

**Understanding Parent Participation in the Postsecondary Education of Students  
with ASD**

BY

Cheryl J. Widman  
B.A. University of Illinois at Chicago, 1991  
M.A.T. National-Louis University, 2009

THESIS

Submitted as partial fulfillment of the requirements  
for the degree of Doctor of Philosophy in Special Education  
in the Graduate College of the  
University of Illinois at Chicago, 2020

Chicago, Illinois

Defense Committee:

Dr. Norma A. Lopez Reyna, Chair and Advisor  
Dr. Lisa Cushing  
Dr. Gena Flynn, College of Education  
Dr. Daniel Maggin  
Dr. Stephen Shore, Adelphi University

This dissertation would not have been possible without my son, Nicolas. His birth led me along the path to where I am today. While fighting for his right to a Free and Appropriate Public Education, I ensured that he would be able to pursue his special interest in computer science that ultimately culminated with a PhD. It was my experience supporting him from pre-k to completion of graduate school that inspired my dissertation research. Finally, he is the computer scientist who wrote the R programming code that allowed me to utilize Mokken Scale Analysis as a method to analyze construct validity for my instrument. In other words, none of this would have been possible without him. The circle is complete.

## **Acknowledgments**

It is with gratitude that I acknowledge the contributions of Special Education Department and Dissertation Committee Chair, Dr. Norma Lopez-Reyna, without whom this dissertation might not have been possible. Her leadership, mentorship, and support were invaluable every step of the way. Additionally, I thank my dissertation committee members, Dr. Lisa Cushing, Dr. Gena Flynn, Dr. Daniel Maggin, and Dr. Stephen Shore for their time and feedback as I progressed from my dissertation proposal defense to dissertation defense. I am grateful to Dr. Cushing for helping me get to the point where I could move forward with a viable project, and to Dr. Maggin for leading me to the literature that would support the utilization of the instrument I authored for my research. With respect to measurement, I must also acknowledge Dr. George Karabatsos for his feedback regarding construct validity. Furthermore, I want to thank Dr. Flynn for sharing a passion for postsecondary student retention, an objective of this research. With gratitude I acknowledge Dr. Stephen Shore for taking the time to support me through this process as he crosses the globe in pursuit of spreading the “Four A’s of Autism, Awareness, Acceptance, Appreciation, and Action.” Finally, I thank my husband, Bo Widman, for his dedication to producing fine cuisine daily, sustenance that kept me going through to the destination of the dissertation journey.

### **Contribution of Authors**

The literature review for the dissertation, Understanding Parent Participation in the Postsecondary Education of Students with Autism Spectrum Disorder, was authored by the Ph.D. candidate, Cheryl J. Widman as required for dissertation proposal defense. Subsequently, it was edited by Norma A. Lopez-Reyna, her advisor, and published by the Journal of Autism and Developmental Disorders on February 18, 2020.

## TABLE OF CONTENTS

<u>CHAPTER</u>	<u>PAGE</u>
<b>I INTRODUCTION .....</b>	<b>1</b>
A. Background.....	1
B. Statement of the Problem.....	2
C. Research Questions.....	6
<b>II LITERATURE REVIEW .....</b>	<b>8</b>
A. Inclusion Criteria .....	15
B. Exclusion Criteria .....	15
C. Reliability and Inter-coder Agreement .....	16
D. General Findings of the Systematic Review.....	18
1. Experimental Design Studies.....	18
2. Descriptive Design Studies.....	19
3. Participants and Variables .....	21
E. Themes Across Study Results.....	22
1. Social Learning /Supports.....	23
2. Functional/Residential Life Supports .....	24
3. Academic Support/Adjustments .....	25
4. Emotional Learning/Supports .....	26
5. Parent/Family Involvement .....	27
6. Vocational Training .....	28
7. Communication Development .....	28
8. Transition Program Needs .....	28
<b>III METHODS.....</b>	<b>38</b>
A. Research Design .....	38
1. Conceptual Framework .....	38
B. Researcher as Instrument/Reflexivity .....	40
1. Instrument .....	43
C. Data Collection Procedure .....	48
1. Sample and Participant Recruitment.....	48
2. Survey Screening Protocol.....	49
a. Screening System.....	50
b. Inclusion Process .....	51
c. Exclusion Process .....	52
3. Inter-rater Reliability .....	54
D. Data Analysis Procedures .....	54
1. Quantitative Data Analysis .....	54
a. Item Average Descriptive Analysis .....	54
b. Mokken Scale Analysis .....	55
c. Kuder Richardson Formula 20 (K-20) Test of Reliability .....	56
E. Qualitative Data Analysis .....	56
a. Grounded Theory. ....	56

b. ATLAS.ti Qualitative Analysis. ....	57
c. Inter-rater Reliability .....	58
<b>IV RESULTS .....</b>	<b>59</b>
A. Participant Engagement .....	59
B. Demographic Data .....	60
1. Parent Level of Education.....	60
2. Students' Educational Achievement.....	61
3. Parent Identity and Income.....	61
C. Quantitative Data Analysis .....	68
1. Social Integration Item Average Analysis.....	68
2. Autonomy Item Averages Analysis.....	70
3. Emotional/Stress Relief Item Averages Analysis.....	71
4. Social Integration Items Mokken Scale Analysis.....	73
5. Autonomy Items Mokken Scale Analysis .....	76
6. Emotional/Stress Relief Items Mokken Scale Analysis .....	80
7. Reliability.....	83
D. Qualitative Data Analysis .....	83
1. Open-Ended Text Response Rates.....	83
2. Results from Grounded Theory Analysis .....	84
3. Results from ATLAS.ti Analysis.....	87
E. Data Merging .....	89
F. Validity .....	90
G. External Validity.....	91
<b>V DISCUSSION .....</b>	<b>98</b>
A. Persistence .....	98
B. PPSASDS .....	100
C. Parent Participation.....	101
D. Intersecting Themes of Participation .....	102
E. Overarching Theme of Participation.....	106
F. Implications for Future Research .....	107
1. The Instrument .....	107
2. Closing Gaps.....	108
G. Implications for Practice.....	108
H. Limitations .....	108
I. Conclusion .....	109
<b>APPENDICES .....</b>	<b>112</b>
APPENDIX A.....	113
APPENDIX B .....	116
APPENDIX C .....	119
APPENDIX D .....	122
APPENDIX E .....	127
<b>CITED LITERATURE.....</b>	<b>128</b>

<b>VITA .....</b>	<b>140</b>
-------------------	------------

## LIST OF TABLES

<u>TABLE</u>		<u>PAGE</u>
I	RESEARCH QUESTIONS, ASSOCIATED DATA COLLECTION, ANALYSIS FOR THE PPSASDS STUDY	7
II	AUTHORS, PARTICIPANTS, DESIGN, DATA COLLECTION PROCEDURE, AND THEMES FOR LITERATURE REVIEW ARTICLES	33
III	PARENT EDUCATION, INCOME, IDENTITY, AND STUDENT EDUCATIONAL ACHIEVEMENT	62
IV	SOCIAL INTEGRATION DOMAIN ITEM AVERAGES	69
V	AUTONOMY DOMAIN ITEM AVERAGES	70
VI	EMOTIONAL/STRESS RELIEF DOMAIN ITEM AVERAGES	72
VII	MOKKEN COEFFICIENT HI AND H SCALABILITY RESULTS: SOCIAL INTEGRATION	74
VIII	SOCIAL INTEGRATION MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n = 36	75
IX	SOCIAL INTEGRATION MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n = 45	75
X	MOKKEN COEFFICIENT HI AND H SCALABILITY RESULTS: AUTONOMY	76
XI	AUTONOMY MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS):n = 36	78
XII	AUTONOMY MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n = 45	79
XIII	MOKKEN COEFFICIENT HI AND H SCALABILITY RESULTS: EMOTIONAL/STRESS RELIEF	80
XIV	EMOTIONAL/STRESS MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n = 36	82
XV	EMOTIONAL/STRESS RELIEF MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n = 45	82



XVI	OPEN-ENDED QUESTIONS THEMES	85
XVII	AUTONOMY DATA COMPARISON	93
XVIII	SOCIAL INTEGRATION DATA COMPARISON	95
XIX	EMOTIONAL/STRESS RELIEF DATA COMPARISON	96

## LIST OF FIGURES

<u>FIGURE</u>		<u>PAGE</u>
I	PRISMA style illustration of the systematic literature review process	17
2	Parents' demonstration of consistent engagement through textual response	84

## **LIST OF ABBREVIATIONS**

ADA	Americans with Disabilities Act
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control and Prevention
EAHCA	Education for All Handicapped Children Act
FAPE	Free and Appropriate Public Education
FERPA	Family Educational Rights and Privacy Act
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IRB	Institutional Review Board
LRE	Least Restrictive Environment
MSA	Mokken Scale Analysis
NLTS	National Longitudinal Transition Study-2
PPSASDS	Parents of Postsecondary Students with Autism Spectrum Disorder Survey
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SSL	Secure Socket Layer
TPSID	Transition Postsecondary Education Programs for Students with Intellectual Disabilities
YNI	Yes/No Interrogative

## SUMMARY

Of the 50,000 youth with Autism Spectrum Disorder (ASD) who achieve adulthood each year, the National Autism Indicators Report disclosed that 36% attend a postsecondary school. Among these, an 80% majority, attended 2-year colleges and 11% attended 4-year colleges (Roux et al., 2015a, 2015b). A systematic review of the literature exposed a gap with respect to the participation of parents of postsecondary students with ASD, a best practice in primary and secondary education.

To understand parent participation in the postsecondary education of their students with ASD, I designed a mixed-methods research study examining three domains of support, autonomy, social integration, and stress/emotional relief. An online dichotomous survey of 45 questions plus 14 open-ended questions collected data contemporaneously from 45 parents. Construct validity as measured through Mokken Scale Analysis rated strongest for social integration with the scalability coefficient  $H=.39$  and standard error of .08, with KR-20 analysis confirming high reliability of .76 for internal consistency.

Quantitative and qualitative results triangulated, with academic and executive function support emerging as additional domains of participation exposed through qualitative elaboration. To generalize, parents were fostering skills which fall under the rubric of self-determination, the development of which is delayed beyond young adulthood among individuals with ASD, particularly skills associated with executive function. Further testing of the dichotomous instrument with larger sample sizes is warranted and suggested.

## I: INTRODUCTION

### Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects social and communication skills. Individuals with ASD experience a limited range of interests, repetitive behaviors, and hypo- or hypersensitivity to sensory stimuli. A Pervasive Developmental Disorder (PDD) with no known cure, ASD is a lifelong disability (NIH, 2019). Lifelong challenges are related to social-communication issues, and as a result, few adults with ASD are employed (Howlin, 2013; Roux et al., 2013, 2017; Taylor & Seltzer, 2010). Roux et al. (2017) found that only 14% of adults with ASD are gainfully employed in the community while 27% have no work or other activities. Among the employed, a majority, 54% of individuals with ASD, worked without pay in a facility with other individuals with disabilities. Based on a study of two groups of adults with ASD, those with employment and those without employment, the data yielded results that indicated significant predictors of employment include disclosure of disability and level of education, with a higher level of education associated with higher probability of employment (Ohl et al., 2017). Similarly, Shattuck and colleagues (2012) found that 55% of those who participated in postsecondary education were employed after high school. Of those who were employed, 28% had attended a 2-year college, 12% had attended a 4-year college, 35% had attended a 2-year or 4-year school, and 9% had attended either a vocational or technical postsecondary school. Based on the rate of participation in postsecondary employment, education appeared to be an important path to employment for individuals with ASD, particularly among those with milder impairment and high ability functional skills (Ohl et al., 2017; Shattuck et al., 2012).

## **Statement of the Problem**

For students who may now be matriculating to postsecondary schools, prevalence of ASD at their time of their birth was 1 in 150 (CDC, 2018). In the last eighteen years, prevalence of ASD has increased 254% to 1 in 59 children among eight-year-old children at 11 sites monitored by Autism and Developmental Disabilities Monitoring (ADDMM) Network in the United States during 2014 (Baio et al., 2018). A broader more recent study based on a nationwide survey conducted in 2016 pegged prevalence of Autism at 1 in 40 among children aged 3 to 17 as reported by the parents of 1.5 million children (Kogan et al., 2018).

As a result of this exponential increase in prevalence, the number of students with ASD attending postsecondary institutions is increasing. Adding to the probability that students with ASD will matriculate to postsecondary options are the improvements in the way students with ASD are educated as well as the U.S. Department of Education funded initiative, Transition Postsecondary Education Programs for Students with Intellectual Disabilities (TPSID). Improved quality of primary and secondary education and mandated Least Restrictive Environment (LRE) should improve educational outcomes for all students with disabilities, so more students with ASD will continue to the tertiary level of education as a result of legislation. Additionally, at least 50,000 youth with ASD will achieve adulthood each year over the next ten years (Roux et al., 2015a). Based on Roux et al. (2015a) findings predicated on National Longitudinal Transition Study-2 Wave 5 (NLTS2) data, at some point after they leave high school, 36% of youth with ASD attend some sort of postsecondary institution, either a 2-year or 4-year college, vocational, business or technical school; and among this group of postsecondary students, 70% will attend a 2-year college at some point during their pursuit of postsecondary education.

In 2016, the U.S. Department of Education National Center for Education Statistics data indicated that among all 2 and 4-year degree granting postsecondary institutions, 56% reported enrollment of at least one student with ASD (Snyder et al., 2016). According to enrollment by type of institution, 78% of 4-year public institutions reported students with ASD, and 70% of 2-year public colleges registered students with ASD at their schools (Raue & Lewis, 2011). An important caveat is that enrollment of students with ASD may be understated due to a significant number of students with disabilities who fail to disclose disability in order to receive accommodations (Newman et al., 2011).

Mamiseishvili and Koch (2012) noted that students with disabilities primarily attend two-year colleges because those institutions may provide more options for support than four-year institutions. Roux et al. (2015b) underscored that two-year colleges provide a “stepping-stone” to four-year colleges. Another factor that could affect school choice is related to distance from home. About 91% of students with disabilities choose to remain in-state for college, and on average, attend a school within 104 miles from home. These students primarily attend 2-year colleges (47%) and most (76%) are enrolled in public institutions (Horn & Nevill, 2006). Students with ASD comprise 2% of the total population of students with disabilities enrolled at all 2 and 4-year postsecondary institutions (Raue & Lewis, 2011).

Mamiseishvili and Koch (2011) found that students with developmental disabilities such as ASD were among those who experience the highest postsecondary failure rate. In their analysis of outcomes up to eight years after high school based on data yielded by the NLTS2, Newman and colleagues (2011) found that the postsecondary graduation rate of young adults with ASD was 39%, one of the lowest graduation rates among postsecondary students with disabilities.

Postsecondary failure is attributable to several factors: the difference in laws that govern secondary and postsecondary schools that shifts responsibilities to the student for obtaining the right to accommodations and modifications, the documentation “disconnect” (Gartland & Strosnider, 2007), the generalized types of accommodations and modifications that may have been available in high school but are not within the scope of reasonable accommodations as established by postsecondary law, and the lack of self-determination skills that contribute to success (Shogren et al., 2014). Reasonable accommodations available at postsecondary institutions have been defined through legislation that challenges Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990. Modifications or academic adjustments that do not affect the quality of education may be available to the student with ASD. Academic adjustments include priority registration, reduction in course load, course substitution that does not diminish the program of study, note takers, recording devices, sign language interpreters, extended time for testing, equipping school computers with screen-reading, voice recognition, or other adaptive software or hardware. Such accommodations may or may not be sufficient for students with ASD, but these are the types of generic reasonable accommodations that may be available at a college or university through a disability resource center (U.S. Department of Education, 2018). Additionally, the U.S. Department of Education (2018) states unequivocally on its website that students are charged with the responsibility to self-identify and seek accommodations if needed. Only 28% of postsecondary students with any disability disclose disability and less than 20% received accommodations (Newman et al., 2011). Roux and colleagues (2015b) also noted that only 49% of those who had disclosed their diagnosis of ASD at two-year colleges received an accommodation or educational support, and that 68% of those individuals receiving support



regarded it as useful. Likewise, at four-year colleges, 30% of students with ASD that disclosed their disability received support with 56% of these individuals reporting usefulness of services. The rate of request/disclosure and usefulness data suggest that generic accommodations available at colleges and universities may be less than adequate for students with ASD when compared to their previous k-12 Individualized Education Program (IEP) that specified individualized supports. This shortfall of available postsecondary supports relative to the IEP could explain lack of utilization and reported efficacy.

Roux et al. (2015b) found that 70% of two-year college students with ASD and 64% of four-year college students with ASD identify as an individual with a disability. In their study of barriers to the use of disability services among postsecondary students with disabilities, Marshak et al. (2010) identified “perceived quality and usefulness of services” as 1 of 5 themes characterizing students’ lack of fully utilizing support or seeking out services. Other barriers included negative experiences with faculty, identity issues, desire to avoid stigma, and insufficient knowledge, all of which may help explain why postsecondary students with ASD may underutilize supports.

Students with ASD are a heterogeneous group of individuals with a Pervasive Developmental Disorder that may have resulted in a wide range of delays in verbal and non-verbal communication skills, social skills, and self-determination skills. As a result of the Least Restrictive Environment (LRE) mandate of IDEA (2004), more students with ASD have been successfully included in general education classrooms. Accordingly, students with a wider range of abilities (not just those with exceptional math and science talent) are matriculating to colleges and universities. Unlike their neurotypically developing peers, the student with ASD may arrive at college without the necessary soft skills that are expected by faculty, staff, and other students

(Dymond et al., 2017; Elias et al., 2019). Without the individualized support provided by their IEP, many are at risk for failure because the generic accommodations that are available on campuses might not fully support the student's communication and social needs or foster the development of self-determination skills. Accordingly, my hypothesis for this study was that parents were filling in the individualized support gap created when their student lost their IEP as a result of matriculating to postsecondary education.

### **Research Questions**

The purpose of this research is to examine the characteristics of parent participation in response to the needs of their postsecondary students with ASD in order to improve retention, graduation rates, and outcomes. To achieve that aim, this study will address four questions: (1) Is the Parents of Postsecondary Students with Autism Spectrum Disorder Survey (PPSASDS) a reliable measure for assessing parent involvement with postsecondary students with ASD, (2) how do parents support social integration, autonomy, and emotional/stress relief, (3) in what other ways do parents support their postsecondary students with ASD, and (4) through merging results, generally what does parent participation look like (see Table 1 below)?

**Table 1**

RESEARCH QUESTIONS, ASSOCIATED DATA COLLECTION, ANALYSIS FOR THE PPSASDS STUDY			
Research Questions	Data Type	Data Collection Methods	Data Analysis
1. Is the PPSASDS a reliable measure for assessing parent involvement with postsecondary students with ASD?	Quantitative Qualitative	Survey	Mokken Scale Analysis (R Package “Mokken”) KR-20 (Excel) Open Coding ATLAS.ti
2. How do parents support Social Integration, Autonomy, and Emotional/Stress Relief?	Quantitative	45 dichotomous questions	Descriptive Item Averages Construct validity: Mokken Scale Analysis Internal Consistency: KR-20
3. In what other ways do parents support their postsecondary students with ASD?	Qualitative	14 open-ended text questions	Open coding ATLAS.ti
4. Through merging results, generally what does parent participation look like?	Integration	Findings from quantitative questions 1 and 2, qualitative findings from question 3	Joint display tables Discussion

## II: LITERATURE REVIEW

Previously published as Supports for Postsecondary Students with Autism Spectrum Disorder: A Systematic Review

Material from: Widman, C.J., Lopez-Reyna, N. Supports for Postsecondary Students with Autism Spectrum Disorder: A Systematic Review. *J Autism Dev Disord* (2020).

<https://doi.org/10.1007/s10803-020-04409-3> (see Appendix E)

In order to survey extant literature examining support specifically for postsecondary students with Autism Spectrum Disorder (ASD), a systematic review of the literature was conducted through a synthesis of an established protocol of quality indicators for special education research and the methodology for PRISMA (Preferred Reporting Items for Systematic reviews and Meta- Analyses). Eight themes were identified describing features of programs, interventions, and supports that were implemented or described in the 21 studies reviewed. One of the themes, parent support, is underexamined in the literature relating to postsecondary institutions. Recommendations for needed research are included.

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects social and communication skills. Individuals with ASD experience a limited range of interests, repetitive behaviors, and hypo- or hypersensitivity to sensory stimuli. A Pervasive Developmental Disorder (PDD) with no known cure, ASD is a lifelong disability (NIH, 2019). Lifelong challenges are related to social-communication issues, and as a result, few adults with ASD are employed (Howlin, 2013; Roux et al., 2013, 2017; Taylor & Seltzer, 2010). Roux et al. (2017) found that only 14% of adults with ASD are gainfully employed in the community while 27% have no work or other activities. Among the employed, a majority, 54% of individuals with ASD, work without pay in a facility with other individuals with disabilities. Based on a study of

two groups of adults with ASD, those with employment and those without employment, the data yielded results that indicate significant predictors of employment include disclosure of disability and level of education, with a higher level of education associated with higher probability of employment (Ohl et al., 2017). Similarly, Shattuck and colleagues (2012) found that 55% of those who participated in postsecondary education were employed after high school. Of those who were employed, 28% had attended a 2-year college, 12% had attended a 4-year college, 35% had attended a 2-year or 4-year school, and 9% had attended either a vocational or technical postsecondary school. Based on the rate of participation in postsecondary employment, education appears to be an important path to employment for individuals with ASD, particularly among those with milder impairment and high ability functional skills (Ohl et al., 2017; Shattuck et al., 2012).

For students who may now be matriculating to postsecondary schools, prevalence of ASD at their time of their birth was 1 in 150 (CDC, 2018). In the last eighteen years, prevalence of ASD has increased 254% to 1 in 59 children among eight-year-old children at 11 sites monitored by Autism and Developmental Disabilities Monitoring (ADDM) Network in the United States during 2014 (Baio et al., 2018). A broader more recent study based on a nationwide survey conducted in 2016 pegged prevalence of Autism at 1 in 40 among children aged 3 to 17 as reported by the parents of 1.5 million children (Kogan et al., 2018).

As a result of this exponential increase in prevalence, the number of students with ASD attending postsecondary institutions is increasing. Adding to the probability that students with ASD will matriculate to postsecondary options are the improvements in the way students with ASD are educated as well as the U.S. Department of Education funded initiative, Transition Postsecondary Education Programs for Students with Intellectual Disabilities (TPSID). Improved

quality of primary and secondary education should improve educational outcomes for all students with disabilities, so more students with ASD will continue to the tertiary level of education as a result of legislation. Additionally, at least 50,000 youth with ASD will achieve adulthood each year over the next ten years (Roux et al., 2015a). Based on Roux et al. (2015a) findings predicated on National Longitudinal Transition Study-2 Wave 5 (NLTS2) data, at some point after they leave high school, 36% of youth with ASD attend some sort of postsecondary institution, either a 2-year or 4-year college, vocational, business or technical school; and among this group of postsecondary students, 70% will attend a 2-year college at some point during their pursuit of postsecondary education.

In 2016, the U.S. Department of Education National Center for Education Statistics data indicated that among all 2 and 4-year degree granting postsecondary institutions, 56% reported enrollment of at least one student with ASD (Snyder et al., 2016). According to enrollment by type of institution, 78% of 4-year public institutions reported students with ASD, and 70% of 2-year public colleges registered students with ASD at their schools (Raue & Lewis, 2011). An important caveat is that enrollment of students with ASD may be understated due to a significant number of students with disabilities who fail to disclose disability in order to receive accommodations (Newman et al., 2011).

Mamiseishvili and Koch (2012) noted that students with disabilities primarily attend two-year colleges because those institutions may provide more options for support than four-year institutions. Roux et al. (2015b) underscored that two-year colleges provide a “stepping-stone” to four-year colleges. Another factor that could affect school choice is related to distance from home. About 91% of students with disabilities choose to remain in-state for college, and on average, attend a school within 104 miles from home. These students primarily attend 2-year

colleges (47%) and most (76%) are enrolled in public institutions (Horn & Nevill, 2006).

Students with ASD comprise 2% of the total population of students with disabilities enrolled at all 2 and 4-year postsecondary institutions (Raue & Lewis, 2011).

Mamiseishvili and Koch (2011) found that students with developmental disabilities such as ASD were among those who experience the highest postsecondary failure rate. In their analysis of outcomes up to eight years after high school based on data yielded by the NLTS2, Newman and colleagues (2011) found that the postsecondary graduation rate of young adults with ASD was 39%, one of the lowest graduation rates among postsecondary students with disabilities.

Postsecondary failure is attributable to several factors: the difference in laws that govern secondary and postsecondary schools that shifts responsibilities to the student for obtaining the right to accommodations and modifications, the documentation “disconnect” (Gartland & Strosnider, 2007), the generalized types of accommodations and modifications that may have been available in high school but are not within the scope of reasonable accommodations as established by postsecondary law, and the lack of self-determination skills that contribute to success (Shogren et al., 2014). Reasonable accommodations available at postsecondary institutions have been defined through legislation that challenges Section 504 of the Rehabilitation Act of 1973 and the ADA of 1990. Modifications or academic adjustments that do not affect the quality of education may be available to the student with ASD. Academic adjustments include priority registration, reduction in course load, course substitution that does not diminish the program of study, note takers, recording devices, sign language interpreters, extended time for testing, equipping school computers with screen-reading, voice recognition, or other adaptive software or hardware (U.S. Department of Education, 2011). Such

accommodations may or may not be sufficient for students with ASD, but these are the types of generic reasonable accommodations that may be available at a college or university through a disability resource center (U.S. Department of Education, 2018). Additionally, the U.S. Department of Education (2018) states unequivocally on its website that students are charged with the responsibility to self-identify and seek accommodations if needed. Only 28% of postsecondary students with any disability disclose disability and less than 20% received accommodations (Newman et al., 2011). Roux and colleagues (2015b) also noted that only 49% of those who had disclosed their diagnosis of ASD at two-year colleges received an accommodation or educational support, and that 68% of those individuals receiving support regarded it as useful. Likewise, at four-year colleges, 30% of students with ASD that disclosed their disability received support with 56% of these individuals reporting usefulness of services. The rate of request/disclosure and usefulness data suggest that generic accommodations available at colleges and universities may be less than adequate for students with ASD when compared to their previous k-12 Individualized Education Program (IEP) that specified individualized supports. This shortfall of available postsecondary supports relative to the IEP could explain lack of utilization and reported efficacy.

