

Limited research on support systems for families of ASD college students exist. Studies primarily explore the needs of ASD students. This study is framed through the lenses of Separation-Individuation Theory, which describes the developmental process as adolescents separate from parents, friends, and significant others while transitioning to coherent self-sufficiency (Mattanah, Hancock, & Brand, 2004), and The Transactional Model of Stress and Coping, which views coping as a transactional process involving cognitive and behavioral efforts to control, lessen, or endure internal and/or external stress related to assessing challenging or threatening situations (Lazarus & Folkman, 1984).
The purpose of this qualitative research study was to ascertain the needs of parents of ASD college students diagnosed during the transition to and attendance at University, a large four-year state school in the northeastern United States, and explore their perceptions of tools and programming University and the University College Support Program (CSP) can provide as support for them. The following research questions guided this study:

1. What are the experiences of parents of students on the autism spectrum as their children transition to and attend college?
2. What do parents of university ASD students report are systemic barriers, which hinder them from coping with the transition and attendance of their child at college?
3. What supports might help parents of ASD students explore their new role and adjust effectively as their children transition to and attend college?
Chapter Two - Literature Review

This qualitative study focused on the experiences of parents as their ASD children transitioned to and attended college. In this chapter I review the literature on: (a) ASD and diagnostic criteria, (b) family experiences when raising an ASD child, (c) the role of parental advocacy for ASD children, (d) the impact of helicopter parenting on both parents and children, (e) challenges in the educational settings, (f) student and parental needs during the transition to college and (g) university perspectives. The roles of Separation-Individuation Theory and The Transactional Model of Stress and Coping are reviewed to examine the importance of a healthy separation between parents and students, and as a framework for understanding how families deal with transitions and other stressful situations, such as the transition of an ASD child to the university.

Autism Spectrum Disorders

Classification, diagnosis, and research of ASD has developed over the past 75+ years since autism was first discussed by Leo Kanner in 1943. He described individuals with impaired sociability, diminished social communication, repetitive and ritualistic behaviors, and strong resistance to changes in routine (Verhoeff, 2013). Hans Asperger, a Viennese pediatrician, in 1944, characterized children with extraordinary gifts in mathematics or natural science who also exhibited creative, original modes of thinking and objective self-appraisal. However, they were clumsy in their social and emotional relationships, lacked empathy, and were unable to read social cues from others. Language acquisition, though not usually delayed, was idiosyncratic, and, as the children got older, their condition did not dissipate (Wolff, 2004). Continuing research since that time has led to many developments and updates in the diagnostic measures for ASD, with the most recent criteria listed in 2013 by the American Psychiatric Association (Diagnostic and Statistical Manual of Mental Disorders, 2013). This latest version added the
term spectrum, and combined previous diagnoses - Pervasive Developmental Disorders, Autistic Disorder, Asperger’s Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. Furthermore, severity level descriptors indicating the level of support needed by ASD individuals were added to clarify and refine the ASD diagnoses (Hodges, Fealko, & Soares, 2019).

ASD is a neurobiological disorder affected by genetic and environmental influences which impact brain development (Hodges et al., 2019). According to Baio et al. (2018), ASD occurs in all groups regardless of racial, ethnic, or socioeconomic standing, though Caucasian children are identified at a higher rate than African American and Hispanic children. Hodges et al. (2019) reported ASD is more common in males. However, accurate numbers are difficult to obtain due to gender bias in diagnosis as females may be less likely to display apparent symptoms and behavior and/or may mask or camouflage their actions.

Clinical evaluation of ASD typically begins with a screening by a pediatrician or other medical professional, following specific age and developmental guidelines. Some early indicators of ASD include poor eye contact, poor social responses, lack of gesturing, and delayed language and social skills (Hodges et al., 2019). As reported by Soke et al. (2018), school age children may be extremely rigid and concrete in their thinking, struggle with understanding emotions, and lack social skills to interact with peers. Comorbid conditions include anxiety, attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), and mood disorders.

**Family Experiences with an Autistic Child**

Prior to understanding the experiences of parents of ASD children, it is important to gain insight into families raising an autistic child, which are likely to be strong contributors to the reactions of parents as their children transition to college. In the following section, I describe the
literature on the positive and negative impact of having an ASD child on family systems, including family unity and empowerment, family discord, family stress associated with raising an ASD child, parental advocacy, and helicopter parenting.

Family systems are impacted positively and negatively when a child receives an ASD diagnosis. For some, this news can provide empowerment, as family members pull together to learn about and share specific information. For others, it can lead to stress and anxiety both within and outside of the home. Myers, Mackintosh, and Goin-Kochel (2009) surveyed 493 parents with an online questionnaire, asking the open-ended question, “How has your child in the autism spectrum affected your life and your family's life?” A qualitative content analysis revealed families often found positive meaning in their adversity, viewed the diagnosis and their response in a positive light, and sharpened their priorities, which resulted in a positive outlook, hope, and increased focus on family over career. Hock, Timm, and Ramisch (2012) conducted qualitative interviews with nine couples and one wife with ASD children, and found parents often acted together as a single unit in multiple roles, such as therapists, caretakers, advocates, and ambassadors. This united front frequently led to an increase in their emotional responses and a deeper intimacy and commitment, not only to their child but toward each other. These studies provide support for the positive effects of having an ASD child on family unity and empowerment.

Conversely, findings from additional qualitative studies have revealed families with an ASD child experience greater levels of stress than families without an ASD child (Altier et al., 2009; Brobst et al., 2009; Rao et al., 2009). Multiple reasons for this stress exist. Altier et al. (2009) interviewed 52 parents of ASD children and found causes for stress were internal, external, and varied. Some specific reasons included confusion about the child’s diagnosis, the
severity of the disorder, lack of social support, the realization that ASD is a lifelong condition, confusion about treatments, and the need for significant parental and family adjustments.

**Parental Discord**

Parental discord often occurs when a family raises an ASD child. Sivberg (2002) administered four psychological tests (i.e., The Sense of Coherence Test, The Purpose in Life Test, The Family Relations Scale, and The Ways of Coping Questionnaire) to an experimental group of 66 parents from 37 families with an ASD child and compared their responses to a control group with the same number of individuals without a family member with a disability. Parents from the families with an ASD child reported lower relationship satisfaction, greater guilt, and greater degrees of blaming themselves for their child’s condition than parents in the control condition. Furthermore, Gray (2003) interviewed 33 families with an ASD child and found some fathers blame ASD on their wives, leading to increased marital discord. Added stress within a family with an ASD child, guilt, blame and lower relationship satisfaction often negatively impact the parental relationship with one another.

**Stress**

Family stress level is often impacted by the reaction of others outside the nuclear family to the ASD child. Woodgate, Ateah, and Secco (2008) interviewed parents in 16 families with an ASD child, and reported they experienced negative reactions from the public toward their children. These results were confirmed by Myers et al. (2009), who reported extended family members occasionally blamed parents for causing their children’s diagnosis. Further, Schall (2000) evaluated data from three families with ASD children who shared personal stories, and Brobst and colleagues (2009) analyzed data from inventories given to 25 couples with ASD children. Families in each study reported they had experienced differing levels of rejection by relatives, friends, neighbors, and strangers they interacted with in the community, and low levels
of social support. These findings indicated negative responses and lack of support from extended family members, friends, and neighbors, as well as adverse reactions from the public, all led to increased stress levels of parents and siblings of ASD children.

Parents of ASD children also experience stress associated with making necessary daily life adjustments. Hutton and Caron (2005) interviewed 21 parents who were the primary caregivers of ASD children; Rao and Beidel (2009) analyzed questionnaires administered to 15 parents of ASD children and 15 parents of typically developing peers. Results from both studies indicated work and social adjustments were necessary, which led to higher levels of anxiety, job stress, and social changes, such as not being able to go to the store, a restaurant, or on vacation. Hock et al. (2012) reported the results of interviews with 19 parents of children with ASD and found parents experienced developmental changes over time in their relationships with each other, may devote more time and energy to their ASD child than their other children, and often overlook their own needs, the needs of other children, and the needs of each other.

These mixed results point to a wide range of responses by parents, other family members, and the community when encountering and working with ASD children. In some cases, parents drew closer together and united in their care for the children. Family members were empowered, experienced a strong bond, and thrived as caretakers and advocates for the child. At other times, an ASD child in the family led to heightened levels of stress, anxiety, parental and familial discord, and difficulty in accomplishing everyday tasks.

**Parental advocacy**

Another experience of many parents of ASD children is their constant and consistent advocacy. Parents of ASD children spend a great deal of time interacting with teachers, doctors, extended family, neighbors, therapists, and caretakers outside the family unit. Quite often they are tasked with advocating on behalf of their children to assure proper growth and development.
For example, Bayat (2007) surveyed 175 parents and other primary caretakers of ASD children ages two to 18, and discovered that, in addition to working as their children’s caregivers, counselors and educators, parents likewise became outspoken advocates on their child’s behalf, while also working as a resource for other parents in a similar situation. Dymond et al. (2017) interviewed 10 parents of university ASD students and six university personnel, reporting parents know their child and his or her needs intimately and can offer a holistic perspective about the types of supports (e.g., academic, social, home, health) their children need to be successful. As such, parents of ASD children play a critical role in their child’s upbringing. Parents of ASD children have the additional role and responsibility of advocacy for their children, both within and outside the family unit, above and beyond families with typically developing children.

*Helicopter parents*

Parents should advocate for their children and look out for their physical and emotional well-being (Foster et al., 2012). Sometimes, however, parents of both ASD children and their typically developing peers become too entangled in their lives, which can lead to negative outcomes. The term helicopter parent refers to the over-involvement and developmentally inappropriate participation of parents in the lives of their children (Segrin et al., 2012). Helicopter parental strategies, while designed to protect children from potentially negative outcomes and ensure success, may lead to children not learning to advocate for themselves, making their own decisions, and assuming personal responsibility (Segrin et al., 2012; Bradley-Geist et al., 2014; Montgomery, 2010).

For example, in a study of college students, LeMoyne and Buchanan (2011) presented statements associated with helicopter parenting to 317 college students to ascertain their attitudes about parental involvement and its impact on student mental health. Results indicated helicopter parenting was negatively associated with psychological well-being, positively associated with
recreational pain pill use, and contributed to an increase in students taking prescription medications for anxiety and depression. Similarly, Segrin et al. (2012) administered questionnaires to 538 parent-young adult pairs. Parents completed measures of overparenting, family enmeshment, parenting styles, and parent-child communication. Children responded to assessments of parent-child communication, family satisfaction, and entitlement. Results indicated over-parenting is linked to lower quality parent-child communication and lower family satisfaction. In addition, over-parenting was a significant predictor of young adults’ sense of entitlement, with the children believing others should solve their problems.

Studies pointing to the potential negative outcomes of helicopter parenting may not deter parents from inappropriately advocating for their children. Anderson and Butt (2017) interviewed 18 families of ASD children and found many parents, despite the risk of being labeled as helicopter parents, still did whatever was necessary to assist their child, adhering to the belief that their son or daughter needed their extra assistance to grow, adapt and succeed in college.

From these studies, it is clear parents of ASD children face the challenge of finding the balance between trying not to over-parent, allowing their child the space to grow, and advocating for them when necessary. Finding this balance is likely to be particularly challenging as ASD adolescents transition to college, as the change represents their movement from the dependence of adolescence to independence as adults.

**Transition to College – ASD Students**

ASD students and their parents, like most families, consider many factors when choosing a college. Some of these include deciding what type and size of school to attend, whether or not to live on campus or commute, assessment of academic and social readiness to attend college, if, when, and how to disclose one’s disability, finding out about appropriate academic supports and
accommodations, identifying necessary social supports, and ascertaining strategies to assist in adjusting to the college environment (Adreon & Durocher, 2007). The United States Department of Education (2017) reported the transition to college can be a difficult process for many students, especially those with a diagnosed disability. Similarly, Francis et al. (2018) administered an online survey to 111 college students with disabilities, including 12 ASD students. Their findings indicated these students faced the same challenges encountered by their classmates, as well as barriers such as low expectations, a lack of knowledge of available resources, and poor collaboration between themselves, family members and school professionals.

Conducting interviews and sharing the stories of 12 ASD college students, Prince-Hughes (2002) found ASD students also experienced anxiety and the need to manage new information as they interact with additional faculty and staff. They encounter social challenges, special testing needs (e.g., the student may need extended time for tests or assignments), learning-style differences, the need for routine, keeping organized and staying on track with assignments, and sensory issues. Safran (2001) conducted a literature review on Asperger Syndrome, an ASD category, and reported difficulties in the transition and adjustment to college for ASD students depended on the severity of their disability, individual needs, and their ability to advocate for themselves based on their knowledge of how to access services.

In addition, specific types of classes are difficult for ASD students. For example, Gobbo and Shmulsky (2014) conducted focus groups with 18 experienced college faculty members who reported ASD students enrolled in classes which emphasized small group work and discussion experienced difficulty as the courses highlighted the use of interpersonal skills. Additionally, students struggled in classes which included critical thinking tasks related to identifying bias and multiple perspectives as students had to imagine the mindset of others.
ASD college students also face the decision of whether or not to disclose their diagnosis to professors, staff, and fellow students. Cox et al. (2017) conducted interviews with 118 ASD adults and reported these students typically disclosed their diagnosis in terms of academics only when needed to acquire formal academic accommodations. With peers, most respondents did not disclose their diagnosis unless the situation or another person’s words or behavior brought the issue to light. Cai and Richdale (2016) conducted focus groups with 23 ASD college students and 15 of their family members. They reported one student, encouraged by her parents, disclosed her diagnosis at enrollment, and that ASD students may choose not to disclose because of fear of stereotyping, negative bias, adverse past experiences, or a belief they no longer have ASD.

In summary, as ASD students transition to and attend college, they experience many of the same stressors as their typically developed peers. They also face additional challenges, including varied ways of processing course information, different methods of interactions with faculty, staff, and classmates, whether or not to reveal their ASD diagnosis and, if they decide to disclose, who to tell on campus and how to let them know. ASD students may also struggle to advocate for themselves, continuing to remain overly reliant on their parents. These struggles are likely to make it difficult for parents to encourage student independence and continue to evolve in their parental roles.

Parental Needs as their ASD Children Transition to College

As demonstrated in a literature review by Dallas, Ramisch, and McGowan (2015), minimal research is available on parent experiences as their ASD students transition to and attend college. The researchers found only six articles written between 2003 and 2014 that reported results of studies of ASD, familial involvement, postsecondary education, and college success. This lack of study suggests a need for research on the experiences of parents as their children transition to and attend college, what support is needed to foster positive parent
needs of parents of university ASD students. Just as ASD students labor with the transition to college, so too do their parents struggle with the movement of their child into a new environment in which they are expected to advocate for themselves with limited or no parental oversight.

Since that review, a few studies have been conducted with parents of ASD young adolescents in regards to their relationships with their children and services post high school graduation. Smith et al. (2014) noted from the results of a literature review of the roles of families in the transition process of their ASD children from high school to the adult world, that parents play critical roles (e.g., caregiver, advocate, and career counselor) in the lives of ASD adolescents in the post-high school transition and beyond. Cheak-Zamora, Teti, and First (2015) conducted focus groups with 19 primary caregivers of ASD adolescents and young adults, and found participants felt overwhelmed, anxious, and in need of some down time. Group members reported few outlets to discuss their own issues and receive assistance, sought more information about their child’s transition, and often took on more responsibility.

