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PARENTING EMERGING ADULTS WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

Little research and literature regarding the relationships of emerging adults with autism and their parent(s) is available. It is critical to demystify the relationships of parents with adult children with ASD, and what their communication on a daily basis looks like. In a planned study, participants will be recruited through social media organizations or service providers. Once participants consent to partake in the study, investigators will provide a demographic survey that will be completed by each participant. Upon completion of the demographic questionnaires, using ecological momentary interventions/assessments, or daily diaries, the study will survey a minimum of 20 parents (maximum of 60) regarding the daily interactions with their adult child with ASD. For the duration of 14 days, the participants will receive an email or text each morning to complete the electronic survey, at the place and time of their convenience, concerning the interaction(s) they had with their child that day. Each survey will take approximately 10-15 minutes or less each and will be asked two or three times throughout the study to complete an interview with principal investigators (PI) over the phone or on Skype/Google Hangout.

The current study will present pilot data collected to test the electronic surveys on Qualtrics, a research software, as well as to test the data collection process and the method by which the data should be gathered. One individual, a middle-aged woman, was requested to complete daily diaries over the course of three days. This study evaluated the effectiveness of the methodology to provide critical feedback prior to initiating the full study.

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Chapter 1

Literature Review of Relevant Research

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is part of a group of disorders termed pervasive developmental disorders (PPD) (Faras, Al Ateeqi, & Tidmarsh, 2010). ASD is characterized by social and communicative impairments, as well as repetitive behaviors and stereotypic movements. These symptoms and impairments fall on a spectrum, ranging from mild to severe autism. Boys are more often diagnosed with autism than girls, surmounting to a 4:1 male-to-female ratio (Fombonne, Zakarian, Bennet, & Meng, 2006). Recent studies conducted by the National Health Interview Survey found that about 1 in 45 American children, aged 3 through 17, have been diagnosed with autism (“New Government Survey”, 2015). This is an increase from the Center for Disease Control’s (CDC) estimation of 1 in 68 American children that are diagnosed with autism. The increase may be linked to overall increased awareness, broader criteria and diagnostic concepts, and more advanced detection and diagnostic methods (Faras et al., 2010).

Many theories have formed over the years of the cause of autism; still, there is not a concrete answer. A child’s genetics may play a role in his or her autism diagnosis. For instance, family studies have shown that having a sibling with autism gives a child a 2- 8% chance of being diagnosed with autism as well (Faras et al., 2010). Furthermore, twin studies have shown that shared genes may carry an increased chance of diagnosis more than shared environment (Chaste & Leboyer, 2012). For instance, monozygotic twins showed higher concordance rates

compared to dizygotic twins for a diagnosis of autism. However, it is important to consider the environmental implications on the diagnosis of autism in a child, such as parental infections.

There is no cure for the symptoms of ASD, however, early intervention practices are critical. Epidemiologist Michael Rosanoff, the Autism Speaks director for public health research stated, “The earlier they have access to care, services and treatment, the more likely they are to progress” (“New Government Survey”, 2015, para. 4). Interventions aim to develop language, social skills, and appropriate behaviors (Faras et al., 2010). The various types of early intervention can help an individual with ASD to develop the skills that are imperative to thrive in a society.

Autism Spectrum Disorder and Emerging Adults

Emerging adulthood is a trying time for any individual who is trying to figure out a place in the world. As autism is a primarily social, behavioral, and communicative disorder, having autism as an emerging adult can pose a wide range of difficulties for an individual. As described by Arnett (2000), emerging adulthood is a period of development starting in the late teens through the mid-twenties, particularly ages 18-25, and is an important time in an individual’s life characterized by identity exploration. It is a time in which an individual has relative independence from his or her parents and start to form and explore on his or her own (Arnett, 2000).

With independence from parents, an individual must learn to thrive in a society that relies on communication and appropriate social interactions. This can be difficult for individuals with

autism, as well as individuals that present autistic features that are considered a part of the general population. A revision of the Diagnostic and Statistical Manual of Mental Disorders deemed autism as a spectrum of symptoms due to the considerations that autistic-like symptoms and features exist within the general population, as well as individuals diagnosed with autism (Ratner & Berman, 2015). These general symptoms can impede on social and identity development in emerging adulthood. The study conducted by Ratner and Berman (2015) sought to find how autistic-like symptoms affect identity “in a population of emerging adults where it is hypothesized that identity development and self-focus are at a peak” (p. 138). It was found that autistic features negatively predict identity commitment; however, they positively predict identity exploration, identity distress, and existential anxiety (Ratner & Berman, 2015). Further analysis showed that the social aspects and difficulties characteristic of autism, such as social relatedness and limited interests, are associated with difficulties engaging components of identity formation, commitment and exploration (Ratner & Berman, 2015).

Along with trying to form an identity and explore the world around them, emerging adults with autism once they graduate, lose the services that have been provided to them since they started intervention. Once the individual turns 21, services provided by the school system are no longer available. A study that interviewed adults with Asperger’s syndrome found that life can prove difficult for those on the spectrum after services are halted. In terms of employment, all participants found it difficult to find employment and retain employment (Griffith, Totsika, Nash, & Hastings, 2012). Many experienced long period of unemployment and did not find it easier to find a job with increasing age and experience (Griffith et al., 2012). Additionally, the services that were available after the age of 21 received negative reviews. The services available to the participants in the study, primarily individuals from Wales, were those meant for people

with intellectual or physical disabilities, or with mental health issues (Griffith et al., 2012). The services were not made to help those with high-functioning autism or Asperger syndrome.