Roux et al. (2015b) found that 70% of two-year college students with ASD and 64% of four-year college students with ASD identify as an individual with a disability. In their study of barriers to the use of disability services among postsecondary students with disabilities, Marshak et al. (2010) identified “perceived quality and usefulness of services” as 1 of 5 themes characterizing students’ lack of fully utilizing support or seeking out services. Other barriers included negative experiences with faculty, identity issues, desire to avoid stigma, and



insufficient knowledge, all of which may help explain why postsecondary students with ASD may underutilize supports.

Students with ASD are a heterogeneous group of individuals with a Pervasive Developmental Disorder that may have resulted in a wide range of delays in verbal and non-verbal communication skills, social skills, and self-determination skills. As a result of the Least Restrictive Environment (LRE) mandate of IDEA (2004), more students with ASD have been successfully included in general education classrooms. Accordingly, students with a wider range of abilities (not just those with exceptional math and science talent) are matriculating to colleges and universities. Unlike their neurotypically developing peers, the student with ASD may arrive at college without the necessary soft skills that are expected by faculty, staff, and other students (Dymond et al., 2017; Elias et al., 2019). Without the individualized support provided by their IEP, many are at risk for failure because the generic accommodations that are available on campuses might not fully support the student's communication and social needs or foster the development of self-determination skills.

Learning more about this generation of postsecondary students with ASD who were educated in primary and secondary schools subsequent to the LRE inclusion mandate will help us understand if and how their needs are being met. Thus, the aim of this inquiry is to explore the experiences of students with ASD through the lens of supports available on postsecondary campuses, to learn how those supports are delivered to them, and to expose any gaps in support. In order to achieve this objective, we conducted a systematic review that synthesized protocols established by Moher et al. (2009) through the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) as well as Maggin and colleagues' (2017) guidelines for

systematic reviews that identify quality indicators aligned with those established for Special Education research (Talbot et al., 2017).

### **Systematic Review Procedures**

Consistent with the PRISMA protocol (Moher et al., 2009), a flow diagram guided the initial procedure for identification, screening, eligibility, and inclusion of documents for review (see Figure 1 below for an illustration of the process). Building upon the Special Education literature review protocol established by Maggin et al. (2017), the articles were initially classified according to research design as well as the variables resulting in findings of the research.

I selected two databases, EBSCOhost and ProQuest, to conduct the electronic search. EBSCO and ProQuest are among the primary databases recommended by US Research I institution libraries, and an analysis of leading academic databases found that ProQuest yielded documents with the highest impact factor (Blessinger & Olle, 2004). Among the three databases examined by Blessinger and Olle (2004), only two remain relevant for the education researcher, EBSCO and ProQuest. Through EBSCOhost, we were able to conduct a simultaneous search of Academic Search Complete, Education Search Complete, and Eric databases. Combined, these databases provide gateways to the largest number of peer-reviewed articles pertinent to education research.

Utilizing the search terms, “Autism, ASD, or Autism Spectrum Disorder AND College AND University,” EBSCOhost yielded 4,920 results and ProQuest resulted in 6,531 articles found in peer-reviewed academic journal articles published after January 1, 2007, a cut-off point consistent with the twelve-year window of dates utilized by Maggin et al. (2017) as part of their study identification procedures established for quality indicators for systematic reviews.

EBSCOhost yielded irrelevant or duplicate articles which were eliminated, reducing the yield to 1,611 documents. Through an examination of references from existing literature reviews, we found 18 more articles. In all, 1,629 articles required vetting. In order to pare irrelevant articles, the search was narrowed using the same parameters as the initial search applied to a secondary search at ProQuest that yielded more relevant articles as many articles located through EBSCOhost were either unrelated to postsecondary students with ASD or were not related to ASD.

Utilizing the keywords “Postsecondary Students with Autism Spectrum Disorder” resulted in 360 articles. These articles could be crosschecked with the top hits of the original query through ProQuest and EBSCOhost in order to determine which articles merited assessment beyond abstract review based on inclusion criteria. This process resulted in the exclusion of 269 documents that did not meet inclusionary criteria.

### ***Inclusion Criteria***

Through the next stage of the examination process, the selection of the remaining 81 articles were displayed on a spreadsheet as per preliminary parameters that were coded for the inclusionary criteria of postsecondary students with ASD, attending a 2-year or 4-year postsecondary institution in the United States, and classified according to whether they were intervention studies or descriptive studies, both involving systematic data collection as prescribed by Maggin et al. (2017). All articles selected were peer-reviewed and published in English subsequent to January 1, 2007.

### ***Exclusion Criteria***

Exclusionary criteria were developed to exclude papers that examined postsecondary students with ASD outside of the US because of the nature of laws that govern postsecondary

education within the United States. Articles that aggregated students with ASD and other disabilities without reporting data separately or were related to transition to college or high school experiences prior to postsecondary were also excluded. Applying these criteria, 35 articles were selected for review and further coded to assess the characteristics of the participants, research design, data collection procedures, and analysis of the data. This process deleted articles that had observational narrative qualities and literature reviews that reported, rather than manipulated variables affecting outcomes. Based upon analysis of the spreadsheets, 14 papers were observational narratives and were excluded from this literature review while 21 articles met all the criteria for inclusion.

### ***Reliability and Inter-coder Agreement***

As a final step to verifying inclusion, ten articles were randomly selected from among the 21 selected articles. These were randomly combined with ten additional articles taken from the articles that were not selected but had required deeper scrutiny to ensure exclusion was merited. The full set of articles were subjected to classification by the second author. Upon application of the inclusionary and exclusionary criteria by the second author, interrater reliability was calculated. Interrater agreement was 100%.

Inter-coder reliability was established based coded features of 7 of the 21 studies (33%). Utilizing the same coding schema, the second author independently coded the seven articles. Reliability was calculated based on the total number of agreements divided by the number of possible agreements. This yielded an agreement index of no less than 90% for each of the seven articles and disagreements were resolved through discussion.

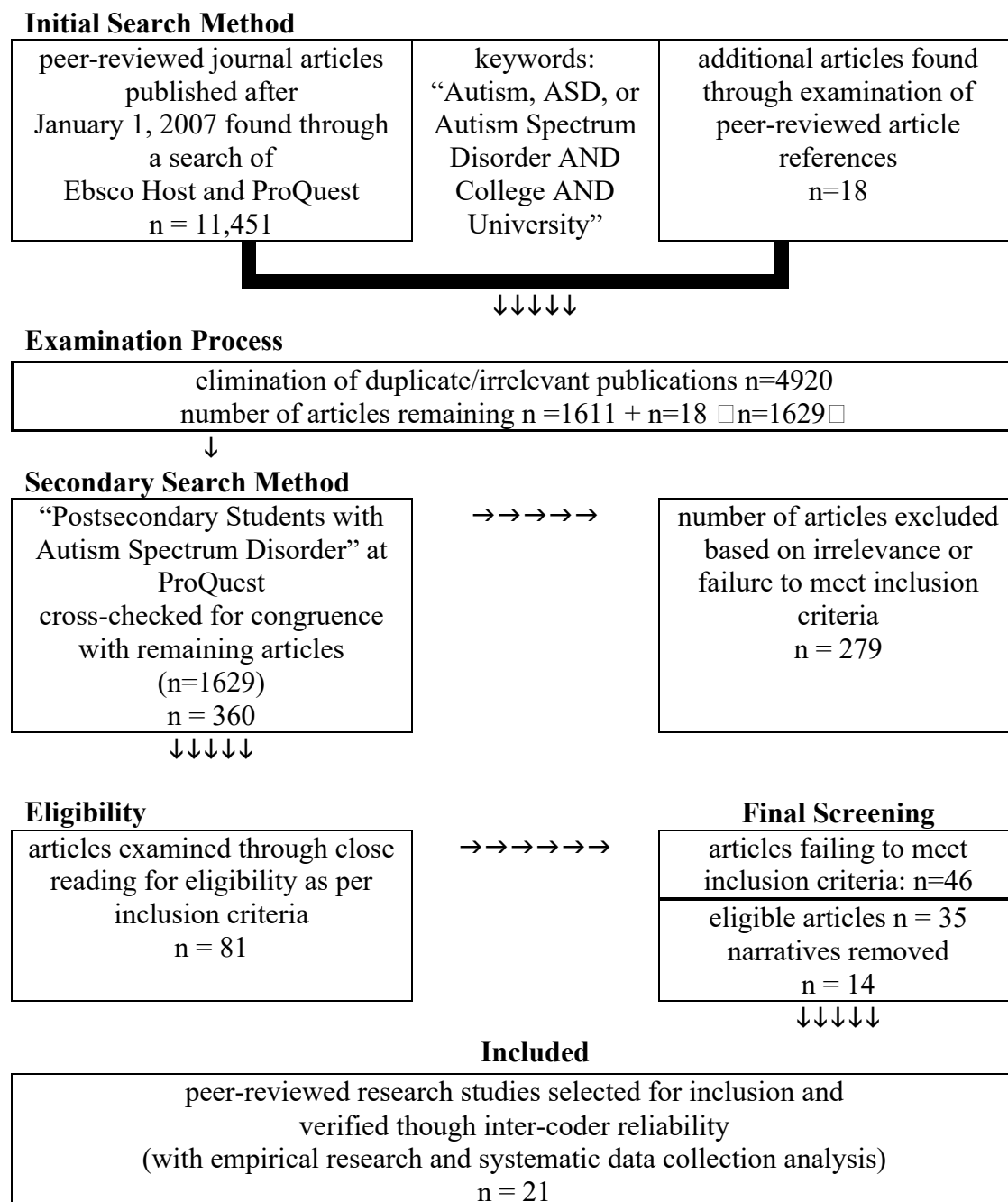


Figure 1. PRISMA style illustration of the systematic literature review process

## **General Findings of the Systematic Review**

In this section, I begin with general information to characterize the content of the 21 articles. This is followed by a detailed description of the results of these studies whereby I outline eight themes.

Utilizing the process established by Maggin et al. (2017), I classified the studies according to research design (see Table 2 below). Based on design, 14 articles (67%) were categorized as descriptive and seven as experimental studies (33%), that included six quasi-experimental studies (Ashbaugh et al., 2017; Gunn et al., 2017; Koegel et al., 2016; Mason et al., 2012; Reed et al., 2016; Pugliese & White, 2014), and one randomized control trial study (White et al., 2016b). Accordingly, most of the articles in this review were classified as descriptive, and among these studies, nine of the data collection procedures included survey/questionnaire protocols. Interview and focus group data informed six studies. Finally, one study was based on the analysis of an ex post facto data set.

The participants in the studies varied. While all of the studies pertained to the experiences of students with ASD, 15 included students with ASD among the participants of the studies. University personnel participated in four of the studies, and although parents of postsecondary students with ASD were participants in five of the studies, they were not the sole subject of any study (Anderson & Butt, 2017; Dymond et al., 2017; Elias & White, 2017; Hendrickson et al., 2017; White et al., 2016a),

### ***Experimental Design Studies***

The seven experimental design studies included interventions that focused on social, communication, functional, and academic skills (see Table 2 below). Ashbaugh et al. (2017) implemented a protocol that taught students social engagement through an organized approach of

keeping track of activities by logging social activities and tracking participation in extracurricular activities, clubs and peer interactions. Another experiment targeted social-communication skills, teaching empathetic listening statements with a conversational partner (Koegel et al., 2016). An intervention which utilized video modeling with the objective of improving social communication skills such as eye contact, facial expressions, and conversational turn-taking was implemented by Mason et al. (2012). Pugliese and White (2014) implemented a Cognitive Behavioral Therapy (CBT) intervention which utilized a pre- and post-treatment single subject design. In another intervention targeting emotional behavior, Gunn and colleagues (2017) addressed the visual scanning, engagement, and verbal interactions of a student teacher with ASD. Reed et al. (2016) addressed academic needs by teaching students split-page notetaking through modeling and prompting. A sole randomized control trial design was implemented by White et al. (2016b) to examine two interventions addressing social-emotional and functional living skills.

### ***Descriptive Design Studies***

Among the 14 descriptive studies, five utilized interviews and of those, one study utilized two data collection sources: interviews and a focus group. There were eight studies that utilized surveys, and among those that utilized survey as a data collection method, three studies utilized surveys which included open ended questions and one study conducted focus groups in addition to administering a survey. Finally, one study was based on the analysis of an ex post facto data set (see Table 2 below).

Three of the studies that included interviews among the data collection procedures utilized Strauss and Corbin's (1998) constant comparison approach to analysis (Anderson & Butt, 2017; Cox et al., 2017; Dymond et al., 2017). Similarly, Cullen (2015) used a 2-step

process with line by line analysis to extract themes from interviews and focus groups, much like White et al. (2016a) who used line-by-line frequency coding for the focus group data. White et al. (2016a) collected data through a Likert-type survey and used descriptive statistics to present results, similar to the quantitative approach by Gelbar et al. (2015) and their utilization of a Likert-scale survey. Barnhill (2016) and Smith (2007) utilized survey data from a query of institutions and used descriptive statistics to present findings. Brown and Coomes (2016) converged data from a survey and open-ended questions in a mixed-methods approach through a concurrent nested framework.

Other descriptive studies applied statistical analysis to their studies. Brown (2017) took survey and open-ended questions and conducted a chi-square test for independence and ANOVA for variables that were continuous and normally distributed. Effect size was measured with Cramer's  $V$  for nominal level variables. Using a Likert survey, Elias and White (2017) analyzed between group differences through MANOVA. Quantitative data in their study were coded using the seven vectors of student development based on Chickering and Reisser's (1993) framework. Also using a Likert-type survey, Hendrickson et al. (2017) used one-way ANOVA for data analysis with an evaluation of effect sizes through Cohen's  $d$ . In order to ensure that the sample size for students was adequate to minimize Type I and Type II errors, they conducted a power analysis. With an ex post facto data set, Roux et al. (2015b) conducted data analysis using descriptive statistics. In her interview of students that included open-ended questions, Wiorkowski (2015) implemented Moustakas's (1990) 6-step model to identify patterns and themes.



### ***Participants and Variables***

Participants in 8 of the 14 descriptive studies included students with examined-academic success ASD (see Table 2 below). In addition, social skills, social achievement, social experiences and social interactions were surveyed by five studies. Independence, housing experiences, and self-determination, and self-regulation skills were measures of four studies. The sole ex post facto study examined the characteristics of 2-year college students with ASD utilizing statistics extracted through analyzing 2009 National Longitudinal Transition Study-2 Wave 5 data.

Participants from postsecondary institutions were the sole subjects in four studies and co-participants in one study that included parents and students (24%). Accommodations such as support groups, counseling, supervised social activities and summer transition programs were probed in one of these studies (Barnhill, 2016). Two investigations looked at reasonable accommodations provided by the law as well as ASD support services such as academic, counseling, transition programs, and mentoring (Brown, 2017; Brown & Coomes, 2016). The examination that included parents and students focused on factors that lead to success such as transition to university, available supports and services, as well as unmet needs (Dymond et al., 2017). One study surveyed services and accommodations that schools were providing to students with ASD (Smith, 2007).

Parents or families were participants in five studies (24%) in conjunction with other participants such as students and/or university personnel as well as parents of students with Attention Deficit Hyperactivity Disorder (ADHD). Accordingly, none of the studies examined parents of postsecondary students with ASD only. Three of these studies were related to college success (Anderson & Butt, 2017; Dymond et al., 2017; Hendrickson et al., 2017). Independence

(Anderson & Butt, 2017), self-determination and self-regulation (White et al., 2016a), as well as socialization and social skills (Anderson & Butt, 2017; White et al., 2016a) were probed. Elias and White (2017) surveyed parents regarding the challenges and needs of their students.

Among the seven experimental studies, a total of 17 college students participated in an array of interventions: learning note-taking skills, participating in social activities, improving social pragmatics and executive functioning for a successful early childhood education practicum experience, improving empathetic listening and language, learning nonverbal social skills, developing problem solving skills to improve interpersonal relationships, building social-communication and executive functioning skills, and comparing two types of social skills interventions to determine viability (in a randomized control experiment).

### ***Themes Across Study Results***

Following the protocol established by Maggin et al. (2017) to examine quality indicators for reviewing Special Education research, we created a spreadsheet to deconstruct the elements of each study according to the following rubrics: purpose, design, research questions, participants, independent variables/measures, dependent variables/measures, data collection procedure, data analysis procedure, results/findings, and conclusions. Through this systemized analysis of the results of 21 studies, eight themes were identified to describe features of programs and supports that were implemented or described in the body of studies. These were: Social Learning/Supports (81%), Functional Life Skills/Residential Skills (67%), Academic Supports (62%), Emotional Learning/Supports (62%), Parent/Family Involvement (33%), Vocational Training (29%), Communication Development (19%), and Transition Needs (14%) (see Table 2 below).

**Social Learning/Supports.** The most widely reported support was in the social domain with 17 of the 21 studies (81%) incorporating social learning/supports into their analysis or including as part of the intervention. Social supports are not among the reasonable accommodations and modification that have been mandated, so these are supports that are targeted to the needs of students with ASD and students with Intellectual Disability (ID). The use of social supports reported in the studies included peer mentors, group activities, participation in clubs and in extracurricular activities. According to Brown (2017), the presence of peer mentoring is the strongest predictor that ASD specific support services are offered on postsecondary campuses, and 5 out of 17 studies reporting social support initiatives included peer mentoring for their students with ASD.

Addressing this issue, the literature documented social integration initiatives such as clubs and college sponsored group activities, social support groups, social skills courses, and student life experiences including interpersonal relationships development. In an exploratory study, Wiorkowski (2015) interviewed 12 college students with ASD regarding their experiences. Among her findings, she noted that students with ASD found social integration to be challenging. Additionally, Ashbaugh et al. (2017) designed an intervention to teach and improve social integration through structured planning. Moreover, two more experimental studies sought to teach social-communication skills in order to improve the social life of students with ASD. Koegel et al. (2016) implemented an intervention to teach empathetic listening and empathetic statement skills. Another intervention tested a video modeling protocol to teach eye contact, facial expression, turn-taking and shared emotions with the objective of improving the social skills of students with ASD (Mason et al., 2012). Accordingly, 4 of the 7 experimental studies focused on social skills training.

In a study by Cullen (2015) analyzing the needs of college students with ASD, one-third of the student participants asserted that their social needs were met through their family, and their family was the source of social support. In contrast, through a query that included parents, Anderson and Butt (2017) found that parents felt they could do little to support their students within the social domain of college life. Parents perceived social support as a gap in the available support for their students with ASD. This finding is supported by White et al. (2016a). In their quest to identify the needs and challenges faced by postsecondary students with ASD, White and colleagues found that parents regarded social support as a challenge. Further evidence of the need for social supports was reported in a study by Elias and White (2017) in their survey of parents of postsecondary students with ASD. In that study, social and independent living domains were identified by parents as the greatest challenges within the context of postsecondary education.

**Functional/Residential Life Supports.** After social supports, implemented functional/residential life supports that foster independent living skills were most widely reported, appearing in 14 of the studies (67%). In her survey of postsecondary schools that reported students with ASD, Barnhill (2016) found that life skills instruction and housing accommodations were among the supports at schools. In addition, residential life assistants were taught about the needs of students with ASD. Sensory accommodations that included quiet floor room accommodations and single rooms (at the reduced price of a single room) were reported by four of the studies. Other independent living skills supports reported were independent living skills such as room cleaning, organizational skills, peer coaching of executive functioning skills (which impact academic as well as independent living skills), self-regulation (in order to independently manage behaviors and emotions), and independent functioning in general.

Independent living skills (which also overlap with social-emotional competence) were taught through three experimental studies. Problem solving skills through teaching Cognitive Behavioral Therapy was the aim of one intervention study (Pugliese & White, 2014). Another intervention sought to improve organizational while teaching social integration skills through a structured approach (Ashbaugh et al., 2017). The third experiment taught self-regulation skills through implementation of a protocol (White et al., 2016b). Overall, these interventions yielded mixed results. All of the studies were small and targeted to the specific needs of the individual.

In their interviews with families, Anderson and Butt (2017) found that parents were providing direct support for functioning such as waking students for class, driving them to school, and helping them organize. In further support of the challenge with daily living tasks, Elias and White (2017) found in their survey of parents of postsecondary students that this was the greatest domain of need along with the social domain.

**Academic Support/Adjustments.** Academic adjustments refer to a set of reasonable accommodations and modifications that have been mandated as well as tested in the courts through litigation challenging Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. Such academic adjustments are not disability-specific and 13 of the 21 studies (62%) reported these generic types of supports: note takers, testing accommodations such as extended time and a separate location for exams, early registration, reduced course load, audio recorder, writing center services, books on tape, calculator, extended time on assignments, preferential seating, frequent breaks, and academic advisors. Additionally, in a survey of students with ASD, Gelbar et al. (2015) reported course waivers and course substitutions as being helpful. Reed et al. (2016) implemented an academic intervention to teach

notetaking skills using graphic organizers to students with ASD and ID and achieved positive results.

According to Anderson and Butt (2017), parents reported supporting students' academic needs through hiring private tutors and helping them with organization. Additionally, parents provided functional support by helping students register for classes, waking them up in the morning, driving them to class, and addressing their emotional needs in terms of coping with stress and anxiety. They also felt there were limits to what they could do and what their student would allow them to do. Similarly, according to Dymond et al. (2017), some parents asserted that they did not know how to help, and the authors explained that The Family Educational Rights and Privacy Act of 1974 (FERPA) posed a barrier in communication between the university and parents. As with Anderson and Butt (2017), Dymond and colleagues (2017) also found that parents hired tutors for the students. In addition, they reported that parents had hired personal assistants for their students.

**Emotional Learning/Supports.** Similar to academic supports/adjustments, emotional supports were referenced in 13 of the studies (62%) for college students with ASD. Among the supports reported were ASD specific individual or group therapy, general counseling, coaching, disability counseling, behavior management program, and counseling for stress. Two interventions addressed emotional needs. Through a feasibility study, Pugliese and White (2014) taught Cognitive Behavioral Therapy (CBT) to students in order to cope appropriately and independently utilizing problem solving skills. White et al. (2016b) implemented a protocol to support emotion recognition and regulation. One study highlighted the role parents play to assist with emotional support (Anderson & Butt, 2017) and underscored the urgent need to address stress reduction.

**Parent/Family Involvement.** Parent/family involvement was referenced in only seven studies (33%), five with parent participants (Anderson & Butt, 2017; Dymond, et al., 2017; Elias & White, 2017; Hendrickson et al., 2017; White et al., 2016a) and two with references to parents, but without their participation (Barnhill, 2016; Cullen, 2015). In their study of successes and barriers, Anderson and Butt (2017) found a subtheme of parents who felt limited by their students' acceptance of support, but parents nonetheless assisted with functional skills such as waking their students for class, driving them to school, and helping with organizational skills. While Barnhill (2017) did not directly query parents, in her study of supports for students, she referenced institutions' communication with parents and families. Through a probe of how student needs were met, one-third of students with ASD reported that they socialized with their parents, satisfying their needs for social interaction (Cullen, 2015). In a study of university personnel and parents, Dymond et al. (2017) found that parents hired tutors, therapists, and personal aides, sensed that university personnel and peers lacked an understanding of the needs and characteristics of students with ASD, and felt hindered by their lack of knowledge regarding their student's progress, which the authors note is the result of barriers imposed by FERPA. With an objective of understanding the needs of college students with ASD, Elias and White (2017) disclosed that parents referenced challenges and needs associated with all eight themes found in this literature review, especially social and independence skills. Through contrasting parent and student perceptions of their college experience, Hendrickson and colleagues (2017) determined that there was often a gap in perceptions, with parents' ratings exceeding their own students' perceptions of student life, independent living skills, and interpersonal relationships. Among challenges identified by White et al. (2016a), eight parents of postsecondary students with ASD

in their study cited social interaction, inadequate social supports, and adaptive behavior as their chief concerns.

**Vocational Training.** Six studies (29%) referred to vocational needs, an important component contributing to successful post-graduation outcomes for those with ASD. Career counseling was described in two studies (Brown, 2017; Brown & Coomes, 2016). Hendrickson et al. (2017) identified learning about job interests as an important component. There were two studies that specifically addressed Vocational Rehabilitation programs (Anderson & Butt, 2017; Barnhill, 2016). Barnhill (2016) found one school had partnered with Vocational Rehabilitation to provide vocational services to students, and she suggested such services could be provided without additional cost to the institution.

**Communication Development.** Support for communication skills was reported in four articles (19%) and typically in conjunction with social skills initiatives. For example, Cullen (2015) examined social communication needs in the context of the social functioning in the classroom while Brown and Coomes (2016) targeted another challenging aspect of classroom communication, that with faculty members. An intervention implemented by Koegel et al. (2016) addressed social communication through teaching students how to listen empathetically and respond with appropriately empathetic statements. In an examination of student needs, Elias and White (2017) reported that parents cited effective communication, a component of interpersonal competence, as a challenge. Accordingly, parents regarded speech language services as a need for their students.

**Transition Program Needs.** Transition programs were noted in only three studies (14%), and such programs were not examined in terms of efficacy. In her survey of 30 postsecondary schools, Barnhill (2016) found that seven of the institutions had a summer



transition program, and two institutions reported that Vocational Rehabilitation had paid for two students' participation in transition programs. In their exploration of current and best practices supporting students with ASD, Brown and Coomes (2016) asserted the facilitation of transition was instrumental in helping students adapt to college. Transition services were a need identified by parents of postsecondary students in Elias and White's (2017) study.

As a result of this inquiry, many of the gaps in the literature have been exposed. For example, what we have learned about parent participation in the postsecondary education of their students with ASD is very limited, even though parents are important stakeholders and invest significant financial resources in the education of their students with ASD. Serious challenges of individuals with ASD such as communication (four studies) vocational needs (six studies), and transition (three studies) are not fully addressed by the research.