More often than not, both students and their parents struggle to find the balance between maintaining a close relationship and allowing each other the freedom and space which hopefully leads to the transition of the student from adolescence to adulthood. Parents with ASD children transitioning to college face the same challenges as those with typically developing children, such as assisting their children in the transition to college by helping them set goals, providing realistic expectations, and challenging them to take more responsibility for their growth and development (Holtz, Owings, & Ziegert, 2006). However, parents of ASD students report the transition for their children is different, and continuing parental guidance is required for student success due to lack of available services for their children. Parents of ASD children use the expression “fall off a cliff” when referring to the lack of adequate services available for their
adolescents as they transition to adulthood (James, 2013). According to Friedman, Warfield, and Parish (2013), as adolescents age out of the school service system, resources of care are often fragmented and lack adequate funding, leading to poor transitional outcomes. In fact, a literature review conducted by Gerhardt and Lainer (2011) found most individuals on the ASD spectrum are unemployed or underemployed, and do not receive appropriate services, which includes transition programming. Sosnowy, Silverman, and Shattuck (2018) suggested services for young adults on the autism spectrum may be inadequate because they are not in sync with young adults’ and parents’ needs, and do not offer the appropriate help for the transition into adulthood.

This lack of resources and services is likely to contribute to stress and confusion for parents of ASD children and create doubt in their minds about their children’s ability to transition successfully. Van Hees et al. (2018) interviewed 60 parents of 34 ASD high school seniors and first-year college students and found parents had low expectations for the successful transition of their children to autonomous behavior and struggled to assist them in learning to be independent. Parents reported being uncertain, overprotective, and persistent in efforts to maintain a certain level of control about the activities of their children. Results also indicated a need to set boundaries to experience separation, while also remaining closely connected.

Further, Morrison, Sansosti, and Handley (2009) conducted a focus group with four mothers of sons with ASD between the ages of 8 and 16 years old who discussed the need for high parental support, more so than their typically developing peers, if their children were going to be successful in college. Pena and Kocur (2013), based on interviews with 18 parents of ASD community college students, found the transition from high school to college was difficult for parents who were used to making decisions for their children, and for the students who relied on their parental guidance more so than typically developing peers. These respondents likewise
NEEDS OF PARENTS OF UNIVERSITY ASD STUDENTS

recognized the importance of gradually backing off and allowing their children more independence in decision making and navigating through the college system.

Madaus (2005), in his role as Director of the University Program from Students with Learning Disabilities at the University of Connecticut provided anecdotal evidence based on his work reported college disability services providers rarely interact directly with students. He indicated parents typically make phone calls and speak on behalf of their children. Parents often used “we” rather than “my son or daughter”, and referred to them in the third person. Some parents, when meeting with an advisor on campus, did not include their children in the conversation, even when the student was present. This hinders student self-determination and independence, and interferes with a student speaking for himself. Brinckerhoff (1996), as the Director of Learning Disabilities Support Services at Boston University, wrote:

Many well-meaning parents and high school personnel have protected these students from failure and stress by making decisions for them. Individualized transition planning should be viewed as a golden opportunity for students to shape their own academic destinies by learning about their disabilities, asking questions, presenting ideas, and advocating for themselves. This process should also be viewed as a critical juncture in students’ lives for focusing attention on what it will take for them to achieve success and independence as adults (p. 120).

He also encouraged parents to assist their children by supporting their dreams, promoting their social development, and inspiring their academic growth.

Each ASD student is unique, and the hope is parents can gradually decrease making decisions for their children while, at the same time, engaging with their children when needed, especially when major changes occur, such as a new roommate or the beginning of a new
NEEDS OF PARENTS OF UNIVERSITY ASD STUDENTS

semester (Pinder-Amaker, 2014; Brown, Wolf, King, & Bork, 2012). Palmer (2006), the parent of an ASD son, based on personal experience, wrote, “One of the most important things we can do as parents is to help individuals on the autism spectrum learn to advocate for themselves. The first step can be to help the child understand his or her differences and strengths and weaknesses…if we accept their differences and treasure our children for who they are, they will, we hope, feel better about themselves” (p. 96). Although minimal literature exists on the experiences of students as they transition, there is even less information available about what can be done to assist parents.

How to Support ASD Students and Their Parents

Although little evidence is available to indicate which supports are needed by parents of ASD college students, part of the solution is likely to fall on colleges and universities. Students diagnosed with disabilities present unique challenges in higher education. Colleges and universities continually strive to be models of diversity and inclusivity, opening their doors and campuses to a wide range of students. Based on interviews with 60 parents of ASD high school seniors and first-year college students about how parents of ASD adolescents cope with the transition of their child into higher education, Van Hees et al. (2018) suggested school personnel should not view family members of ASD students as a problem. Rather, they should be viewed as a system challenged by the transition of their children to college who should be supported by communicating information about ways to adapt to changes, and that students should be encouraged to develop independence while, at the same time, learning to ask for help when necessary.

A review of research related to the transition to adulthood for ASD adolescents conducted by Hendricks and Wehman (2009) led them to recommend that family members be educated and well-equipped to assist their ASD adolescent. An important component of a
support program for ASD students and their families is to recognize the uniqueness of each student and familial situation, tailor a program which address individual and familial needs, and not generalize programming. Rather, according to Henninger and Taylor (2013), the unique profile of ASD and social and environmental factors which influence outcomes must be considered. Pellicano, Dinsmore and Charman (2014a, 2014b) conducted interviews, led focus groups, and administered questionnaires to 72 participants in the ASD community – adults on the autism spectrum, family members, practitioners, and researchers. They found understanding stakeholder perspectives offers valuable insight and guidance toward developing more impactful research which aligns with the priorities of the autism community, namely improving the daily lives of those on the autism spectrum. Overall, both parents and young adults made it clear supports and services needed to be flexible enough to meet individual needs and be more comprehensive, continuous, and integrated to be most useful. Students should receive specific assistance where needed, and parents should receive up-to-date academic information, behavioral support plans, and appropriate school resources both before and while their children are enrolled in college.

**College Support Programs That Include Parents**

Recognizing the rising number of ASD students attending college, some universities have developed specific departments and programming for ASD students, while others integrate ASD services into offerings provided by the Office of Disability Services. University, the school referenced in this study, is a Northeastern State University, and provides support for ASD students and their parents under the auspices of the Psychology Department. ASD students are able to join The College Support Program (CSP), “a comprehensive program that assists students through the provision of direct service and collaboration with University services that address executive functioning, social competence, academic skills, self-care, self-advocacy, and career
preparation” (University, 2020b). According to the CSP website (University, 2020b), their services include weekly meetings between the student and a CSP coordinator, assistance with defining and developing strategies to meet identified academic and life goals, relationships with trained peer mentors, social activities, and referrals for academic, social, and emotional support through university learning centers and counseling services. Additionally, the CSP works with students to develop independent life skills, such as learning to live with others in a dormitory, advocating for themselves, participating in campus activities, and domestic skills such as banking and hygiene. Currently there are 20 ASD students enrolled in the program (CSP Program Coordinator, personal communication, August 1, 2020).

The CSP is student-centered in their approach, but also requires undergraduates to sign a written release which indicates who can view their university records. With this release, students can allow individuals (e.g., parents, family members) to access their university records, discuss questions and concerns with faculty and staff, and monitor their progress. The CSP hosted their first parent orientation in August 2020. Staff leaders offered one session for parents of new students, and one for parents of continuing students. Topics included the role of the CSP staff, university staff and faculty, student responsibilities, family boundaries, and the importance of directing students toward independent living (CSP Program Coordinator, personal communication, August 1, 2020).

**Theoretical Frameworks**

This study is situated within two theoretical frameworks, Separation-Individuation Theory and The Transactional Model of Stress and Coping. Understanding the needs of parents as their ASD children transition to and attend universities is framed within these two theories, examining the process of parents and children separating from each other, their individual
development apart from each other, and exploring ways parents cope with stress, anxiety, uncertainty, and the transition to new situations.

**Separation-Individuation Theory (SIT)**

According to Mattanah et al. (2004), separation-individuation is a developmental process which occurs as an adolescent separates from parents, friends, and significant others while transitioning to coherent self-sufficiency, which begins to occur with the transition to college. Meeus et al. (2005) posited, based on the results of questionnaires given to 3000 adolescents ages 12-24 without disabilities, that separation and individuation are two separate, parallel processes, where adolescents separate psychologically from their parents as they age and, at the same time, experience a change in their identity.

A majority of the research on separation-individuation focuses on factors which affect the child’s emotional, social, and academic development, with studies exploring this process through the eyes of parents only as dyads with their children. In relation to healthy student adjustment, Mattanah et al. (2004), utilizing responses to various inventories from 404 college students without disabilities, found the best predictor of strong college adjustment academically, socially, personally, and emotionally, was the combination of a secure attachment relationship to parents, along with a healthy level of separation. Successful individuation is related to secure and lasting relationships with others, while at the same time allowing for personal growth and development. College students and parents often struggle to find a balance during this time of transition. Engels (2001), based on the results of self-reports completed by 412 adolescents without disabilities, indicated positive parental attachment significantly contributed to adolescents feeling good about themselves. Results of online surveys of 75 college Freshmen found the mental health of college students is positively impacted if they can maintain a balance and remain simultaneously emotionally connected to and functionally independent from their parents (Yelle,
Kenyon, & Koerner, 2009). According to Rice, Cole, and Lapsley (1990), results of questionnaires administered to 240 college Freshmen indicated the feeling of positive separation was a better predictor of college adjustment than independence from parents or family cohesion, and independence from parents had little to do with general college adjustment.

Some studies explored separation within the context of parent-child dyads. Separation responses to questionnaires by 81 mother-son pairs and 68 father-son pairs revealed anxiety related to being apart from a significant other, sadness concerning imminent or existing loss, and anger or frustration about the inability to remain in close proximity (Bartle-Haring, Brucker, & Hock, 2002). Kins et al. (2011) administered questionnaires to 232 emerging adults (mean age 23) without disabilities and 442 parents. They found parental separation anxiety is positively related to separation-individuation pathology in emerging adults and allies with problems in adolescent identity development and lower general well-being. These findings were consistent regardless of whether the young adults lived at home or on their own. Kins, Soenens, and Beyers (2012) surveyed 232 emerging adults ages 21-26 and found dependency-oriented psychological control by parents was related to dysfunctional dependence. When parents are intrusive and manipulative in an effort to keep their children dependent on them, the emerging adult is more likely to report a strong fear of abandonment and loss of important others.

Parents who do not allow their children to separate and function with a growing sense of independence hinder their ability to handle stress and change independently. Although prior research did not take into consideration the unique characteristics of ASD adults, these studies indicate the importance of both separation and individuation as adolescents transition to adulthood, moving from interdependence to independence.
**Transactional Model of Stress and Coping**

As stress and coping are central issues for parents when their ASD children transition to and attend college, the Transactional Model of Stress and Coping can provide specific markers to point out thoughts, feelings, and behaviors. This model, first proposed by Lazarus et al. (1984), “views the person and the environment in a dynamic, mutually reciprocal, bidirectional relationship” (p. 293). This paradigm measures five concepts including stress, appraisal, coping, precursors of stress and coping, and short and long-term adjustments. Managing stress and coping are processes concerned with change related to specific situations and contexts. Individuals appraise situations, interact with the environment and those within it, assign new meanings to the circumstances, and adapt accordingly (Lazarus et al., 1984). Social support is an important factor in the stress and coping process and influences the cognitive assessment of stressful situations. Schwarzer and Knoll (2007), reporting on four longitudinal studies and one experimental study, wrote “Coping, then, is the result of this cognitive appraisal. The more support is available, the better coping is facilitated” (p. 244). Ascertaining parental stressors, coping mechanisms, and support systems when working with their ASD children will provide information to assist in addressing the research questions in terms of possible college supports.

**Summary**

To summarize, Separation-Individuation Theory posits the transition to adulthood is a time for children to set out on their own, make important decisions, learn to advocate for themselves, and accept responsibility for their choices and actions. This move toward autonomy is part of the normal developmental process. Many parents of ASD college students struggle during this transition and experience a wide range of emotions as they continue to hover over their children. Parents may want to let their children go, but know they must keep a close eye, while at the same time allowing their son or daughter to become independent and transition in a
healthy manner academically, socially, and emotionally. Colleges face the challenge, with all of their students, in walking a fine line between listening to and often relying on parental input, while allowing students to develop a sense of independence. The relationship of schools with parents is often contentious, as colleges seek to protect their students, not only as a matter of policy, but also to keep in concert with the law, from parents who may be overzealous or not want to let go. Depending on the parental involvement in the life of an ASD child, this affiliation of colleges and parents may swing to either end of the pendulum, and result in much more problematic transitions for the student, or greater compliance.

Separation-Individuation Theory provides some basic foundational ideas to frame the college transition for both students and parents. College students attempt to separate from their parents, transition to university life and adulthood, make decisions for themselves, and deal with the consequences. Parents continue to look for ways to act as advocates for their adult children, struggle to cut the cord, and make great efforts to find a balance between allowing their children the space to make their own decisions and take on their own responsibilities. Parents who over-advocate for their college children, hover over them and incessantly worry, may experience their own anxiety, not separate themselves from their children, and not allow them to develop in a healthy manner. Healthy separation from parents can allow students to transition successfully and develop in a healthy manner academically, socially, and emotionally. Parents who can learn to cope with their college ASD children’s transition may find a smoother transition for themselves and experience less anxiety and the need to remain over-protective.

The Transactional Model of Stress and Coping examines five factors during periods of transition in the lives of individuals and families, including stress, appraisal, coping, precursors of stress and coping, and short and long-term adjustments. This model can provide the current study with a baseline as to how parents, children, and family systems adjust to changes as an
ASD adolescent transitions to college. Social support for students and parents, methods of adaptation to change, and stress management may impact this important family milestone, with coping strategies influencing the smooth or rocky adjustment for both parents and students as the college experience begins and progresses.

**Conclusion**

In summary, prior literature indicates parents of ASD children experience additional stressors than parents of typically developing children, work as team members with medical professionals, therapists, child-study teams, social service agencies, and other family members to assist their child, and often engage in helicopter parenting. However, services for ASD individuals typically lessen or end as adolescents transition to adulthood, with colleges providing services for ASD students, but not their parents. These lack of services and limited research into parental experiences presents a gap in the literature, leads me to investigate the experiences of parents of students on the ASD spectrum as their adolescents transition to and attend college, discover barriers which hinder parents during this time, and parental supports to assist them in managing separation and coping with stress.
Chapter 3 - Methodology

As demonstrated in Figure 1, the purpose of this study was to explore the needs of parents of ASD college students and their perceptions of tools and programming the university could provide to support them in their journey. To achieve this goal, I sought to answer three research questions related to the experience of parents, systemic barriers, and perceived needed supports. The Transactional Model of Stress and Coping and the Separation-Individuation Theory framed the questions and results.

Research Design

Figure 1: Relationship between goals, research questions, and conceptual framework.
This study is qualitative. Participants were interviewed and transcripts analyzed using iterative categorization which, “is suitable for use with inductive and deductive codes and can support a range of common analytical approaches, e.g., thematic analysis...constant comparison, analytical induction, content analysis, conversational analysis, discourse analysis... and narrative analysis” (Neal, 2016, p. 1096). Following the steps outlined in a template by Neal (2016), outlined below in the Data Analysis section and Appendix H, my goal was to delve deeply into and compare participant responses, discover emerging themes, and analyze responses to answer the research questions. See Table 2 (p. 41) for the study timeline.