Emerging adulthood is also a time in which an individual may choose to go to college. A person with autism who chooses to go to college may find him or herself in a world that is closed off from a very social environment. A study conducted by White et al. (2016) used focus groups and online surveys to determine the needs and difficulties of college-bound and college-enrolled students with autism. The online survey and focus groups determined that the services needed are those that address common difficulties with emotional regulation, stress management, socialization, transition to independence, intimacy, and academics, which were then grouped into social needs, self-determination needs, and self-regulation needs (White et al., 2016). It was discovered that social difficulties were an important need that should be addressed, especially with facilitating age-appropriate social interaction without the help of older adults or the participants' parents. Self-determination and self-regulation also proved to be important to the participants. As a result, White et al. (2016) proposed that development of skills in all three areas should positively affect the students' readiness for the transition into college. Furthermore, supports at college could increase a student's quality of life, academic and social success, and symptomatic impairment (White et al., 2016). Trying to navigate society as an individual with autism can be a daunting task. Emerging adulthood is a time of exploration and self-discovery. It is difficult to achieve these goals if one has difficulty communicating or functioning appropriately in a social setting.

Parenting Emerging Adults with Autism Spectrum Disorder

Emerging adulthood is a difficult time for all parties involved, including parents. This can be magnified when their emerging adult child has autism. According to Burke and Heller (2016), parents of adults with ASD experience worse well-being compared to those of adult children with other disabilities. After surveying 130 parents of parents of adults with ASD about caregiving satisfaction, self-efficacy, and burden, Burke and Heller (2016) found that an increase in future planning and community involvement was correlated with a higher caregiving satisfaction and caregiving self-efficacy. However, if their child experienced maladaptive behaviors and poor health, parents experienced a greater caregiving burden (Burke & Heller, 2016). With so few studies available regarding the transition to adulthood for those with autism spectrum disorder, Cadman et al., (2012) piloted a study in which they observed 192 families that were caring for a person aged 14-24 years with a childhood diagnosis of ASD or ADHD, with 101 of those families having a child with ASD. A stress-appraisal model was utilized to determine caregiver burden as it related to family background, primary stressors, primary appraisal (need), and use of services or resources (Cadman et al., 2012). Although it was found that both disorders were correlated with a great level of caregiver burden, it was profoundly greater in the families with children with ASD. Caregiver burden within both disorders was most often correlated with the child's unmet needs, particularly within the domains of depression, anxiety, and inappropriate behavior (Cadman et al., 2012). Caregiver burden associated with the

families of young people with ASD had significant associations between burden and unmet needs in the domains of social relationships and mental health issues.

Problem Solving in Caregivers and Emerging Adults with ASD

Problem solving is an essential part of being a successful individual in a society that is constantly changing. Emerging adults with autism spectrum disorder, however, can find problem solving an especially difficult task, especially when asked to do so in a short amount of time or under any form of stress or pressure. Azad et al. (2016) examined problem solving, particularly in the context of parent-teacher relationships and the use of collaborative problem solving to address the challenges of a student with ASD. Eighteen teachers and 39 parents of children with ASD were asked to discuss and provide solutions to a problem that the child with ASD was experiencing at home, as well as in school. The individuals then reported their problem-solving behaviors. It was discovered that parents and teachers utilized very little core elements of problem solving, however, they did display moderate levels of behaviors that prompted the problem-solving process (Azad et al., 2016). Additionally, teachers utilized more problem-solving than parents, but both parents and teachers reported more use of problem-solving than was actually observed during their discussion. One explanation for this difference could be attributed to socioeconomic status, racial/ethnic and cultural expectations that affect the behavior of parents. For instance, Cheatham and Ostrosky (2011) stated that during IEP (individualized educational plan) meetings, teachers ask parents for goals by providing their own goals and following that up with a pause, prompting parents to respond with their goals. In this study, Spanish-speaking parents did not recognize the pauses as prompts to give their recommendations

for goals for their child (Cheatham & Ostrosky, 2011). The difference in culture led to this miscommunication. An additional reason for the difference in use of problem-solving between teachers and parents could be because parents often assume that their role during IEP meetings should be that of a passive listener role (Burke, 2012). This could be due to the fact that roles are not discussed with parents before or during IEP meetings and parents are usually presented with completed reports during IEP meetings, leaving little opportunity for feedback and discussion (Burke, 2012). These problem-solving skills and parent-teacher communication can improve the outcome for children and emerging adults with ASD.

One study conducted by Yakubova and Taber-Doughty (2016) aimed to evaluate the effectiveness of multicomponent intervention to increase and improve the use of problem-solving in students with ASD during vocational tasks. To do so, Yakubova and Taber-Doughty (2016) used a multiple-probe across-student approach on four male high school students with ASD in order to demonstrate the effectiveness of point-of-view video modeling coupled with sessions in which the students could practice, as well as a cue sheet to solve problems that students could come across during vocational tasks. After the students with autism completed this intervention, each improved problem-solving performance, as well as generalized these skills to another untrained setting. Out of the four students, three of them maintained problem-solving performance at the 6-week check-up (Yakubova & Taber-Doughty, 2016). They concluded that students with autism spectrum disorder can learn to use problem-solving on their own with the help of previous intervention.