Although Autism is a communication disorder and parents in the Elias and White (2017) study regarded speech/language services as a need, there are no studies that specifically examined the provision of those services to students with ASD. The question remains why so few communication supports were implemented or addressed by researchers given the nature of ASD. For those with ASD who have experienced atypical development and delay of speech, the need for communication services is real. Odd prosody and/or dysfluency can be a lifelong impairment which may prove to be a barrier to employment and community integration after school is over. Effective verbal communication affects outcomes not just in terms of navigating through college life, but in terms of postgraduate life. Social communication was the primary focus of studies, rather than speech communication. While Ashbaugh and colleagues (2017) and Koegel et al. (2016) implemented effective interventions that taught specific social-communication skills, those experiments were small studies that may or may not be

generalizable across populations of individuals with ASD. Explicit instruction is highly effective for individuals with ASD as interventions demonstrate, but this population of individuals is heterogeneous to the extent that such protocols may need to be specific to the individual rather than a group of individuals. Barriers to effective verbal communication persist through postsecondary education as noted by Brown and Coomes (2016).

Students with ASD attend postsecondary schools to increase the probability they will become employed, but only six studies addressed vocational needs. Given the importance of postsecondary education as a path to employment (Ohl et al., 2017; Shattuck et al., 2012), there is a gap in interventions designed to ensure that students with ASD have acquired the skills needed to obtain employment once the degree is completed. For example, preparing individuals with the vocational skills such as writing a resume, practicing job interviews, understanding the soft skills requisite to be successful on the job, and providing opportunities for an internship all serve to provide students with experiences that aid in obtaining a job and successfully transition to employment.

With respect to transition, there are two periods of transition in the life of a postsecondary student with ASD: one to postsecondary education, and one from postsecondary education to employment or graduate school. There are no studies in this review that examine transition from college to employment or graduate school, but two articles reference transition to postsecondary education. Barnhill (2016) reports that 7 out of 30 universities in her study offered transition programs. Based on Brown and Coomes (2015) findings, transition appears to be within the domain of services provided by 2-year colleges, with 42% of 2-year colleges surveyed reporting such services.

Finally, parents or references to parents account for 7 of the 21 studies reviewed, with parent participants in five. Parents practices of support were not the primary focus of any of these studies. Although parents are primary stakeholders financially and emotionally in the education of postsecondary students with ASD, few studies examined parents, perhaps due to FERPA. There may also be the expectation among postsecondary personnel that students with ASD have achieved the same level of autonomy as typically developing peers. This expectation was exemplified by a university staff member who expressed frustration over a student's lack of expected autonomy (Dymond et al., 2017). Other studies included parents reporting students' challenges with self-determination skills such as autonomy and self-regulation (Elias & White, 2017; White et al., 2016a), but the authors did not disclose if or how parents are supporting these needs.

We question if parents are filling in the individual needs and challenges that they perceive as gaps in the support services provided by postsecondary institutions. Although they have identified self-determination skills as a challenge, we wonder if parents are teaching their children these skills. Parents may, in fact, continue their role as parent/partner, a best practice per IDEA in pre-k through high school. This review reveals that we know little about how, and the extent to which, parents are fulfilling the social needs of their students, and what other skills they are supporting.

Examining parents of postsecondary students with ASD is a recent phenomenon. Four of the parent articles were published in 2017, two in 2016, and one in 2015. Three of the articles addressed parents, but how parents participated was not the objective of the inquiry. One researcher referred to parent communications between the postsecondary schools and parents, but did not further explore the nature or frequency of communication (Barnhill, 2016). Another

study disclosed that one-third of the students felt their social needs were being met by parents, but parents' perspectives were not examined (Cullen, 2015). Similar to the Dymond et al. (2017) study, Elias & White (2017) polled parents to learn about their students' needs and challenges.

Further research is needed to fill the gap in transition to and from postsecondary education, in vocational education to ensure a path to employment, and in understanding how parents are directly involved in ensuring success of their students. Accordingly, compared with the considerable body of research supporting parent participation as a best practice in birth through high school, the extant inquiry addressing parent postsecondary participation remains scant, particularly with respect to students with ASD.

**Table 2**  
**AUTHORS, PARTICIPANTS, DESIGN, DATA COLLECTION PROCEDURE,**  
**AND THEMES FOR LITERATURE REVIEW ARTICLES**

Authors	Participants	Design	Data Collection Procedure	Themes
Anderson & Butt (2017)	35 families	Descriptive	Interviews	Academic Supports Social Learning/Support Functional/Residential Life Skills Emotional Learning/Support Vocational Training Parents/Family Involvement
Ashbaugh (2017)	Three college students (two females, one male)	Quasi-experimental	Activity Log	Social Learning/Support Functional Residential Life Skills
Barnhill (2016)	30 colleges	Descriptive	Survey	Academic Supports Social Learning/Support Functional, Residential Life Skills Emotional Learning/Support Vocational Training Parents/Family Involvement Transition Program/Needs
Brown (2017)	469 individuals at postsecondary institutions	Descriptive	Survey	Academic Supports Social Learning/Support Functional, Residential Life Skills Emotional Learning/Support Vocational Training

Authors	Participants	Design	Data Collection Procedure	Identified Themes
Brown & Coomes (2016)	146 individuals from 367 two-year public institutions	Descriptive	Survey	Academic Supports Social Learning/Support Communication Development Functional, Residential Life Skills Emotional Learning/Support Vocational Training Transition Program/Needs
Cox et al. (2017)	Nine adults with ASD	Descriptive	Interviews	Academic Supports Social Learning/Support Emotional Learning/Support
Cullen (2015)	24 students from five universities (10 females, 14 males) aged 18-29	Descriptive	Interviews, Focus Groups, Questionnaire	Academic Supports Social Learning/Support Communication Development Functional, Residential Life Skills Parents/Family Involvement
Dymond et al. (2017)	Six parents, five university personnel at a public research university	Descriptive	Interviews	Academic Supports Social Learning/Support Functional, Residential Life Skills Emotional Learning/Support Parents/Family Involvement

Authors	Participants	Design	Data Collection Procedure	Identified Themes
Elias & White (2017)	22 parents of postsecondary students with ASD	Descriptive	Survey, Questionnaire	Academic Supports Social Learning/Support Communication Development Functional; Residential Life Skills Emotional Learning/Support Vocational Training Parents/Family Involvement Transition Program/Needs
Gelbar et al. (2015)	35: 17 males, 15 females	Descriptive	Survey Questionnaire	Academic Supports Social Learning/Support Functional/Residential Life Skills Emotional Learning/Support
Gunn et al. (2017)	One student	Quasi-Experimental	Observation, Anecdotal records	Social Learning/Support
Hendrickson et al. (2017)	16: eight students with ASD and their parents	Descriptive –	Assessment, Survey	Social Learning/Support Functional/Residential Life Skills Vocational Training Parents/Family Involvement
Koegel et al. (2016)	Three male adults ages 19-26	Quasi-experimental	Observation (via videotape)	Social Learning/Support Communication Development

Authors	Participants	Design	Data Collection Procedure	Identified Themes
Mason et al. (2012)	Two male students, aged 26 and 19	Quasi-experimental	Observation	Social Learning/Support
Pugliese & White (2014)	Five male undergrads with ASD aged 18 to 23 years old	Quasi-experimental –	Assessment, Questionnaire	Functional/Residential Life Skills Emotional Learning/Support
Reed et al. (2016)	Three students: two male, one female	Quasi-experimental –	Grading (based on model)	Academic Supports
Roux, et al. (2015b)	Data set of students who received special education services under the special education categorical qualification of Autism.	Descriptive	Wave 5 Data from NLTS2 collected in 2009	Academic Supports Emotional Learning/Support
Smith (2007)	29 postsecondary institutions (19 four-year, 6 two-year, two technical, two other)	Descriptive	Survey	Academic Supports Emotional Learning/Support
White et al. (2016a)	Eight parents; 30 educators/support staff, five students	Descriptive	Surveys, Focus Groups	Social Learning/Support Functional/Residential Life Skills Emotional Learning/Support Parents/Family Involvement



Authors	Participants	Design	Data Collection Procedure	Identified Themes
White et al. (2016b)	Eight college students with ASD (five males, three females)	Quasi-experimental	Assessment, Questionnaire	Social Learning/Support Functional/Residential Life Skills Emotional Learning/Support
Wiorkowski (2015)	12 adults (five women and seven men with ASD)	Descriptive	Interviews	Academic Supports Social Learning/Support Functional/Residential Life Skills

### III: METHODS

In this section, I describe the research design, instrument, participants, recruitment, survey screening protocol, data collection, and data analysis procedures. I utilized a mixed methods design that was guided by Creswell and Creswell (2018) for the quantitative and qualitative components as well as Corbin and Strauss (2008) for open-coding and analysis of textual data.

#### **Research Design**

The convergent single-phase mixed methods design consisted of four steps. First, I collected qualitative and quantitative data contemporaneously through the same instrument. Second, I analyzed quantitative data separately from the qualitative data. The third step merged the results from both data sets, while the fourth and the final step required comparative analysis (Creswell & Creswell, 2018). Through this design for mixed methods, the aims of the study were: a) to determine if the Parents of Postsecondary Students with Autism Spectrum Disorder Survey (PPSASDS) is a reliable measure for assessing parent participation with their postsecondary students with ASD, b) to gather data quantitatively to learn how parents support social integration, autonomy, and emotional/stress relief, c) to learn through qualitative examination other ways parents support their postsecondary students with ASD, and d) through merging quantitative and qualitative results, what do we learn generally about parent participation?

#### ***Conceptual Framework***

As an investigator, my research was guided by constructivist pragmatism and my study was structured along these principles. Given the gap in the literature, it was important to take a constructivist approach to learning about how parents participate in the postsecondary education

of their students with ASD. Thus, I used grounded theory for qualitative analysis in order to construct a rudimentary understanding of the phenomenon. At the same time, as a pragmatist, adding quantitative methods to a study provided another dimension in the examination process. This study then, rooted in grounded theory for qualitative analysis and coupled with quantitative analysis, expanded beyond a basic understanding of the characteristics of parent participation.

The instrument was designed and piloted in a study that utilized a mixed methods concurrent nested approach whereby data were collected contemporaneously with an open-ended question embedded in the query subsequent to a questionnaire (Creswell, 2003, 2007; Creswell & Creswell, 2018). To gain a more complete understanding of how parents participate in the postsecondary education of their students with ASD, this study was also structured according to concurrent nesting but the revised instrument included more open-ended questions that elicited information regarding areas of support that had been identified in the pilot study.

With the goal of expanding beyond the data gathered through the pilot research that tested the first iteration of the PPSASDS, open-ended questions were embedded within each set of questions to further explore the three domains critical to outcomes success and which underpinned the conceptual lens of this investigation, social integration and self-determination (Tinto, 1975; Wehmeyer, 1999) plus emotional/stress relief. Increasing the number of open-ended questions based on the examined domains of support provided more evidence for how parents supported their postsecondary students with ASD. Embedding open-ended questions within each domain prompted parent responses that supplemented the yes/no items. These embedded probes relieved parents of having to remember what they wanted to add until the end of the survey, as required with the considerably shorter pilot research survey. My intent was to reduce the load on

parents' executive function short-term memory in order to obtain richer detailed textual responses that provided more information about areas of support associated with each domain.

This approach to mining data through open-ended responses was rooted in the grounded theory of Corbin and Strauss (2008), the objective of which was to construct knowledge about how parents supported their postsecondary students with ASD.

### **Researcher as Instrument /Reflexivity**

My quest for understanding how parents support their postsecondary students with ASD has been inspired and informed by my 14 years of experience as the mother of a postsecondary student who was first an undergraduate and then a graduate student with ASD. While he was an undergraduate, I was driven by my desire to ensure my son's postsecondary success because I had staked a significant emotional and financial investment in his education. I assumed my experience was not unique, so I was prompted to learn if parents were similarly concerned about the two domains that drove my quest to ensure my son's postsecondary success, autonomy and social integration. It was these two domains that I investigated in my exploratory pilot project which I had framed through the conceptual lens of Tinto and Wehmeyer.

Without knowing about Tinto (1975, 1988, 1993, 1997), I had instinctively understood the importance of social integration for postsecondary success given my own failure to achieve social integration and a 20-year struggle to complete an undergraduate degree as a student at an urban commuter university where students rushed off to work as soon as classes ended. Reading Tinto's books and papers offered an understanding of my own undergraduate experience while validating my intuition that there was a link between social integration and persistence through timely graduation.

At the same time, Wehmeyer's (1999) self-determination research confirmed what I understood as a mother of an only child with a pervasive developmental disorder: I knew my son needed to achieve autonomy both for college success and life after college. Parents of a child with a disability may worry about whether or not their child will be able to achieve full functional independence. Fortunately, postsecondary schools provide an important period of developmental opportunity half-way between home and community/work life, forestalling full independence while presenting sufficient time to foster the requisite skills. While he was at college, I taught my son the skills associated with autonomy, so I wondered how other parents helped develop those skills.

I was able to help my son navigate through the postsecondary experience based on my own experience plus my ability to finance his undergraduate education. Accordingly, I am privileged in that there are many parents of students with ASD who neither have knowledge of the postsecondary experience nor the financial wherewithal to ensure their student completes an undergraduate education. Moreover, as the literature review exposes, some parents expressed concern about academic and social-emotional supports. In the absence of these supports through the campus disability resource center, some parents disclosed that they had privately contracted with individuals outside of the university for support needs, an expense many cannot afford (Dymond et al., 2017).

Admittedly, my privilege allowed me to explore the experiences of individuals who enjoy the same socio-economic status as me. As a former urban special educator, however, I believe understanding the experiences of underrepresented minorities and their parents is an important aim. I believe that disability resource centers and college programs targeting students with ASD need to do a better job of including parents and adapting parent practice to support all students.

Institutions should press for the removal of the legal obstruction imposed by FERPA and allow parents to support their students' singular needs however and whenever needed.

As parents, we are first degree relatives of individuals with ASD and some of us experience many of the same characteristics as that of our children, perhaps to a lesser or less debilitating degree. I attended Temple Grandin's presentation at Clemson University in April, 2018 where she noted that once their children or grandchildren are diagnosed with ASD, adult relatives discover, too, that they have autism. There is evidence to support Grandin's assertion as more researchers examine Broader Autism Phenotype (BAP) among first degree relatives of children diagnosed with ASD (Casanova & Casanova, 2019; Eriksson et al., 2012; Kanner, 1943; Rubenstein & Chow, 2018; Wainwright et al., 2010).

This is the insight that I bring to my research as a parent who seeks to learn from other parents. My combination of experience, understanding of autism, and over 20 years of reading the research on this topic have contributed to what I examine in my own research. I would posit that my experience as a parent of an individual with ASD means that I can better relate in terms of how I construct my study in a way that may better suit the needs of participants. As a demonstration of this assertion, I offer my decision to author a dichotomous response instrument rather than a Likert-type questionnaire based on my own experiences and frustration with "shades of grey" surveys. I specifically chose to utilize a "yes or no" questionnaire because I believed it was a better fit for my participants, parents within the autism community. My son experienced significant speech delay, so I used to communicate with him using "yes or no" questions because he could say "yes" or "no," but not respond in full sentences. My questions were short ("Are you hungry? Yes or no?"), and I always stated each positively. I still do ("Did you have a good day?"). This "yes or no" interrogative process always averted frustration on his

part. Additionally, my understanding of executive function impairment informed the decision to embed open-ended questions within the domains of support.

It is with this parent perspective that I moved forward with the inquiry into parent participation in the postsecondary education of their students with ASD. My experience informed me. What I have learned from the literature instructed me. My pilot research guided me. With the implementation of this inquiry, I was mindful of the need to stand aside and allow participants' data to speak and tell their story.

### ***Instrument***

The parents completed the Parents of Postsecondary Students with Autism Spectrum Disorder Survey (PPSASDS) consisted of 45 yes-or-no questions that included the two domains surveyed in the pilot study, autonomy and social integration, and a third domain, stress/emotional relief, the theme that emerged from the pilot study. Among the 45 dichotomous items, 15 measured Social Integration, 16 measured Autonomy, and 14 measured Emotional/Stress relief. Embedded within each set of domain questions were open-ended probes that allowed parents the option of providing more details about their support that may not have been queried through the dichotomous items: four questions were included among the Social Integration items, five within Autonomy, and four within Emotional/Stress Relief. Finally, the survey ended with the same open-ended question as the pilot questionnaire, "In what other ways have you supported your student?" Thus, there were 13 embedded open-ended questions plus one final open-ended question, totaling 14.

Utilizing a written question format allowed parents to avoid surprising situations that could occur in interviews could have resulted in incomplete responses. Additionally, a concurrent design kept the ideas fresh in parents' minds while a sequential design might have

resulted in some loss of details that would have been forgotten as parents responded to questions. Thus, the written format provided parents with time to ponder their response and ensure it was complete.

As with the pilot, social integration items on the PPSASDS were based on Tinto's (1975, 1988) reflection on the characteristics of student leaving as well as his social integration model tested and validated by Terenzini and Pascarella (1977). The autonomy questions were adapted from Wehmeyer's (1999) functional model of self-determination and *The Arc's Self-Determination Scale* (Wehmeyer, 1995; Wehmeyer & Kelcher, 1995). Tinto and Wehmeyer provided the conceptual lens for this study as social integration and independent living are critical to postsecondary success and adulthood outcomes in general. The questions for the other domains were drawn from the types of supports identified as themes in the literature.

The pilot survey included a dichotomous response protocol requiring a yes or no answer. I based dichotomous assessment on the premise that first degree relatives of individuals with autism may have some characteristics of autism even if they have not been diagnosed with ASD. Supporting Temple Grandin's assertion that parents and grandparents learn that they, too, have autism is Baron-Cohen and colleagues' (2007) study. They found a disproportionately high incidence of autism among first degree relatives of students studying math and/or science. The authors reasoned that systemizing is a trait associated with autism and is most likely found among mathematicians. Additionally, as long as 75 years ago, Kanner described autistic-type characteristics presented by the parents and grandparents of children with autism that he studied (Kanner, 1943). Studies of what is known as Broader Autism Phenotype (BAP) continue through today and are regarded as integral to understanding the genetic component of Autism (Rubenstein & Chawla, 2018; Wainwright et al., 2010). BAP is defined by a wide spectrum of



traits associated with ASD and is more common among parents of children with ASD than in parents of typically developing children (Rubenstein & Chawla, 2018). According to their systematic review of percentage estimates in the literature, Rubenstein and Chawla (2018) determined that there was a wide range of BAP among parents ranging from 2.6% to 80%. Rubenstein and Chawla (2018) found that BAP was more common among fathers than in mothers, but in a Swedish study, Eriksson et al. (2012) cautioned that psychiatric symptoms in mothers of children with Autism Spectrum Disorder may represent a female phenotype which may also be associated with ASD, resulting in lower diagnosis of females with ASD. Similar to Rubenstein and Chawla's (2018) findings, Eriksson et al. (2012) reported that male first-degree relatives experienced a higher rate of ASD and BAP.

As parents of students with ASD may have traits consistent with BAP or ASD, they may experience difficulty analyzing shades of gray typical of a Likert-type survey. Consistent with their children, 15% of parents experience the same type of language and communication deficits as their children with ASD (Ruser et al., 2006). Another challenge among readers with ASD are the difficulties associated with the evaluation of a multiple-choice task (Jolliffe & Baron-Cohen, 1999) and based on the BAP research of parents, the multiple-choice item might pose a problem for them, too. To address these issues, I determined that a dichotomous instrument was appropriate to survey parents of postsecondary students with ASD because this type of assessment would eliminate the gray scale by providing only two options for response, "yes" or "no." Requiring individuals to determine the degree to which they agree or disagree with a statement can potentially confound the participant, result in errors and/or bias, or cause them to fail to complete the survey. "Not applicable" might prove confusing ("not applicable" because there is no relevance or "not applicable" as a statement of neutrality with respect to the question).

A careful exploration of research with individuals with ASD and parents of students with ASD reveals a growing body of evidence to support the use of dichotomous response items. In the assessment utilized to diagnose adults with Asperger Syndrome, Baron-Cohen and colleagues (2005) included the “tendency to see issues in black and white” as a probe in their instrument. Baron-Cohen and colleagues’ (2005) Adult Asperger Assessment is composed of “yes or no” questions. In an examination of current and former college students with ASD, Gelbar et al. (2015) disclosed that 35 of the 86 participants (40.7%) initially recruited for their study failed to complete the Likert-type survey, disqualifying them from participation. In a study of parents of students with ASD and Attention Deficit and Hyperactivity Disorder (ADHD), Elias and White (2017) lost 17 participants (11.9%) through incompleteness of their Likert and two-question survey, including seven respondents who the researchers disqualified because they finished too quickly. Through a study of middle and high school students with ASD aged 13 through 21, Chou et al. (2017) found that participants had difficulty with some items of the Arc’s Self Determination Scale (Wehmeyer & Kelchner, 1995) that were double-negative statements. All probes of the PPSASDS, were stated positively, simply, and unambiguously to avoid challenges associated with language-based comprehension, an issue for many with ASD and perhaps for their parents, too (Jolliffe & Baron-Cohen, 1999; Ruser et al., 2007; Tirado & Saldaña, 2015). Although there were only five participants surveyed through the pilot research, all parents completed the survey and anecdotally commented on the ease with which they were able to complete it.

In further support of the utilization of a dichotomous survey, the Yes/No Interrogative (YNI) in sociology, Raymond (2003) asserted the importance of YNIs as critical to the practice of law, noting that in a court, comments which go beyond “yes” or “no” may be removed from

the legal record. Additionally, the author underscored the use of YNIs in the practice of medicine where it is used ubiquitously in the questioning of patients. Raymond (2003) argued that perhaps the most important justification for the use of the YNI is that “yes” or “no” queries have developed in every language, despite differences in culture and socio-economic status. As such, the dichotomous (YNI) type of survey may impose no cultural or socio-economic barriers or bias, accessible by anyone, regardless of native language, level of education, socio-economic status, or neurodivergence.

As McCoach, Gable, and Madura (2013) affirmed, it was important to consider the target audience and the type of rating scale that audience could successfully utilize when determining the number of scale points of their instrument. They warned that rating scales with a smaller number of points are less sensitive, and as such less reliable. The mitigating factor for this dichotomous approach is predicated on how “thoughtfully and reliably” respondents could answer the questions (McCoach et al, 2013, p. 65), and the target audience for this study may experience neurological differences that render a 4, 5, or more points rating scale a barrier to completion as well as a threat to validity. Gelbar and colleagues (2015) found their survey a barrier to completion as did Chou et al. (2017) who utilized an assessment previously found to have good validity and reliability. Accordingly, those who perceive the world in “black and white” (Baron-Cohen et al., 2005) might find a dichotomous approach more user-friendly, producing data that are more reliable with results that are more valid than other forms of assessment.

## **Data Collection Procedure**

### ***Sample and Participant Recruitment***

I submitted to the Institutional Review Board of the University of Illinois at Chicago (IRB ) the documents explaining the research protocol that included the PPSASDS (see Appendix B), the Demographics Questionnaire (see Appendix C), Informed Consent (see Appendix D) as well as the recruitment scripts specific to the Website, Twitter, Social Media and Email plus the “Thank you” message upon completion of the PPSASDS. Upon approval by the IRB (see Appendix A), I moved forward with recruitment.

Utilizing a snowball recruitment strategy to find parents of postsecondary students with ASD as participants in my research, I advertised my study through the approved email, social media, and online recruitment scripts (see Appendix A). The email recruitment script was distributed to the College Autism Network Virtual Association of Scholars (CANVAS), a closed google group, of which I am a member. CANVAS scholars further distributed my email by forwarding it to parents at their universities. Additionally, I distributed the social media script to my Facebook, Twitter, and LinkedIn contacts, who shared my script with their followers. Each script included the link to a generic URL, [collegestudentparentsstudy.com](http://collegestudentparentsstudy.com), as required by the IRB in order that parents clicking on the link would not be tracked and associated with a link that referred to autism (see Appendix A). I configured the [collegestudentparentsstudy](http://collegestudentparentsstudy.com) link with automatic forwarding to the secure socket layer (SSL) website I created, [MyASDStudentInCollege.com](http://MyASDStudentInCollege.com), where my online script resided. After reading the online recruitment script at [MyASDStudentInCollege](http://MyASDStudentInCollege.com), parents could self-identify if they qualified as a parent of a current or former postsecondary student with ASD. To qualify for participation, parents confirmed that their child had received a formal diagnosis of Autism Spectrum Disorder

(ASD) per DSM 5, or High Functioning Autism (HFA) or Asperger Syndrome (AS) per DSM-IV and is or has been a postsecondary student in the US. If parents decided they qualified, they clicked on the link that forwarded them to UIC Qualtrics, the host for the updated version of the Parents of Postsecondary Student with Autism Spectrum Disorder Survey (PPSASDS).

Once on the Qualtrics site, parents were required to read, attest to having a postsecondary student diagnosed with ASD, and digitally executed the Consent Agreement (see Appendix D) before gaining access to the survey. Parents who completed the entire survey as well as the demographics questionnaire were provided a note of thanks with my email address so that they could request the \$20 Starbucks gift certificate, the reward for participation. Among those who completed the survey, each survey was screened to protect the integrity of the data. A total of 45 surveys emerged from the screening process, and the parents who completed those surveys received \$20 Starbuck gift cards electronically via email. I included only the 45 vetted surveys in this study.

### ***Survey Screening Protocol***

Utilizing a paid online survey to attract participants proved to be fraught with risks to validity. Removing such a risk to validity requires the establishment of a detailed process to immediately identify those who do not meet the criterion to participate or those whose sole motive is to obtain a gift card. Due to the requisite generic URL utilized for recruitment, the risk that any parents of college students, not just those with ASD, was introduced. Thus, I created a systematic procedure to screen out invalid surveys, a process that required an understanding of the behavioral differences between participants who are parents of postsecondary students with ASD, and those who are not the qualified participants for this study.

According to Creswell and Creswell (2018), one begins the process of qualitative analysis by examining data for content and expectations for depth of responses. The pilot research for this dissertation study established a baseline for tone and participant behavior, both of which are integral to credibility. In the pilot project, the parent participants of postsecondary students with ASD all responded to the single open-ended question. Their “voices” were clear, authentic, and in some cases, filled with rich detail that related, for example, their concerns about social integration, autonomy, and emotional support/stress relief needs.