**Setting and Sample**

The setting for this study was a university in the Northeastern United States. University consists of 5 campuses, with an enrollment of more than 71,000 students from all 50 states and more than 125 countries (University, 2020a). The Office of Disability Services provides academic services and accommodations, as well as tools, resources, and support to assist students with disabilities to become responsible decision-makers and self-advocates in charge of their own future (ODS, 2020). The College Support Program (CSP) provides additional support services and resources for students on the autism spectrum. Currently there are 20 ASD students enrolled in the program. The CSP offered an orientation session for parents of new and continuing ASD students enrolled in the program prior to the fall semester to review general information, but provides no additional resources or supports throughout the academic year geared toward parents and caregivers of the ASD students (CSP Program Coordinator, personal communication, July 10, 2020).

I recruited participants for this study utilizing the following procedures. First, I received a Letter of Consent from the CSP Program Coordinator providing permission, CSP support, and access to parent contact information (see Appendix A). With Institutional Review Board (IRB)
approval, I participated in two inaugural CSP orientation sessions with parents of ASD students enrolled in the CSP. One group consisted of parents of incoming Freshmen; the other group were parents of returning students. Each meeting lasted approximately 90 minutes and served dual purposes. First, the Program Coordinator reviewed the role and goals of the CSP, discussed parental boundaries and expectations, and answered questions. At the conclusion of this segment, The Program Coordinator introduced me and related my background as a college academic advisor and parent of an ASD child. She turned the meeting over to me and I talked about my personal background, professional experiences, and this current study. I spoke to the parents in both groups for approximately 15 minutes.

At the conclusion of my presentation, I asked parents if they had any feedback or questions regarding my family history, work experience, and the research study. Finally, I informed the parents that I was awaiting approval of my dissertation proposal from my committee before proceeding with the next steps in the study. I asked them to think about whether or not they would be interested in being interviewed as participants in this project, and, once the proposal is approved, the CSP Program Coordinator would follow up with an email to parents of CSP students to re-introduce me, review this research project, and gauge their interest (see Appendix B). Parents who responded positively received a follow-up email from me which included an IRB approved consent form indicating their willingness to participate in the study (See Appendix C) and to engage in a recorded online interview (see Appendix D). Instructions were provided to return the signed forms electronically. Once the consent was signed, I sent a demographic questionnaire to each participant and arranged individual interview appointments.

The sample for this study consisted of nine parents of current and incoming ASD students enrolled at University, who are also members of the CSP. To be included in this study, parents had at least one ASD child who attends the University. Demographic information for the nine
participants was collected prior to their interviews. There were six female and three male interviewees. Five respondents were in the 50–59-year age range, four were in the 40–49-year age range. All parents interviewed held a bachelor’s degree, with seven of nine participants having earned graduate degrees. Five parents work in education, four do not. One participant identified as Asian, six Jewish, and two Caucasian. Interviewees included two married couples. The respondents’ children were all male: seven were freshmen, one was a sophomore and one was a junior. Seven participants reside in the same state as University and two live outside of the state. As this study was conducted in the fall months of 2020, due to the CoVid 19 pandemic, University courses and services were completely remote. One student, whose parent was in this study, was living on campus in the Chabad House; the remainder were attending classes remotely from their parents’ home (See Table 1 and 2).

**Table 1**

*Participant/Student Connection*

<table>
<thead>
<tr>
<th>Name (Pseudonym)</th>
<th>Student Information</th>
<th>Home Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sue</td>
<td>Male/Sophomore/Jewish</td>
<td>In state – living on campus</td>
</tr>
<tr>
<td>Ann</td>
<td>Male/Freshman/Caucasian</td>
<td>In State – living at home</td>
</tr>
<tr>
<td>Ben</td>
<td>Male/Freshman/Caucasian</td>
<td>Out of State – living at home</td>
</tr>
<tr>
<td>Jen</td>
<td>Male/Freshman/Jewish</td>
<td>In State – living at home</td>
</tr>
<tr>
<td>Lauren</td>
<td>Male/Junior/Jewish</td>
<td>Out of State – living at home</td>
</tr>
<tr>
<td>Kelly</td>
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</tr>
<tr>
<td>Jim</td>
<td>Male/Freshman/Jewish</td>
<td>In State – living at home</td>
</tr>
<tr>
<td>Denise</td>
<td>Male/Freshman/Asian</td>
<td>In State – living at home</td>
</tr>
<tr>
<td>Art</td>
<td>Male/Freshman/Jewish</td>
<td>In State – living at home</td>
</tr>
</tbody>
</table>
Table 2

*Participant Demographic Information*

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td>Age Range</td>
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<td>40-49 years old</td>
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<tr>
<td>50-59 years old</td>
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<td>Undergraduate Degree</td>
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</tr>
<tr>
<td>Graduate Degree</td>
<td>7</td>
</tr>
<tr>
<td>Works in Education</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td>Ethnicity</td>
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<td>Asian</td>
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</tr>
<tr>
<td>Caucasian</td>
<td>2</td>
</tr>
<tr>
<td>Jewish</td>
<td>6</td>
</tr>
<tr>
<td>Married to Each Other</td>
<td></td>
</tr>
<tr>
<td>Married Couples</td>
<td>2 – 4 individuals married to each other</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
</tr>
<tr>
<td>Reside in the same state as University</td>
<td>7</td>
</tr>
<tr>
<td>Reside out-of-state</td>
<td>2</td>
</tr>
<tr>
<td>Child/Student Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
</tr>
<tr>
<td>Child/Student Year at University</td>
<td></td>
</tr>
<tr>
<td>Freshmen</td>
<td>7</td>
</tr>
<tr>
<td>Sophomore</td>
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</tr>
<tr>
<td>Junior</td>
<td>1</td>
</tr>
<tr>
<td>Senior</td>
<td>0</td>
</tr>
</tbody>
</table>
Data Collection

Data was collected in the form of a demographic questionnaire and individual interviews. The demographic questionnaire was emailed to each participant to gather preliminary background information (see Appendix E). Demographic data included questions from categories formulated by the U.S. Census Bureau (2016), such as family name, gender of participant, gender of ASD child, age range of parent, age of ASD child, number of people in the household and their genders and ages, level of parental education, and parental employment information. I developed a personal data form for each participant and assigned each respondent a pseudonym, which was included on all data, as well as marked on the demographic form (see Appendix F). I stored all returned demographic and personal data forms in a locked drawer in a locked office, and tabulated results were kept on a password protected laptop and password protected flash drive.

Over the span of three months, I conducted one semi-structured interview with each participant. Each interview included pre-determined, open-ended questions from a pre-approved script (see Appendix G). The questions were reviewed by my dissertation chair, dissertation committee, peer group, and the CSP Program Coordinator. Interview questions focused on student and family background, family transitions and separation, and parental support systems. The semi-structured interviews consisted of specific questions designed to initiate a discussion of parent and family background, individual and family stress, individual and family coping mechanisms, individual and familial support systems, the separation process as their child transitioned to and attended University, and the perceived barriers they experienced. I set the context by defining my area of interest, the purpose of this study, and asking participants questions which sought to open up and not limit their responses (Mears, 2012). Using a semi-
structured questioning format allowed interviewees and me the space to deviate from the script in order to elaborate on various topics as they became part of the conversation (Gill et al., 2008).

I began the interviews by gaining the trust of the participants (Harvey, 2011). Zuckerman (1972) suggested interviewers thoroughly prepare prior to conducting an interview to illustrate their own knowledge, be in a position to answer questions, and speak to the relevance of the research project. Therefore, prior to beginning the interviews, I spoke with participants and related my own story to them as the parent of an ASD child and college academic advisor. Sharing my story, asking for feedback, and entertaining questions were designed to build trust with respondents. Awareness of these factors guided my presentation during the orientation session and directed me when preparing for individual interviews.

Table 2 illustrates the research questions and sources of data to answer each. Initial interview questions confirmed demographic information from the previously completed questionnaire. Open-ended questions were asked to ascertain information from parents both about their ASD child and their own parental experiences. Where necessary, I asked probing questions to address separation and individuation difficulties, perceived parental stress, coping mechanisms, and social support. Probing questions were adapted from The Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), The Jalowiec Coping Scale (Harwood et al., 2009), The Social Support Questionnaire (Sarason et al., 1983), and The Psychological Separation Inventory (Rice, 1992). The Perceived Stress Scale measures stress and how respondents feel their lives are unpredictable, uncontrollable, and overloaded (Padden, Connors & Agazio, 2011), and has acceptable reliability (i.e., Cronbach’s measure of internal reliability of >.70; Lee, 2012), and evidence of validity as a psychometrically sound stress measure (Siqueira Reis, Ferreira Hino, & Romelio Rodriguez, 2010; Denovan et al., 2019). The Jalowiec Coping Scale measures coping thoughts and behaviors when responding to a specifically identified
stressor (Padden et al., 2011), has acceptable evidence of reliability based on a mean Cronbach’s score >.70, and a validity index of .85 (Ulvik et al., 2008). The Social Support Scale provides information pertaining to the perceived number of social supports and satisfaction with available social support (Sarason et al., 1983), has acceptable evidence of reliability based on a Cronbach score >.85, and validity coefficients >.8 (Liu, Li, & Lian, 2008). The Psychological Separation Inventory assesses independence from parents, has evidence of reliability based on a Cronbach score range of .73 to .94, and validity scores of .49 to .96 when correlated to scores on adolescent adjustment scales (Rice, 1992).

**Table 3**

*Research Questions and Data Collection Methods*

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Data Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Question 1</strong></td>
<td></td>
</tr>
<tr>
<td>What are the experiences of parents of students with ASD when their children transition to and attend college?</td>
<td>Individual interview questions from pre-approved script</td>
</tr>
<tr>
<td><strong>Question 2</strong></td>
<td></td>
</tr>
<tr>
<td>What do parents of university ASD students report are systemic barriers which hinder them from coping with the transition and attendance of their child at college?</td>
<td>Individual interview questions from pre-approved script.</td>
</tr>
<tr>
<td><strong>Question 3</strong></td>
<td></td>
</tr>
<tr>
<td>What support do these parents need to help them adjust effectively as their children transition to and attend college?</td>
<td>Individual interview questions from pre-approved script.</td>
</tr>
<tr>
<td><strong>Demographic Information</strong></td>
<td></td>
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<td></td>
<td>Pre-interview questionnaire</td>
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</tbody>
</table>
Participants were informed at the beginning of the interview that they were free to stop at any time and could choose not to answer any questions. Each interview concluded with the opportunity for participants to ask me questions. I also informed participants I would email them a copy of the interview once it was transcribed for their review and feedback.

Parental interviews were conducted separately to allow respondents the opportunity to tell their own story without having to corroborate or contradict the account of the other parent. This also allowed for privacy in their responses (La Rossa & Gelles, 1981). Parents of the same student were interviewed separately. According to Valentine (1998), interviewing multiple members of the same household separately can provide richer responses by pointing to family patterns of behavior and exploring familial relationships. This was important information in the current study because mothers and fathers may have different roles in the family system when working with an ASD child, present different views about ASD, and may be reluctant to talk about their relationship in the presence of each other.

All interviews were conducted via WebEx, a video conferencing tool, as we were in the midst of the COVID-19 pandemic requiring social distancing. Online interviews provided both advantages and disadvantages. According to Salmons (2012), videoconferencing provides the opportunity for a live, synchronous conversation, both verbally and on screen. Tuttas (2015) reported videoconferencing more closely resembles an in-person meeting than email, online forums, and instant messaging – additional options during this time. In accordance with the findings of Chen and Hinton (1999), video conferencing decreased travel expenses, and time for the participants and the researcher. Online interviews also provided respondents the opportunity of comfort and allowed them to set aside time while at home in the midst of their busy schedules (Bampton & Cowton, 2002). WebEx also provides built-in recording.
Conversely, since online tools typically project individuals from the waist up, I was not able to observe the full scope of the respondents’ body language which may tell a different story than their answers (Irani, 2019). In addition, it is possible I did not see all visual cues, such as head nods and eye gaze, and that the interview might be perceived as more formal with less ordinary exchanges than in person (O’Conaill, Whittaker, & Wilbur, 1993). Participants online sometimes become highly formal in their communication style, perhaps leading to emotional distance and impersonal interactions. Knowing these limitations, I remained cognizant of their impact during the online interviews, attempted to make the process more conversational, and watched the recorded interviews several times to observe participants’ body language and emotional reactions.

To assure confidentiality, taped interviews were dated and transcribed using online voice to text transcription software within 48 hours of the interview completion to ensure the integrity of the recording, as well as provide immediate feedback for the researcher and participants. Once each interview was transcribed, I reviewed each recording and transcript line-by-line to assure the accuracy of the transcriptions. Recordings in WebEx, and transcripts as Word documents, were password protected, and stored on a password protected computer.

Data Analysis

Following the procedures described by Cresswell and Cresswell (2018), I evaluated the data by preparing and organizing the information for analysis (i.e., coding data, revealing themes). Preparing and organizing the information for analysis involved organizing the data from the initial demographic questionnaire to identify participants and their background information on a spreadsheet. Next, data was transcribed as described above. Once data was transcribed, I followed the procedures described by Neale (2016) to iteratively code the data for thematic analysis. Appendix H contains a detailed description of my coding procedures and data analysis.
Researcher Role and Positionality

As the primary researcher, I collected all data, conducted all interviews, sent, and received recordings for transcription, and analyzed the collected information. I am an academic advisor at University, a doctoral student in the University Graduate School of Education, and the parent of an ASD adolescent. My researcher positionality is influenced by prior knowledge gained through academic coursework and research, lived family experiences, and more than 30 years working in education. These experiences provided me with the unique advantage of a deeper understanding of both parental and student needs (Baker-Rogers, 2018). My role, professional experiences, and family situation likewise forced me to remain aware of my preconceived ideas and biases, which had the potential to impact data collection and analysis. The validity section below describes reflexivity and the process I utilized to make sure my personal history and experiences did not impact the results.

Validity

Multiple procedures (Cresswell & Cresswell, 2018) were utilized to present accurate results, including member checking, peer review, and reflexivity. Member checking provided an opportunity for the research participants to review and approve the information in their interviews (Carlson, 2010). Transcripts were sent to interviewees for examination to check the accuracy of the data. Respondents had the opportunity to determine if they agreed their words matched their intended meaning, and to adjust their responses if needed (Shenton, 2004). If the participants disagreed, I probed further to make sure the questions were clear and the responses were accurate. Peer review, done by my dissertation chair, dissertation committee, peer group, and the Program Coordinator of the CSP were conducted to maintain the integrity of the process and provide feedback regarding the interview protocol. Their feedback was from written comments to the question protocol, as well as oral feedback during committee meetings. This
was important as their fresh perspectives enabled me to refine my methods, incorporate different
perspectives, challenge preconceived assumptions, and provide greater depth in explanations of
research design and findings (Shenton, 2004). Reflexivity refers to researcher recognition that
they have “a significant influence on the development of the research and the engagement of the
participants” (Curtin & Fossey, 2007, pp. 92-93). Keeping a journal allowed me to reflect on my
own thoughts, feelings, uncertainties, and preconceived ideas which might impact the study.