Methodology

In the current study, the data are based on daily diaries completed by caregivers of emerging adults with autism. A daily diary methodology has been used in other research projects concerning ASD. According to Repetti, Reynolds, and Sears (2015), daily diaries, or ecological momentary interventions/assessments, can use three different approaches to scheduling data collection. Researchers can use experience sampling methods, which utilizes signal-contingent recording to randomly sample immediate experiences in natural, everyday contexts (Repetti et al., 2015). Furthermore, daily diaries can use interval-contingent sampling, in which respondents are asked to complete reports on their states and/or experiences at scheduled times throughout the day, usually before bed or in the morning (Repetti et al., 2015). Finally, researchers may use event sampling, wherein participants complete a survey whenever an event meeting a predetermined definition has occurred. Due to the scheduling of daily diaries and the ease of completing them, participant burden is fairly low (Repetti et al., 2015). Daily diaries boast various advantages compared to other methods of study, such as reducing bias from retrospective assessments, increasing ecological validity, since daily diaries are completed in a natural setting, and multiple assessments can be accomplished over a time, allowing for temporal relationships to be examined (Heron & Smyth, 2010).

The questions within daily diaries are an important aspect to the design of the research project. Three types of broad questions can be answered with daily diaries: collecting dependable information at the person-level, amassing estimates of within-person change over a period of time, including the individual differences in those changes, and conducting analyses of changes and the individual differences in those changes (Bolger, Davis, & Rafaeli, 2003). Additionally,

research questions addressed through daily diary data regarding families are all used to describe the characteristics of daily family life with greater precision and ecological validity. These questions are aimed to test whether stable individual difference variables predict daily descriptions of states and behaviors within the family, whether micro-level fluctuations in characteristics of daily family life are associated with short-term changes in the states, behaviors, and/or perceptions of individual family members, and finally, to test between-person or between-family differences in micro-level, within-subject associations, such as the impact of chronic stress (Repetti, Reynolds, & Sears, 2015).

Answering multiple questions throughout the day is easier with advancing technology and smartphones. For instance, Heron and Smyth (2010) conducted a study in which twenty-seven participants used palmtop computers and mobile phones in order to receive ambulatory treatment for various conditions, such as weight loss, anxiety, diabetes treatment, and eating disorders. Ecological momentary interventions can be delivered successfully through such technology and is received well and accepted by participants (Heron & Smyth, 2010). Adherence to completing an electronic daily diary seems to be sufficient, as Whalen et al. (2006) demonstrated through their study of mothers and children (with and without ADHD) reporting on moods, behaviors, and social contexts every 30 minutes during non-school hours for 7 days. The participants completed at least 71% of prompted diaries, with some completing 100% (Whalen et al., 2006).

Research Question

The current study addresses the following research question: What are the daily experiences of parents of emerging adults with ASD? The investigation used a daily diary approach to understand more about the parents of emerging adults with ASD who provide ongoing support to their adult children.

Chapter 2

Method

The current study presents a pilot study that was intended to test the feasibility of a daily diary methodology for use with parents of emerging adult children with ASD. It is important to validate the methodology before initiating the full study with parents, to ensure that valid data can be collected. Pilot data was collected from an individual in order to check that the daily diary survey worked, as well as to check if the data collection processes were sufficient.

Participants

To collect pilot data, one middle-aged woman was asked to complete daily diaries scheduled for 6:30 a.m. and 6:30 p.m., respectively. The participant is a parent of two emerging adults, although her adult children do not have ASD. She completed the electronic surveys over a course of three days. The times listed were the scheduled times in which the surveys were sent to the participant, however, she could complete them at the time and place of her convenience.

Materials

Qualtrics, an online survey tool designed to distribute, analyze, and report surveys, was used for the daily diaries. This tool was used to collect demographic information, as well as to distribute surveys. See the Appendix for these surveys.

Procedure

The participant was instructed to complete the diaries however she wished. As a special education teacher, she chose to complete the surveys based upon her interaction with some of the children in her classroom with ASD (not emerging adults). The participant is in daily contact with these children, except for the weekends, and is the primary support for these children throughout the school day. She is fluent in English and has access to a computer and smartphone daily. She completed each survey on the computer.

Chapter 3

Results

As the point of pilot data was to test the research software as well determine the best method by which to gather data, some parts of the survey were not completed by the participant. The following results are based on the completed parts of the surveys.

For all three days of the pilot study, the participant communicated with her son/daughter, or in this case, her students. She took the survey five times during the course of the three days of the pilot study. Figure 1 shows the various ways the participants communicated with her son/daughter and/or her students. Throughout the three days of the electronic survey, the participant communicated mostly through text message and in person with her son/daughter or students, with one instance communicating both via text message and in person.