An examination of tone, behavior, and credibility of text responses was determined as the first step in establishing a protocol for screening for survey validity and was performed as part of a larger systematic process as soon as a survey was submitted to Qualtrics. While the expectation was not that parents would respond to every question, I did expect parents would respond to at least one open-ended question. Hence, at least one response with an explanation or detail became the baseline for inclusion. Preferring to err on the side of caution, surveys that did not respond to at least one of the open-ended questions beyond a “no,” “na,” or a similar non-response were excluded.

**Screening System.** To establish a system that allowed parent voice and demographics triangulation, I created a protocol using a spreadsheet of deidentified data where the demographic data and open-ended responses from each survey was deconstructed. Every completed survey was included in this spreadsheet which is titled, “Systemized Data Screening Checklist.” This checklist included the following data: parent identification as mother or father, student age, highest level of education the student achieved, type of school the student attended, the type of degree the student was pursuing, the type of institution the student was currently attending, name of the institution or institutions the students currently or previously attended, the

source of financing for the student's education, as well as the parent's demographic data including race/ethnic identity, level of education, income, parents' responses to open-ended questions copied and pasted directly from each survey, and geographical coordinates.

One level of screening entailed the exclusion of respondents outside of the United States. Although Qualtrics does not collect IP addresses, it records instead the geographical coordinates for an approximate location of where each survey was submitted, thereby allowing confirmation that the survey was completed by a parent in the United States. However, an issue that can confound geo-coordinate data is the use of a Virtual Private Network (VPN), which can mask the actual physical location of an individual. One can connect to a U.S. VPN from anywhere in the world. Moreover, one can also "spoof" location while using a mobile phone so the GPS is rendered inaccurate. Hence, it was apparent that this information would require confirmation through further screening of the written responses on the survey.

**Inclusion Process.** The screening process included several steps. First, I checked the geographic coordinates to confirm the survey had been submitted in the United States. If the survey was submitted in the United States, I checked to ensure that coordinates were not duplicates of previous responses. If the coordinates were domestic and unique, I proceeded to the second step to see if there were responses to the open-ended questions. By the time I finished copying and pasting the open-ended responses from the survey to the checklist, I had a good sense of content and tone, particularly if the participant had responded to multiple questions. The next step was to look for inconsistencies, a type of triangulation among responses within each set of responses.

All the demographic data regarding the parent and student had to be consistent. For instance, some parents indicated other sources of financial support that were not included among

the questionnaire options but were viable sources of financial support. Such additions added to authenticity. For example, one mother in XState who indicated her son was a student at the University of XState at XCity wrote that her son's "grandparents education account" helped finance his education. Additionally, in another response she wrote, "We only suggested a smaller caseload after he didn't pass his classes first semester freshman year. He said he didn't want to write essays, but I believe it was more he was overwhelmed." She also selected the option that her student attended a 4-year university and added the text, "has taken a semester off." Hence, this parent answered more than one open-ended question, referred to her student as being "overwhelmed," which is a common experience among individuals with ASD, and volunteered information ("semester off") that was nowhere else on the survey from where it could have been lifted. This survey was regarded as valid.

In another example, one father wrote in response to the second open-ended question early in the survey, "He's going to a community college," and responded to the last question in demographics questionnaire with the name of the community college. Inasmuch as the questionnaire follows the survey, and the very last question requests the college/university of attendance, the parent probably did not expect to be asked about the school, so the information he provided early in the process was noteworthy, particularly since his geo-coordinates placed him in XState, within proximity to the named community college. To the last question, the father responded, "I can't think of anything else," unlike many who simply responded "no," "na," "nothing," or "none" while failing to respond to more than one question. Thus, these are two examples that required more scrutiny prior to acceptance. The majority of surveys that were used included responses to multiple open-ended questions.



**Exclusion Process.** Parents outside of the United States who sent their students to college in this country had to be excluded from participation as they may be unaware of the policy and laws that govern U.S. postsecondary education. Their students were unlikely to have had an IEP prior to attending college, and so they would not have this knowledge and experience that greatly influence the perceptions at a postsecondary school. While parents may speak or write English as a second language, they may not understand the purpose of the survey or for whom it is intended, or not respond themselves but have another individual (such as their student) respond or translate the survey for them, so they were less likely to respond to open-ended questions. I assumed that such communication obstacles would impede the voice of the parent, which was a barrier to authenticating validity.

Other surveys were submitted with unintelligible gibberish. Several surveys combined gibberish (repeated “onoe” in multiple surveys as an open-ended response) with suggestions such as “Seek Out Feedback & Apply It. Create Opportunities to Engage With Alumni.” Some surveys were submitted several times by the same individual using the exact same verbiage every time with the exact same school every time. Other individuals seemed to take the survey over and over again using a different email address in the hope there would be an improvement in the answers provided, presumably in hopes that one of their entries would result in a gift card. All surveys with “Nothing,” “No,” “NA,” “None” in the open-ended items were excluded.

I monitored my email several times daily for notification of parents requesting their \$20 Starbucks card which prompted me to review the survey. Using this systematic protocol established for screening data, I was able to quickly ascertain whether or not a gift card should be distributed in line with the recruitment protocol which asserted, “if you qualify.” Through this

process of systematic analysis, out of a total of 227 attempts, 45 completed surveys (19.8%) were included. Among the excluded 175 (77.1%), seven surveys were abandoned as incomplete (3%).

### ***Inter-rater Reliability***

Through an online random number generator, I selected survey numbers that included 12 surveys that passed the inclusion process plus 12 surveys that were excluded. The surveys selected yielded the sample utilized for inter-rater reliability testing. Blind copies of the text were provided to the second rater, a faculty member with a thorough understanding of the selection criteria, who followed a procedure to select or exclude surveys as follows: 1) the geo-coordinates were verified as the United States, 2) the content of the open-ended questions was relevant to the topic probed, 3) parent voice was consistent with the parent of a postsecondary student with autism, and 4) overall consistency was demonstrated across education demographic items and open-ended responses. Utilizing this protocol, 100% inter-rater concordance was achieved.

### **Data Analysis Procedures**

#### ***Quantitative Data Analysis***

**Item Average Descriptive Analysis.** Each item on the PPSASDS instrument was stated positively, and the scale was scored with 0 for no and 1 for yes. An item that received a score of 1 was positively associated with the characteristic being examined. Conversely, 0 scores reflected no relationship with the characteristic. The closer the average for each item or domain was to 1, the stronger the characteristic identified by the item. If the average of all items for one domain was .5, that was regarded as a neutral outcome. A strong positive was indicated by a score of .81 to 1, a score from .61 to .80 was interpreted as positive, scores from .51 to .60 as neutral/positive, and from .40 to .49 were negative/neutral. A score from .39 to .20 was construed as negative whereas a score between .19 to 0 yielded a strong negative score. These

averages measured the frequency to which parents agreed with each other, and at the same time, the average provided an indication as to the relevance of the question with respect to the types of support that parents provided to their students.

**Mokken Scale Analysis.** One of the objectives of this study was to determine if the PPSASDS is a reliable measurement tool for assessing parent involvement in the postsecondary education of their students with ASD. Therefore, I selected to quantitatively examine the construct validity of the dichotomous items through Mokken Scale Analysis (MSA), which is particularly useful during the construction phase of a questionnaire for measurement of traits or behaviors based on a dichotomous Item Response Theory (IRT) model (Kuijpers et al., 2016; Sijtsma & van der Ark, 2016). At its core, the PPSASDS is a psychometric instrument where the behavior data yielded are monotonic and, thus, non-parametric. While dichotomous IRT models are often associated with large data samples, Wind (2019) notes that MSA is viable with smaller sample sizes.

MSA measures latent variable construct validity through three scalability coefficients,  $H_i$  the scalability coefficient for single items,  $H_{ij}$  the scalability coefficient for scaling pairs of items, and  $H$  the scalability coefficient for an entire scale. Mokken established the floor for scalability of the coefficients,  $H_j$ ,  $H_{ij}$ , and  $H$  at .3 (Kuijpers et al., 2013). Moreover, Mokken set three scalability thresholds where  $.3 \leq H < .4$  is weakly scalable,  $.4 \leq H < .5$  is moderately scalable, and  $H \geq .5$  is strongly scalable (Kuijpers et al., 2013; Mokken, 1971). One assumption of nonparametric data is that they conform to the model of monotonic homogeneity, so that no item nor pairs of items should yield a coefficient of  $<0$ . Thus, pairs of items,  $H_{ij}$  will score  $> 0$  to conform with monotonicity, and provide another measure for reliability of the construct validity for the latent variable being measured (Sijtsma & van der Ark, 2016).

Data generated through utilization of Package “mokken” for R for the PPSASDS (van der Ark, Straaten, & Koopman, 2018) included both the scalability coefficients and the standard error for each of the three scalability coefficients. Accordingly, the standard error data relate to the reliability of the scalability coefficient, rather than the mean, because data yielded by the PPSASDS are not parametrically distributed in the form of a normal distribution..

**Kuder Richardson Formula 20 (K-20) Test of Reliability.** Analogous to Cronbach’s  $\alpha$ , KR-20 measures internal consistency among dichotomous items, and it is utilized to determine reliability for the degree to which a single construct is measured (Kuder & Richardson, 1937). Accordingly, KR-20 calculation utilizing an Excel spreadsheet for the data generated by the PPSASDS provided another assessment of reliability, to supplement and provide evidence for triangulation with the standard error generated by MSA. Through his examination of the integration of measures for reliability and standard error of measurement, Horn (1971) provided the mathematical evidence for the relationship between measures of reliability such as KR-20 and standard error of measurement. Through MSA, the standard error generated measures the reliability for the scalability of the item or items, and therefore, it provides another measure of reliability. While Horn (1971) noted that KR-20 may provide a larger measure of reliability than KR-21, he also underscored the difference between the two measures is  $\leq .5$  (p. 66) with the caveat of rare exceptions.

### ***Qualitative Data Analysis***

**Grounded Theory.** For a grounded theory approach to the analysis of qualitative data, Corbin and Strauss (2008) suggested reading all the text without comment or notation in order to experience the writer’s perspective. Consistent with this process, I reread parents’ responses to the open-ended questions at least three times before I started to take memos, ascribing a

conceptual label to each memo. The conceptual label was derived from the text, usually through a repetition of words. Creating a memo involved dialoging with the concept in order to initiate analysis, and through an analysis of the wording of the respondent's text, the conceptual label was constructed. As a result of dialoging, dimensions, or variations of the concept emerged as well as properties, or characteristics, of each concept. The analysis process continued through saturation, whereby each theme could be fully described in terms of dimensions and properties, and no new themes emerged from the data.

To process the textual data, I created a spread sheet for the 13 embedded questions and the final question, whereby I could group comments particular to each question according to similarity of words used. This allowed me to summarize the themes of their comments. The next step was to create a summary of the memos to begin to translate the comments into codes according to memos yielded by the groupings of comments.

The final question was unique in that it was not a guided question that followed dichotomous items within a particular domain. Instead, this final question asked parents, "*In what other ways have you supported your student at their college or university?*" The word, "other," signaled to parents to provide supplemental information, thereby facilitating the possible emergence of themes other than Social Integration, Autonomy, and Emotional/Stress Relief.

**ATLAS.ti Qualitative Analysis.** As a means of confirmation or corroboration to the protocol for grounded theory, I utilized ATLAS.ti to label parents' responses to all questions. Using the two procedures, open coding and ATLAS.ti, allowed me to compare my qualitative results. For example, ATLAS.ti generated a report that allowed me to examine the number of times a particular label was attached to a comment, and to see the cooccurrence of labels and their frequency, thereby revealing latent relationships between the labels. ATLAS.ti also allowed

me to produce a document of quotations along with the labels that I had assigned through that computer program which facilitated comparison of that output with the previously derived themes and codes on the spreadsheets that I had created. Thus, ATLAS.ti served to triangulate results between qualitative methods.

**Inter-rater Reliability.** Similar to the process of survey selection, utilizing an online random number generator I selected a sample among the 13 domain-embedded open-ended questions for inter-rater vetting. The numbers generated were questions 13 (Social Integration Domain), 38 (Autonomy Domain), and 56 (Emotional/Stress Relief). There were 22 text responses for question 13, 18 text responses for question 38, and 17 text responses for question 56. Both the researcher and a second rater, intimately familiar with the research questions and the context of the data collection, coded and derived themes and ideas that were evident in the comments. The two raters then compared and discussed their themes and ideas and while some of the codes were labeled differently, there was consensus on the identified topics and themes expressed by the respondents.

## IV. RESULTS

There were 227 attempts to complete the survey, and through the systematic screening process to identify valid surveys, 45 completed surveys (20%) qualified to be included in this study. I excluded 175 surveys (77%) based on the established criteria. Seven surveys were abandoned as incomplete (3%). Among the 45 surveys included in this study, 45 parents responded to 45 yes or no questions and 14 open-ended question on the Parents of Postsecondary Students with Autism Spectrum Disorder Survey (PPSASDS). After I screened the surveys for inclusion, I deidentified the valid surveys before proceeding to analyze them quantitatively and qualitatively. I removed all identifiable data used during the screening process in order to proceed with the protocols I utilized for data analysis.

### **Participant Engagement**

The majority of the 45 participants responded in less than 20 minutes to 45 dichotomous items, 14 open-ended questions, and 16 multiple choice responses on the demographic questionnaire. Only 11 participants spent more than 20 minutes to complete the survey and questionnaire, while one participant spent two hours for completion.

As all parents answered the open-ended question in the pilot study, an expected survey-engagement behavior for this research, 40 out of 45 participants (89%) in this research study responded to seven or more open-ended questions. Some parents responded to every open-ended question with considerable detail that resulted in pages of text. Among the 45 participants, eight parents (17.8%) had responses to all the open-ended questions (a behavior consistent with the pilot study), 12 parents (26.7%) responded to seven or more questions, and 20 parents (44.4%) responded to at least one-half of the questions (see Figure X). Consistent with high engagement

behavior, 43 out of 45 parents (96%) reported involvement in high school which included attending IEP meetings.

## **Demographic Data**

### ***Parent Level of Education***

Among the 45 participants, 41 were mothers and four were fathers. Of the four fathers, two held master's degrees, while two held bachelor's degrees. Out of 41 mothers, three held PhDs, one had a professional degree, 13 had master's degrees, 14 had bachelor's degrees, four had an associate degree, three had some college, but no degree, and there were three mothers who completed high school. In all, 42% of all parents held a graduate degree at the master's level or higher, 44% held at least a 2-year college degree, 7% had some college, and 7% reported their highest level of education as a high school diploma (see Table 3 below).

### ***Students' Educational Achievement***

According to parents, one of their students held a master's degree, eight students completed a bachelor's degree, another completed four years of college, two held a 2-year associate degree, and 33 students had completed high school. Current student enrollment included one student in a doctorate program, one student in a masters' program, 21 students in bachelors programs, 12 in 2-year programs, two in technical school programs, seven are no longer in school because they completed a bachelor's degree, and one is no longer enrolled after the completion of a master's degree (see Table 3 below ). Thus 9 out of 45 completed postsecondary education (20%) while 36 out of 45 (80%) are still enrolled in school. Thirty parents (67%) reported their student had a college transition plan, and 29 (64%) parents reported they participated in the college transition plan.



***Parent Identity and Income***

Among the 43 parents who disclosed race/ethnicity, 36 were White (84%), four were Black (9%), two were Latina (4%), one was Asian (2%), and two preferred not to disclose. Five parents reported income below \$30,000 per year while 11 reported more than \$150,000 per year. The skew was toward the higher end of income distribution as another 9 of the 42 parents who disclosed income indicated their household was in the \$100,000 - \$150,000 range. Accordingly, 20 out of 43 families (47%) had household income that was  $\geq$  \$100,000.

**TABLE 3**  
**PARENT EDUCATION, INCOME, IDENTITY, AND STUDENT EDUCATIONAL ACHIEVEMENT**

Parent (Mom Dad)	Age of Student	Type of postsecondary school attended	Degree Currently Pursuing	What is the highest level of education your student <u>completed</u>	What is your student's current enrollment?	Household Income: What is your total annual household income?	What is the highest level of education that <u>you</u> completed? If currently enrolled, mark the previous grade or highest degree received.	How do you identify?
Mom	23-27	2-year college	2-year college	HS diploma	Technical Trade Program	50,000- 74,999	HS diploma	African American
Mom	18-22	2-year college	Vocational	HS Diploma	Technical/Trade program	75,000- 99,999	Associates	White
Mom	23-27	4yr university	4-yr degree	HS Diploma Certificate of Completion Technical Certification	4-year college degree	<30,000	Master's degree	White
Mom	18-22	2-year college	2 year degree	HS Diploma	2-year college	50,000- 74,999	Bachelors	Hispanic/Latino
Mom	18-22	4 year university "Has taken a semester off"	4-year university	HS Diploma	4 year college degree	Prefer not to answer	HS diploma	White

Mom	23-27	2-year college, 4-year university	4-year university degree	4 year degree	No longer attending	50,000- 74,999	Masters	White
Mom	18-22	4-year university	4-year university	4-year degree	No longer attending	100,000- 150,000	Masters	White
Mom	18-22	4-year university	4-year university	HS diploma	4-year degree	50,000- 74,999	Bachelors	White
Mom	18-22	4-year college	Her current college offers Associates Degrees with the option of continuing on for Bachelor's Degrees	HS diploma	2 year degree (Her current college offers Associates Degrees with the option of continuing on for Bachelor's Degrees)	150,000 or more	Professional degree	White
Mom	23-27	4-year university	4-year university	4-yr degree (BA, BS)	No longer attending	75,000- 99,999	Bachelors	Asian
Mom	28-32	4yr university Master's	"He finished his degree"	Masters	"He finished his degree"	150,000 or more	Masters	White
Mom	18-22	2-year college	2 year degree	HS diploma	2-year college	150,000 or more	Bachelors	White
Mom	18-22	2-year college	2-yr degree	HS diploma	2-yr degree	100,000- 150,000	Bachelors	White
Mom	18-22	2-year college	2-yr degree	HS diploma	2-yr degree	50,000- 74,999	Masters	White
Mom	18-22	2-year college	2-yr degree	HS diploma	2-yr degree	150,000 or more	Masters	White

Mom	18-22	2-year college	2-yr degree	HS diploma	2-yr degree	Prefer not to answer	Masters	White
Mom	23-27	4-yr university/graduate school	Masters In Business Admin	4-yr degree	Masters	<30,000	Bachelors	African American
Mom	23-27	4-year degree	Graduated (4- year University degree)	4-yr degree	No longer attending	150,000 or more	Bachelors	White
Mom	18-22	4-year university	4 yr degree	HS diploma	4 yr degree	100,000-150,000	PhD	White
Dad	18-22	2-year college	2-yr degree	HS diploma	2-yr degree	Prefer not to answer	Masters	White
Mom	23-27	2-year college	2-yr degree	2-yr degree	2-yr degree	50,000-74,999	Associates	African American
Mom	33 or older	4-year college	4-year degree	4-yr degree	No longer attending	50,000-74,999	Bachelors	African American
Mom	18-22	4-year university non degree program for students with intellectual disability	Certificate of completion	HS	BA	150,000 or more	Masters	White
Mom	18-22	4-year university	4-year degree	HS diploma	4-year degree	30,000-49,999	Associate of Arts	White

Mom	23-27	4-year university	4-year degree	HS diploma	2-yr degree	<30,000	1 or more years of college no degree	Prefer not to answer
Mom	18-22	4-year university	4-year degree	HS diploma	2-yr degree	<30,000	Bachelors	White
Mom	28-32	2-yr & 4-year university	Doctor of Veterinary Medicine	Technical Certification Two-Year College degree (Associate's Degree) Four-Year College degree (Bachelor's Degree)	Doctorate	30,000-49,999	Bachelors	White
Mom	18-22	4-year university	2-yr degree	Hs diploma	2-yr degree	100,000-150,000	Bachelors	White
Mom	18-22	4-year university	4-year degree	HS diploma	4-year degree	75,000-100,000	Masters	White
Mom	18-22	4-year university	4-year degree	HS diploma	4-year degree	50,000-74,999	Masters	White

Mom	18-22	4-year university & other Bellevue College is a four year college that used to be a community college so it has aspects of both	4-year university	HS diploma	4-year degree	100-150,000	PhD	White
Mom	18-22	4-year university	4-year degree	HS diploma	4-yr degree	30,000-49,000	Bachelors	White
Dad	18-22	4-year university	4-year degree	4-year degree	No longer attending	100,000-150,000	Masters	White
Mom	33 or older	Two-Year College Four Year University Other (please specify) Four Yr. College for Working Adults	He has 4-year degree in Art and one in Accounting.	4-year college	No longer attending	75,000-99,999	Bachelors	White
Mom	18-22	4-year university	4 year degree	Hs diploma	4-year degree	150,000 or more	Bachelors	White

Mom	23-27	4-year university	4 year degree	Hs diploma	4-year degree	150,000 or more	1 year of college or more no degree	White
Mom	23-27	2-yr & 4-yr university	4-yearr university	2-yr	4-year degree	150,000000 or more	Masters	White
Mom	18-22	4-yr university	4-year university	HS diploma	4-year degree	150,000000 or more	HS diploma	White
Mom	18-22	4-yr university	4-year degree	HS diploma	4-year degree	<30,000	Associate of Arts	White
Mom	18-22	4-year	4-year degree	HS diploma	4-year degree	100,000-150,000	More than 1 year of college, no degree	Prefer not to answer
Mom	18-22	Master of Arts	4-yr degree	HS diploma	4-yr degree	50,000-74,999	Masters	White
Dad	18-22	4-year university	4-yr degree	HS diploma	4-yr degree	100,000-150,000	Bachelors	White
Dad	18-22	4-year university	4-yr degree	HS diploma	4-yr degree	100,000-150,000	Bachelors	White
Mom	18-22	4-year university	4-yr degree	HS diploma	4-yr degree	50,000 - 74,999	Masters	Hispanic/Latino
Mom	18-22	4-year university	4-yr degree	HS diploma	2-yr degree	150,000,000	PhD	White

*Note:* Students' highest level of education and current enrollment are reported by parents.

### ***Quantitative Data Analysis***

To determine if parents were supporting skills associated with the three domains surveyed through this inquiry, the instrument was constructed so that 15 dichotomous items examined social integration, 16 dichotomous items examined autonomy, and 14 dichotomous items examined Emotional/Stress relief. The 14 open-ended questions provided parents with the opportunity to add comments that went beyond the scope queried through the dichotomous items, thereby enriching the data yielded qualitatively.

Analyzed here are two sets of data for each domain, one where  $n = 36$ , and one where  $n = 45$ . The reason I broke out the data into two sets is due to the last flurry of nine participants, eight of whom had students participating in the same postsecondary autism program. The participation of those eight parents increased the sample size by 22%, so I wanted to understand if and how those participants with students in the same autism program impacted the data relative to the first dataset of 36.

### ***Social Integration Item Average Analysis***

For both Social Integration datasets, 7 out of 15 items (47%) items averaged 0.81 or higher, indicating strong parent participation for those items. One item (7%) among both datasets scored in the .61 to .80 range, a positive result for that characteristic. Three items (20%) scored in the neutral/positive range of .49 to .58 for both datasets, while one item (7%) in both sets scored in the negative/neutral range of .40. Finally, three items (20%) scored in the negative range on both datasets, including one strong negative of .19 where  $n = 36$ , and one item scoring 0 on both datasets. The item (7%) which scored zero for both datasets was, “I suggested to my student to join a fraternity/sorority.” In its entirety, the Social Integration Domain set of items averaged .63 where  $n = 36$ , and .64 where  $n = 45$ . Accordingly, there was little difference in



average scoring between the two datasets, and both were within the positive scoring range above .60 (see Table 4 below).

**TABLE 4**  
SOCIAL INTEGRATION DOMAIN ITEM AVERAGES

Social Integration Items	Characteristics of Parent Support	
	Average Score n=36	Average Score n=45
1. I suggested to my student to live on campus.	.50	.56
2. I suggested to my student to have a roommate.	.19	.22
3. I suggested to my student to join a fraternity/sorority.	0	0
4. I suggested to my student to attend summer school before he/she started his/her freshman year.	.33	.33
5. I suggested to my student to attend the college orientation program before he/she started his/her freshman year (if it was available).	.94	.93
6. I suggested to my student to use campus meal plan.	.50	.58
7. I suggested to my student to attend campus activities (including arts, political, and social).	.94	.96
8. I suggested to my student to attend sporting events on campus.	.44	.47
9. I suggested to my student to belong to clubs (and/or extramural activities) on campus.	.92	.91
10. I suggested to my student to make new friends on campus.	.92	.93
11. I suggested to my student to attend activities with friends on campus.	.83	.84
12. I suggested to my student to get together with a friend(s) on campus.	.86	.87
13. I suggested to my student to sit with friend(s) in his/her classes.	.50	.49
14. I suggested to my student to work with other students in class.	.81	.82
15. I suggested to my student to find a study group on campus in order to socialize.	.72	.69
Social Integration Domain Average	.63	.64

Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative.

### *Autonomy Item Averages Analysis*

The Autonomy Domain included ten items (63%) that scored in the strongly positive range above or equal to .81 for both datasets. Additionally, five of the items (31%) scored in the positive range of .61 to .80. One item (6%) within both datasets fell within the positive/neutral to positive range with scores of .58 where  $n = 36$  and .56 where  $n = 45$ . There were no neutral/negative or negative scores among items for the domain. The only difference in scores was in the average score for the Autonomy Domain where  $n = 36$ , which yielded a positive score of .77 which is above the positive/neutral range which starts at .61 but still less than the threshold for a strong positive of .81. However, where  $n = 45$ , the average for the Autonomy Domain scored strongly positive at .81 (see Table 5 below).

**TABLE 5**  
AUTONOMY DOMAIN ITEM AVERAGES

Autonomy Items	Average Score	Average Score
	$n=36$	$n=45$
1. I suggested to my student to choose their school.	.72	.73
2. I suggested to my student to get help in order to register for classes.	.78	.78
3. I suggested to my student to get disability accommodations.	.92	.93
4. I suggested to my student to arrange their schedule in order to manage the workload.	.86	.87
5. I suggested to my student to get up in the morning on their own.	.86	.87
6. I suggested to my student to get to school and/or classes on their own.	.81	.82
7. I suggested to my student to manage time for homework and non-academic activities.	.92	.93
8. I suggested to my student to do his/her own laundry.	.78	.80

9. I suggested to my student to make his/her own meals or snacks.	.64	.62
10. I suggested to my student clean his/her own room.	.94	.93
11. I suggested to my student to practice good hygiene.	.92	.91
12. I suggested my student get plenty of rest every night.	.83	.84
13. I suggested to my student to maintain his/her own bank account.	.72	.76
14. I suggested my student use and manage credit card to make purchases.	.58	.56
15. I suggested to my student to self-advocate.	.97	.96
16. I suggested to my student to set academic and or vocational goals.	.92	.91
<hr/>		
Autonomy Domain	.77	.83

Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative.