Table 4

*Study Timeline*

<table>
<thead>
<tr>
<th>Date</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>August 2020</td>
<td>Initial meeting with parents of ASD students enrolled in University and the CSP</td>
</tr>
<tr>
<td>September 2020</td>
<td>Email to parents with researcher contact information.</td>
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<tr>
<td>October 2020</td>
<td>Email to parents with consent forms and demographic questionnaire</td>
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<tr>
<td></td>
<td>Record information from returned questionnaires</td>
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<tr>
<td></td>
<td>Schedule interviews</td>
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<tr>
<td>October – December 2020</td>
<td>Conduct interviews</td>
</tr>
<tr>
<td>December 2020</td>
<td>Transcription and data analysis</td>
</tr>
<tr>
<td>January – May 2021</td>
<td>Write up findings</td>
</tr>
<tr>
<td>June 2021</td>
<td>Dissertation Defense</td>
</tr>
<tr>
<td>October 2021</td>
<td>Graduation</td>
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</tbody>
</table>
Chapter IV - Results

Research Question 1: What are the experiences of parents of students on the autism spectrum as their children transition to and attend college?

Three themes emerged from the data that described the experiences of parents of students on the autism spectrum during the transition and enrollment of their children in college. The process produced a wide range of emotions, led parents to engage in behavior as helicopter parents, and revealed their continued use of the pronouns “I” and “We” when discussing the admissions process of their children, as well as their interactions with University personnel, and conversations with their children.

Table 5

Reported Experiences of Parents

<table>
<thead>
<tr>
<th>Theme</th>
<th>Respondents</th>
</tr>
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<tbody>
<tr>
<td>Emotional Experience</td>
<td></td>
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<tr>
<td>Anxious/Nervous/Frustrated</td>
<td>6</td>
</tr>
<tr>
<td>Concern/Fear/Worry</td>
<td>5</td>
</tr>
<tr>
<td>Angry/Upset</td>
<td>3</td>
</tr>
<tr>
<td>Act as Helicopter Parent</td>
<td>8</td>
</tr>
<tr>
<td>Use of “We” and “I”</td>
<td>8</td>
</tr>
</tbody>
</table>

Theme 1: Emotional Experience

A majority of the nine parents interviewed reported a wide range of emotional experiences as their children transitioned to and began attending college, albeit from home in most cases. Feelings described by respondents during this process included anxiety, nervousness, frustration, concern, fear, worry, anger and being upset.
Anxious/Nervous/Frustrated

Feelings of anxiety, nervousness and frustration were commonplace among a majority of those interviewed in this study. Six respondents reported being anxious, nervous, and frustrated when going through the transition process, and as their children started attending college classes. Art, the father of a freshman, related the anxiety felt by both him and his wife. He described, “An anxious period for six months at least...and over time we became a little more comfortable with it”. Likewise, Jen, the mother of a freshman, prior to learning her son would remain at home and attend classes remotely due to the CoVid pandemic, related, “I wish he had one more year (at home)...he’s always been a few years behind and I was really nervous about him going but I knew he had to go or he might never go”. When asked about her son being proactive during the admissions process, Denise, the mother of a freshman, described her frustration at having to push her son to engage in the school search and application process. She offered, “I think I had to push him to do it...he wanted to go to college but would spend more time playing games than applying”. Jim, also a freshman parent, described his frustration when interacting with his son, who is living at home and attending classes remotely due to the CoVid pandemic,

When he is living at home it is hard. I don’t want to be interacting with him at the level of a teenager in the home...do this do that, don't do that don't do that, how dare you...and I won't allow you and you know those kinds of things.

Concern/Fear/Worry

Many parents interviewed related emotions of concern, fear and worry regarding their child’s transition to college. Five respondents experienced these emotions, with some providing examples to solidify their reactions. Sue, whose son is a sophomore, and able to live on campus during the Covid pandemic, provided two poignant instances: first she indicated her son was
used to having his own room when growing up, and spoke of the need for him to have a single room when living on campus,

   We got him a single because one less thing to have to worry about. I think if his best friend from middle school wanted to room with him we would have considered that but like he already had his own room.

She did not elaborate on her concern about her son having a roommate. In spite of the CoVid pandemic, her son was able to live on campus in the Chabad house. She spoke of how all of her college age children are encouraged to follow a family rule of checking in once per day,

   We have a rule that's kind of been dropped in our house but theoretically, technically, our kids are supposed to show us they're alive at least once throughout the day so that we don’t worry that they were abducted.

Denise, the parent of a freshman, did not speak about her other children, but indicated she is worried about her kids because of her lack of understanding of the American university system. She and her husband immigrated from China to the United States and her schooling was quite different,

   With my kids, I am worried about them. I have to be honest...I haven't read anything helpful for parents...especially for me and my husband...we didn’t attend college here in the US...everything it's very different... how there are different things I cannot grasp. The college life here is unknown to us. I cannot grasp the dynamic. I don’t know what I don’t know.

Jen, prior to learning her freshman son would be at home during the year due to the CoVid pandemic, was fearful he would be overwhelmed, unsure about time management, and remain in his room and not socialize with other students,
Maybe it’s me being afraid that he's going to be overwhelmed by like, you know, figuring out how to get where he needs to go and planning enough time in between and, you know, spending too much time in his room and all of that stuff.

**Angry/Upset**

Three respondents indicated feelings of anger and being upset during the transition period and during the school year. In the context of the CoVid pandemic and University courses offered in an all-virtual learning environment, Ben was angry about whether or not the CSP would be helpful for his freshman son learning from home. He indicated being angry and upset about whether or not his son would be able to succeed as a college student,

If I can find all those resources (college support programs, disability services, forms), and they all exist and let's say (the Program Coordinator) can put that all together for me and everything...Does Jim have the capacity to learn it or not? I don’t know that, and (the Program Coordinator) doesn’t know that...and really like who tells me that...like I can keep hitting my head against the wall, but he's not going to learn that skill...is that where we’re at? Or is he capable of learning that skill and then we can figure out a way to do that.

He also indicated anger regarding lack of support in certain areas with his son being home and the arguments which ensue regarding assignments and the lack of support from University and the CSP,

How far do I let him fail...this is where CSP is not equipped...how do I teach him...to walk him back through this stuff...even though they say they are...they are not. And I can't teach it to him...I'm not qualified to teach it to him. I end up doing it and saying to him today, today we have to do the reading, tomorrow we have to do you know I’m on his ass to do it. he hates and resents me for it but it's not going to get done so I left it
alone for a week with Michael is his adviser to CSP his mother was like let me handle it and then what ended up happening was we were sitting there on Sunday night writing a paper where he hadn't read the stuff so it's really fun to write a paper when nobody in the room has read the material, and we had to stay up almost all night to write a paper with him.

Denise was upset about being unsure and uncertain, relieved that her son spent his freshman year at home, learning remotely, “I am still unsure about what will happen...I feel lost with things. I am still unsure and very nervous. I am happy that he is still at home...more time to think ahead and prepare him a little bit better”.

**Theme 2: Act as Helicopter Parent**

Eight of the nine interviewees described themselves as helicopter parents to varying degrees during both the college search process and as their sons were attending college classes. Due to the CoVid pandemic and students learning remotely while living at home, helicopter parenting was extended into the academic year. Denise, whose son is a freshman, described the home classroom setup and daily interactions with her son. She reported,

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We emptied the study for him and gave him a workspace...the door is open and every time we go by we look in and he sees us. He is getting used to it...trying to write down all of his assignments every week. And sometimes between classes there is not a lot of time, so he has to decide whether or not to stop and have lunch or just have a bar. Since I am home I try to prepare food for him. I have a lot of things ready for him...that will be a big adjustment for him. He doesn't need to worry about a lot of things.
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Art related he and his wife often discussed their roles in working with their freshman son. He indicated she is more likely to hover, but students and families on the autism spectrum should be
treated differently, with parents permitted more access and all parties aware of a different timeline.

I’m not saying there should be full access...there has to be someone to draw the line...but we're not talking about a typical kid either so I understand all the things you want to teach a typical kid to be independent...and we want to teach the same things here...but it needs to be a different timeline or a different sort of progression....You have to have a different support mechanism in place for a child on the spectrum.

Ann, whose son is a freshman, described the back and forth between hovering and teaching a child to think and act independently. “I think it's hard to go between being the helicopter mom that the autistic child really needs, versus the a-little less helicopter mom”. Jim likewise described the balancing act between being overbearing but also keeping an eye on his freshman son. The CoVid pandemic and his son being home often led to the dynamic of parents and students interacting in ways which would not be the case if campuses were open,

When he is living at home it is hard. I don’t want to be interacting with him at the level of a teenager in the home do this do that don't do that how dare you and I won't allow you and you know those kinds of things...We're not reading his emails but when you say how much independence do I give him that's already a patronizing stance like that means that you're the gatekeeper for his independence. And that's not a great position to be in. It may actually be true you know...but it's really not about how much independence do I give him...it’s how much self-restraint am I going to exercise on myself...still being a bonded and impaired helicopter parent right. You're only not acting because you're watching, and I can give him this independence but I'm still watching. It’s really about how much you are going to fire yourself from doing those jobs, not about granting him something as a gift from the almighty and loving parent.
Theme 3: Use of “We” and “I”

While most college students receive assistance from family members, educators, and friends during the college search, some families may struggle to fully engage their students in the process. In the case of the nine respondents in this study, eight used the words “I” and “We” rather than “him” or “he” (referring to their son) quite often when discussing this process. Ben, the father of a freshman, described his parenting style, using the “I” and “We” descriptors quite frequently,

We met with everybody...really truly met with everybody...as I mentioned I am now a helicopter dad so before they sent the paperwork, I had applied for him to have accommodations at the ODS (Office of Disabilities Services), and had filled out all the forms and everything...when they got to me I was like - I've already done all that and I've already done this...since you know so I can being a Navy kid. I can fill out forms and stand in line like nobody else. I called and talked to someone there. I talked to (the Program Coordinator) and she told me who they normally worked with so I got in touch with that person and started working with them and I filled out all the forms and had them in...I am keen to see if it is because of this distance...we're in Florida...or if it is truly that the system is not really what we need it to be for Jim. I was very clear up front of what we needed from them...and while they felt like they could provide all of it I have had many challenges with it". We met with all of them and had long discussions especially over the summer once he had been selected we had long discussions with them about his needs and what they can do to help.

Jen, whose son is a freshman, related her comfort level about her son choosing a school with a smaller campus,
We never even looked at University. I found that he like...I felt comfortable on the smaller campuses because I went to a small school and one day I said to him you know, it'll be nice you'll see the same people over and over...and he's like well I do that at high school...I don't think I want to see the same people over and over...I kind of want to like not be able to be invisible but be able to you know just kind of blend in a little more than I don't know I thought he just felt like...we went to look at Ramapo and he's like it's so small and I thought all right so maybe and my husband for the whole time kept saying why don't we just look at University? I said no it’s not for him.

Jim described the ability of his wife and himself to research schools and make decisions regarding their freshman’s college future,

The fact that my wife and I have six master’s degrees between us probably put us in the position that most people aren't as far as our comfort with universities. Our ability to assess them, our professional level of research and analysis. You know I think that we've got a lot of tools that work already. I could imagine parents who don't have knowledge or familiarity with higher education institutions would be in a much more difficult position than we were.

Sue, whose son is a sophomore and had the experience of a year of college and living on campus prior to being interviewed, described how “we” found a major which he would like and where he would excel,

Okay, so we've compensated. We’ve had a lot of conversations...in the spring he took what he needed to take over the summer…used his HS math teacher to do a ton of tutoring with him. Got through what he needs to get his stuff, and he changed majors. He moved into the School of Arts and Sciences and we found him a different major that will still get them to his ultimate goal.
Research Question 2: What do parents of university ASD students report are systemic barriers which hinder them from coping with the transition and attendance of their child at college?

Two major themes emerged from respondents as they described systemic barriers when working with University and CSP personnel which hindered parent coping with the transition process and student enrollment. The first theme pointed to the lack of communication from University and CSP staff regarding ASD support programs for students, families, high school counselors, and community social service agencies. Parents described doing a majority of the research during the college search on their own, with some stumbling across information about support systems for their ASD sons. Respondents also indicated University faculty and staff were not well informed about working with college students on the autism spectrum. Parental experiences revealed their interactions with a majority of faculty and staff at University showed lack of awareness of the CSP, and no formalized training on campus for those working with ASD students, both in and out of the classroom. The second theme relates to the timeliness and awareness of student and parental needs during the college search/application process, and once students enrolled and began taking classes. Respondents point to lack of information during the admissions process, once their students were admitted to school, and once classes started. They spoke of a delay of vital services, and were unsure about the role and value of the CSP.
Table 6

Systemic Barriers reported by Parents of ASD Students

<table>
<thead>
<tr>
<th>Theme</th>
<th>Respondents</th>
</tr>
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<tbody>
<tr>
<td>Lack of Communication</td>
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<tr>
<td>Lack of information and communication from University and the CSP</td>
<td>6</td>
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<tr>
<td>for high school students, families, and guidance counselors</td>
<td></td>
</tr>
<tr>
<td>Lack of communication with and education for University faculty and</td>
<td>4</td>
</tr>
<tr>
<td>staff</td>
<td></td>
</tr>
<tr>
<td>Timeliness and Awareness of Student and Parental Needs</td>
<td></td>
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<tr>
<td>The role and value of the CSP</td>
<td>8</td>
</tr>
<tr>
<td>Lack of information from University and the CSP once students are</td>
<td>4</td>
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<tr>
<td>admitted to the program</td>
<td></td>
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<tr>
<td>Intake/interview process – too much paperwork and overuse or autism</td>
<td>2</td>
</tr>
<tr>
<td>as a label</td>
<td></td>
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<tr>
<td>Buy-in from the University Office of Career Services</td>
<td>3</td>
</tr>
<tr>
<td>Delay in student services – tutoring, peer mentors, and academic</td>
<td>1</td>
</tr>
<tr>
<td>coaching</td>
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</tr>
</tbody>
</table>

Theme 4: Lack of Communication

Lack of Communication from University for High School Students, Families, and Guidance Counselors

Two-thirds of parents interviewed indicated the systemic barrier of lack of communication from University and the CSP during their children’s high school years. Kelly, who works in special education with younger children, and whose son is a freshman, found high school personnel ill-equipped to help her and her son in the college search and transition process,
“I know what to do with a kid up to 14, but he got into high school, I didn’t know that I should have been working with the school team on the transition to adulthood when he was 14. Right, like? They asked me the questions they needed to ask but we didn’t go any further. Like, they are like, “do you want him to go to college?” Yes. But we should have gotten more into detail about independent living, is he going to be able to live independently? What are his social needs? What if college doesn’t work out? We did none of that.

Jen, a freshman mom, likewise working in special education with younger children, prior to learning her son would have an extra year living at home due to the pandemic explained,

But it still makes me crazy. Nobody helped us...I had to do all the research myself on all of these programs...the guidance counselor was very well meaning but said, maybe if he starts at a community college until he gets more comfortable and will still be at home...and I’m like, but I don’t think that’s going to be best for him.