Figure 1. *How did you communicate with your son/daughter?*

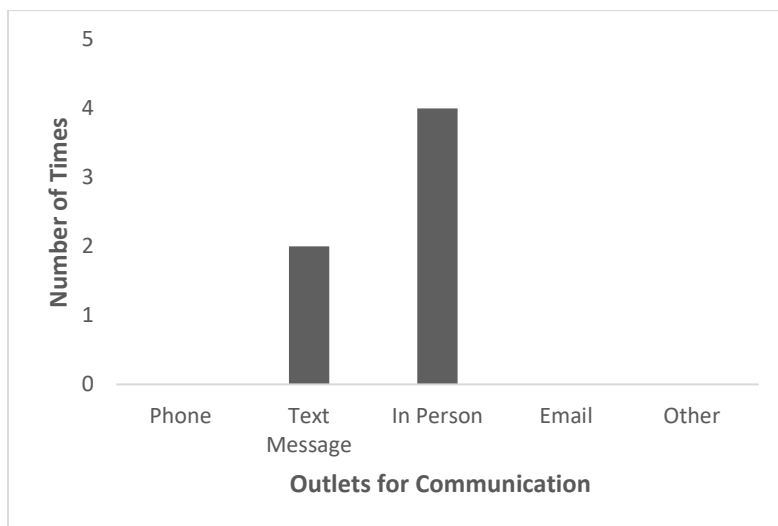
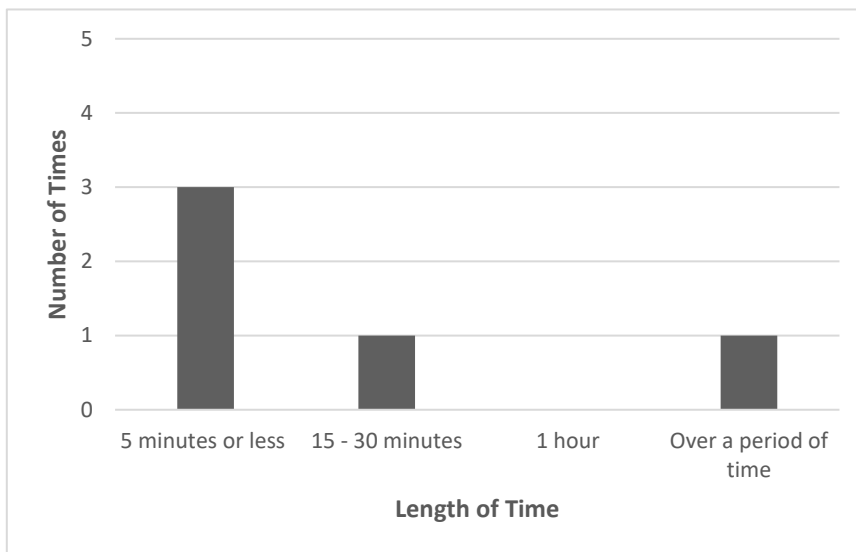


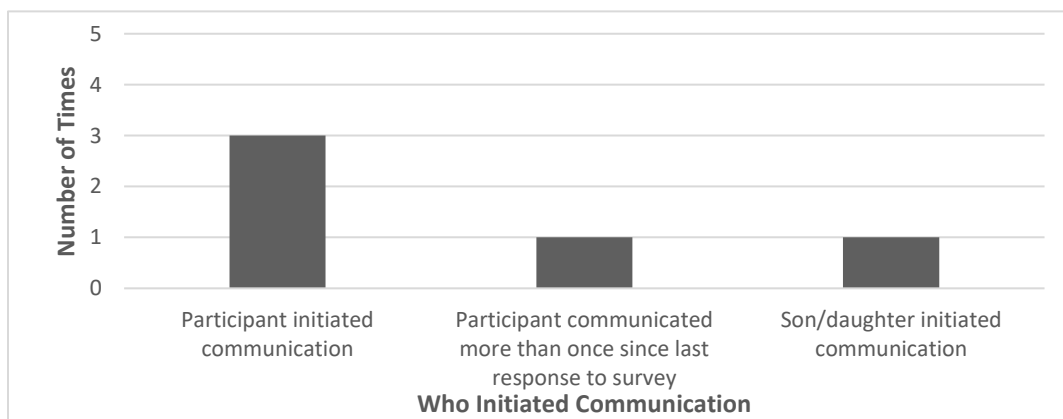
Figure 2 shows that the length at which the participant communicated with her son/daughter or students varied significantly throughout the three days.

Figure 2. How long did the communication last?



The participant reported who initiated the communication event, shown in Figure 3. In the first report on the second day, the participant reported that she communicated twice with her son/daughter or student since she last responded to the survey, in which she initiated all instances of communication