### ***Emotional/Stress Relief Item Averages Analysis***

The Emotional/Stress Relief Domain had one item that scored 1 when  $n = 36$ . This item, “I engaged in troubleshooting problems with my student,” scored .98 when  $n = 45$ . This probe was 1 of 3 items among both datasets (21%) that scored in the strongly positive range  $\geq .81$ . In addition, for both datasets, 6 out of 14 items (43%) scored within the positive range of  $\geq .61$  and  $\leq .80$ . Four items (29%) scored within the neutral/positive and neutral/negative range of  $\geq .40$  and  $\leq .61$  across both data sets. One item (7%) scored in the negative range of  $\leq .39$  within both datasets. There was little difference in the average Emotional/Stress Relief Domain: Where  $n = 36$ , the score was a positive .68, and where  $n = 45$  the score was also a positive .69 (see Table 6 below).

**TABLE 6**  
**EMOTIONAL/STRESS RELIEF DOMAIN ITEM AVERAGES**

Emotional/Stress Relief Items		Average Score n=36	Average Score n=45
1.	I suggested to my student to get counseling on campus for managing depression, anxiety, and/or stress.	.64	.67
2.	I found a counselor/therapist off-campus for my student to help manage depression, anxiety, and/or stress.	.50	.51
3.	I helped my student manage depression, anxiety, and/or stress over financing their own education.	.50	.49
4.	I addressed my student's depression, anxiety and/or stress by helping my student find scholarships/financial aid.	.47	.53
5.	I relieved my student's depression, anxiety, and/or stress by supporting them financially.	.69	.76
6.	I suggested to my student to take fewer classes than a full-time course load.	.69	.67
7.	I suggested to my student to attend summer school.	.50	.47
8.	I suggested to my student to concentrate solely on classes.	.39	.38
9.	I suggested ways to my student to reduce sensory stress in their living environment.	.75	.73
10.	I suggested to my student to work on problem management skills.	.78	.80
11.	I suggested to my student exercise to manage depression, anxiety, and/or stress.	.78	.78
12.	I suggested to my student to pursue their special interest (e.g., hobbies).	.86	.89
13.	I engaged in troubleshooting problems with my student.	1	.98
Emotional/Stress Relief Domain		.68	.69

Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative.

### ***Social Integration Items Mokken Scale Analysis***

Among 5 out of 15 items (33.3%) within the Social Integration Domain and across both datasets, the scalability coefficient,  $H_i$ , rated  $\geq .5$ , indicating strongly scalable items. For the  $n=36$  dataset, three items (20 %) rated  $\geq .4$  but  $< .5$ , indicative of moderate scalability. For the larger dataset of  $n = 45$ , two items (13%) rated  $\geq .4$  but  $< .5$ , or moderately scalable. For three items (13%) where  $n = 36$  and two items (13%) where  $n = 45$ , the scalability coefficient,  $H_i$ , rated according to weak scalability,  $\geq .3$  but  $< .4$ . Four items on both scales rated less than Mokken's floor of scalability at  $\geq .3$  while one more item where  $n = 45$  scaled below .3 as well, for a total of 5 items (33%) among the larger dataset. Standard errors for individual items ranged from a low of .02 to a high of .25 (see Table 7 below).

Among the pairs of items for the dataset of 36 participants, a total of 61 out of a possible 91 pairs (67%) met the requirements for scalability, including 35 pairs that scored 1. In all 52 pairs scored  $> .5$  (57%) while 14 pairs of items were negative (15%) and thus failed the monotonicity test (see table 8 below). For the dataset of 45 participants, a total of 59 pairs (65%) met scalability with a coefficient of  $H_{ij}$  of  $> .3$ , and 31 pairs scoring 1 plus another 21 pairs scoring strong for scalability, totaling 52 pairs at  $> .5$  (57%). Sixteen pairs (18%) failed the monotonicity test (see Table 9 below). For the entire domain where  $n = 36$ , the scalability of the coefficient  $H$  for the set of items scored a moderately scalable .4 with standard error equal to .09. When  $n = 45$ , the scalability was coefficient  $H$  was reduced to .39 with a standard error of .08 for the set of items (see Table 7 below).

**TABLE 7**  
**MOKKEN COEFFICIENT HI AND H SCALABILITY RESULTS: SOCIAL INTEGRATION**

Social Integration Domain	n = 36 Scalability Coefficient <i>H<sub>i</sub></i> (SE)	n = 45 Scalability Coefficient <i>H<sub>i</sub></i> (SE)
I suggested to my student to live on campus.	.19 (.14)	.27(.12)
I suggested to my student to have a roommate.	.43 (.15)**	.45 (.12)**
I suggested to my student to join a fraternity/sorority.	Omitted (no variability)	Omitted (no variability)
I suggested to my student to attend summer school before he/she started his/her freshman year.	.19 (.18)	.26 (.15)
I suggested to my student to attend the college orientation program before he/she started his/her freshman year (if it was available).	.41 (.25)**	.20 (.25)
I suggested to my student to use campus meal plan.	.27 (.12)	.26 (.12)
I suggested to my student to attend campus activities (including arts, political, and social).	.65 (.02)*	.65 (.02)*
I suggested to my student to attend sporting events on campus.	.32 (.11)***	.28 (.11)
I suggested to my student to belong to clubs (and/or extramural activities) on campus.	.53 (.14)*	.55 (.11)*
I suggested to my student to make new friends on campus.	.62 (.11)*	.60 (.11)*
I suggested to my student to attend activities with friends on campus.	.70 (.10)*	.68 (.09)*
I suggested to my student to get together with a friend(s) on campus.	.70 (.11)*	.68 (.10)*
I suggested to my student to sit with friend(s) in his/her classes.	.28 (.12)	.25 (.11)
I suggested to my student to work with other students in class.	.36 (.15)***	.32 (.14)***
I suggested to my student to find a study group on campus in order to socialize.	.49 (.14)**	.46 (.12)**
Social Integration Domain	.40 (.09)**	.39 (.08)
KR-20	.80	.76

For Mokken Scalability Coefficient: \* = strong scalability, \*\* moderate scalability, \*\*\*=weak scalability; for Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative.

**TABLE 8**  
SOCIAL INTEGRATION MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n=36

PPSASDS	Question	1	2	4	5	6	7	8	9	10	11	12	13	14	15
Question	Qualtrics	Q 2	Q 3	Q 5	Q 6	Q 8	Q 9	Q 10	Q 11	Q 14	Q 15	Q 16	Q 18	Q 19	Q 20
1	Q2		1	-.17	0	.67	1	0	.33	1	.67	.60	-.33	-.43	0
2	Q3	1		.36	1	1	1	-.29	1	1	1	1	-.14	.27	-.03
4	Q5	-.17	.36		1	-.17	-.50	.10	0	0	.50	.4	.33	1	.40
5	Q6	0	1	1		0	-.06	-.13	-.09	.46	.4	.42	1	1	1
6	Q8	.67	1	-.17	0		1	.13	1	1	.67	.60	-.22	-.14	0
7	Q9	1	1	-.50	-.60	1		1	1	.46	1	1	1	-.24	1
8	Q10	0	-.29	.10	-.13	.13	1		1	1	1	1	.25	.68	.78
9	Q11	.33	1	0	-.09	1	1	1		.27	.60	.61	1	.17	.54
10	Q14	1	1	0	.46	1	.46	1	.27		1	.61	1	.17	.54
11	Q15	.67	1	.50	.40	.67	1	1	.60	1		1	1	.17	.54
12	Q16	.60	1	.40	.42	.60	1	1	.61	.61	1		1	.26	.72
13	Q18	-.33	-.14	.33	1	-.22	1	.25	1	1	1	1		1	.60
14	Q19	-.43	.27	1	1	-.14	-.24	.68	.17	.17	0.17	.26	1		.80
15	Q20	0	-.03	.40	1	0	1	.78	.54	.54	0.54	.72	.60	.80	

Scalability:  $.3 \leq Hij < .4$  is weakly scalable,  $.4 \leq Hij < .5$  is moderately scalable, and  $Hij \geq .5$  is strongly scalable

**TABLE 9**  
SOCIAL INTEGRATION MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n=45

PPSASDS	Question	1	2	4	5	6	7	8	9	10	11	12	13	14	15
Question	Qualtrics	Q 2	Q 3	Q 5	Q 6	Q 8	Q 9	Q 10	Q 11	Q 14	Q 15	Q 16	Q 18	Q 19	Q 20
1	Q2		1	-.05	-.20	.72	1	.14	.55	1	.74	.70	-.33	-.35	.10
2	Q3	1		.40	-.50	1	1	-.13	1	1	1	1	-.17	.44	.36
4	Q5	-.05	.40		1	-.11	-.50	0	.25	0	.57	.50	.35	1	.57
5	Q6	-.20	-.50	1		-.15	-.07	-.43	-.10	.29	.21	.23	1	.60	.52
6	Q8	.72	1	-.11	-.15		1	.21	.57	1	.51	.42	-.29	-.08	.01
7	Q9	1	1	-.50	-.07	1		1	1	.46	1	1	1	-.22	1
8	Q10	.14	-.13	0	-.43	.21	1		1	1	1	1	.07	.46	.54
9	Q11	.55	1	.25	-.10	.57	1	1		.27	.70	.71	1	.09	.64
10	Q14	1	1	0	.29	1	.46	1	.027		1	.62	1	.19	.52
11	Q15	.74	1	.57	.21	.51	1	1	.70	1		1	1	.13	.59
12	Q16	.70	1	.50	.23	.42	1	1	.71	.62	1		1	.19	.76
13	Q18	-.33	-.17	.35	1	-.29	1	.07	1	1	1	1		1	.56
14	Q19	-.35	.44	1	.60	-.08	-.22	.46	.09	.19	.13	.19	1		.82
15	Q20	.10	.36	.57	.52	.01	1	.54	.64	.52	.59	.76	.56	.82	

Scalability:  $.3 \leq Hij < .4$  is weakly scalable,  $.4 \leq Hij < .5$  is moderately scalable, and  $Hij \geq .5$  is strongly scalable

### *Autonomy Items Mokken Scale Analysis*

Within the Autonomy Domain, one item for both datasets scored with a coefficient of  $>.5$ , indicating a strongly scalable item, but when  $n = 36$ , two items at  $>.5$  rated strongly scalable. For both datasets, two items scored moderately scalable with a coefficient of  $\geq .4$  but  $<.5$  while another item for each dataset also scored moderately scalable. When  $n = 36$ , six items (38%) are weakly scalable with the  $H$  coefficient  $\geq .3$  but  $<.4$ , yet when  $n = 45$ , four items (25%) are weakly scalable. When  $n = 36$ , five items (31%) are below the scalable threshold of  $.3$ , and when  $n = 45$ , eight items (50%) are  $<.3$ . Among the items scored jointly for the dataset of 36, 63 out of 120 possible pairs (44%) met the requirements for scalability, with 13 pairs scoring 1 and 26 pairs in all strongly scoring  $>.5$  (22%) (see Tables 11 and 12 below). With the dataset for 45 participants, 48 out of 120 pairs met the threshold for scalability, with 9 pairs scoring 1 and another 21 pairs scoring strongly, totaling 30 out of 120 which were strongly scalable (25%) (see Table 12). For the entire Autonomy Domain, when  $n = 36$ , the  $H$  coefficient of scalability was  $.31$  with a standard error of  $.11$ , or weakly scalable. With  $n = 45$ , the coefficient  $H$  scored  $.28$  with a standard error of  $.09$ , or unscalable (see Table 10 below).

**TABLE 10**  
MOKKEN COEFFICIENT  $H_i$  AND  $H$  SCALABILITY RESULTS: AUTONOMY

Autonomy Domain	n = 36 Scalability Coefficient $H_i$ (SE)	n = 45 Scalability Coefficient $H_i$ (SE)
I suggested to my student to choose their school.	.23 (.13)	.16 (.12)
I suggested to my student to get help in order to register for classes.	.42 (.10)**	.42 (.09)**
I suggested to my student to get disability accommodations.	.11 (.09)	.11 (.008)
I suggested to my student to arrange their schedule in order to manage the workload.	.38 (.16)***	.35 (.13)***
I suggested to my student to get up in the morning on their own.	.42 (.13)**	.39 (.11)***



I suggested to my student to get to school and/or classes on their own.	.30 (.14)***	.29 (.12)
I suggested to my student to manage time for homework and non-academic activities.	.53 (.15)*	.50 (.14)*
I suggested to my student to do his/her own laundry.	.28 (.13)	.23 (.12)
I suggested to my student to make his/her own meals or snacks.	.18 (.15)	.13 (.14)
I suggested to my student clean his/her own room.	.36 (.12)**	.30 (.09)**
I suggested to my student to practice good hygiene.	.53 (.15)*	.46 (.13)**
I suggested my student get plenty of rest every night.	.43 (.11)**	.40 (.10)**
I suggested to my student to maintain his/her own bank account.	.35 (.12)***	.26 (.12)
I suggested my student use and manage credit card to make purchases.	.30 (.17)***	.01 (.16)
I suggested to my student to self-advocate.	-.15 (.05)	.02 (.12)
I suggested to my student to set academic and or vocational goals.	.38 (.18)***	.35 (.15)***
Autonomy Domain	.31 (.11)***	.28 (.09)
KR-20	.84	.79

*Note:* For Mokken Scalability Coefficient: \* = strong scalability, \*\* moderate scalability, \*\*\*=weak

scalability; for Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative.

**TABLE 11**  
**AUTONOMY MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n = 36**

PPSASDS	Question	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Question	Qualtrics	Q23	Q24	Q25	Q26	Q28	Q29	Q30	Q32	Q33	Q34	Q36	Q37	Q39	Q40	Q42	Q43
1	Q23		.31	.54	.45	.45	.21	.08	.31	-.25	-.39	.08	.08	.59	.14	-.39	.54
2	Q24	.31		.71	.74	.74	.27	1	.20	.22	.36	.57	.57	.31	.36	-.29	.57
3	Q25	.54	.57		.61	-.16	-.24	-.09	-.29	-.04	-.09	-.09	-.20	.54	.43	-.09	.27
4	Q26	.45	.74	.61		.30	.26	.61	.23	.06	.42	.61	.28	.45	-.03	-.16	.61
5	Q28	.45	.74	-.16	.30		.50	1	.49	.06	.42	.61	.76	.45	-.03	-.16	.23
6	Q29	.21	.27	-.24	.26	.50		1	.27	.11	.38	.59	.38	.41	.27	-.24	.17
7	Q30	.08	1	-.09	.61	1	1		.57	.48	.46	.64	1	.08	.43	-.09	.27
8	Q32	.31	.20	-.29	.23	.49	.27	.57		.41	1	1	.38	.31	-.29	-.29	.14
9	Q33	-.25	.22	-.04	.06	.06	.11	.48	.41		1	1	.48	.06	-.06	1	.48
10	Q34	-.39	.36	-.09	.42	.42	.38	.46	1	1		1	1	.31	-.71	-.06	-.09
11	Q36	.08	.57	-.09	.61	.61	.59	.64	1	1	1		1	.54	-.14	-.09	.27
12	Q37	.08	.57	-.20	.28	.76	.38	1	.36	.48	1	1		.54	-.14	-.20	.60
13	Q39	.59	.31	.54	.45	.45	.41	.08	.31	.06	.31	.54	.54		-.03	-.39	1
14	Q40	.14	.36	.43	-.03	-.03	.27	.43	-.29	-.06	-.71	-.14	-.14	-.03		-.71	.43
15	Q42	-.39	-.29	-.09	-.16	-.16	-.24	-.09	-.29	1	-.06	-.09	-.20	-.39	-.71		-.09
16	Q43	.54	.57	.27	.61	.23	.17	.27	.14	.48	-.09	.27	.60	1	.43	-.09	

Scalability:  $.3 \leq Hij < .4$  is weakly scalable,  $.4 \leq Hij < .5$  is moderately scalable, and  $Hij \geq .5$  is strongly scalable

**TABLE 12**  
**AUTONOMY MOKKEN SCALABILITY FOR COEFFICIENT HIJ, (PAIRS OF ITEMS): n = 45**

PPSASDS	Question	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Question	Qualtrics	Q23	Q24	Q25	Q26	Q28	Q29	Q30	Q32	Q33	Q34	Q36	Q37	Q39	Q40	Q42	Q43
1	Q23		.18	.55	.32	.32	.15	.09	.24	-.34	-.36	-.02	.03	.50	.25	-.36	.32
2	Q24	.18		.57	.79	.79	.36	1	.14	.20	.57	.68	.63	.21	.28	.36	.68
3	Q25	.55	.57		.62	-.15	-.22	-.07	-.25	-.07	-.07	-.10	-.18	.56	.40	-.07	.27
4	Q26	.32	.79	.62		.42	.39	.62	.17	-.07	.23	.42	.21	.34	-.20	.42	.71
5	Q28	.32	.79	-.15	.42		.60	1	.38	-.07	.23	.42	.61	.34	-.20	.42	.42
6	Q29	.15	.36	-.22	.39	.60		1	.22	-.004	.19	.39	.31	.34	.10	.39	.39
7	Q30	.09	1	-.07	.62	1	1		.58	.46	.29	.63	1	.12	.40	-.07	.27
8	Q32	.24	.14	-.25	.17	.38	.22	.58		.46	.58	.69	.29	.27	-.20	-.25	.06
9	Q33	-.34	.20	-.07	-.07	-.07	-.004	.46	.46		1	1	.54	-.02	-.06	.20	.20
10	Q34	-.36	.57	-.07	.23	.23	.19	.29	.58	1		1	1	.12	-.20	-.07	-.10
11	Q36	-.02	.68	-.10	.42	.42	.39	.63	.69	1	1		1	.34	.10	-.10	.18
12	Q37	.03	.63	-.18	.21	.61	.31	1	.29	.54	1	1		.43	-.03	-.18	.41
13	Q39	.50	.21	.56	.34	.34	.34	.12	.27	-.02	.12	.34	.43		-.15	-.32	.67
14	Q40	.25	.28	.40	-.20	-.20	.10	.40	-.20	-.06	-.20	.10	-.03	-.15		-.80	.10
15	Q42	-.36	.36	-.07	.42	.42	.39	-.07	-.25	.20	-.07	-.10	-.18	-.32	-.80		.45
16	Q43	.32	.68	.27	.71	.42	.39	.27	.06	.20	-.10	.18	.41	.67	.10	.45	

Scalability:  $.3 \leq Hij < .4$  is weakly scalable,  $.4 \leq Hij < .5$  is moderately scalable, and  $Hij \geq .5$  is strongly scalable

### *Emotional/Stress Relief Items Mokken Scale Analysis*

There were no strong scalability items for the Emotional/Stress Relief Domain. Across both datasets, one item rated (.7%) moderately scalable between  $\geq .4$  but  $< .5$  while another four (29%) rated at the threshold for scalability at  $H_i \geq .3$  (see Table 13 below). When examined jointly for the dataset where  $n=36$ , a total of 48 pairs out of a possible 156 (31%) scored at or above .3, while 5 pairs scored 1 and another 17 scored strongly at  $\geq .5$ , yielding a total of 22 pairs out of a possible 156 (14%) rating strong scalability (see Table 14 below). For the larger group of 45 participants, 47 pairs out of 182 (26%) were at or above the scalability floor of .3, and among those 10 pairs scored 1 and another 19 pairs scored  $\geq .5$ , totaling 29 out of 182 (15%) with a strong scalability coefficient of  $\geq .5$  (see Table 15 below). Although the set of items across both datasets yielded the same value for  $H$  of .28, standard error differed between the two datasets. When  $n = 36$ , the standard error was .07, and was reduced to .06 when  $n = 45$  (see Table 13 below).

**TABLE 13**  
MOKKEN COEFFICIENT  $H_i$  AND  $H$  SCALABILITY RESULTS: EMOTIONAL/STRESS RELIEF

Emotional/Stress Relief Domain	n = 36 Scalability Coefficient $H_i$ (SE)	n = 45 Scalability Coefficient $H_i$ (SE)
I provided emotional support for my student.	.27 (.14)	.26 (.13)
I suggested to my student to get counseling on campus for managing depression, anxiety, and/or stress.	.36 (.09)***	.38 (.08)***
I found a counselor/therapist off-campus for my student to help manage depression, anxiety, and/or stress.	.27 (.11)	.17 (.10)
I helped my student manage depression, anxiety, and/or stress over financing their own education.	.33 (.10)***	.36 (.09)***
I addressed my student's depression, anxiety and/or stress by helping my student find scholarships/financial aid.	.27 (.11)	.28 (.09)
I relieved my student's depression, anxiety, and/or stress by supporting them financially.	.28 (.10)	.26 (.10)

I suggested to my student to take fewer classes than a full-time course load.	.25 (.11)	.22 (.10)
I suggested to my student to attend summer school.	.22 (.12)	.22 (.11)
I suggested to my student to concentrate solely on classes.	.19 (.16)	.21 (.14)
I suggested ways to my student to reduce sensory stress in their living environment.	.35 (.10)***	.37 (.09)***
I suggested to my student to work on problem management skills.	.34 (.11)***	.37 (.10)***
I suggested to my student exercise to manage depression, anxiety, and/or stress.	.43 (.09)**	.42 (.09)**
I suggested to my student to pursue their special interest (e.g., hobbies).	-.08 (.14)	-.07 (.14)
I engaged in troubleshooting problems with my student.	Omitted (no variability)	.19 (.04)
Emotional/Stress Relief Domain	.28 (.07)	.28 (.06)
KR-20	.74	.73

*Note:* For Mokken Scalability Coefficient: \* = strong scalability, \*\* moderate scalability, \*\*\*=weak

scalability; for Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative.

**TABLE 14**  
*EMOTIONAL/STRESS MOKKEN SCALABILITY FOR COEFFICIENT  $H_{ij}$ , (PAIRS OF ITEMS): n=36*

PPSASDS	Question	1	2	3	4	5	6	7	8	9	10	11	12	13
Question	Qualtrics	Q45	Q46	Q47	Q49	Q50	Q51	Q53	Q54	Q55	Q57	Q58	Q59	Q60
1	Q45		1	1	1	1	.28	-.44	-.1	-.29	-.33	.36	.36	.42
2	Q46	1		.69	.23	.35	.15	.15	.23	.41	.30	.61	.80	-.25
3	Q47	1	.69		0	.18	.09	.27	.11	0	.11	.50	1	.60
4	Q49	1	.23	0		.53	.82	.46	.11	.29	.56	.25	.50	-.20
5	Q50	1	.35	.18	.53		.42	-.16	.06	-.08	.53	.47	.74	.15
6	Q51	.28	.15	.09	.82	.42		.35	.27	.07	.36	.10	.46	-.15
7	Q53	-.44	.15	.27	.46	-.16	.35		.46	.53	.36	.46	.28	-.44
8	Q54	-.1	.23	.11	.11	.06	.27	.46		.43	.56	.50	.50	-.60
9	Q55	-.29	.41	0	.29	-.08	.07	.53	.43		.71	.36	-.29	-.54
10	Q57	-.33	.30	.11	.56	.53	.36	.36	.56	.71		.17	.50	-.07
11	Q58	.36	.61	.50	.25	.47	.10	.46	.50	.36	.17		.20	.23
12	Q59	.36	.80	1	.50	.74	.46	.28	.50	-.29	.50	.20		-.03
13	Q60	.42	-.25	.60	-.20	.15	-.15	-.44	-.60	-.54	-.07	.23	-.03	

Scalability:  $.3 \leq H_{ij} < .4$  is weakly scalable,  $.4 \leq H_{ij} < .5$  is moderately scalable, and  $H_{ij} \geq .5$  is strongly scalable

**TABLE 15**  
*EMOTIONAL/STRESS RELIEF MOKKEN SCALABILITY FOR COEFFICIENT  $H_{ij}$ , (PAIRS OF ITEMS): n=45*

PPSASDS	Question	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Question	Qualtrics	Q45	Q46	Q47	Q49	Q50	Q51	Q53	Q54	Q55	Q57	Q58	Q59	Q60	Q61
1	Q45		1	1	1	1	.34	-.50	-1.14	-.32	-.36	.38	.36	.44	-.05
2	Q46	1		0.61	.32	.38	.18	.10	.29	.47	.38	.67	.70	-.20	1
3	Q47	1	.61		-.02	.07	.11	.09	-.07	.04	.02	.35	.61	.61	1
4	Q49	1	.32	-.02		.51	.81	.46	.16	.31	.66	.32	.59	-.23	1
5	Q50	1	.38	.07	.51		.49	-.13	.08	-.13	.53	.58	.81	.25	-.88
6	Q51	.34	.18	.11	.81	.49		.32	.22	.04	.26	.12	.34	-.06	-.32
7	Q53	-.50	.10	.09	.46	-.13	.32		.43	.65	.25	.50	.25	-.50	-.50
8	Q54	-1.14	.29	-.07	.16	.08	.22	.43		.34	.64	.52	.57	-.71	1
9	Q55	-.32	.47	.04	.31	-.13	.04	.65	.34		.56	.41	-.32	-.59	1
10	Q57	-.36	.38	.02	.66	.53	.26	.25	.64	.56		.24	.59	-.09	1
11	Q58	.38	.67	.35	.32	.58	.12	.50	.52	.41	.24		.29	.25	-.25
12	Q59	.36	.70	.61	.59	.81	.34	.25	.57	-.32	.59	.29		-.03	-.29
13	Q60	.44	-.20	.61	-.23	.25	-.06	-.50	-.71	-.59	-.09	.25	-.03		-.13
14	Q61	-.05	1	1	1	-.88	-.32	-.50	1	1	1	-.25	-.29	-.13	

Scalability:  $.3 \leq H_{ij} < .4$  is weakly scalable,  $.4 \leq H_{ij} < .5$  is moderately scalable, and  $H_{ij} \geq .5$  is strongly scalable

### ***Reliability***

To triangulate measures of reliability, Heijden et al. (2003) compared MSA scalability results to Cronbach's  $\alpha$  for polytomous items in their examination of unidimensionality and reliability. They utilized Cronbach's  $\alpha \geq .70$  to confirm MSA scalability with the moderate level,  $H \geq .40$ , and the strong level at  $> .50$ . Similarly, in order to compare Mokken coefficients with KR-20, I produced Tables 17, 18, and 19 (below) to juxtapose the KR-20 score with Mokken levels of scaling for each set of items of the three domains measured through  $H$ .