Ann, a freshman parent, discussed the need for colleges to provide information, not only about their programming, but the transition process as well,

We’re hit also with the transition to college and because he was doing very well, high-functioning, I don't think we understood the kinds of supports that might be available in college and it would be helpful as a parent to have something like when the schools do the college fairs to pass something along to the parents...I mean they mail things all the time about loans to the parents you know...stick something in there... you're going to be transitioning now to the Division of Vocational Rehabilitation Services or whatever it is that state vocational rehab services and now's the time to think about it when you're picking colleges...and maybe we’re the only ones who missed it, but I didn't
feel like there was a lot of communication for transition and even when we have we've had a horrible time with the person in our region.

**Lack of Communication with and Education for University Faculty and Staff**

Lack of education for faculty and staff was a major concern for four respondents. The greatest wish from Lauren, a junior mom, is for University to mandate, and the CSP to provide, mandatory training for faculty and staff,

I've had many conversations about this and about really about trying to provide education to professors around autism and the CSP program and how to work with students...but my feeling is like if University is going to provide a program like CSP, then it should be mandatory for professors who have students in their classes to understand autism and understand get a little tutorial from the CSP program...I actually think it should be mandatory for staff. Just like sexual harassment training, this should be part of it...so that would be my greatest wish for University.

She then went on to provide a real-life example of what happened during a previous semester with her son who is a junior,

I mean last year Tom had a problem with a professor, I think she is from another country and is very unfamiliar with autism...who became afraid of him because he had an outburst in class and even though this letter was sent to her...she kind of freaked out and you know she didn't allow us (referring to her son) back into class. Yeah it was a significant...the dean got involved...and what I was stunned and scared out of my mind where was that if my son hadn't been in the CSP program and didn't have somebody advocating for him they probably would have called University police to escort him out...and completely shook me to the core because if he if didn’t have somebody there, and the police had to escort him out, that would be a traumatic experience. The Program
Director and I've had many conversations about this and about really about trying to provide education to professors around autism and the CSP program and how to work with students...but my feeling is like if University is going to provide a program like CSP, then it should be mandatory for professors who have students in their classes to understand autism and understand get a little tutorial from the CSP program...so that would be my greatest wish for University.

Art, a freshman dad, concurs with the importance of training for faculty and staff to receive training on working with students with disabilities,

I have some windows open on my browser with exactly what you are describing which have to be completed by the end of November...business conduct, bullying...things like that. I don't think it would take a lot of time for everybody to get the 30 minutes or awareness training. I assumed wrongly they would understand what that means to be on the spectrum and know how to deal with it but that is not necessarily true”...do professors know or teaching aides know that he is on the spectrum...that if they get an email from him and it's unclear or awkward or different...I don’t have clear examples for you...if they know that the child is on the spectrum and high functioning, they are going to read the email through a different lens. Not necessarily treat them differently, I understand whatever academic requirements there are things like that, that's different. What I would want to know that they’re aware and doing whatever they can to be considerate of his circumstances and situation.

Theme 5: Timeliness and Awareness of Student and Parental Needs

The Role and Value of the CSP

Eight of the nine respondents supplied mixed comments about the role of the CSP and the services and supports it can provide for their son. Sue, a sophomore mother with a master’s
degree in special education, was aware of and in contact with the CSP prior to her son’s enrollment. She seemed perplexed about the small number of students enrolled in the CSP, the small staff, and what role it plays in university life,

I always knew about the CSP for years based on going to the ASPEN (Autism Spectrum Education Network) conference which I referenced to you. I had met the previous director. So, it was definitely on my radar, I'll tell you what else is kind of extraordinary is that you know even the CSP program is serving students…there are so many students on the campus but not serving that many…whether that's parents can’t afford the extra fees…or that people don't know about it…or whether it's that there's just limited spots…cause you know they have funding for X number of employees but like it's kind of shocking that it’s so small…Now look, it doesn't mean that all of the students need that support and lots and lots of you know, college students who are on the spectrum who are super awkward no social skills. But academically they have no issue with keeping up with their academics. And so why should they need this program to teach them how to talk to girls?

Ben, a freshman father, in addition to repeating his role as a helicopter parent, recounted several disagreements with the CSP Program Coordinator. He very strongly expressed the feeling that the CSP is not equipped to work with individual students on the spectrum.

I am still checking his email and I am still like reminding him and I am fighting with (the Program Coordinator) about the schedule that they have to help him do a schedule. One of the things Jim can’t see – I have a paper due next Tuesday...in order to do that, how do I back out my routine so that today I do the reading, tomorrow I write an outline, the next day I start writing, the next day I edit. He doesn’t know how to back...so here is where my disagreement comes with the helicopter thing. How far do I let him fail...this is
where CSP is not equipped...how do I teach him...to walk him back through this stuff...even though they say they are...they are not.

In another part of the interview, Ben also stated,

I would say that...so I'm not going to BS you I felt very beginning I told my wife I said that I thought the CSP program...we've been to a ton of these programs in which they say a lot of really good things...but can they live up to it most of them don't...I would personally say that CSP has not lived up to the promise.

Jen feels that her freshman son, attending school from home due to the CoVid pandemic, would be fine without the CSP and questioned whether it was needed for him,

My biggest you know he can be doing what he's doing here without the program...they hooked him up with a tutor for writing but really he could be doing what he's doing...it’s the social piece...maybe it’s me being afraid that he's going to be overwhelmed by like you know figuring out how to get where he needs to go and planning enough time in between and you know spending too much time in his room and all of that stuff I really was leaning on you know the peer mentors and you know their ability to pull him out to social events so everything's been really like the social events have been not great. And I don’t know if you heard about what happened last week. He didn’t even go and I’m glad I didn’t force him...we got this whole letter from (The Program Coordinator) about how they were hacked and there were people who were using racial slurs and LBTQ and it was a horror show...and so there is no social piece...in a way we're lucky because his three friends are at home too, so they still see each other on the weekends and you know, he still has his job...he works for a restaurant delivering...so all that is I don't really know what the CSP can do for him.
Jim spoke about the CSP not working for his freshman son attending classes remotely during the first semester of freshman year,

I mean it has been a bumpy road these last five weeks with Judah in the CSP and finding the right tutoring and communicating with parents, setting academic standards, and in being responsible for his work, and in personal upkeep, sleep schedules, eating, hygiene. The global system, like I said, is still not transitioned. So, you know if the CSP had been the thing that made Judah successful at University, no he has not been successful at University. Because we’re only two months in...I think how it's been these two months continued exactly the same way, Judah doesn't get a four-year degree...the level of executive function that's happening in his own ownership and independence right now...I think all parties would agree is on a learning curve and that's what you would expect from somebody who needs to pay $7,000 for support right and hopefully the support group would not be like well you need to be more independent so you're not causing us these problems...and where that's going to take some uncomfortable amounts of attention...the jury’s out on the whole system.

Three parents had a more positive take on the value of the CSP. According to Art, a freshman father,

CSP was the deal maker...it was the reason...without it...95% sure it would have been too much. I wasn’t aware of any support programs...It would have been like throwing him to the wolves...throwing him into the deep end and leaving him, and us, to figure everything out. And that would be, in a school as large as University is, it would have been too much...it might not have been...I think we wouldn't have imagined it to be too much and would have opted for a much smaller school. He got a full ride to a much smaller school. We view that as something which would have been much more
manageable for him and for us... much more so than University...without the CSP....that would have been probably our first choice. It would have been the alternative.

Denise, a freshman mom, likewise, had a positive response about the CSP, “We are able to contact the Program Coordinator which has been very helpful”. Kelly, also the mother of a freshman indicated the value of the CSP lies in communication with both students and parents.

I mean, the Program Coordinators have their role or whatever, they do that (meet) with the students more than the parents, but to have and that’s fine, but the parents need to know too especially when our children are on the spectrum. Okay, so you are going to talk to the kids about it and the kids won't even tell that they went to this meeting.

Lauren, the mother of a junior, praised the CSP program, “CSP has been a life saver and amazing...CSP has been great”.

**Lack of Information from the CSP and University Once Students are Admitted to the Program**

Jim, the father of a freshman, summarized the feeling of several parents regarding communication from the CSP prior to the start of school and early on during the first semester, particularly with his son attending classes remotely from home,

The support systems in place for him are really important. But he is also not accessing or understanding the importance of those support systems. He’s not there yet. The support system is supposed to keep us out of it...so he can be an independent functioning person in the university with their support. It’s not there yet.

Lauren, the parent of a junior, who experienced difficulty in navigating University administrative systems for the past few years reported,

University isn’t very good...for example...tuition payments. We just got a couple of phone calls saying basically that we haven't made tuition payments...and we’re like...no one sent us anything. It's like the expectation that you just go on, and that is
something like another ridiculous thing that University doesn’t do. Send us the bill...I think if they had a better online system...that would be helpful...I don't feel like as a parent I know what's happening unless CSP sends me something...and then I feel like I'm kind of the last person to know so I think you know University could be better about that. I mean I know that there is that I know students are sent information, but I never really know what's happening...like what I mean I know that they're going to expand some residential halls for spring, but what about dining services. Better communication would be helpful.

Kelly, a freshman mom was not concerned about her son leaving home and moving to campus, but indicated a strong desire for communication with parents stated,  

I’ll tell you when you mentioned that you wanted to put something together, again the reason isn’t because I am feeling transition issues like, oh my gosh what am I going to do without my kid, and now that I don’t have time, that is definitely not where I am. I am more of a—I need information. I need to know things.

Intake/interview process - too much paperwork; overuse of Autism as a label

Two parents were critical of the intake process for the CSP, describing endless paperwork and a difficult interview process. Ben, a freshman dad reported,  

I went on the website and found all of the ODS forms. I called and talked to someone there. I talked to Lauren and Lauren had told me who they normally worked with there so I got in touch with that person and started working with them and I filled out all the forms and had them in.

Jen, a special education teacher, whose son is a freshman, was surprised at the number of times the word autism was used during the intake process. She remembered,
Having the word autism thrown at your kid a lot. A lot. Even when we went down for our initial interview, we talked to Ron about it already but I was shocked about how often it was like you know and then the Autism Services and the Autism this and Autism that...he doesn’t think of himself...he doesn’t define himself that way.

*Delay in Student Services*

Sue, whose son is a sophomore, recalled her son’s and families’ experience during the prior year when her son was starting out as a freshman and living on campus. She was concerned new students should be better prepared by the CSP to start their first year, with academic tutors, peer mentors, and a better sense of what to expect in class prior to the first day of school. She indicated,

But even before the summer we were saying…but I think there are things that have corrected themselves this year you know he didn't have tutoring set up until weeks into the semester. He didn't have his academic coach set up until a few weeks into the semester...I started like all of this stuff only was able to happen after the first day of class and...he came home after the first day of class and one of the first things he said to me was that everyone seemed to have books and I didn’t know I was supposed to have books…and I’m like I didn’t know how to get books either…ask (the Program Coordinator) how to get books.

*Buy-in from Career Services*

Three parents spoke about the importance of University Career Services guiding their children in discovering a career path based on their interests. Kelly, a freshman mom, discussed the value of her son receiving help in exploring career options, including companies interested in and able to hire interns and graduates who are on the autism spectrum,
Because he likes, you know, he likes planting and gardening. So that would be really beneficial if I could if you know, if, you know, CSP or um, what is it, ODS (Office of Disability Services)? If they can, you know, help him to hone in on that skill, even if its learning, um, learning that maybe he has some interest so we can help in getting a job in this area or that area. Like that would be helpful for me...Or have the companies who have an interest in hiring kids, you know, so I asked you if your son was heading to University. And the reason we chose University.

Ben, a freshman dad discussed the idea that many students and young adults on the autism spectrum have unique abilities which would be beneficial to employers if they were willing to think outside the box and see the best these young people have to offer.

(There are) some bizarrely talented people in all kinds of different areas and so I can tell you that people going into your jobs fair don't have an understanding of what Agility is and how it works in the technology world...companies are going to be looking for that and they're going to have an eye out to know that these people have a background in it and then understanding in it but beyond that...kids like Jim...are perfect in that world because it is not, please sit down and write requirements and then work on something...it is truly like on your feet... development, understanding of systems and people and how they interact with them and things like that. So, these autistic kids really fit into that world because they have the scientific mind, but they are also married with a fantasy artistic part of themselves that allows them to express themselves and it brings a lot out of them. My point of the whole thing is that Jim could be so many different things - so I'm not that concerned at University of what he learns and how he learns it and all this kind of stuff. I'm interested in him doing well and getting through it so that you can move to the next phase of his life...and so with the CSP and Career Services and those people we
were hoping that they would give him some coping mechanisms and skills and some understanding and to help his professors understand him...and it may be too much to ask for.

When discussing the value of preparing her son for a career, Ann, whose son is a freshman, discussed the overwhelming nature of a University Career Fair. She described how the noise, lights and crowds might negatively impact her son and hurt his chances at being his best when meeting with an employer.

It’s easy to see a kid...you know...kid that needs...his remaining difficulty is the thing that I said the sensitivity to anything that's perceived criticism...and he can be having a great day or something, and they could be checking bags or something, and it should come into a career fair like you say, your backpacks over here, and he might if someone a security guard says no wait you're supposed to be in the other line...that could be enough of a set off that puts him in a mood that triggers a dark cloud.

Research Question 3: What supports might help parents of ASD students explore their new role and adjust effectively as their children transition to and attend college?

When discussing support which might help parents of ASD students as their children transition to and attend college, two major themes emerged. The first theme indicated the need for better communication with students, parents and high school educators during the college search, the admissions process, and once students are enrolled in classes. As communication is a dialogue, parents indicated the need for University and CSP staff to ask what individual and family needs are, listen carefully to responses, and involve families in the college process. The second theme points to the need for University and the CSP to provide more parental education and educational resources as their children transitioned to college and adulthood. The benefit of the CSP as a resource was discussed, including whether or not there was value based on families
paying an extra fee for the service. Though these themes were prevalent, all nine respondents did not see the usefulness of being part of a parental support group. Respondents were fearful group meetings would turn into sessions where parents simply aired their complaints and criticized University and CSP personnel.

**Table 7**

*Parental Solutions*

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Theme 6: Fixing Communication

The Need for more Communication and Information while Children are in High School for Parents and Counselors

All nine parents interviewed indicated the need for more communication, information, and resources while their children were still in high school as they researched colleges which could provide a strong academic environment in the appropriate major, as well as support services. Lauren, the mother of a junior, summarized her experience,

We considered the University of Rochester. And then I researched all the schools that had support programs. University did not come up in my list at all. It was like, it was hidden, right? So, I looked at all the schools and then we honed in on those schools. So, for instance, Adelphi came up um, and that really was the first choice for me. Ramapo came up and that was up there, the second choice I think. Iona came up, although, you know it has crosses in the brown. It has a support program, so we were open to it and we visited. Drexel came up. University never came up.

She described the need for a central location for information during the college search to help families research colleges,

And we were the ones who found many of these schools that have support for kids on the spectrum. I don't think high schools do enough...If we could do it...for example, his psychopharmacologist asked us to it to give her the list that we came up with to give to some of her other clients. Coming out with books these days it's like ridiculous...but there should be websites that you can go to...but they're not comprehensive. There are and there are lists you can go to, but they are not comprehensive...you have to be able to fit your students. It would be great if there was some sort of website that you can go to that...
you could put in what you're interested in and see what schools come out that fit your child’s profile.