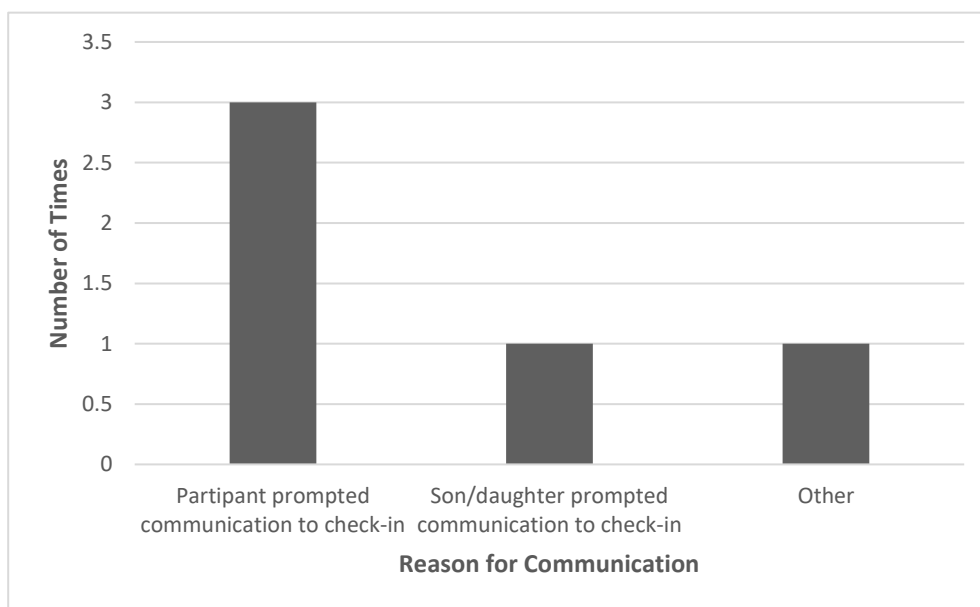
Figure 3. Who initiated contact?



Three communication events prompted by the participant were to check in with her son/daughter or student, and once was reported as “other”, in which the purpose stated was to

remind one of her students about expectations and materials needed throughout the school day and small talk. The participant reported once that her son/daughter prompted communication to check in. Figure 4 displays the reasons for the communication events that the participant reported.

Figure 4. What prompted you or your son/daughter to reach out?

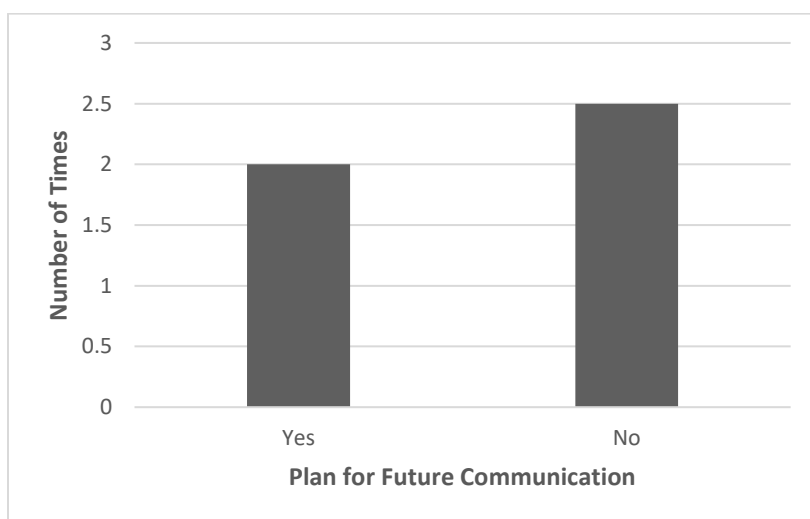


An important aspect of the survey and study was to find out how participants and their son/daughter problem-solved through communication. Over the course of the three days and five reports, the participant problem-solved with her son/daughter or student three times. The first time the participant reported that she problem-solved with her student, the student was unable to find the materials he or she needed for class. The participant and the student were able to backtrack and recall where the student last had the materials needed. In the second instance of problem-solving, the participant and the student were able to problem-solve to make sure the student's homework was complete. For the third time, the participant reported that she did not know the

nature of the problem that needed to be solved. In all three cases of problem-solving that the participant reported, the participant and her student were able to make progress toward addressing the problem. The participant, in all five cases of her reports of whether she problem-solved with her son/daughter or student, did not know or was unsure of whether her son/daughter/student communicated their problems with anyone else.

Figure 5 displays the participant's plans for future communication with her son/daughter/student. In one report, the participant stated that she did make plans to communicate with her son/daughter/student, in which she checks-in every day to make sure things are going smoothly with that individual.

Figure 5. Did you make a plan for future communication with your son/daughter?



The last series of questions asked the participant to report on the affect of her son/daughter/student at the beginning and end of the communication event, as well as her affect and how she felt at the end of the event. For all questions, the participant was asked to rate the event or emotion on a scale of 1-5. Table 1 exhibits how the participant answered the questions that required a rate of 1-5. The sections marked with an “X” indicates that the participant did not answer the question for that day.

Table 1. Electronic survey: rating questions

Questions (Rate 1-5; 1 = worst; 5 = best)	Answers					Average
<i>Date Code</i>	<i>1.1</i>	<i>2.1</i>	<i>2.2</i>	<i>3.1</i>	<i>3.2</i>	
How would you describe your son/daughter's general affect at the START of the communication?	2	4	X	X	1	2.3
How would you describe your son/daughter's general affect at the END of the communication?	4	4	X	X	X	4
How would you describe YOUR general affect at the START of the communication?	X	4	4	4	4	4
How would you describe YOUR general affect at the END of the communication?	4	4	4	4	2	3.6
Did you feel more confident or more uncertain? (confident = 1; uncertain = 5)	2	2.4	2.3	2.3	4.1	2.6
Did you feel more comforted or more worried? (comforted = 1; worried = 5)	1.9	2.3	2.4	2.2	4	2.6
Did you feel more calm ore more aggravated? (calm = 1; aggravated = 5)	X	2	1.9	1.9	4	2.5
Did you feel more encouraged or more discouraged? (encouraged = 1; discouraged = 5)	2.5	2	2.3	1	4.1	2.4

Chapter 4

Discussion

As the study has not yet been fully conducted and the pilot data is the only data recorded to test the electronic surveys, the prospective study should be discussed.