For the Social Integration Domain, when  $n = 36$ , KR-20 = .80, but when  $n = 45$ , KR-20 = .76. The Autonomy Domain yielded a KR-20 score of .84 with  $n = 36$  while the KR-20 score was .79 when  $n = 45$ . The set of items within the Emotional/Stress Relief Domain yielded a KR-20 score of .74 when  $n = 36$  and a KR 20 score of .73 when  $n = 45$ . All KR-20 scores fell within the strong range for reliability.

### **Qualitative Data Analysis**

#### ***Open-Ended Text Response Rates***

Open-ended text responses were embedded within each set of dichotomous items for each domain. There were four questions that were embedded within the Social Integration Domain, five questions among the Autonomy Domain items, and four questions within the Emotional/Stress Relief set of items. Overall, eight parents (18%) responded to all of the 14 open-ended questions, and 20 parents (44%) responded to at least 50% of the questions. The highest response rate was 42% for the first domain queried, Social Integration. The second domain was Autonomy with a 39% response rate, and Emotional/Stress relief was the final domain examined with a 38% response rate. For the final open-ended question which asked

parents if they had anything to add, 44 out of 45 parents (98%) submitted an informative response (see Figure 2 below).

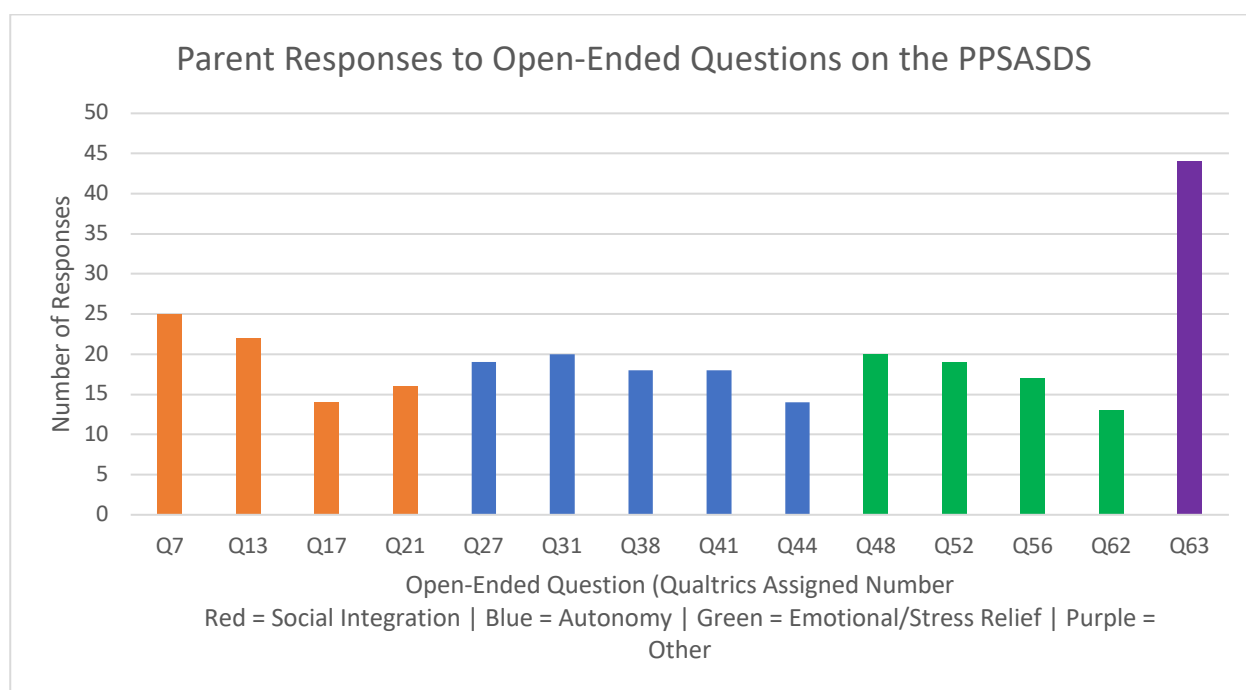


Figure 2. Parents' demonstration of consistent engagement through textual response

### ***Results from Grounded Theory Analysis***

Writing memos allowed me to see parent comments that were related, so related comments were grouped together according to concept. The conceptual groupings were translated into labels, and those labels constructed the themes. For example, some comments for question 17 were conceptually grouped as “making friends – encouraged to make friends” and this group included the following text:

Encouraged him to make friends

Most of his friends he met thru first responders.

My son would only spend time between classes by himself or with 1 or 2 people he was friendly with



Not only was my student encouraged by my suggestions to engage socially with his peers, his teammates also included him & encouraged it as well.

He made some friends through band and other subjects.

“Making friends – encouraged to make friends” was ascribed the label, “Social Integration.”

Question 63 included comments such as

We bought time management supplies such as planners and wall calendars for him to track assignments.

We monitored his emails to make sure he was aware of group project meetings--this was because for a long time he wasn't reading emails and failed a class due to not meeting project deadlines.

We constantly reminded him to check in with his case manager at the disabilities office to make sure he was getting assistance as needed.

These text responses generated the memo “academic support through executive function fostering.” Academic support was a recurring theme, and executive function fostering was among many concepts related to the Management label.

Other themes included teaching financial management, financial support, supporting counseling needs, social problems and social stress, help with transportation, and commuting, Autism Program, self-care, anxiety, depression, stress, stress relief, supporting autonomy, and goal setting (see Table 16 below)

<b>Table 16</b>	
<b>OPEN-ENDED QUESTIONS THEMES</b>	
<b>Question Number</b>	<b>Themes</b>
Q7	Commuting Avoiding social stress
Q13	Social Integration

Q17	Social integration Social problems Academic Support
Q21	Social integration Autonomy Counseling Academic Support
Q27	Academic Support (including academic stress relief) Management (functional skills) Autonomy Autism program
Q31	Management (functional skills) Autonomy achieved Transportation help Autism Program
Q38	Parent fostered skills before college Self-care autonomy Self-care fostered/supported
Q41	Money, finances Teaching skills Management
Q44	Supporting autonomy, goal setting, academic goals Autism program replacing parent support
Q48	Anxiety, depression, stress Therapy, counselors Autonomy
Q52	Overwhelmed physically and socially Parents providing financial support out of duty
Q56	Academic stress relief Stress relief in general Supporting autonomy Self-care Autonomy
Q62	Stress relief strategies

	Talking, interests, academic stress relief by extending time to finish school
Q63	Academic support Vocational Support Autonomy -driving Stress relief-Emotional and moral support TYPES OF HELP: Help with organizing Help with communication Financial support Provided transportation Autism program

---

### ***Results from ATLAS.ti Analysis***

According to ATLAS.ti, Autonomy registered number one with a count of 102, Stress Relief came in second with 81 comments, Academic support scored in third place with 48 comments, in fourth place Social Integration and Management Activities both scored the same with 46 comments, followed by Financial Management with 35 comments. In order of frequency, other comments scoring in the double digits were labeled Leisure Activities (24), Self-Care (23), Self-Regulation (16), Commuting and Disability Resource Center Guidance (15), Vocational (11), and Goal Setting (10).

Another spreadsheet that I generated through ATLAS.ti allowed me to see the cooccurrence of labels and their frequency. For example, Autonomy plus Management Activities had the highest frequency of cooccurrence at 28, followed by Academic plus Stress Relief with 23. Other high frequency intersections included Autonomy plus Stress Relief (22), Autonomy plus Financial Management (19), Financial Management plus Management Activities (18), Autonomy plus Self-Care (17), Social Integration plus Autonomy (13), Management Activities plus Academic (11), and Autonomy plus Academic (10). These cooccurrences indicated the overlap of themes within parents' text responses. They also provide more qualitative information

about the label, rather than viewing the label in isolation, thereby providing more information about emerging themes.

Utilizing ATLAS.ti, I produced a document of quotations along with the labels that I had assigned through that computer program. I compared results of that output with the labels on the spreadsheets I created for qualitative analysis. For example, I grouped most of the statements for Question 7 under the theme of “living at home” and “commuting.” These included comments such as, “Decided he would go to school from home,” “He did not want to live on campus and chose a college he could commute to,” “My student is attending community college so housing is not available,” “My child who started college attends a commuter college and commutes to the school from home,” and “My son attends a local college. No reason to dorm although it is an option available.” Commuting is a high-frequency label assigned to these quotations through ATLAS.ti, which confirms the theme I found by grouping the comments from different responses.

Accordingly, through the comparison of the two methods, I found concordance among labels and themes. Through the grouping of comments, the labels that I assigned included commuting, social integration, social problems, academic support, autonomy, management (functional skills), self-care, academic stress relief, financial management, stress relief, and help (finances, transportation, organizing, communication, academic), and Autism programs. The last open-ended question asked, “*In what other ways have you supported your student at their college or university?*” resulted in parents underscoring the types of help that they were providing their students such as academic, emotional, organizing, communication, financial, and transportation help.

ATLAS.ti contributed quantification and intersections of the different labels, thereby providing links between the different relationships among the domains being surveyed as well as the new themes that emerged. In general, the text exposed parent support that were supplemental to Social Integration, Autonomy, and Emotional/Stress Relief such as Academic Support, four subthemes of Autonomy including Commuting, Management (functional skills), Financial Management and Self-Care, Emotional/Stress Relief, and themes of help including Financial Support, Transportation, Organizing, Communication, and Academic. Similarly, based on ATLAS.ti, Autonomy is the thread that binds together many of the themes such as functional skills, financial management skills, self-care, academics, commuting.

### **Data Merging**

According to ATLAS.ti, Autonomy registered the highest label count at 102, and it is also the domain with the highest average item score of .83, the only domain to fall within the strongly positive range,  $\geq .81$ , when  $n = 45$ . Among open-ended embedded responses, Autonomy registered second with a 40% response rate. Additionally, Autonomy is associated with the highest score for internal consistency among items with a KR-20 score of .79 when  $n = 45$  (.84 when  $n = 36$ ). While the  $H$  coefficient for Autonomy scored at .31 for  $n = 36$ , its score of .28 when  $n = 45$  reaches scalability if rounded to tenths at .3 (see Table 17 below).

Social Integration scored the highest response rate to open-ended embedded questions at 42%. In addition, Social Integration dichotomous items yielded a positive average of .64 when  $n = 45$ , and .63 when  $n = 36$ . For internal consistency, Social Integration items scored strongly with a KR-20 score of .76 when  $n = 45$  and .80 when  $n = 36$ . For the scalability coefficient,  $H$ , the Social Integration set of items scored in the moderate range of .4 when  $n = 36$  and .39 when  $n = 45$  (.4 if rounding to tenths) (see Table 18 below).

Emotional/Stress Relief scored in third place among the question response rates at 38%, and third for KR-20 strength at .73 when  $n = 45$  and .74 when  $n = 36$ , still strong numbers for internal consistency. Although Emotional/Stress Relief item average scores were less than that of Autonomy, the domain scored higher averages than Social Integration, at .69 when  $n=45$  and .68 when  $n = 36$ . The Emotional/Stress Relief scores for the scalability coefficient  $H$  were the same when  $n = 36$  or  $n = 45$ , at .28, scores which, if rounded to tenths at .3, would reach the bottom threshold for scalability (see Table 19 below).

### **Validity**

According to Creswell and Creswell (2018), validity of convergent methods should be predicated on quantitative construct validity and qualitative validity through triangulation. These requirements for this convergent mixed methods study have been achieved. All three domains chosen for examination, Social Integration, Autonomy, and Emotional/Stress Relief were associated with strong participation support by parents. According to ATLAS.ti, Autonomy registered number one with a count of 102. Similarly, Autonomy was the Domain with the highest item average of .83, so parents responded similarly to dichotomous questions as well as open-ended responses. Stress Relief came in second with 81 comments, and Emotional/Stress Relief also scored second highest for its item average of .69. Social Integration was a label that was less frequent than both Autonomy and Social Integration, and it also scored third according to the item average computation with a score of .64. All three Domains rated high for internal consistency as measured through KR-20: .76 for Social Integration, .79 for Autonomy, and .73 for Emotional/Stress Relief. Scalability for coefficient  $H$  for all Domains would be scalable if rounded to tenths, with Social Integration moderately scalable at .4 (see Tables 17, 18, 19 below).

## External Validity

Although this investigation had 45 participants, the results were similar to that of the pilot study with only five participants. For example, Autonomy was still the domain with the stronger item average of .83 across 45 participants through 16 items that measured Autonomy. On the pilot PPSASDS there were 14 items that yielded an average score of .81 across five participants. Accordingly, for both studies, the Autonomy scores ranked strongly positive, indicating that parents strongly agreed with each other through their responses to the items.

Similarly, within the Social Integration Domain, results were similar for both studies even though the newer version of the PPSASDS has 15 items while the pilot version had 14 items. For example, in this study where  $n=45$ , the item average score was .64. This compares with the item average of .69 on the pilot study with five participants. Both scores are in the positive range the studies.

This research validated the results of the pilot study that found Emotional/Stress Relief was a theme meriting further examination. With a positive item average score of .69, Emotional/Stress Relief was an important domain of participation among parents of postsecondary students with ASD. Parents provided talk therapy and therapists to their students. Students experienced academic stress, so parents sought ways to relieve stress by ensuring students took a reduced course load, extended the length of time that students had to finish their degrees, had their student switch schools so they could attend a school with better supports.

Finally, two of the domains surveyed here, Social Integration and Autonomy, were regarded as the most significant challenges and needs in another study of parents of postsecondary students with ASD (Elias & White, 2017), underscoring the need for further examination. Additionally, the conceptual lens for this research was rooted in the role of Social

Integration in Tinto's (1975) model of retention as well as autonomy, a domain of Wehmeyer's (1999) model of self-determination. The literature is rich with evidence of the importance of these two domains for students with and without disabilities. This study adds to the literature by explaining how parents coached their postsecondary students with ASD so they could achieve social integration and autonomy.



**TABLE 17**  
**AUTONOMY DATA COMPARISON**

Autonomy Domain	n = 36 Scalability Coefficient <i>Hi</i> (SE)	n = 45 Scalability Coefficient <i>Hi</i> (SE)	Average Score n=36	Average Score n=45
I suggested to my student to choose their school.	.23 (.13)	.16 (.12)	.72	.73
I suggested to my student to get help in order to register for classes.	.42 (.10)**	.42 (.09)**	.78	.78
I suggested to my student to get disability accommodations.	.11 (.09)	.11 (.008)	.92	.93
I suggested to my student to arrange their schedule in order to manage the workload.	.38 (.16)***	.35 (.13)***	.86	.87
I suggested to my student to get up in the morning on their own.	.42 (.13)**	.39 (.11)***	.86	.87
I suggested to my student to get to school and/or classes on their own.	.30 (.14)***	.29 (.12)	.81	.82
I suggested to my student to manage time for homework and non-academic activities.	.53 (.15)*	.50 (.14)*	.92	.93
I suggested to my student to do his/her own laundry.	.28 (.13)	.23 (.12)	.78	.80
I suggested to my student to make his/her own meals or snacks.	.18 (.15)	.13 (.14)	.64	.62
I suggested to my student clean his/her own room.	.36 (.12)**	.30 (.09)**	.94	.93
I suggested to my student to practice good hygiene.	.53 (.15)*	.46 (.13)**	.92	.91
I suggested my student get plenty of rest every night.	.43 (.11)**	.40 (.10)**	.83	.84
I suggested to my student to maintain his/her own bank account.	.35 (.12)***	.26 (.12)	.72	.76

I suggested my student use and manage credit card to make purchases.	.30 (.17)***	.01 (.16)	.58	.56
I suggested to my student to self-advocate.	-.15 (.05)	.02 (.12)	.97	.96
I suggested to my student to set academic and or vocational goals.	.38 (.18)***	.35 (.15)***	.92	.91
<hr/>				
Autonomy Domain	.31 (.11)***	.28 (.09)	.77	.83
<hr/>				
KR-20	.84	.79	(.81 pilot average)	

*Note:* For Mokken Scalability Coefficient: \* = strong scalability, \*\* moderate scalability, \*\*\*=weak scalability; for Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative

**TABLE 18**  
SOCIAL INTEGRATION DATA COMPARISON

Social Integration Domain	n = 36 Scalability Coefficient <i>H</i> <sub>i</sub> (SE)	n = 45 Scalability Coefficient <i>H</i> <sub>i</sub> (SE)	Characteristics of Parent Support	
			Average Score n=36	Average Score n=45
I suggested to my student to live on campus.	.19 (.14)	.27(.12)	.50	.56
I suggested to my student to have a roommate.	.43 (.15)**	.45 (.12)**	.19	.22
I suggested to my student to join a fraternity/sorority.	Omitted (no variability)	Omitted (no variability)	0	0
I suggested to my student to attend summer school before he/she started his/her freshman year.	.19 (.18)	.26 (.15)	.33	.33
I suggested to my student to attend the college orientation program before he/she started his/her freshman year (if it was available).	.41 (.25)**	.20 (.25)	.94	.93
I suggested to my student to use campus meal plan.	.27 (.12)	.26 (.12)	.50	.58
I suggested to my student to attend campus activities (including arts, political, and social).	.65 (.02)*	.65 (.02)*	.94	.96
I suggested to my student to attend sporting events on campus.	.32 (.11)***	.28 (.11)	.44	.47
I suggested to my student to belong to clubs (and/or extramural activities) on campus.	.53 (.14)*	.55 (.11)*	.92	.91
I suggested to my student to make new friends on campus.	.62 (.11)*	.60 (.11)*	.92	.93
I suggested to my student to attend activities with friends on campus.	.70 (.10)*	.68 (.09)*	.83	.84

I suggested to my student to get together with a friend(s) on campus.	.70 (.11)*	.68 (.10)*	.86	.87
I suggested to my student to sit with friend(s) in his/her classes.	.28 (.12)	.25 (.11)	.50	.49
I suggested to my student to work with other students in class.	.36 (.15)***	.32 (.14)***	.81	.82
I suggested to my student to find a study group on campus in order to socialize.	.49 (.14)**	.46 (.12)**	.72	.69
Social Integration Domain	.40 (.09)**	.39 (.08)	.63	.64
	KR-20	.80	.76	(vs .69 pilot average)

*Note:* For Mokken Scalability Coefficient: \* = strong scalability, \*\* moderate scalability, \*\*\*=weak scalability; for Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative. neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative.

**TABLE 19**  
EMOTIONAL/STRESS RELIEF DATA COMPARISON

Emotional/Stress Relief Domain	n = 36 Scalability Coefficient <i>Hi</i> (SE)	n = 45 Scalability Coefficient <i>Hi</i> (SE)	Average Score n=36	Average Score n=45
I provided emotional support for my student.	.27 (.14)	.26 (.13)	.94	.96
I suggested to my student to get counseling on campus for managing depression, anxiety, and/or stress.	.36 (.09)***	.38 (.08)***	.64	.67
I found a counselor/therapist off-campus for my student to help manage depression, anxiety, and/or stress.	.27 (.11)	.17 (.10)	.50	.51

I helped my student manage depression, anxiety, and/or stress over financing their own education.	.33 (.10)***	.36 (.09)***	.50	.49
I addressed my student's depression, anxiety and/or stress by helping my student find scholarships/financial aid.	.27 (.11)	.28 (.09)	.47	.53
I relieved my student's depression, anxiety, and/or stress by supporting them financially.	.28 (.10)	.26 (.10)	.69	.76
I suggested to my student to take fewer classes than a full-time course load.	.25 (.11)	.22 (.10)	.69	.67
I suggested to my student to attend summer school.	.22 (.12)	.22 (.11)	.50	.47
I suggested to my student to concentrate solely on classes.	.19 (.16)	.21 (.14)	.39	.38
I suggested ways to my student to reduce sensory stress in their living environment.	.35 (.10)***	.37 (.09)***	.75	.73
I suggested to my student to work on problem management skills.	.34 (.11)***	.37 (.10)***	.78	.80
I suggested to my student exercise to manage depression, anxiety, and/or stress.	.43 (.09)**	.42 (.09)**	.78	.78
I suggested to my student to pursue their special interest (e.g., hobbies).	-.08 (.14)	-.07 (.14)	.86	.89
I engaged in troubleshooting problems with my student.	Omitted (no variability)	.19 (.04)	1	.98
Emotional/Stress Relief Domain	.28 (.07)	.28 (.06)	.68	.69

KR-20      .74      .73

*Note:* For Mokken Scalability Coefficient: \* = strong scalability, \*\* moderate scalability, \*\*\*=weak scalability; for Item Averages, .81 to 1 = strong positive, .61 to .80 = positive, .51 to .60 = neutral/positive, .50 = neutral, .40 to .49 = neutral/negative, .39 to .20 = negative, .19 to 0 = strong negative.

## V. DISCUSSION

Through the conceptual lens of Tinto (1975) and Wehmeyer (1999), I structured my original pilot study to examine parent participation in the postsecondary education of their students with ASD based on their support of Social Integration and Autonomy, informed by the support I provided when my son was a postsecondary student. As a result of the pilot study, I found evidence of such support and learned that parents were also supporting Emotional/Stress Relief. This was worthy of further examination given that many individuals with ASD experience cooccurring depression, anxiety, ADHD, and other neurological disorders (Matson & Williams, 2013; Mosner et al., 2019).

For those of us who played an active role in the academic lives of our students throughout primary and secondary school, it seems probable that we would continue to play a similar role in the postsecondary lives of our students as well. As parent partnership is a mandated best practice through IDEA, it is a logical extension of that practice which may lead parents into active postsecondary participation. With students with ASD losing most of the individualized accommodations and modifications from their IEP that contributed to their success prior to college, the continued need for parental support is underscored.

### **Persistence**

When I launched this investigation, I hoped parents would be willing to take the time to provide detailed responses to the open-ended questions. They went well beyond what I had hoped for. As I proceeded through the process of collecting, reading, analyzing, and presenting the findings, an unexpected outcome from this research emerged. I realized there was a connection between parents' fostering of persistence and their own persistence, whether it was

spending time providing rich textual responses to open-ended items on the PPSASDS survey or their willingness to do whatever it takes to ensure their students' persistence.

Parents' persistent participation does not end with high school. Parents in this study were involved in high school and attended IEP meetings (43 out of 45), participated in their student's transition to college planning (29 out of 45), and their participation continued through postsecondary education. They demonstrated another level of involvement by participating in this research and by persisting until the end of the survey. This persistent behavior is likely consistent with parents who have actively participated since their child's primary education and have opted to extend their participation into postsecondary education.

With respect to the survey for this study, parents demonstrated commitment to the process by providing me with information about their experiences. Apparently, they did not suffer survey fatigue, given their completion of 45 questions on the PPSASDS, 14 of which are open-ended responses, plus 16 questions included with the demographic questionnaire, totaling 75 questions in all. One parent wrote volumes and spent two hours engaged in the survey response. This attribute of persistence was evident in student persistence as parents reported that 10 out of 45 of their students completing at least a bachelor's degree. These parents do not give up easily, nor do their students.

While Tinto's (1975) model was based on an examination of students, through this research, parents were studied and found to demonstrate the attributes of persistence and commitment which they, in turn, modeled for their students. Parents in this study demonstrated commitment, which underlies persistence in Tinto's (1975) model based on students. They made a financial commitment as evidenced by 35 out of 45 parents (75.6%) investing in their student's

college education. They had an emotional commitment to their student's success, so they were also investing in the time they spend accommodating their student's needs.

Tinto's model also takes into account the role of the family, in particular the socioeconomic status of student families. He noted that students from wealthier families are more likely to persist, but income alone is not the sole factor. Instead, Tinto (1975) underscored the role of parent's level of education along with their expectations of persistence on the part of their student. In this study, while 48% of parents reported income of \$100,000 or more, 52% had income of less than \$100,000, including 5 parents (12%) with income of less than \$30,000. Consistent with Tinto's (1975) note about parents' education, 87% of the parent participants in this study completed at least a 2-year college degree, and among this group, 42% held a graduate degree. Accordingly, parents were well-educated, and they expected achievement from their students. The attribute they shared is the expectation that their student would succeed. Thus, with their knowledge of their students' needs, they persisted in a participatory role to ensure success and persistence.

### **The PPSASDS**

The first objective of this study was to learn if the PPSASDS is a reliable measure for assessing parent involvement with postsecondary students with ASD." Based on the item averages and reliability signaled through strong KR-20 scores, the instrument demonstrated internal validity, and it was therefore a reliable measure for assessing parent involvement with their postsecondary students with ASD. For the Social Integration Domain, the KR-20 was .76. The Autonomy Domain yielded a KR-20 score of .79, and the set of items comprising the Emotional/Stress Relief Domain yielded a KR-20 score of .73. All KR-20 scores fell within the strong range for reliability.



## Parent Participation

The response to the second question, “How parents support social integration, autonomy, and emotional/stress relief?” is clear. It is the parent who provided the college Individualized Education Program to shore up the gaps created by the generic postsecondary services that may not fully accommodate the needs of their student. For example, parents fostered social integration by suggesting to their student to attend campus activities, to join clubs on campus, to make new friends on campus, and to attend campus activities with their friends. They nurtured autonomy by suggesting their student self-advocate, set academic and vocational goals, practice self-care independently, manage time for homework and non-academic activities, choose their school, and seek help for registering for classes. To provide Emotional/Stress Relief, parents confirmed they provided emotional support for their students, suggested they get campus counseling to cope with depression, anxiety, or stress, helped troubleshoot problems with them, suggested their student pursue their hobbies and exercise for stress relief, and supported them financially to relieve depression, anxiety, or stress. This was triangulated through an item average of .76 with the demographics score of 78% of parents who partially or fully paid for college. Additionally, parents provided academic stress relief by suggesting students reduce their course load.