Ann, a freshman mom, reported the need for guidance counselors and state representatives to be a bigger part of the college search process, with more information getting to them which would then be shared with parents and high school students,

I think that's a big part of it is getting...like if they did tabling somewhere for the guidance counselors but also...I guess for the state reps there's a disconnect for DVRS but as far as the colleges go, it’s not just special education kids. I think there is already a fairly good system in place for kids who are compared to our kids who are atypical. I think even for myself graduating, I had a bit of a school phobia and there was not a lot of oversight 30 years ago for...I was in all the A level...in the high classes and college program stuff...but then there wasn't any real oversight to taking my SATS...and I think it's a good thing that a lot of students will sort of put off...it’s a little better at now catching that but if you have to consider high-functioning but maybe a little phobic about school or have other issues...they're missing that group of kids that is looking for colleges that is looking for that that will benefit from that experience and they may also not be catching the ones who are graduating...who are in junior or senior year and getting them back in line with the state.

The Need for more Information about CSP when Investigating Schools

Six of the nine respondents had no idea the CSP existed when starting the college search for their sons, and indicated University and the CSP should do a better job marketing their existence, services and supports. According to Jim,

As it turned out, University has this CSP program which nobody knows anything about...and you don't advertise...and we had ruled you out because you don't have this
program, and we stumbled across it one day...you can't even find it. It’s not in admissions, it’s not in the university self-description.

Denise, whose son is a freshman, could not remember how she heard about the CSP, “We looked at 10 or more schools...and also came across the CSP program...I can’t remember how we heard about it”. Art concurred, “I wasn’t aware of any support programs...It would have been like throwing him to the wolves...throwing him into the deep end and leaving him, and us, to figure everything out”.

**The Need for Someone from the College to Listen to Families**

Three respondents were most appreciative as they explained having someone at the University simply to listen to their experiences was most helpful. As stated by freshman mom Denise,

> I just feel like the fact that you are just listening to my experiences with my son...that makes me very happy. Giving me a chance to share and someone is paying attention. Knowing someone wants to help even if it's just to listen. I appreciate that.

Ann explained the importance of listening to each student and family story to determine what supports are needed. Parents have questions, need to be listened to, and receive assistance to prepare their children not only for the transition to college, but also what types of services they may need later on,

> I think it also helps to prepare the parents for what you’re going to need later on...we knew he was doing so well we thought does he even need the support? He may not need support. We may not even need help with the transition.
The Need for Information about the CSP and University once Students are Admitted to the Program

Though each student and family situation are unique, more general information about expectations and the role of CSP would be helpful, especially for new students and their families. Three parents indicated a need for information about the CSP and University once their child was admitted to both college and the program. Lauren, whose son is a junior, found hearing from current students extremely helpful,

When I started...one I remember going to view the CSP at University...there was a student panel...I loved that...not sure if they are still doing that...that was really helpful to learn about the program and hear from students in the program. I remember having a parent orientation of new and returning parents and that was helpful too.

Sue, the parent of a sophomore, indicated students and families should be made more aware of the expectations placed on students prior to the start of a semester,

I had suggested to the Program Coordinator last year I said you know next year you should be like meeting with the freshman the incoming freshman before classes get started like all of this stuff only was able to happen after the first day of class and…he came home after the first day of class and one of the first things he said to me was that everyone seemed to have books and I didn’t know I was supposed to have books…and I’m like I didn’t know how to get books either.

Due to lack of communication from University, Art, whose son is a freshman, put forth an idea to help with parental engagement,

I think that there should be waivers for certain kids who even legally are adults...some kind of a waiver which grants access to everything that is going on...everything a 17-year-old would get. There are special circumstances...you shouldn’t have to push for that or
fight for that...I think it should just be an automatic thing...and it just makes everything as if the child is 17...so parents are copied on everything. Every correspondence to the kid so parents make sure they are not missing anything.

**Theme 7: Responding to Parental Wisdom**

**The Need for more Parent Education/Educational Resources**

Seven of the nine interviewees reported the need for more educational resources for parents and students. Lauren the mother of a junior, provided what she thought would help her as her son proceeds through college,

I would like a professional who has experience with college students on the spectrum or who has an experience with what resources I can get for my kid. I am struggling with my kid right now...I really just want information...I am more interested in the information. I am more interested in what happens in DVRS. Are they really, am I really not going to get any services because we fall into this income bracket or what is he eligible for? What should he be doing? Things like that.... I am more of a—I need information. I need to know things. I need to talk to parents who are going through this because may there is a 19-year-olds’ mom on this call, and they have two more years of experience and want to share that with me. I want to learn and when I have something to offer I want to offer that so that to me is more important because that is what I need.

Denise, the mother of a freshman, wondered if, “Perhaps if there was a website...somewhere I could look to see...a place to find out questions to ask and who I should contact”. Ann, likewise, a freshman mother, reaffirmed the need for information at the state level,

Even moving toward legislation. For training of people that they would all have in common the same information...and with DVRS...21 counties...it's not a lot to ask if they can have one designated person per county does the cases for autistic kids...How hard is
that? They do it with early intervention...they need to tweak it a little more as the kids get older on the secondary level.

Lauren would have appreciated help in receiving information for herself and to provide to extended family members,

People we can call on and ask questions. Our husbands, our wives, our mentors, our brothers, our sisters, whoever our mentors are. I want to be able to give those answers to him and continue to support him. So that, that might be that is why I hope I can be helpful.

Kelly, a freshman mom working in special education with younger students, also added, I am actually more of a “how do I continue to support this young adult as a young adult...What are my resources that I can continue to learn so I can share them with him? So, that continues to be a stressor for me”.

_The CSP as a Good Resource_

Four respondents reported a positive experience with the CSP, relating the program as the reason for their choice of University, as well as how it has helped their son. According to Art, the father of a freshman,

CSP was the deal maker...it was the reason...without it...95% sure it would have been too much...He got a full ride to Ramapo College which is 20 minutes from our house and much smaller. It’s like a speck. We view that as something which would have been much more manageable for him and for us.... much more so than University...without the CSP....that would have been probably our first choice. It would have been the alternative.

Denise, whose son is a freshman, echoed this sentiment regarding choosing University because of the CSP,
I talked to (The Program Coordinator) before we decided that he would go to University...we felt like University program has a lot more to offer otherwise I wouldn't feel comfortable because it is part of the Psychology department...contacting (The Program Coordinator) we felt he would be getting a lot more support...much more targeted for what he needed. If this program did not exist I would not have any confidence. He would get completely lost.

Sue, the parent of a sophomore, described her view that the CSP works well with the university at large,

It seems that the CSP has a very good relationship with University…my experience is all with (The Program Coordinator) so I couldn’t tell you how the other counselors are…she is so excellent. I know that I know that I mean there's very good communication...I mean I remember she did do which was fantastic she had they had like a couple of orientations may be ahead of time before school started...and they showed the kids the bus route...that was great...Our experience was great because (The Program Coordinator) is super communicative.

Ann, a freshman mom, complimented the help her son received early on in his first semester, especially because he was attending classes remotely due to the CoVid pandemic,

The support...I think that's like it really helped him the first couple of weeks it was a lot of me having to make sure he was up for his class and you have something scheduled now and he didn't understand but you know when it's assuming you know things.

**The Need for a Parent Support Group**

When discussing supports for parents as their children transitioned to college, I asked each respondent whether or not they saw value in belonging to a parental support group. All nine
respondents indicated they would not benefit, would not participate, and did not see the value in such a group.
Chapter V - Discussion

The purpose of this study was to explore the needs of parents of college students on the autism spectrum as their children transitioned to and attended college. Systemic barriers were identified which hindered reported student success, and parental suggestions were provided to ease the stress of the application, transition, and enrollment processes for their children. Three research questions were answered, and the data revealed seven major themes:

1. Emotional Experience
2. Act as Helicopter Parent
3. Use of “We” and “I”
4. Lack of Communication
5. Timeliness and Awareness of Student and Parental Needs
6. Fixing Communication
7. Responding to Parental Wisdom

In the following sections, I will discuss, in detail, findings in the context of Separation-Individuation Theory and the Transactional Model of Stress and Coping. Additionally, implications for University, the CSP, parents of college students on the autism spectrum, and ASD students are described with suggestions for practical changes and further research.

Research Question One – Parental Experiences

Research question one explored parental experiences while working with their children, University, and the CSP during the college search and application process, the transition to college, and enrolling in classes. Overall, parents reported the transition process as a time of great emotion, while describing their continued helicoptering (hovering) over their children. Interview responses to questions reinforced parental affinity to speak with stakeholders - high school counselors, college faculty and staff, and me as interviewer using the first-person
language of “We” and I”, instead of “Him” or “He” when referring to their children, as if they themselves were the students.

Theme number one (i.e., Emotional Experience) emerged from responses indicating this period of the college search and transition was an emotional experience for parents. A majority of parents reported feelings of anxiety, concern, worry, fear, and distress during the college admissions process, and as their children enrolled in and attended University. These findings are similar to those of several prior studies. Cheak-Zamora et al. (2015) found that during the transition period to adulthood, primary caregivers felt overwhelmed and anxious. Similarly, Van Hees et al. (2018) found parents of college students on the autism spectrum were uncertain during the transition process. This uncertainty led to parental feelings of stress and anxiety as parents struggled to cope with familial changes as well as letting their children transition from dependence to independence. In the current study, parents reported emotional responses were caused by lack of information, minimal parental educational resources, and perceived limited communication with University faculty and staff, which led to confusion and a sense of not knowing critical information needed to make important decisions. This finding concurs with the notion put forth by James (2013) in which parents “fall off a cliff” in terms of accessing services for children transitioning to adulthood, and Friedman et al. (2013) who reported resources of care are often fragmented and lack adequate funding which leads to poor transitional outcomes.

The emotional responses of parents of college students on the autism spectrum in this study impacted parental ability, either on their own or with assistance, to identify stressors, appraise the situation, cope, recognize the precursors of stress and coping, and make short and long-term adjustments (Lazarus et al., 1984). This lack of insight into their own stressors and coping mechanisms was evident during the interviews as parents expressed frustration when working with high school and college staff, as well as with their children. They were upset,
NEEDS OF PARENTS OF UNIVERSITY ASD STUDENTS

angry, confused, and, at times extremely uncertain about where to find good information, what steps to take next, what questions to ask, who to turn to for assistance, and how to handle these feelings and those of their children.

The impact of these negative parental feelings cannot be overstated. When adolescents on the autism spectrum separate from their parents, transition to college, and seek to establish their individual identities and independence, the attitudes, emotions, and behaviors of parents significantly impact their children’s mental health. Kins et al. (2012) found dependency-oriented psychological control by parents was related to dysfunctional dependence by adolescents and young adults. Also, Kins et al. (2011) reported parental separation anxiety is positively related to separation-individuation pathology in emerging adults, and allies with problems in adolescent identity development and lower general well-being. Contrasting results from Engles (2001) reported positive parental attachment significantly contributed to adolescents feeling good about themselves, and Rice et al. (1990) found the feeling of positive separation was a better predictor of college adjustment than independence from parents or family cohesion in typically developing peers.

The implications of these findings point to the need for University and CSP personnel to assist parents to experience a smoother transition of their children to University by raising their own awareness of the range of parental emotional responses and reacting accordingly. Parents should not be viewed as a problem by University faculty and staff (Van Hees et al., 2018), but as parts of the support system challenged by their child’s transition. Educators, when possible, should provide emotional support and resources, not only for students but also their parents, and teach and equip parents of ASD students to assist their children while coping with their own emotions (Hendricks et al., 2009). This can be done by educators' use of effective listening skills, clear and detailed communication, and including families as part of the team supporting
the student and each other during the transition to college and toward independence. In addition, CSP staff members can learn and utilize effective techniques to teach parents to assist in the separation from their children and cope with their emotions. Further, the CSP can provide a list of counselors and other resources, both on and off campus, for parents to access if they struggle when coping with their emotions.

Parents, for their part, should listen to recommendations for their children from University and the CSP, try to work as team members with faculty and staff, and gradually allow the students to separate, establish their own identities, and move toward independence. Parental awareness of their own emotional responses and stressors, as well as utilizing available resources, can help them cope with familial changes in a healthy manner.

Theme number two (i.e., Helicopter Parenting) which emerged as a result of responses from eight of the nine respondents, revealed a high level of helicopter parenting (overparenting) during the transition process and as their sons started attending college classes. As this study took place during the CoVid pandemic, all University classes were offered remotely, with eight students, including seven freshmen, continuing to live at home. This situation strengthened the opportunity for helicopter parenting, lengthening the time period students lived with parents, and exacerbating its impact. Parents reported numerous discussions within their families and with University and CSP personnel in an attempt to determine their role in their children’s transition and once their sons started taking classes. Parents often went back and forth trying to walk the line between over-involvement and teaching their children to become independent. Without guidance, parents reported this was no easy task.

Over-involvement and developmentally inappropriate parental participation can negatively impact the child’s development and transition to adulthood, interfering with their ability to advocate for themselves, make their own decisions, and assume personal responsibility
Parents in this study appeared to mean well, but their helicopter parenting style was known to lead to negative consequences, including student anxiety and depression (Lemoyne et al., 2011), lack of independence, lower parent-child communication, and elevated family stress levels (Segrin et al., 2012). No doubt the parents in this study did not know the potential negative consequences of their actions.

Due to lack of knowledge, parents may require both educational and emotional support to assist them in learning how to lessen their helicopter behavior, and subsequently deal with their overbearing emotional responses. University faculty and staff should remain patient when working with parents of students with ASD and provide resources which can assist them educationally and emotionally. Parents should learn to be good listeners, follow the lead of University faculty, staff, and the CSP, and gradually back away from hovering over their children. Students need to feel the emotional connection and support but have the confidence to advocate for themselves and develop their own identities. While parents may ultimately have their children’s best interest at heart, their over-parenting may lead to negative outcomes including anxiety and depression (Lemoyne et al., 2011), lack of independence, lower parent-child communication, and elevated family stress levels (Segrin, et al., 2012). This balance is often difficult for both parents and children during the college years (Engels, 2001). However, according to Mattanah et al. (2004), a strong predictor of healthy college adjustment academically, socially, personally, and emotionally, was the combination of a secure attachment relationship to parents, along with a healthy level of separation and positive adjustment. Further, the mental health of college students is positively impacted when they are able to find the balance between separation from parents, moving toward functional independence, while maintaining an emotional connection to parents (Yelle, et al., 2009). As parents continue to
search for the best ways to help their children without hovering, they should take advantage of available emotional and educational resources to learn steps they can take to manage their behavior and gradually let go.

Theme number three (i.e., the use of “We” and “I”) - arose based on responses from eight of the nine parents who frequently used “I” and “We”, rather than “Him” or “He” when discussing the transition and enrollment of their sons to University. Parents described their children in the first person as if they were their children while providing information about the college search, ASD support programs, filling out college applications and other documentation, choosing classes, picking a major, and working on assignments. This finding emanates from their lifelong advocacy for their children and supports previous research done by Bayat (2007) which indicated parents of children on the autism spectrum serve the roles of caregivers, counselors, educators, and strong advocates. These types of parental assistance are important and can lead to positive outcomes such as those reported by Dymond et al. (2017) in that parents typically know their children’s needs better than anyone, and can offer insights into the best types of supports for the student to be successful (e.g., academic, social, home, health).