Participants

Participants for this study will be recruited nationally via service providers and online social media groups. Investigators will contact administrators and/or service providers within these groups and organizations and ask permission to recruit within. Parents who self-select to be a part of the study can contact the researchers to express their interest, whether it be through email or phone. A script will be used for the formal recruitment of participants, which can be found in the Appendix.

Once interest is expressed, a series of eligibility questions will be asked via email to parents:

1. Is your child 18 years or older?
2. Has your adult child received a diagnosis of autism spectrum disorder?
3. Has your adult child finished high school?
4. Are you in regular contact with your adult child with ASD?
5. Do you feel like you are one of your adult child's main sources of support?
6. Are you fluent in English?

7. Do you have an email address and access to a computer/tablet/smartphone daily to respond to a web survey?

Eligible participants will be sent informed consent through email or mail when an agreement to participate in the study has been reached. Participants will sign a copy of the consent form and sent it to the researchers and will receive a copy of the consent form for their own records. Additionally, participants will be informed and reminded that they are under no obligation to participate and stay in the study and may withdraw at any point. It is expected that a minimum of 20 participants, with a maximum of 60 participants, will partake in this study. The number of participants depends on the unique population we are seeking within the availability of the participation pool.

Procedures & Methods

The study will utilize ecological momentary assessments, or daily diaries, with parents of emerging adults with autism spectrum disorder answering questions on an electronic survey system called Qualtrics. The participants will answer these questions at least once a day for 14 days. For the duration of the 14 days, the participants (parents) will be asked to partake in two or three 20-30-minute phone interviews. After the initial analysis is complete, the participants will be contacted again to give feedback on themes.

After the consenting to participate in the study, participants will be prompted to provide the research team and investigators with contact information and they will be asked to complete a demographic questionnaire. A link will be provided to each participant to the demographic questionnaire after they provide their contact information.

Once the demographic questionnaire is completed, participants will receive an email each morning for 14 days with a link to the electronic survey on Qualtrics. If at any time throughout the day the participant comes into contact with their adult child, whether it be through phone call or in person, they can use the link to record their experience. The participants will receive an additional email or text each evening to remind them to complete the survey if they have not, or if they have anything to add to the survey they last completed. The surveys can be completed from the participants' homes or any other location of their choosing, where they feel comfortable and it is convenient for them. Each survey will take 10-15 minutes or less to complete. Additionally, participants will be reminded two or three times throughout out the course of the 14-day period that they are able to share photographs of their adult children, but it is not required. As stated, parents will also be asked if they are willing to schedule an interview with researchers, which will last about 20-30 minutes. This interview may take place by phone or Skype/Google Hangout, depending on preference or availability of the participants. The interview will be audio-recorded and will be conducted in a place of the participants' choosing, however, the principal investigator(s) (PI) will remind the participants to choose setting that allow for privacy. The PI will conduct the interviews form a private location as well. The questions for the semi-structured interview can be found in the Appendix. At the end of the 14 days, the participants will fill out a final survey to give feedback on themes. The final survey questions are shown in Table 2.

Table 2. Final survey

Questions	Answers
Over the course of the 14 days, was the amount of contact you had with your son or daughter typical? (Choose one)	<input type="radio"/> No, it's usually a lot less than this. <input type="radio"/> Yes, this was pretty typical. <input type="radio"/> No, it's usually a lot more than this.
Over the course of the 14 days, was the type of contact you had with your son or daughter typical? (Choose one)	<input type="radio"/> Yes <input type="radio"/> No (please explain) _____
Is there anything else you want to tell us?	OPEN-ENDED

Conclusions

Although the current study only presents information on one pilot participant, the results suggest that the methodology of data collection and data synthesis should be effective to gather the desired information. The information provided from the participants will help us understand how we, as a society, can aid parents of emerging adults with ASD. Furthermore, we may also learn how we can help emerging adults with ASD be more independent as they progress through adulthood.

Appendix

Table 3. Demographic survey: parent/caregiver information

Demographic Information Test	
PARENT/CAREGIVER INFORMATION: Please provide the following information about the parent/caregiver who will be answering the surveys and interview questions. You may decline to answer any questions you are uncomfortable answering. Your answers will be entered into a document with identifying information removed.	
<i>Questions</i>	<i>Answers</i>
Current age:	(Open-ended)
Gender:	(Open-ended)
Race/Ethnicity (check all that apply):	<input type="checkbox"/> African American/Black <input type="checkbox"/> American Indian/Alaskan Native <input type="checkbox"/> Caucasian/White <input type="checkbox"/> Hispanic <input type="checkbox"/> Multiethnic <input type="checkbox"/> Other
Relationship status:	<input type="checkbox"/> Single, never married <input type="checkbox"/> Married <input type="checkbox"/> Domestic partnership <input type="checkbox"/> In a relationship <input type="checkbox"/> Divorced <input type="checkbox"/> Separated <input type="checkbox"/> Widowed