Accordingly, parent participation was particular to the needs of their student, providing support that went beyond the purview of Disability Resource Centers, and even Autism programs. Although the last 8 out of the total 45 participants had students in the same college Autism program, the average item scores had modest increases in all three domains when the sample size increased: the Social Integration item average increased from .63 to .64, the Autonomy item average increased from .77 to .83, and the Emotional/Stress Relief item average

increased from .68 to .69. While one might expect that autonomy in particular might decrease if students participated in an Autism program, it is surprising to see that Autonomy was the domain with the greatest item average increase. So, despite the cost of Autism programs (and a few parents reporting that their participation is discouraged by some programs), parents were still not completely ceding support to others. Coincidentally, Autonomy was the domain with the biggest shift in other measures, as well, when sample size increased to 45 participants as a result of eight additional parents participating with students in the same program. The decline in the H coefficient for scalability was reduced by .03 and confirmed through the KR-20 measure for internal consistency which dropped by .05. This is a very small change but suggests a trend in the data which implies that, while more parents agreed more with each item of support (and each other), as indicated by the individual item averages, their consistency among types of support within the domain changed relative to the first group when  $n=36$ . To illustrate this, there was a perfect score of 1 for 13 joint items when  $n=36$ , but there were only 9 joint items scoring 1 when  $n=45$ . For strong scalability of  $>0.5$  for *Hij*, that measure of joint items dropped from 23 pairs when  $n=36$  to 21 pairs when  $n=45$ . Additionally, moderate scalability joint items of  $\geq 0.4$  declined from 16 pairs when  $n=36$  to 13 pairs when  $n=45$ . Most of the decline resulted in an upward shift to weakly scalable where  $Hij \geq 0.3$  increased from 11 pairs when  $n=26$  to 15 pairs when  $n=45$ . Finally, unscalable items increased by 5 pairs.

### **Intersecting Themes of Participation**

The third research question asked, “in what other ways do parents support their postsecondary students with ASD?” This question is best answered through an examination of the intersecting themes of participation that branch out from the original three domains. The

cooccurring themes form a web of support that is woven into the three domains queried in this study.

When I examined the domains of Social Integration, Autonomy, and Emotional/Stress Relief through this study, I found new themes as well as relationships between themes and the three domains. For example, Autonomy plus Management Activities had the highest cooccurrence frequency, and this underscores the critical relationship between independence and executive function. Autonomy requires the acquisition of Executive Function skills, and parents were primarily compensating for and fostering these skills if we compare the scores of highest frequency label (102) with highest item average (.83) and highest KR-20 score (.79). The expectation that students with ASD should have achieved functional autonomy on par with neurotypical peers by the time they reach college was expressed by a university staff member in the Dymond et al. (2017) study. This is an errant assumption, which parents understand, and prompts them to aggressively foster functional independence, as one parent expressed surprise (I didn't think he'd manage, but mostly he did.") while another expressed relief ("He has done great advocating for himself after a VERY bumpy first semester... I couldn't jump in too much. [it is a 4-hour plane ride away from us]"). The delay in the acquisition of Executive Function skills is further supported by evidence from neuroscience (Demetriou et al., 2018; Luna et al., 2007). There is a developmental delay in the region of the brain that processes skills associated with executive function (Luna et al., 2007). A meta-analysis of Executive Function in ASD found that across studies, individuals with ASD performed significantly worse than neurotypical controls (Demetriou et al., 2018). Accordingly, students with ASD are arriving on campus without fully developed Executive Function skills, and parents are responding to this

developmental need by continuing to teach these skills on an individualized basis according to the needs of their student.

The next highest cooccurrence was Autonomy plus Stress Relief, because parents were helping their students to figure out ways to independently relieve stress, essentially fostering independent emotional regulation. Independent stress relief takes many forms including academic stress relief through independently managing course load (“The most classes he takes is 2 each semester,” “After failing classes the first year, we settled on a three-course load,” “We only suggested a smaller caseload [sic] after he didn’t pass his classes first semester freshman year,” and “He is taking a reduced work load next semester as he has realized he took on too much.”). Additionally, parents encouraged students to find stress relief on their own (“He found his own off-campus therapist,” and “He found a very good counselor and she was very helpful.”) and suggested outlets for stress management (“My student found a bowling team to help him manage stress,” “proximity provided stability and reduced stress and worries,” “I encouraged my child to maintain his religious beliefs and participate in the religious community near his... campus,” “I have always suggested different techniques, exercises & other tools to assist my student in dealing with his sensory issues,” and “He gets plenty of exercise. He pursues his special interest.”).

With the next highest cooccurrence, Autonomy plus Financial Management followed by Financial Management plus Management Activities, parents were tutoring their students in financial literacy for independent functioning (“We talk a lot about budgeting,” “Managing finances is a work in progress!”, and “He has to maintain his budget with the help of a college coach.”). Budgeting, for example, is a kind of planning activity for allocation of income. Paying bills on time tasks working memory and is an important organizational activity that requires an

understanding of budgeting. Additionally, money management is an important acquisition as one moves on to a job which facilitates financial independence after college. Students needed to develop executive function skills associated with independent financial management, and parents were consciously fostering development while sometimes lamenting over students' inability to understand money ("...she doesn't grasp the concept of money," "He spends all of the money he makes through an on-campus job as a teaching intern on fishkeeping, his special interest," and "Very poor at money management. He does have a credit card, but I hold onto it except for specific situations.") With executive function developmentally delayed in ASD, parents are concerned about their students' ability to achieve financial independence, so they are teaching it ("I suggested that my student only use a debit card not credit. Do not want him to be in debt.").

Additionally, the other cooccurring labels involved different types of autonomy and executive function: Autonomy plus Self-Care, Social Integration plus Autonomy, Management Activities plus Academic, and Autonomy plus Academic. For example, parents fostered independent hygiene ("He has a shower schedule.") and supported social integration (I suggested that my son join clubs to find peers with common interests" and "There were all sorts of opportunities to socialize,"). They monitored academic management activities ("My student had no problem keeping his schedule") and promoted academic autonomy ("I wanted him to choose his school based on his comfort level," "Allowing him the experience of attending classes & other pursuits teaches him how to manage & navigate more than one thing" and "My student loved the independence of living on campus"). Thus, parents open-ended responses provided evidence for how the themes of participation intersected.

The unifying theme within this study is autonomy owing to its redundancy associated with labels of parent participation. If one examines autonomy more closely, what emerges is its

role as one of the four domains associated with Wehmeyer's (1999) functional model of self-determination, which provided the conceptual lens for autonomy in this investigation. Through a review of Wehmeyer's model, one begins to see how Autonomy threads together all the other domains associated with the Self-Determination Model including Self-Regulated Behavior, Psychological Empowerment, and Self-Realization. All of the domains and themes in the study deconstructed into subthemes of the model, whether it was self-regulation through problem solving ("We have encouraged independence and problem solving on his own"), psychological empowerment through social inclusion ("I hope this year she will join a club"), or self-realization through helping students capitalize on their strength (I try to support my child in every way possible with regards to her higher education including advising her on getting her master degree in teaching math").

### **Overarching Theme of Participation**

The final research question asked, "through merging results, generally what does parent participation look like?" Through deconstructing all of the data yielded quantitatively and qualitatively item by item and line by line, and then merging all of the data together, the overarching theme of parent participation was the fostering of all the skills associated with self-determination. Accordingly, one could generalize results as parent participation characteristics translated into fostering self-determination. Wehmeyer's (1999) model of self-determination deconstructs Autonomy into an array of characteristics such as self- and family care, management functions, recreational, social, and vocational activities, in addition to the other features of the self-determination model such as regulated behavior, coping with stress, social inclusion, self-realization, as well as goal setting, problem solving, and self-regulation. Parents were supporting all of these skills associated with self-determination. Parents wrote about all

these topics, perhaps not enough to constitute a major theme for each, but taken as a whole, these were the types of supports parents reported on, whether through answering yes or no questions, or providing a textual response. Parents coached students to go on to graduate school (self-realization), taught their students budgeting (management functions), helped them utilize services offered through Disability Resource Centers (use of community resources), or suggested counseling and reducing academic load to relieve stress. Thus, parents' support incorporated every aspect of the self-determination model. Largely, parents were compensating for a lack of these skills by coaching them, each according to the specific needs of their student.

Committed and persistent, parents' behavioral characteristics fit Tinto's model (1975) with its emphasis on commitment and persistence through graduation, attributes which they modeled for their students. While they were committed to fostering social integration of their students, parents understood that achieving autonomy and other self-determination skills would be integral to success once their student graduates, so they were persistently coaching their students. In other words, they were preparing their students for life after graduation.

## **Implications for Future Research**

### ***The Instrument***

While results triangulated, with even stronger triangulation if Mokken scalability  $H$  scores were rounded to tenths, the PPSASDS can still be improved both in terms of scalability and standard error, which should continue to be reduced as sample size increases. MSA was utilized in conjunction with this instrument's construction, and the scalability coefficient,  $H_{ij}$ , yielded by joint items, implied that a continued honing of the instrument and paring of pairs with negative coefficients might improve internal consistency. Negative coefficients signaled lack of monotonicity, an assumption for nonparametric items. This suggests removal from the set of

items. Through item winnowing, scalability might improve from weakly scalable or moderately scalable to strongly scalable coefficients. Accordingly, the PPSASDS warrants further refinement and testing with a larger sample size.

### ***Closing Gaps***

Further research is needed to fill the gap in transition *from* postsecondary education, one which is important to fill in order to improve postsecondary outcomes and employment among individuals with ASD who hold college degrees. Additionally, understanding how parents may be involved with promoting successful transition should also be examined. Compared with the considerable body of research examining parents from birth through high school, there is still much research to be done examining the participation of parents as they continue to coach self-determination skills as their children with ASD matriculate from postsecondary education to careers, further education, and community life.

### **Implications for Practice**

The results from this study may contribute to a greater understanding of the support needs of postsecondary students with ASD as well as inform coursework designed to accommodate the developmental needs of students with ASD. Autism programs as well as postsecondary institutions in general could implement a course based on Tinto's (1975) model of social integration and Wehmeyer's (1999) model of self-determination. These skills should be taught directly to students with ASD and could be administered as part of a transition program or a foundational course during the school year.

### **Limitations**

The participants in this study, according to self-reported data, were predominantly higher income, with 48% of participants reporting income of \$100,000 or more, and White females



(n=36) from east of the Mississippi River where 89% of participants were located. Hence, one cannot generalize findings across populations of parents, particularly with the underrepresentation of Asians and African Americans and no representation among other traditionally underrepresented groups of Americans. Whether or not geographic location in the United States would have an impact on parent responses is hard to discern here, but the participation skew was eastward, so a large swath of the country was not proportionally represented.

It is also important to underscore that autism prevalence rates in the United States among whites, blacks, and Latinos differ, with blacks and Latinos under-identified relative to whites. In this study, however, the proportion of white parents participating is significantly greater than prevalence data would imply. According to the CDC (2018) data, 51% of the children identified with ASD are white, 22% are black, 21% are Hispanic, and 5% are Asian. As reported in this inquiry, there were 84% white, 9% black, 5% Hispanic, and 2% Asian participants, resulting in an underrepresentation of minority parents.

Additionally, although sample size proved sufficient for this study, a larger sample size would be optimal and could be expected to reduce the standard error which occurred when participants increased from 36 to 45. Moreover, there were items on the current version of the PPSASDS that failed the monotonicity test as evidenced by negative values for the scalability coefficient *Hij*. It will be important to pare the instrument of negative pairs and retest with the improved instrument across a larger sample size, optimally with better geographic and demographic representation.

## Conclusion

As Wehmeyer (2014) underscored, self-determination is a family affair, and the role of parents has been underexamined in terms of how they promote self-determination among their children with disabilities. This study helped to fill in some of the gap by explaining parent participation in the postsecondary education of their students with ASD within the context of promotion of self-determination skills.

Parents of postsecondary students foster the acquisition of self-determination skills due to the relationship between self-determination and executive function related to organization, planning, self-regulation, working memory, decision making, stress management, and self-awareness. The developmental delay in the maturation of executive function implies that the acquisition of some self-determination skills may still be in progress as students with ASD reach postsecondary schools, and this developmental delay may continue to be a lifelong challenge for some individuals with ASD (Demetriou et al., 2018; Luna et al., 2007). Parents help organize, remind, assist in goal setting, decision making, problem-solving, and they provide strategies for social integration and the utilization of community resources. At the same time, they are providing an important intervention at the time it may be needed the most to facilitate development, late adolescence/early adulthood (Luna et al., 2007).

Given the delay in neurological maturation associated with executive function and how parents address this developmental need, it may be that parent participation across the academic life of students with ASD is a best practice. Parents understood the specific needs of their students, and they were able to provide help that postsecondary institutions may not have available, particularly support related to direct instruction of self-determination skills. Simply stated, the hypothesis for this study proved correct: parents were filling in the gap of services

created by the shift from IDEA (2004) in high school to the generic accommodations and modifications available at postsecondary institutions provided as a civil right through the Rehabilitation Act of 1973 and the ADA of 1990. With the escalating cost of postsecondary education, parent participation may also be a cost-effective solution to providing individualized support for students with ASD from both the standpoint of parents and institutions.

As more students with ASD continue to matriculate to postsecondary education thanks to the mandate of Least Restrictive Environment, parent partnership may be an efficient solution to ensuring postsecondary success. Parents are committed to aiding the persistence of their students through graduation, and that is an outcome that benefits educational institutions, not just families.

## APPENDICES

## APPENDIX A: Institutional Review Board Approval Notice



**Approval Notice**  
**Initial Review – Expedited Review**

May 20, 2019  
 Cheryl Widman  
 Special Education  
 Phone: (312) 493-9757 / Fax: (312) 996-5651

RE: **Protocol # 2019-0428**  
**“Understanding Parent Participation in the Postsecondary Education of Students with Autism Spectrum Disorder”**

Dear Ms. Widman:

Members of Institutional Review Board (IRB) #2 reviewed and approved your research protocol under expedited review procedures [45 CFR 46.110(b)(1)] on May 18, 2019. You may now begin your research.

Your research meets the criteria for approval under the following category: Protocol reviewed under expedited review procedures [45 CFR 46.110] **Category: 7**

Please note the following information about your approved research protocol:

**Please note that as per the revised Federal Regulations (2018 Common Rule) and OPRS policies your research does not require a Continuing Review; therefore, the approved documents are stamped only with an approval date. Although your research no longer requires a Continuing Review, you will receive annual reminder notices regarding your investigator responsibilities (i.e., submission of amendments, final reports, and prompt reports), and will be asked to complete an Institutional Status Report which will be sent to you via email every 3 years. If you fail to submit an Institutional Status Report, your research study will be administratively closed by the IRB. For more information regarding Continuing Review and Administrative Closure of Research visit: <http://research.uic.edu/node/735>.**

<b><u>Protocol Approval Date:</u></b>	May 18, 2019
<b><u>Approved Subject Enrollment #:</u></b>	120
<b><u>Performance Sites:</u></b>	UIC
<b><u>Sponsor:</u></b>	None

**Research Protocol(s):**

- a) Understanding Parent Participation in the Postsecondary Education of Students with Autism Spectrum Disorder; 05/05/2019



Documents that require an approval stamp or separate signature can be accessed via [OPRS Live](#). The documents will be located in the specific protocol workspace. You must access and use only the approved documents to recruit and enroll subjects into this research project.

**Recruitment Material(s):**

- a) Online Recruitment Script; Version 1.3; 05/13/2019
- b) Parent Twitter Recruitment Script; Version 1.3; 05/13/2019
- c) Parent Email and Social Media Recruitment Script; Version 1.3; 05/13/2019
- d) Post-Survey Thank-You Script; Version 1; 04/07/2019

**Informed Consent(s):**

- a) Parents of ASD Students (Consent); Version 1.3; 05/13/2019
- b) Research involves activities related to screening, recruitment, or determining eligibility per 45 CFR 46.116(g).
- c) A waiver of consent has been granted under 45 CFR 46.116(f) for students as secondary subjects (minimal risk).
- d) A waiver of documentation of consent has been granted under 45 CFR 46.117 for the online survey; minimal risk; subjects will be provided with an information sheet containing all of the elements of consent.

Please remember to:

**Use only the IRB-approved and stamped consent document(s) when enrolling new subjects.**

→ Use your **research protocol number** (2019-0428) on any documents or correspondence with the IRB concerning your research protocol.

Review and comply with the [policies](#) of the UIC Human Subjects Protection Program (HSPP) and the guidance [Investigator Responsibilities](#).

**Please note that the UIC IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.**

**Please be aware that if the [scope of work](#) in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS office at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS via [OPRS Live](#).



Sincerely,

Allison A. Brown, PhD  
IRB Coordinator, IRB # 2  
Office for the Protection of Research Subjects

cc: Norma Lopez-Reyna, Special Education, M/C 147

## APPENDIX B: PPSASDS

Leave box empty - For office use only

Postsecondary Students with Autism Spectrum Disorder Survey (PPSASDS), Version 2

The following is a set of questions that can be responded with yes or no. This survey consists of 45 yes or no questions with various opportunities to add additional information embedded throughout the survey, with one concluding question that allows you to add any additional information you would like to share.

1. I suggested to my student to live on campus.	Yes _____ No _____
2. I suggested to my student to have a roommate.	Yes _____ No _____
3. I suggested to my student to join a fraternity/sorority.	Yes _____ No _____
4. I suggested to my student to attend summer school before he/she started his/her freshman year.	Yes _____ No _____
5. I suggested to my student to attend the college orientation program before he/she started his/her freshman year (if it was available).	Yes _____ No _____
<i>Opportunity: What additional information would you like to provide related to your above responses?</i>	
6. I suggested to my student to use campus meal plan.	Yes _____ No _____
7. I suggested to my student to attend campus activities (including arts, political, and social).	Yes _____ No _____
8. I suggested to my student to attend sporting events on campus.	Yes _____ No _____
9. I suggested to my student to belong to clubs (and/or extramural activities) on campus.	Yes _____ No _____
<i>Opportunity: What additional information would you like to provide related to your above responses?</i>	
10. I suggested to my student to make new friends on campus.	Yes _____ No _____



11. I suggested to my student to attend activities with friends on campus.	Yes _____ No _____
12. I suggested to my student to get together with a friend(s) on campus.	Yes _____ No _____
<b>Opportunity:</b> What additional information would you like to provide related to your above responses?	Yes _____ No _____
13. I suggested to my student to sit with friend(s) in his/her classes.	Yes _____ No _____

14. I suggested to my student to work with other students in class.	Yes _____ No _____
15. I suggested to my student to find a study group on campus in order to socialize.	Yes _____ No _____
<b>Opportunity:</b> What additional information would you like to provide related to your responses above?	

1. I suggested to my student to choose their school.	Yes _____ No _____
2. I suggested to my student to get help in order to register for classes.	Yes _____ No _____
3. I suggested to my student to get disability accommodations.	Yes _____ No _____
4. I suggested to my student to arrange their schedule in order to manage the workload.	Yes _____ No _____
<b>Opportunity:</b> What additional information would you like to provide related to your responses above?	
5. I suggested to my student to get up in the morning on their own.	Yes _____ No _____
6. I suggested to my student to get to school and/or classes on their own.	Yes _____ No _____
7. I suggested to my student to manage time for homework and non-academic activities.	Yes _____ No _____
<b>Opportunity:</b> What additional information would you like to provide related to your responses above?	
8. I suggested to my student to do his/her own laundry.	Yes _____ No _____
9. I suggested to my student to make his/her own meals or snacks.	Yes _____ No _____

10. I suggested to my student clean his/her own room.	Yes _____ No _____
11. I suggested to my student to practice good hygiene.	Yes _____ No _____
12. I suggested my student get plenty of rest every night.	Yes _____ No _____
<i>Opportunity: What additional information would you like to provide related to your above responses?</i>	
13. I suggested to my student to maintain his/her own bank account.	Yes _____ No _____
14. I suggested my student use and manage credit card to make purchases.	Yes _____ No _____
<i>Opportunity: What additional information would you like to provide related to your responses above?</i>	
15. I suggested to my student to self-advocate.	Yes _____ No _____
16. I suggested to my student to set academic and or vocational goals.	Yes _____ No _____
<i>Opportunity: What additional information would you like to provide related to your responses above?</i>	

1. I provided emotional support for my student.	Yes _____ No _____
2. I suggested to my student to get counseling on campus for managing depression, anxiety, and/or stress.	Yes _____ No _____
3. I found a counselor/therapist off-campus for my student to help manage depression, anxiety, and/or stress.	Yes _____ No _____
<i>Opportunity: What additional information would you like to provide related to your above responses?</i>	
4. I helped my student manage depression, anxiety, and/or stress over financing their own education.	Yes _____ No _____
5. I addressed my student's depression, anxiety and/or stress by helping my student find scholarships/financial aid.	Yes _____ No _____

Leave box empty - For office use only

## APPENDIX C: Demographics Questionnaire

### Parents of Postsecondary Students with Autism Spectrum Disorder

Please read and respond to each of the 16 demographic questions below. Upon completion and submission of this survey, you will immediately receive a message requesting that you send an email address to where the \$20 Starbucks gift card can be sent to thank you for your participation.

<p>1. Parent Identification (who is completing his survey)</p> <p><input type="radio"/> Mother</p> <p><input type="radio"/> Father</p>
<p>2. How old is your student?</p> <p><input type="radio"/> 18 - 22</p> <p><input type="radio"/> 23- 27</p> <p><input type="radio"/> 28 - 32</p> <p><input type="radio"/> 33 or older</p>
<p>3. Type of Postsecondary School Your Student Attended (Check all that apply)</p> <p><input type="radio"/> Two-Year College</p> <p><input type="radio"/> Four Year University</p> <p><input type="radio"/> Other (please specify)_____</p>
<p>4. What degree is your student currently pursuing?</p> <p><input type="radio"/> Two-Year College Degree</p> <p><input type="radio"/> Four Year University Degree</p> <p><input type="radio"/> Other (please specify)_____</p>
<p>5. Were you “an involved parent” in high school (attended IEP meetings, parent-teacher conferences)?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>
<p>6. In <u>high school</u>, did your student have a Transition to College Plan?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>
<p>7. In <u>high school</u>, did you participate in creating your student’s Transition to College Plan?</p>

<input type="radio"/> Yes <input type="radio"/> No
8. What is the highest level of education your student <u>completed</u> (check all that apply)? <input type="radio"/> High School Diploma <input type="radio"/> Certificate of Completion <input type="radio"/> Technical Certification <input type="radio"/> Two-Year College degree (Associate's Degree) <input type="radio"/> Four-Year College degree (Bachelor's Degree) <input type="radio"/> Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA) <input type="radio"/> Professional degree (for example: MD, DDS, DVM, LLB, JD) <input type="radio"/> Doctorate degree (for example: PhD, EdD)
9. What is your student's current enrollment? <input type="radio"/> Technical/Trade program <input type="radio"/> Two-Year College degree (Associate's Degree) <input type="radio"/> Four-Year College degree (Bachelor's Degree) <input type="radio"/> Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA) <input type="radio"/> Professional degree (for example: MD, DDS, DVM, LLB, JD) <input type="radio"/> Doctorate degree (for example: PhD, EdD) <input type="radio"/> No longer attending
10. At any time during your student's college/university experience, did your student live at home? <input type="radio"/> Yes <input type="radio"/> No
11. At any time during your student's college/university experience, did your student live on campus residential housing? <input type="radio"/> Yes <input type="radio"/> No
12. How was your student's education at their college/university financed? (Check all that apply.) <input type="radio"/> Academic Scholarship <input type="radio"/> Department of Vocational Rehabilitation <input type="radio"/> Student Self-Financed <input type="radio"/> Student Job <input type="radio"/> Parent Financed 100% <input type="radio"/> Parent Partially Financed 50% or More But Less Than 100% <input type="radio"/> Parent Partially Financed Less Than 50% <input type="radio"/> Other _____
13. Household Income: What is your total annual household income? <input type="radio"/> Less than \$30,000 <input type="radio"/> \$30,000 to \$49,999

- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 to \$149,999
- ☐ \$150,000 or more
- ☐ Prefer not to answer

14. Your Education: What is the highest level of education that you completed? If currently enrolled, mark the previous grade or highest degree received.

- ☐ 12th grade, no diploma
- ☐ High school graduate - high school diploma or the equivalent (for example: GED)
- ☐ Some college credit, but less than 1 year
- ☐ 1 or more years of college, no degree
- ☐ Associate degree (for example: AA, AS)
- ☐ Bachelor's degree (for example: BA, AB, BS)
- ☐ Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
- ☐ Professional degree (for example: MD, DDS, DVM, LLB, JD)
- ☐ Doctorate degree (for example: PhD, EdD)
- ☐ Other \_\_\_\_\_

15. How do you identify?

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ Hispanic or Latino
- ☐ Not Hispanic or Latino
- ☐ Other
- ☐ Prefer not to answer

16. We are also interested in knowing what schools our students with ASD are enrolled in (or were enrolled in). Please indicate the name of the college/university below. (After you complete this question and submit your answer, a page will appear that will allow you to provide your email address.) \_\_\_\_\_

## APPENDIX D: Informed Consent Agreement

1 of 5



**University of Illinois at Chicago  
Research Information and Consent for Participation in  
Educational Research  
Understanding Parent Participation in the  
Postsecondary Education of Students with Autism Spectrum Disorder**

**Principal Investigator/Researcher Name and Title:** Cheryl Widman, M.A.T., PhD Candidate  
**Faculty Advisor Name and Title:** Dr. Norma Lopez-Reyna, Associate Professor and Department Chair  
**Department and Institution:** Special Education, UIC College of Education  
**Address and Contact Information:** c/o Dr. Norma Lopez-Reyna, 1040 West Harrison Street, M/C 147  
 Chicago, IL 60607

**About this research study**

You are being asked to participate in a research study. Research studies answer important questions that might help change or improve the way we do things in the future.

**Taking part in this study is voluntary**

Your participation in this research study is voluntary. You may choose to say “no” to this research or may choose to stop participating in the research at any time. Deciding not to participate, or deciding to stop participating later, will not result in the loss of any services, class standing, and/or professional status to which you are entitled, and will not affect your relationship with the University of Illinois at Chicago (UIC).