Conversely, negative consequences can also result from parents not separating from their children, using “We” and “I”, and not having the ability to separate and allow their children to develop their own individuality and learn from their own experiences. The respondents in this study who portrayed their role this way mimicked those parents of college students with disabilities written about by Madaus (2005), who related examples of parents who referred to their children in the third person, made phone calls to speak for their children, used “We” when conversing with faculty and staff about their children, and would often speak in on-campus meetings as if their children were not in the room. This inability for parents to separate and view their children as unique, independent individuals separate from themselves can lead to
pronounced stress and difficulty in coping during this period of transition. While it is natural for parents to wish to continue to advocate for their children, it is important for them to gradually back away and seek to imitate the views of the parents of college students interviewed by Pena et al., (2013), who recognized the importance of gradually backing off and allowing their children more independence. While parental advocacy can have positive impact on the transition process for them and their children, students need to be included. The children need a voice in learning about supports they require when mapping out their own plans.

This finding is also critical because when parents go beyond the helicopter mode and cannot see any separation between themselves and their children, negative outcomes may occur. Individuation and healthy student adjustment academically, socially, personally, and emotionally is tied to a combination of secure relationships with parents and a healthy level of separation (Mattanah et al., 2004). A proper balance is the best course of action, although difficult to achieve, with students remaining simultaneously emotionally connected to their parents while striving to become functionally independent (Yelle et al., 2009). Three decades ago, Lazarus (1984) described people as relating to each other dynamically and in a bi-directional manner which enabled them to identify stress and adapt in the proper way. Today this continues to be the case. When parents are too attached to their adult children as they transition to college and adulthood, stress may increase for both parties and lead to unhealthy results.

For the best outcomes, University faculty and staff should be properly informed and encouraged to recognize the challenges faced by families of those on the autism spectrum. To support students and families in the best possible manner, faculty and staff can learn to attend to each situation in an appropriate manner, patiently work with students and parents to help them achieve a healthy separation, allow for student independence, and provide resources to help with the accompanying stress. Just as many students on the autism spectrum have an Individualized
Education Plan when they are in grades K-12, college students must be afforded the same consideration when they enroll in college, viewed as individuals with unique needs, and not put into one-size-fits-all program. Gently reminding parents of the primary functions and goals of University and the CSP for their children may assist in the separation process. Faculty and staff continually referring to the students by name may be a way to model language which reflects student independence and assist parents to stop using “We” and “I”, and begin to see their children as independent of themselves when discussing support services. Parents may not even be aware of their overreaching behavior, and must learn to recognize the difference between helping their children and advocating when necessary, yet separating from them in a healthy manner.

Research Question Two – Systemic Barriers

Research question two addressed the perceived systemic barriers described by parents of University students on the autism spectrum during the transition period and after enrolling in college courses. Overall, results pointed to the lack of communication with parents, students, counselors, faculty, and staff, as well as a deficit in timely responses to student and parental needs. Two major themes emerged. First, the lack of information and communication from University and the CSP for high school students on the autism spectrum, their families, and guidance counselors regarding support programs, as well as lack of communication with and education of University faculty and staff. Secondly, a deficit in the timeliness and awareness of student and parental needs.

Theme four (i.e., Lack of Communication) emerged when two-thirds of the respondents in this study expressed dissatisfaction with the information available to them as they researched college programs for their sons. They described little to no help in finding support systems on college websites, a lack of information for and knowledge from high school guidance counselors,
and little to no interaction with college personnel working in support services for prospective and current ASD students. Those interviewed described doing most or all of the searching and research themselves, feeling alone and without help throughout the process, including the lack of involvement of their sons. They further indicated minimal interaction with high school guidance counselors, and limited knowledge from those school professionals regarding college support services for students on the autism spectrum. This is valuable information as parents and high school students are beginning the transition to college, children should be in the process of separating from their parents, taking the lead in the college search and application process, working with high school and college personnel, and developing their identities in terms of what they are looking for in a college and the future.

Positive parental adjustment is reflected when parents allow their children the freedom to express what they are looking for and begin to back away. This is critical, per Yelle et al. (2009), who reported positive parental adjustment significantly contributed to the young adults having positive self-esteem and feeling good about themselves. Additionally, while parents probably wish to continue to advocate for their children, especially when major life changes occur, the hope is to gradually let the students begin to make their own decisions and take responsibility for themselves (Pinder-Amaker, 2014). However, if limited information is available, or if there is no one to assist students in finding appropriate programming, parents who have played this role of advocacy for years and are used to doing all the work for their children, are likely to eventually take over, become frustrated, and not allow proper separation from their children to take place.

Additionally, lack of information can lead to increased stress, both individually and in the family unit due to the importance of the college decision. Although, as recommended by Hendricks et al. (2009) that family members be educated and well-equipped to assist their children on the autism spectrum, parents in this current study reported not receiving enough or
appropriate information. For the best outcomes, educational materials for people of all ages involved, those on the spectrum, families, and educational and support professionals should be readily available, easy to find, and lead to answers rather than additional questions and stress.

The systemic barrier of lack of communication also came across with four respondents expressing concern regarding the minimal communication with University faculty and staff regarding their sons’ autism diagnosis and available support systems. Parents pointed to a lack of educational resources and training materials for University personnel to help them learn how to properly assist ASD students whom they teach and interact with on a daily basis. The fact that less than half of those interviewed felt this way may point to five of the seven students being first-year college students. Three of the four parents who voiced this concern were parents of upperclassmen who already attended college and their experiences of interactions with University faculty and staff. This finding is important because faculty and staff play an important role in fostering student development. It would be helpful if they were informed about ASD in order to provide the best possible direction and support for their students. This finding relates to results reported by Gobbo et al. (2014) who found faculty members working with college students on the autism spectrum reported students with ASD struggled when working in small groups or participating in discussions. Knowing faculty and staff are knowledgeable about how to best assist students on the autism spectrum can help parents to better cope with their own sadness of separation and the frustration of not being able to assist their children in the manner they had always employed (Bartle-Haring et al., 2002), yet feel relief that University personnel are looking out for their children.

Coping with change and loss is not an all or nothing proposition, but a dynamic, ever-changing process which impacts the parent-child relationship (Lazarus, 1984). Parents who experience stress and are trying to cope with their children going to college want to feel
confident the students will not only receive a proper and excellent education, but will be supported and assisted throughout the process both in and out of the classroom. To increase the likelihood of success, colleges must provide mandatory training, resources, and support for faculty and staff to assist them in working effectively with students on the autism spectrum. Raised awareness on campus, required workshops in person or online, information about relevant websites, professional development conferences, and guest speakers in the classroom are just some of the ways colleges can educate their faculty and staff. While some faculty and staff may only view their jobs as engaging in minimal contact with students, they may be called upon by students for accommodations, such as separate testing spaces or extended time, witness student behavior outside of the norm (extreme anxiety, student meltdowns, speaking out of turn), interact individually with students during office hours, and attend social functions at club meetings and awards ceremonies. Interactions both in and out of the classroom may cause students on the autism spectrum to struggle with adjusting to new or different situations. Faculty and staff should, at the very least, be aware of the differences in all students and provide assistance and resources when necessary.

Theme five (i.e., Timeliness and Awareness of Student and Parental Needs) emerged as respondents in this study were extremely engaged and honest in their appraisal of the responses from University faculty, staff, and members of the CSP. Eight of the nine parents interviewed provided mixed feedback on the role and value of the CSP. Four parents indicated the CSP was the deciding factor leading their sons and families to choose University. Four respondents questioned whether or not the program would help their sons both during the first-year transition and in subsequent years.

The four respondents who praised the CSP, described it as life saver, pointed to the program as one of the critical reasons their sons attended University. They used descriptors such
as, “amazing”, “great”, “helpful”, and “the dealmaker...it was the reason” (for choosing University). This finding points to the positive impact of the CSP on the students and families, the critical role the supports provided, and the perception that student success was linked to participation in the program. Parents who recognized the need for support for themselves realized this can assist with their interactions with their children and lead to college success (Morrison et al., 2009). The CSP website describes itself as a service, assisting ASD students in developing goals leading toward social development, academic progress, self-advocacy, and career preparation (University, 2020b). Resources such as peer mentors, access to tutoring, small social gatherings, and academic coaching all point toward the goal of student independence, movement toward separation from parents, and reduced stress levels (University, 2020b). This process can likewise be helpful to parents if they are confident someone is watching out for their children.

Those who were not convinced of the value of the CSP discussed issues such as lack of information once students were admitted, an awkward interview process, and questioned the importance but perceived lack of connection with University Career Services. Others described engaging in heated debates with CSP staff members over the best course of action for their children, thus enacting the strong emotions they often experience as noted in the findings. While parental advocacy from the parents interviewed in this study was critical when the children were younger, moving into college provides the opportunity for individualized transition planning by the students as they continue to explore their own identities, advocate for themselves, and present their own ideas about what will provide the best assistance (Brinckerhoff, 1996).

The range of responses, with four parents questioning the value of the CSP, and four others praising the program, is important as it points to the CSP as an evolving support program. Oftentimes parents of students on the autism spectrum have low expectations of their child’s
transition to college, movement toward independence, and ultimate success (Van Hees et al., 2018). This leads them to wish to maintain a certain level of control. University faculty and staff who work with the CSP and provide services for students should be aware of the importance of their work, listen carefully to students and families, seek to address student and parental concerns, and remain dynamic and flexible, recognizing each unique student and family situation.

Research Question 3 – Fixing Communication and Responding to Parental Wisdom

Research question three explored insights from parents on their recommendations for services for themselves and their children. All nine respondents were extremely passionate and forthcoming in providing suggestions which they felt would allow the University and the CSP to help them and their children. These parental solutions indicated two major themes. First, they proposed ways University and the CSP could do a better job of communicating prior to students enrolling at University, provide additional information to students and parents, listen to parental needs, and increase interaction and information once students were admitted to the program. The second theme centered around parental suggestions for online resources, looking at other college programs to use as a model for the CSP, and, while not willing to be part of a support group, their willingness to speak with parents of prospective and newly admitted students, sharing their own experiences.

Theme six (i.e., Fixing Communication) grew out of respondents who were extremely grateful at being asked to participate in this study because they viewed me as a researcher, fellow parent of a child on the autism spectrum, and University staff member, as someone at the college who was asking them about their individual needs and took the time to listen to their concerns. Hearing individual stories and evaluating appropriate support services is necessary to reach successful outcomes. University faculty and staff listening to the needs of students and parents
confirms the findings of Pellicano et al. (2014a, 2014b) who reported understanding the individual perspectives of those on the autism spectrum and responding appropriately is necessary for successful outcomes. CSP and University cannot provide a “one size fits all” approach, but rather must listen to students and parents who present their distinctive needs as the students transition to and attend University, providing resources and programming on an individual level.

Theme seven (i.e., Responding to Parental Wisdom) is critical in assisting parents during the period of transition and enrollment of their children in college. Parents typically know their children better than anyone, can work as partners with college personnel, and provide specific information regarding their children which can lead to the best individualized plan of action. In agreement with Henninger et al. (2013), the tools needed to assist adolescents on the autism spectrum and their families cannot be generalized but must consider student and family uniqueness both socially and environmentally. These findings are important because campus resources and support for college students and their families should be based on the needs of those in the program. In the case of students on the autism spectrum, and with a group of 20 students enrolled in the CSP, supports should be individually tailored based on collaboration between CSP staff, their students, and parents. While a major goal of University and the CSP is to teach students independence, each student in the CSP has their own timetable and may (or may not) become fully independent during their college years at their own pace.

Seven of the nine respondents cited a need for additional parental education and resources, while less than half saw the CSP as a good resource for them. This finding is critical in that, since the CSP is a relatively new and evolving program, it brings awareness of parental perceptions to faculty and staff, who can subsequently work to continue to evolve it into a strong and dynamic program. A major goal would be to become a library of resources for parents and
students enrolled in the program, as well as the greater community of high school counselors, teachers, and University faculty and staff. Per the findings of Sosnowy et al. (2018), for best outcomes, the CSP should offer appropriate resources, based on student and parent needs, seeking to address real issues and challenges, not perceived generalized theoretical models.

**Additional Findings**

This study revealed additional interesting findings only slightly related to the research questions and based on parental demographic information. The respondents’ level of education (i.e., all nine participants held Bachelor’s Degrees; seven earned Graduate Degrees), and their familiarity with higher education, might have led them to an awareness of the importance of searching for support programs, as well as feeling comfortable when speaking with college administrators, faculty and staff. The seven students whose parents were interviewed were neither first generation college students nor minority students from urban areas. This is important because awareness of available college support programs for children on the autism spectrum may not be apparent to parents who never enrolled in higher education classes themselves. First generation college students and their families may not be aware such programs exist. It is critical for student success, parental transition, and equity in higher education for University and the CSP to promote, communicate, and provide information to all students, not just those whose families are familiar with higher education and possible support programs. Respondents and their families were able to go online and find information about the CSP.

Further, all respondents were working professionals, and their families were able to afford the 7000-dollar fee required for their children to participate in the CSP. These findings are important because it is likely the CSP is not an affordable program for all University applicants on the autism spectrum, with limited or no access to underrepresented, underserved, first-generation college students. Students from school and neighborhood environments where parents
have not gone to college, have limited technology, receive little or no information from high school counselors, or cannot afford the extra fee do not have the same access to the CSP as the respondents in this study. This lack of access not only excludes many students from this program, but also limits the ability of University to provide equitable service to a neuro-diverse student population. To resolve this inequity, steps should be taken by both University and the CSP to generate additional sources of revenue, lower program costs, increase marketing about the CSP to larger groups of prospective students and families, and increase accessibility for students and families who cannot currently afford to be a part of the CSP. Information about the CSP and college support programs should likewise be available to high school teachers and counselors in all socioeconomic groups, with a special emphasis on reaching out to schools with prospective first-generation college students from underserved communities. University as a state-supported institution of higher learning has an obligation to reach and be available to members of all communities. With an enrollment of more than 70,000 students, having a program with only 20 students indicates the need for marketing, finance, education, and partnering with various stakeholders to expand the ability of more students to utilize the services. This low number of participants also indicates the program is still in the early stages of developing their presence on campus and has a lot of opportunity for growth.

Although demographics of the families were similar, responses from parents pointed to varied family situations, unique students, and a wide range of challenges of the transition to and enrollment in college for their children. One result which was unanimous, with all nine parents in agreement, was zero interest in a parent support group. While some parents indicated they would be fine speaking individually to other parents to receive or deliver important information, they indicated this would be a one-time event, not an ongoing endeavor. Parents did not perceive support groups as “support”. They cited lack of time, the uniqueness of their situations, and fear
of a parental support group turning into nothing more than an opportunity for complaints as reasons for not having an interest in a support group. This finding is in contrast to the report of Schwarzer et al. (2007) who indicated better coping is possible when more support is available. This is important because it points to the University and the CSP developing support strategies for parents which provide excellent communication, up-to-date information, and providing appropriate resources which parents can access on their own, not as part of a support group.

**Limitations**

There were several limitations in this study. The number of participants was relatively small (nine), including two married couples. While their responses provided rich and detailed data which, and in many cases, confirmed prior research, the information gathered comes from a small group of parents whose children all attend the same University and are part of the CSP. All participants were parents of boys enrolled in the CSP. This factor may skew the results, as parents of girls on the autism spectrum may or may not have different needs, require other types of support services, and respond to separation, individuation, and stress in a different manner than their male counterparts. Five of the students were incoming freshmen who recently experienced and completed the transitional process of researching colleges, filling out applications, undergoing a CSP interview, and starting college classes for the first time. Lack of variety in class year of students may impact student and parental experiences and change the data, with parents of upperclassmen relating different experiences.