Table 3. Demographic survey: parent/caregiver information (continued)

Education (please check highest level completed):	<input type="checkbox"/> Some high school <input type="checkbox"/> High school/GED <input type="checkbox"/> Some college or technical school <input type="checkbox"/> Associate's degree <input type="checkbox"/> Bachelor's degree <input type="checkbox"/> Master's degree <input type="checkbox"/> Doctorate/professional degree
Employment status (select one; please provide a brief description):	<input type="checkbox"/> Not employed outside the home <hr/> <input type="checkbox"/> Employed full-time outside the home <hr/> <input type="checkbox"/> Employed part-time outside the home <hr/> <input type="checkbox"/> Self-employed <hr/>
Annual family income:	<input type="checkbox"/> Less than \$20,000 <input type="checkbox"/> \$20,001 to \$40,000 <input type="checkbox"/> \$40,001 to \$60,000 <input type="checkbox"/> \$60,001 to \$80,000 <input type="checkbox"/> \$80,001 to \$100,000 <input type="checkbox"/> More than \$100,000 <input type="checkbox"/> I would prefer not to respond
How many children do you have, including your son/daughter with ASD?	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> More than 4
Do you live with your son/daughter with ASD? If no, please briefly describe where your son/daughter lives.	<input type="checkbox"/> Yes <input type="checkbox"/> No <hr/>
Is there anything else you would like us to know about your family?	Open-ended

Table 4. Demographic survey: adult child's information

Demographic Information Test	
YOUR ADULT CHILD'S INFORMATION: Please provide the following information about your adult son or daughter with ASD. You may decline to answer any questions you are uncomfortable answering. Your answers will be entered into a document with identifying information removed.	
<i>Questions</i>	<i>Answers</i>
Current age:	Open-ended
Gender	Open-ended
Race/Ethnicity (check all that apply):	<input type="checkbox"/> African American/Black <input type="checkbox"/> American Indian/Alaskan Native <input type="checkbox"/> Caucasian/White <input type="checkbox"/> Hispanic <input type="checkbox"/> Multiethnic <input type="checkbox"/> Other
Relationship status:	<input type="checkbox"/> Single, never married <input type="checkbox"/> Married <input type="checkbox"/> Domestic partnership <input type="checkbox"/> In a relationship <input type="checkbox"/> Divorced <input type="checkbox"/> Separated <input type="checkbox"/> Widowed

Table 4. Demographic survey: adult child's information (continued)

Education (please check highest level completed):	<input type="checkbox"/> Some high school <input type="checkbox"/> High school (completed with modified diploma) <input type="checkbox"/> High school (standard diploma)/GED <input type="checkbox"/> Some college or technical school <input type="checkbox"/> Associate's degree <input type="checkbox"/> Bachelor's degree <input type="checkbox"/> Master's degree <input type="checkbox"/> Doctorate/professional degree
When did your son/daughter complete high school programming?	Open-ended
Did your son/daughter participate in any post-secondary transitioning program? If yes, please provide a brief description.	<input type="checkbox"/> Yes _____ <input type="checkbox"/> No
Employment status (select one; please provide a brief description):	<input type="checkbox"/> Not employed outside the home _____ <input type="checkbox"/> Employed full-time outside the home _____ <input type="checkbox"/> Employed part-time outside the home _____ <input type="checkbox"/> Self-employed _____
When was your son/daughter diagnosed with ASD?	Open-ended
What was the specific diagnosis given?	<input type="checkbox"/> Autism <input type="checkbox"/> Autism spectrum disorder (ASD0) <input type="checkbox"/> Asperger syndrome (AS) <input type="checkbox"/> Pervasive developmental disorder – not otherwise specified (PDD-NOS) <input type="checkbox"/> Other: _____

Table 4. Demographic survey: adult child's information (continued)

What type of professional gave the diagnosis?	<input type="checkbox"/> Pediatrician <input type="checkbox"/> Nurse practitioner <input type="checkbox"/> Developmental pediatrician <input type="checkbox"/> Neurologist <input type="checkbox"/> School psychologist <input type="checkbox"/> Other school based professional <input type="checkbox"/> Speech-language pathologist <input type="checkbox"/> Other: _____
If known, please identify the tests that were used to determine the diagnosis	<input type="checkbox"/> Autism Diagnostic Observation Schedule (ADOS) <input type="checkbox"/> Autism Diagnostic Interview (ADI) or Autism Diagnostic Interview-Revised (ADI-R) <input type="checkbox"/> Childhood Autism Rating Scale (CARS) <input type="checkbox"/> Professional determination of match to DSM criteria <input type="checkbox"/> Other: _____
Has your son/daughter also been diagnosed with intellectual disability?	<input type="checkbox"/> Yes <input type="checkbox"/> No
How does your son/daughter communicate? Please consider both your son/daughter's ability to produce as well as receive or understand communication?	Open-ended
Considering what you know about ASD, what do you think of as areas of strength for your son/daughter?	Open-ended
Considering what you know about ASD, what do you think of as areas of weakness/need for your son/daughter?	Open-ended
Are you satisfied with your son/daughter's level of community engagement or participation in events outside the home? Please briefly explain.	<input type="checkbox"/> Yes _____ <input type="checkbox"/> No _____

Table 4. Demographic survey: adult child's information (continued)

Please rate the level of difficulty your son/daughter has in the following areas:				
	<i>No difficulty</i>	<i>Mild difficulty</i>	<i>Moderate difficulty</i>	<i>Severe difficulty</i>
Carrying out daily routines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Handling stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Basic interpersonal interactions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respect and warmth in relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Responding to social cues in relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complex interpersonal interactions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Forming relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interacting according to social rules	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Maintaining social space	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Abstract thinking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Organization and planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive flexibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Judgement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Applying knowledge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Focusing attention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Solving simple problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Solving complex problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Making decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is there anything else you would like us to know about your son/daughter?	Open-ended			

The recruitment script is as follows:

Recruitment Script
(Via email or social media)

Hello! We are a team of researchers from Nazareth College in New York and Penn State University in Pennsylvania, looking for parents of adult children (over the age of 18) who have autism spectrum disorder (ASD).

We'd like to invite you to participate in a research study investigating the experiences and perspectives of parenting an adult with ASD. Specifically, you would be asked to participate in a series of short daily surveys for a period of two weeks about your interactions with your adult child. You may also elect to participate in short (20-30 minutes) interviews about your experiences.

If you are willing to participate in this study, please contact Megan Tobin at (585) 503-7475 or mtobin9@naz.edu or Kathryn Drager at (814) 863-2426 or kdd5@psu.edu. Thank you very much!

Table 5. Interview questions

Semi-Structured Interview Questions	
<i>Questions</i>	<i>Probes</i>
Tell us about the nature of the problem that you worked on solving with your son or daughter during your call on _____.	Was this a new problem or a chronic/ongoing problem?
Now tell us about how you worked to solve the problem. If possible, please try to think about the steps you took as you worked together.	As relevant follow-up probes may include: <ul style="list-style-type: none"> • Whose idea was it? • Did you consider any other possible solutions? • What was the outcome?
Did one person do the majority of the work to solve the problem, or was it a shared effort?	Did one of you have to compromise or did you ultimately agree on the solution?
How confident do you feel about your son or daughter's ability to implement the solution you identified?	Has there been any progress toward actually solving the problem since you talked with your son or daughter?

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Academic Vita

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EDUCATION

Bachelor of Science, Communication Sciences and Disorders

May 2018

The Pennsylvania State University, University Park, PA

Schreyer Honors College

- Minor in Human Development and Family Studies
- Honors Thesis Working Title: "Parenting an Emerging Adult with Autism Spectrum Disorder"

TEACHING EXPERIENCE

Teaching Assistant

January 2018 – May 2018

The Pennsylvania State University, University Park, PA

CSD 462: Clinical Bases of Language Disorders

Teaching Assistant

August 2017 - December 2017

The Pennsylvania State University, University Park, PA

HDFS 129: Introduction to Human Development

Virtual Tutor

September 2017 – November 2017

The Pennsylvania State University, University Park, PA

Hazelton Integration Project

Afterschool Scholars Program

RESEARCH

Communication Sciences and Disorders

January 2015 – Present

The Pennsylvania State University, University Park, PA

Honors Thesis Research

Research advisor: Kathryn Drager, Ph.D., CCC-SLP

- Purpose of the research is to investigate the experiences of parents of emerging adults with Autism Spectrum Disorder (ASD)
- Using ecological momentary assessment to investigate the experiences of the specified population
- Data will be analyzed qualitatively

WORK EXPERIENCE

Clerical Assistant/Receptionist

*The Pennsylvania State University, University Park, PA
College of Health and Human Development, Office of the Dean*

**August 2017 – April 2018
August 2015 – April 2016**

- Clerical duties
- Filing
- Mailing
- Other duties as requested or needed

Clerical Assistant

*The Pennsylvania State University, University Park, PA
College of Health and Human Development, Finance Office*

August 2016 – April 2017

- Clerical duties
- Filing
- Mailing
- Other duties as requested or needed

Campsite Supervisor

Campsite Counselor

South Whitehall Township Parks and Recreation, Allentown, PA

June 2017 – August 2017

June 2015 – August 2016

- Facilitate opportunities for group problem solving amongst campers
- Encourage respect for personal property, camp equipment and facilities
- Set a good example for campers in all areas, including cleanliness, punctuality, clean-up chores, rules, and sportsmanship
- Guide campers in successful participation in all aspects of camp activities
- Communicate with parents about participant's experiences and report concerns to Camp Leadership
- Assist in maintaining accurate program records including incident reports, logbook documentation, and daily attendance

HONORS & AWARDS

Dean's List

The Pennsylvania State University, University Park, PA

Fall 2014 - Present

Schreyer Honors College

The Pennsylvania State University, University Park, PA

EXTRACURRICULAR AND VOLUNTEER EXPERIENCE

Monarch

THON Special Interest Organization

The Pennsylvania State University, University Park, PA

2014 – Present

Dancer Relations Committee Member

2014 - 2017

THON Volunteer

The Pennsylvania State University, University Park, PA