This study took place during the CoVid-19 pandemic. Six of the seven students lived at home and attended courses remotely. This severely impacted their transition as they had not yet moved to campus, interacted in person with University faculty and staff, socialized in person with their peers, nor experienced campus social life. In addition, they were working from home under the watchful eyes of their parents. The transition to college only took place academically;
the social and emotional separation and individuation was delayed. In some cases, this led to
greater familial stress for parents who struggled with their sons still being home, while at other
times, it brought a sense of relief to parents who did not think their children (or themselves) were ready for the transition away from home to campus, and movement toward greater independence.

**Recommendations for Further Study**

Overall, findings indicated University and the CSP, as they seek to provide resources and support services for new and continuing students on the autism spectrum, are succeeding in some areas and not meeting the mark in others. Parents, prospective students, and current students need access to better communication, more information, and clarity about the role of the CSP in the transition to and enrollment at University. Parents wish to be more involved in the transition process, wanting to work as partners with CSP staff to assist their children in achieving independence and success.

Further research should be conducted with a more wide-ranging variety of parents with children on the autism spectrum, including high school students, female students, college upperclassmen, and graduate students. In addition, information should be gathered from siblings and extended family members to determine the impact of ASD on them, familial considerations and interactions, and resources which can assist them. High school guidance counselors should be interviewed to determine their needs, provide strategies for success, and to make sure all stakeholders are on the same page when working with students and their families.

Results of this study also point to the need for research on the best methods of communication, education, and information for college faculty and staff to help them work effectively with ASD students. How to deliver this information, appropriate material and
resources, and an efficient delivery system should be researched to provide a smooth, easy to
use, and informative program.

To summarize the importance of this research study, as the number of students on the
autism spectrum continues to rise, all members of this group on college campuses need access to
services to help them grow and develop in a healthy manner, establish independence, transition
successfully to college and, later on into adulthood and a career. Likewise, the growing number
of parents with children on the autism spectrum require services from colleges to provide them
with good information, help them to assist their children during this time of transition, and
receive tools to help them cope with their own emotions as the students transition from high
school to college, during their time on campus, and into adulthood and a career. Further, not only
members of college communities charged with working with students on the autism spectrum,
but all college personnel should receive information, training, and educational resources
concerning these students to assist them in providing support so the students are able to learn
effectively, interact appropriately, and transition from high school to college and then to
adulthood and a career.

On a personal note, parental responses brought back memories, as the parent of an ASD
child, of my meetings with my son’s child study team in K-12 schools when he was younger.
While other parents encouraged me to listen and follow the school plan, there were, at times,
contentious meetings and heated debates with healthcare professionals and school counselors in
order to keep vital services for my son for a longer period of time. I learned from this project I
am not alone, and that, with proper support and information, I will be able to better cope with my
son’s transition from high school to college and into a career.
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https://doi.org/10.1371/journal.pone.0109946


Appendix A

Letter of Consent from the CSP Program Coordinator

Letter of Cooperation

Date: 9/1/20

Re: Letter of Cooperation for the College Support Program – University

Dear Thomas Moore,

This letter confirms that I, The Program Coordinator of the CSP, as an authorized representative of The College Support Program at University, allow the Principal Investigator access to conduct study related activities at the listed site(s), as discussed with the Principal Investigator and briefly outlined below, and which may commence when the Principal Investigator provides evidence of IRB approval for the proposed project.

-Research Site: The College Support Program, University, 152 Frelinghuysen Road, Piscataway, NJ 08854

· Study Purpose: The purpose of this qualitative interview research study is to collect information on the needs of parents as their children diagnosed with Autism Spectrum Disorders (ASD) transition to college in order to develop supports to assist them (parents).

· Study Activities: Interviews with parents of current University students.

· Subject Enrollment: 9 parent interviews

· Site(s) Support: The site agrees to assist with initial contact and introduction to possible study participants, and provide space to conduct the interviews.

· Data Management: Participants will receive pseudonyms and their identities and responses will be confidential and known only to the researchers. Taped interviews will be transcribed as soon as possible to ensure the integrity of the recording, as well as provide
immediate feedback for the researcher and participants. Interview responses will be coded on an excel spreadsheet located on a password protected computer.

- **Other**: The CSP agrees to support the research study until completion.

- **Anticipated End Date**: December 31, 2021

We understand that this site’s participation will only take place during the study’s active IRB approval period. All study related activities must cease if IRB approval expires or is suspended. I understand that any activities involving Personal Private Information or Protected Health Information may require compliance with HIPAA Laws and University Policy.

Our organization agrees to the terms and conditions stated above. If we have any concerns related to this project, we will contact the Principal Investigator. For concerns regarding IRB policy or human subject welfare, we may also contact the University IRB (see orra.university.edu/hbpp).

Regards,

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Program Coordinator

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(University, 2019c)
Appendix B

Initial Email sent by the CSP Program Coordinator

Good morning,

My name is ________ and I am the Program Coordinator of the College Support Program at University. I hope you are doing well and that your son/daughter (individualized) is having a great semester thus far. I am writing to introduce you to Tom Moore, a student in the Graduate School of Education at University. Tom also works at University as an academic advisor in the Business School, and is the parent of a 15-year-old son diagnosed with Autism.

Tom is currently working on a research proposal to gather information from parents of University College Students diagnosed with Autism, with the goal of providing resources and support for you as a parent. He is seeking your help in finding out about your children and their needs as they enrolled, transitioned, and began attending college. Further, he is interested in your needs as a parent who is not only assisting your child throughout their college years, but also experiencing your own transition and changes in your life. From the information you provide, we at the CSP will begin the process of gathering and providing resources for you as parents to help you with questions and concerns you have, and to support you as you continually adjust to your child attending college as a young adult.

Please let me know if you would be interested in speaking about this further. If yes, respond to this email and I, along with Tom, will call you at a time convenient for you to provide more in-depth details about the project timeline and procedure.

Thanks so much and I look forward to hearing back from you.

Sincerely,

_________
Program Coordinator - College Support Program
University
Appendix C

Interview Consent Form

I, Thomas Moore, am a Doctoral Student in the Graduate School of Education at University, and I am conducting interviews for a dissertation project. I am studying: The Needs of Parents of Autism Spectrum Disorder (ASD) students enrolling at University.

During this study, you will be asked to answer some questions to elicit information about your child and your needs as parents as your ASD child transitions to college. This interview was designed to be approximately 45 minutes to 1-hour in length. However, please feel free to expand on the topic or talk about related ideas. Also, if there are any questions you would rather not answer, or that you do not feel comfortable answering, please say so and we will stop the interview or move on to the next question, whichever you prefer.

This research is confidential. Confidential means that the research records will include some information about you and this information will be stored in such a manner that some linkage between your identity and the response in the research exists. Some of the information collected about you includes your age, race, gender, marital status, income level, number of children, job status and level of education. Please note that I will keep this information confidential by limiting individuals’ access to the research data and keeping it in a secure location on a password protected laptop and a flash drive which will be locked in the researcher’s office. The data gathered in this study are confidential with respect to your personal identity unless you specify otherwise.

The research team, dissertation advisor, peer dissertation group, and the Institutional Review Board at University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a
professional conference, only group results will be stated. All study data will be retained indefinitely.

You are aware that your participation in this interview is voluntary. You understand the intent and purpose of this research. If, for any reason, at any time, you wish to stop the interview, you may do so without having to give an explanation. There are no foreseeable risks to this study. You have been told that the benefits of taking part in this study may be the opportunity to express your needs as your child transitions to college, provide solutions, and participate in future support systems. You will not be compensated for participating in this study.

The recording(s) will be used for analysis by the research team, a teaching tool for the researcher, and for educational purposes. The tapes will not be used for commercial purposes, nor shared with anyone outside of the research team.

The recording(s) will include anonymous identifiers of subjects which will be kept in a secure location, with coding of individual data likewise remaining anonymous. If you say anything that you believe at a later point may be hurtful and/or damage your reputation, then you can ask the interviewer to rewind the recording and record over such information OR you can ask for certain text be removed from the dataset/transcripts.

The recording(s) will be stored on a password protected laptop and a flash drive which will be kept in a locked desk with a link to subjects’ identity. Subject names will remain anonymous and coded for confidentiality. The recordings will be retained indefinitely.

If you have any questions about the study or study procedures, you may contact myself at

Tom Moore
Rutgers Business School – New Brunswick
100 Rockafeller Road
Piscataway, NJ 08854
tmoore@business.rutgers.edu
732-822-5708
You may also contact my dissertation advisor:

Dr. Judith Harrison  
Graduate School of Education  
Rutgers University  
10 Seminary Place – Room 239  
New Brunswick, NJ 08891  
848-932-0808  
judith.harrison@rutgers.edu

If you have any questions about your rights as a research participant, you can contact the Institutional Review Board at Rutgers (which is a committee that reviews research studies in order to protect research participants).

Institutional Review Board  
Rutgers University, the State University of New Jersey  
Liberty Plaza / Suite 3200  
335 George Street, 3rd Floor  
New Brunswick, NJ 08901  
Phone: 732-235-9806  
Email: humansubjects@orsp.rutgers.edu.

You will be offered a copy of this consent form that you may keep for your own reference. Once you have read the above form and, with the understanding that you can withdraw at any time and for whatever reason, you need to let me know your decision to participate in today's interview.

Participant Name:

Participant Signature: Date:

Principal Investigator: Thomas Moore – Rutgers Graduate School of Education
Appendix D:

Addendum: Consent to Audio/Visually
Record or Photograph Subjects

You have already agreed to take part in a research study entitled: The Needs of Parents of University Students on the Autism Spectrum, conducted by Thomas Moore. I am asking your consent to allow me to interview you online via a WebEx link, and video and audio record the session as part of the research. You do not have to consent to be recorded or videotaped in order to take part in the main research.

The recordings will be used for analysis and educational purposes.

The recordings may include the following information that can identify you: video and audio tape of the interview. Participants will be given pseudonyms and their information will remain confidential.

The recordings and interview transcripts will be stored in a linked filed cabinet in a locked office with no link to subjects’ identity, and retained indefinitely.

The recordings will not be used by us or distributed to investigators for other research.

Your signature on this form permits the investigator named above to record and/or photograph you as described above during participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written consent.
<table>
<thead>
<tr>
<th><strong>AGREEMENT TO BE RECORDED</strong></th>
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<tbody>
<tr>
<td><strong>Subject</strong> (Print): ___________________________</td>
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<td><strong>Subject Signature</strong> ___________________________</td>
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<tr>
<td><strong>Investigator/Person</strong> (Printed): ___________________________</td>
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<td><strong>Signature</strong> ___________________________</td>
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Appendix E

Demographic Questionnaire

Please complete the following items and email them to me as an attached Word Document

1) Family name

2) Gender of parent participant

3) Age range of parent participant
   a) 30 - 30
   b) 40 - 49
   c) 50 - 59
   d) 60 and older

4) Parent participant education level

5) Parent participant employment information

6) Number of people in the household
   a) Gender
   b) Age

7) Gender of ASD child

8) My ASD college student is a
   _____ Freshman
   _____ Continuing Student
   _____ Transfer Student
Appendix F

Personal Data Sheet

<table>
<thead>
<tr>
<th>Name</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age Range</th>
<th>Parental Education Level</th>
<th>Parental Employment Information</th>
<th>Number of People in the Household</th>
<th>Number of Children</th>
<th>Ages of Children</th>
<th>Gender of ASD Child</th>
<th>Age of ASD Child</th>
<th>Class Year of ASD Child</th>
</tr>
</thead>
</table>

Appendix G

Interview Protocol

Student Information

1) Tell me about your son/daughter? When did he/she first receive an ASD diagnosis?
2) What is it like for your child when trying something new? Can you give me an example?
3) Can you think of a time when your son or daughter had a difficult time transitioning from one activity to another? What was that like for them? How did they respond? What was the outcome?

Parental Information

1) Upon hearing that your child was diagnosed with an Autism Spectrum Disorder, what was the experience like for you? How did you feel? How did you respond?
2) Did you utilize support systems for yourself as your child was growing up? If yes, who provided support? For example, school resources, counselors, church membership, other parents, support groups? What was the experience like? If no, why did you not seek services for yourself?

College Transition

1) What aspects of your child’s transition to college were you confident about?
2) What concerns did you have? What concerns do you still have?
3) What concerns did you have for yourself? What concerns do you still have?
4) What aspects of your child’s transition to college are you confident about?
5) What aspects of this next stage in your life are you confident about?

College Support Program

1) University College Support Program is seeking to start a support group for parents whose children are enrolled at University, have a diagnosis of ASD, and are members of the College Support Program. Would you be interested in participating in this group?
2) If yes, why, and what format would be most beneficial for you? Structured? Semi-structured? Non-structured?
3) If not, are there reasons why you are not interested in participation?

Probing Topics from the Perceived Stress Scale

Have you been upset because of something which happened unexpectedly?
Do you sometimes feel that you are unable to control the important things in your life?
Are there times when you are not confident about handling personal problems?
Are there times when you cannot cope with all the things you had to do?
Do you sometimes get angry because difficulties are piling outside of your control?
Probing Topics from the Social Support Questionnaire

Who can you count on to help you out in a crisis situation and listen when you need to talk?
Who can you count on to be dependable when you need help?
Who can you count on to console you when you are upset?

Probing Topics regarding Coping Strategies from the Jalowiec Coping Scale

Try to keep life as normal as possible  
Think positively and that things could be much worse  
Keep a sense of humor  
Think about the good things in your life  
Try to handle things one step at a time  
Try to keep the situation under control  
Try to keep busy  
Try to keep feelings under control  
Try to find out more about the problem

Probing Topics from the Psychological Separation Inventory

Functional, emotional, conflictual, and attitudinal independence from mother and father

Research Questions

1) What are the experiences of parents of students with ASD when their children transition to and attend college?
2) What do parents of university ASD students report are systemic barriers which hinder them from coping with the transition and attendance of their child at college?
3) What support do these parents need to help them adjust effectively as their children’s transition to and attend college?
Appendix H

Data Analysis

Iterative coding for thematic analysis (Neale, 2016)

I. Participant number, pseudonym, file identifiers – from demographic questionnaire

II. Developed a clear labeling system (numbers, letters, colors)

a) Deductive Coding
   1) Grouped data into categories based on similarities for each respondent
   2) Grouped data into categories across cases
   3) Grouped and prioritized data as it relates to research questions and theoretical models
   4) Labeled information on an Excel spreadsheet using qualifiers and identifiers

b) Larger themes were broken into subcategories based on similarities and differences
   1) Identified duplication, complementarity, and contradictions
   2) Assessed the nature and range of findings

c) Interpreted similar and dissimilar data – looked for connections
   1) Summarized key points
   2) Looked for complex commonalities and differences
   3) Reviewed, rationalized, and re-grouped
   4) Looked for a logical order and emerging narrative

III. Interpretive Analysis

a) Identified patterns, associations, concepts and explanations

b) Ascertained how the findings complement or contradict previous literature
   1) Identified themes within and across each category
   2) New categories and themes
   3) Relation back to the respondents, theories and research questions
   4) Mapping back and forth from the starting point of the study to its conclusion
   5) Write up themes
   6) Extract quotes which support the data