This consent form will give you information about the research study to help you decide whether you want to participate. Please read this form and ask any questions you have before agreeing to be in the study.

You are being asked to participate in this research study because you reside in the U.S. and are a parent of a past or present U.S. postsecondary (college, university) student who has been diagnosed with Autism Spectrum Disorder (ASD).

A maximum of 120 subjects will be enrolled in this research study.

**Important Information**

This information gives you an overview of the research. More information about these topics may be found in the pages that follow.

<b>WHY IS THIS STUDY BEING DONE?</b>	The purpose of the research is to learn about how parents of students with ASD participate in postsecondary education. The aim of this research is to understand how parents help their students.
--------------------------------------	---

UIC IRB Social, Behavioral, and  
Educational Research Informed Consent  
Template: 11/30/2018  
Do NOT Change This Field – IRB Use ONLY

Page of 5

[Widman Parents of ASD Students]<sup>1</sup>  
[Version 1.3, May 13, 2019]

	Research that can identify attributes which contribute to success may help to construct a model for the types of support that positively contribute to academic success, leading to improved graduation rates and ultimately employment for students with ASD. The findings may be useful to postsecondary institutions that serve this population of students and promote partnerships with parents as a way of improving graduation rates.
<b>WHAT WILL I BE ASKED TO DO DURING THE STUDY?</b>	<p>Using Qualtrics.com, you will confidentially complete an online survey that will consist of 45 very brief questions to which you respond “yes” or “no” and 14 open-ended questions to which you may optionally provide a text response. Responses will be transmitted over an SSL encrypted connection to ensure security and IP addresses will be masked in order to maintain confidentiality and prevent the collection of IP addresses or any other identifying data. Data will be collected in the aggregate after the completion of multiple surveys so that data cannot be associated with any one individual.</p> <p>Using Qualtrics.com, you will confidentially complete a short online questionnaire that provide multiple-choice responses to 15 questions that are primarily related to education. You will be asked 1 question relating to the school your student attends (attended). Security and IP addresses will be masked in order to maintain confidentiality and prevent the collection of IP addresses or any other identifying data. Data will be collected in the aggregate after the completion of multiple surveys so that data cannot be associated with any one individual.</p>
<b>HOW MUCH TIME WILL I SPEND ON THE STUDY?</b>	On the Parents of Postsecondary Students with Autism Spectrum Disorder Survey, the 45 yes or no questions can be answered in about 10 minutes while the 14 open-ended text responses may take anywhere from 0 to 10 minutes, depending upon whether or not you choose to add comments or simply decide to skip them. Additionally, the Parents Demographic Questionnaire will take about 5 minutes to complete. The total estimated time to complete both the Survey and Questionnaire will be 15-25 minutes.
<b>ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?</b>	There is no direct benefit to you as a parent or your student.
<b>WHAT ARE THE MAIN RISKS OF THE STUDY?</b>	This research has minimal risks. All the information you provide to me is confidential, and all data will be aggregated in order to protect the identity of individual participants. Only I will have access to the data. However, there is the potential risk of a breach of privacy and confidentiality by accidental disclosure of your participation if you

	or another individual discloses your participation. Additionally, online communications are never completely secure, and I will try to protect your privacy to the fullest extent that is technically possible. Social media websites collect information about user activities. According to the privacy policy of Qualtrics.com, they will not track information about the computer you use and submit that information to third parties or advertisers. I will not receive this information.
<b>DO I HAVE OTHER OPTIONS BESIDES TAKING PART IN THE STUDY?</b>	You have the option to not participate in this study. Your participation in this research is voluntary. If you decide to participate, you are free to withdraw at any time.
<b>QUESTIONS ABOUT THE STUDY?</b>	<p>For questions, concerns, or complaints about the study, please contact the researcher conducting this study, Cheryl Widman, PhD Candidate, at ##### or email her at <a href="mailto:cwidma3@uic.edu">cwidma3@uic.edu</a>. You may also contact Cheryl Widman's Faculty Sponsor, Dr. Norma Lopez-Reyna by email at <a href="mailto:nlr@uic.edu">nlr@uic.edu</a> or by phone at (312) #####</p> <p>If you have questions about your rights as a study subject; including questions, concerns, complaints, or if you feel you have not been treated according to the description in this form; or to offer input you may call the UIC Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at <a href="mailto:uicirb@uic.edu">uicirb@uic.edu</a>.</p>

**Please review the rest of this document for details about these topics and additional things you should know before making a decision about whether to participate in this research. Please also feel free to ask the researchers questions at any time.**

During this study, Cheryl Widman, PhD Candidate, will collect information about you for the purposes of this research. You are being asked to answer 45 yes or no as well as 14 optional text response questions regarding the support of your postsecondary student with ASD. In addition, you will answer 15 multiple-choice demographic questions plus 1 short answer question relating to you and your student's college education. My aim is to understand how parents foster social integration and independence in addition to supporting emotional needs of their college students.

#### **What about privacy and confidentiality?**

Efforts will be made to keep your personal information confidential; however, we cannot guarantee absolute confidentiality. In general, information about you, or provided by you, during the research study, will not be disclosed to others without your written permission. However, laws and state university rules might require us to tell certain people about you. For



example, study information which identifies you and the consent form signed by you may be looked at and/or copied for quality assurance and data analysis by:

- Representatives of the university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for the Protection of Research Subjects.
- Other representatives of the State and University responsible for ethical, regulatory, or financial oversight of research.
- Government Regulatory Agencies, such as the Office for Human Research Protections (OHRP).

A possible risk of the study is that your participation in the study or information about you might become known to individuals outside the study. Your survey and questionnaire data will be coded and stored on a password-protected and encrypted disk which is not connected to the internet to prevent access by unauthorized personnel.

Your individual data will be stripped of all direct and indirect identifiers and your email address will be destroyed after the gift card is emailed to you.

When the results of the study are published or discussed in conferences, no one will know that you were in the study.

**What are the costs for participating in this research?**

There are no costs to you for participating in this research.

**Will I be reimbursed for any of my expenses or paid for my participation in this research?**

You will receive a \$20 Starbucks gift card for completion of the survey and questionnaire. If you do not finish the study, you will not be compensated. If you complete the study, you will receive a total of \$20. You will receive your payment within approximately 1 day after completion and will be sent to the email address you provided.

**Can I withdraw or be removed from the study?**

If you decide to participate, you have the right to withdraw your consent and leave the study at any time without penalty.

**Remember:**

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

**Consent of Subject**

I have read the above information. *By signing this Consent document and agreeing to participate, I attest that I am the parent of a current or former postsecondary student who has been formally diagnosed with Autism Spectrum Disorder.* I have been given an opportunity to

UIC IRB Social, Behavioral, and  
Educational Research Informed Consent  
Template: 11/30/2018  
Do NOT Change This Field – IRB Use ONLY

contact the researchers and ask questions, and my questions have been answered to my satisfaction. I agree to participate in this research by typing my initials below. **PLEASE PRINT OUT A COPY OF THIS DOCUMENT FOR YOUR RECORDS.**

---

Signature

## APPENDIX E: Springer Approval for Author's Reuse

Screen Shot 2020-02-2

### Author Reuse

Authors have the right to reuse their contribution's Version of Record, in whole or in part, in their own thesis. Additionally, they may reproduce and make available their thesis, including Springer Nature content, as required by their awarding academic institution.

Authors must properly cite the published contribution in their thesis according to current citation standards.

Material from: 'AUTHOR, TITLE, published [YEAR], [publisher - as it appears on our copyright page]'

If you are any doubt about whether your intended re-use is covered, please contact [bookpermissions@springernature.com](mailto:bookpermissions@springernature.com) for confirmation.

4 at 12.52.10 PM.png 1,602×712 pixels 2/24/20, 12{54 PM

file:///var/folders/s\_/x5rt0hp147l\_f\_5sfjvnbsqh0000gn/T/com.appl...ion-CxpDRmOG/Screen%20Shot%202020-02-24%20at%2012.52.10%20PM.png  
Page 1 of 1

### CITED LITERATURE

- Anderson, C., & Butt, C. (2017). Young adults on the autism spectrum at college: Successes and stumbling blocks. *Journal of Autism and Developmental Disorders*, 47(10), 3029-3039.  
<https://doi-org.proxy.cc.uic.edu/10.1007/s10803-017-3218-x>
- Ashbaugh, K., Koegel, R. L., & Koegel, L. K. (2017) Increasing social integration for college students with autism spectrum disorder. *Behavioral Development Bulletin*, 22(1), 183-196. <http://dx.doi.org/10.1037/bdb0000057>
- Baio, B. J., Wiggins, L, Christensen, D. L., Maenner, M. J., Daniels, J, Warren, Z, Kurzius-Spencer, M, Zahorodny, W, Robinson, Rosenberg, C., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L-C., Harrington, R., Lopez, M., ...Braun Dowling, N. F. (2018). *Prevalence of autism spectrum disorder among children aged 8 years — Autism and developmental disabilities monitoring network, 11 sites, United States, 2014*. <https://doi.org/10.15585/mmwr.ss6706a1>
- Baron-Cohen, S., Wainwright, S., Robinson, J., & Woodbury-Smith, M. (2005). *The adult asperger assessment (AAA); A diagnostic method*. *Journal of Autism and Developmental Disorders*, 35(6), 807-819. <https://doi-org.proxy.cc.uic.edu/10.1007/s10803-005-0026-5>
- Barnhill, G. P. (2016). Supporting students with asperger syndrome on college campuses: Current practices. *Focus on Autism and Other Developmental Disabilities*, 31(1), 3-15.  
<https://doi.org/10.1177/1088357614523121>
- Brown, K.R. (2017). Accommodations and support services for students with autism spectrum disorder (ASD): A national survey of disability resource providers. *Journal of Postsecondary Education and Disability*. 30(2), 141-156.

Brown, K. R., & Coomes, M. D. (2016). A spectrum of support: Current and best practices for students with autism spectrum disorder (ASD) at community colleges. *Community*

*College Journal of Research and Practice*, 40(6), 465-479.

<http://dx.doi.org/10.1080/10668926.2015.1067171>

Centers for Disease Control and Prevention (CDC). (2018). *Autism spectrum disorder (ASD):*

*Data and statistics – prevalence:* <https://www.cdc.gov/ncbddd/Autism/data.html>

Chickering, A. & Reisser, L. *Education and Identity*. (2<sup>nd</sup> ed.). Jossey-Bass.

Chou, Y-C., Wehmeyer, M.L., Shogren, K.A., Palmer, S.B., & Lee, J. (2017). Autism and self-

determination: Factor analysis of two measures of self-determination. *Focus on Autism*

*and Other Developmental Disabilities*, 32(3), 163-175. <https://doi->

[org.proxy.cc.uic.edu/10.1177/1088357615611391](https://doi-org.proxy.cc.uic.edu/10.1177/1088357615611391)

Corbin, J. & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. (3<sup>rd</sup> ed.). Sage Publications, Inc.

<http://dx.doi.org/10.4135/9781452230153>

Cox, B. E., Thompson, K., Anderson, A., Mintz, A., Locks, T., Morgan, L., Edelstein, J., &

Worlz, A. (2017). College experiences for students with autism spectrum disorder:

Personal identity, disclosure, and institutional support. *Journal of College Student*

*Development*, 58(1), 71-87. <http://dx.doi.org/10.1353/csd.2017.0004>

Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed method approaches*

(2<sup>nd</sup> ed.). Sage Publications, Inc.

Creswell, J.W. (2007). *Qualitative Inquiry and Research Design: Choosing among five*

*approaches*. (2<sup>nd</sup> ed.). Sage Publications, Inc.

- Creswell, J. W. & Creswell, J.D. (2018). *Research design: Qualitative, quantitative, and mixed method approaches* (5<sup>th</sup> ed.). Sage Publications, Inc.
- Cullen, J. A. (2015). The needs of college students with autism spectrum disorders and Asperger's syndrome. *Journal of Postsecondary Education and Disability*, 28(1), 89-101.
- Demetriou, E.A., Lampit, A., Quintana, D.S., Naismith, S.L., Song, Y.J.C., Pye, J.E., Hickie, I., & Guastella, A.J. (2018). Autism spectrum disorders: A meta-analysis of executive function. *Molecular Psychiatry*, (23), 1198-1204. <https://doi.org/10.1038/mp.2017.75>
- Dymond, S. K., Meadan, H., & Pickens, J. (2017). Postsecondary education and students with autism spectrum disorders: Experiences of parents and university personnel. *Journal of Developmental and Physical Disabilities*, 29(5), 809-825.  
<https://doi.org/10.1007/s10882-017-9558-9>
- Elias, R., & White, S. W. (2017). Autism goes to college: Understanding the needs of a student population on the rise. *Journal of Autism and Developmental Disorders*, 48(3), 732-746.  
<https://doi-org.proxy.cc.uic.edu/10.1007/s10803-017-3075-7>
- Elias, R., Muskett, A.E., & White, S.W. (2019). Educator perspectives on the postsecondary transition difficulties of students with autism. *Autism*, 23(1), 260-264.  
<https://doi-org.proxy.cc.uic.edu/10.1177/1362361317726246>
- Eriksson, M.A., Westerlund, J., Anderlid B.A., Gillberg, C., & Fernell, E. (2012). First-degree relatives of young children with autism spectrum disorders: Some gender aspects. *Research in Developmental Disabilities*. 33, 1642-1648.  
<https://doi.org/10.1016/j.ridd.2012.03.025>

- Gartland, D., & Strosnider, R. (2007). The documentation disconnect for students with learning disabilities: Improving access to postsecondary disability services. *Learning Disability Quarterly*, 30(4), 265-274. <https://doi-org.proxy.cc.uic.edu/10.2307/25474638>
- Gelbar, N. W., Shefcyk, A., & Reichow, B. (2015). A comprehensive survey of current and former college students with autism spectrum disorders. *Yale Journal of Biology and Medicine*, 88, 45-68.
- Gunn, S. L., Sellers, T. P., Lignugaris/Kraft, B. (2017). Application of coaching and behavioral skills training during a preschool practicum with a college student with autism spectrum disorder. *Clinical Case Studies*, (16)4, 275-294.  
<https://doi-org.proxy.cc.uic.edu/10.1177/1534650117692673>
- Hendrickson, J.M., Woods-Groves, S., Rodgers, D.B., & Datchuk, S. (2017). Perceptions of students with autism and their parents: The college experience. *Education and Treatment of Children*. 40(4), 571-596. <https://doi.org/10.1353/etc.2017.0025>
- Horn, J.L. (1971). Integration of Concepts of Reliability and Standard Error of Measurement. *Educational and Psychological Measurement*, 31, 51-74.
- Horn, L. & Nevill, S. (2006). *Profile of undergraduates in U.S. postsecondary education institutions: 2003–04: With a special analysis of community college students (NCES 2006–184)*. U.S. Department of Education.
- Howlin, P. (2013). Social disadvantage and exclusion: Adults with autism lag far behind in employment prospects. *Journal of the American Academy of Child and Adolescent Psychiatry*, 52(9), 897-899. <https://doi.org/10.1016/j.jaac.2013.06.010>

- Jolliffe, T. & Baron-Cohen, S. (1999). A test of central coherence theory: Linguistic processing in high-functioning adults with Autism or asperger syndrome: Is local coherence impaired? *Cognition*. 71, 149-185. [https://doi.org/10.1016/S0010-0277\(99\)00022-0](https://doi.org/10.1016/S0010-0277(99)00022-0)
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*. 2(3), 217-250.
- Koegel, L. K., Ashbaugh, K., Navab, A., & Koegel, R. L. (2016). Improving empathic communication skills in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 921-933.  
<https://doi-org.proxy.cc.uic.edu/10.1007/s10803-015-2633-0>
- Kogan, M.D., Vladutiu, C.J., Schieve, L.A., Ghandour, R.M., Blumberg, S.J., Zablotsky, B., Perrin, J.M., Shattuck, P., Kuhlthau, K.A., Harwood, R.L., & Lu, M.C. (2018). The prevalence of parent-reported autism spectrum disorder among U.S. children. *Pediatrics*, 142(6). <https://doi.org/10.1542/peds.2017-4161>
- Kuder, G.F., & Richardson, M.W. (1937). The theory of the estimation of test reliability. *Psychometrika*, (2), 151–160. <https://doi.org/10.1007/BF02288391>
- Luna, B., Doll, S.K., Hegedus, S.J., Minshew, N.J., & Sweeney, J.A. (2007). Maturation of executive function in autism. *Biological Psychiatry*, (61), 474-481.  
<https://doi.org/10.1016/j.biopsych.2006.02.030>
- Maggin, D. M., Talbott, E., Van Acker, E. Y., & Kumm, S. (2017). Quality indicators for systematic reviews in behavioral disorders. *Behavioral Disorders*, 42(2), 52-64.  
<https://doi.org/10.1177/0198742916688653>
- Mamiseishvili, K., & Koch, L. C. (2011). First-to-second year persistence of students with disabilities in postsecondary institutions in the United States. *Rehabilitation Counseling Bulletin*, 54 (2), 93-105. <https://doi.org/10.1177/0034355210382580>



- Mamiseishvili, K., & Koch, L. C. (2012). Students with disabilities at 2-year institutions in the United States: Factors related to success. *Community College Review*, 40(4), 320-339.  
<https://doi-org.proxy.cc.uic.edu/10.1177/0091552112456281>
- Marshak, L., Van Wieren, T., Ferrell, D.R., Swiss, L., & Dugan, C. (2010). Exploring barriers to college student use of disability services and accommodations. *Journal of Postsecondary Education and Disability*, 22(3), 151-165.
- Mason, R. A., Rispoli, M., Ganz, J. B., Boles, M. B., & Orr, K. (2012). Effects of video modeling on communicative social skills of college students with asperger syndrome. *Developmental Neurorehabilitation*, 15(6), 425-434.  
<http://dx.doi.org.proxy.cc.uic.edu/10.3109/17518423.2012.704530>
- Matson, J.L. & Williams, L.W. (2013). Differential diagnosis and comorbidity: Distinguishing autism from other mental health issues. *Neuropsychiatry*, (2)3, 233–243.
- McCoach, D. B., Gable, R. K., & Madura, J. P. (2013). *Instrument Development in the Affective Domain School and Corporate Applications (3rd ed.)*. Springer.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *BMJ: British Medical Journal*, 339. <https://doi.org/10.1136/bmj.b2535>
- Mosner, M.G., Kinard, J.L. Shah, J.S, McWeeny, S., Greene, R.K., Lowery, S.C., Mazefsky, C.A., & Dichter, G.S. (2019). Rates of co-occurring psychiatric disorders in autism spectrum disorder using the mini international neuropsychiatric interview. *Journal of Autism and Developmental Disorders*, 49(9), 3819–3832. <https://doi.org/10.1007/s10803-019-04090-1>

- Moustakas, C. (1990). *Heuristic research: Design, methodology, and applications*. Sage Publications, Inc.
- NIH National Institute of Neurological Disorders and Stroke (2019). *Pervasive developmental disorders page*. <https://www.ninds.nih.gov/Disorders/All-Disorders/Pervasive-Developmental-Disorders-Information-Page>
- Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D., Wei, X., Cameto, R., Contreras, E., Ferguson, K., Greene, S., & Swarting, M. (2011). *The post-high school outcomes of youth with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2011-3005)*. SRI International. <https://ies.ed.gov/ncser/pubs/20113005/pdf/20113005.pdf>
- Ohl, A., Sheff, M. G., Small, S., Nguyen, J., Paskor, K., & Zinjirian, A. (2017). Predictors of employment status among adults with autism spectrum disorder. *Work*, 56 (2), 345-355. <https://doi.org/10.3233/WOR-172492>
- Pugliese, C. E., & White, S. W. (2014). Brief report: Problem solving therapy in college students with autism spectrum disorders: Feasibility and preliminary efficacy. *Journal of Autism and Developmental Disorders*, 44, 719-729. <https://doi-org.proxy.cc.uic.edu/10.1007/s10803-013-1914-8>
- Raue, K., and Lewis, L. (2011). *Students with Disabilities at Degree-Granting Postsecondary Institutions (NCES 2011–018)*. U.S. Department of Education, National Center for Education Statistics. U.S. Government Printing Office.
- Raymond, G. (2003). Grammar and social organization: Yes/no interrogatives and the structure of responding. *American Sociological Review*, 68(6), 939-967. <https://www-jstor-org.proxy.cc.uic.edu/stable/1519752>

- Reed, D. K., Hallett, A., & Rimel, H. (2016). Note-taking instruction for college students with autism spectrum disorder. *Exceptionality*, 24(4), 195-212.  
<https://doi.org/10.1080/09362835.2015.1107833>
- Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 52(9), 931-939. <https://doi.org/10.1016/j.jaac.2013.05.019>
- Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015a). *National Autism indicators report: Transition into young adulthood*. Drexel University.  
<http://drexel.edu/Autismoutcomes/publications-and-reports/publications/Employment-Outcomes-of-Young-Adults-on-the-Autism-Spectrum/#sthash.MmJ3Q6cX.dpbs>
- Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., Edwards, A. D., Wei, X., McCracken, M., & Yu J. W. (2015b). Characteristics of two-year college students on the Autism spectrum and their support services experiences. *Autism Research and Treatment*, 2015, 1-10.  
<https://doi.org/10.1155/2015/391693>
- Roux, A. M., Rast, J. E., Anderson, K. A., & Shattuck, P. T. (2017). *National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood*. Drexel University. <http://drexel.edu/Autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Developmental-Disability-Services-and-Outcomes-in-Adulthood/#sthash.1qnw0hVu.dpbs>

- Rubenstein, E. & Chawla, D. (2018). Broader Autism phenotype in parents of children with Autism: A systematic review of percentage estimates. *Journal of Child and Family Studies*. 27, 1705-1720. <https://doi-org.proxy.cc.uic.edu/10.1007/s10826-018-1026-3>
- Ruser, T.F., Arin, D., Dowd, M., Putnam, S., Winklowshy, B., Rosen-Sheidley, B., Piven, J., Tomblin, B., Tager-Flusberg, H., & Folstein, S. (2007). Communicative competence in parents of children with Autism and parents of children with specific language impairment. *Journal of Autism and Developmental Disorders*. 37, 1323-1336. <https://doi-org.proxy.cc.uic.edu/10.1007/s10803-006-0274-z>
- Shattuck, P.T., Narendorf, S.C., Cooper, B., Sterzing, P.R., Wagner, M., & Taylor, J.L. (2012). Postsecondary education and employment among youth with autism spectrum disorder. *Pediatrics*, 129(6), 1042-1049. <https://doi.org/10.1542/peds.2011-2864>
- Shogren, K. A., Kennedy, W., Dowsett, C., & Little, T. D. (2014). Autonomy, psychological empowerment, and self-realization: Exploring data on self-determination from NLTS-2. *Exceptional Children*, 80(2), 221-235. <https://doi.org/10.1177/001440291408000206>
- Smith, C. P. (2007). Support services for students with Asperger's syndrome in higher education. *College Student Journal*, 41(3), 515-531.
- Snyder, T.D., de Brey, C., and Dillow, S.A. (2016). *Digest of Education Statistics 2015 (NCES 2016-014)*. National Center for Education Statistics, Institute of Education Sciences, U.S. Department of Education.
- Strauss, A.L., & Corbin, J.M. (1998). *Basis of qualitative research: Techniques and procedures for developing grounded theory* (2<sup>nd</sup> ed.). Sage Publications, Inc.

- Talbott, E., Maggin, D. M., Van Acker, E. Y., & Kumm, S. (2017). Quality indicators for reviews of research in special education. *Exceptionality*, 26(4), 245-265.  
<https://doi.org/10.1080/09362835.2017.1283625>
- Taylor, J.M., & Seltzer, M.M. (2010). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41(5), 566-574.  
<https://doi.org/10.1007/s10803-010-1070-3>
- Terenzini, P., & Pascarella, E. T. (1977). Voluntary freshman attrition and patterns of social and academic integration in a university: A test of a conceptual model. *Research in Higher Education*, 6, 25-43.  
<http://www.springer.com/education+%26+language/higher+education/journal/11162>
- Tinto, V. (1975). Dropout from higher education: A theoretical synthesis of recent research. *Review of Educational Research*, 45, 89-125.
- Tinto, V. (1988). Stages of departure: Reflections on the longitudinal character of student leaving. *The Journal of Higher Education*, 59(4), 438-455.  
<http://www.jstor.org/stable/1981920>
- Tinto, V. (1993). *Leaving college*. The University of Chicago Press.
- Tinto, V. (1999). Classrooms as communities: Exploring the educational character of student persistence. *Journal of Higher Education*, 68 (6), 599-618.
- Tirado, M.J. & Saldaña, D. (2016). Readers with Autism can produce inferences, but they cannot answer inferential questions. *Journal of Autism and Developmental Disorders*, 46, 1025-1037. <https://doi-org.proxy.cc.uic.edu/10.1007/s10803-015-2648-6>

U.S. Department of Education. (2011). *Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities*.

<https://www2.ed.gov/about/offices/list/ocr/transition.html>

U.S. Department of Education. (2018). *Free and Appropriate Public Education*.

<https://www2.ed.gov/about/offices/list/ocr/frontpage/pro-students/issues/dis-issue03.html>

Wainwright, S., Auyeung, B., Allison, C., & Baron-Cohen, S. (2010). Defining the broader, medium and narrow Autism phenotype among parents using the Autism spectrum quotient (AQ). *Molecular Autism*. 1(10). doi: 10.1186/2040-2392-1-10

Wehmeyer, M.L. (1995). *The arc's self-determination scale: Procedural guidelines*. The Arc of the United States and Michael Wehmeyer.

<http://www.ou.edu/content/dam/Education/documents/miscellaneous/sd-scale-procedural-guidelines.pdf>

Wehmeyer, M. L. (1999). A functional model of self-determination: Describing development and implementing instruction. *Focus on Autism and Other Developmental Disabilities*, 14(1), 53-62. <https://doi-org.proxy.cc.uic.edu/10.1177/108835769901400107>

Wehmeyer, M.L. (2014). Self-determination: A family affair. *Family Relations*, 63(1),178-184. <https://doi.org/10.1111/fare.12052>

Wehmeyer, M.L. & Kelchner, K. (1995). The arc's self-determination scale adolescent version. *The Arc of the United States and Michael Wehmeyer*.

<http://www.thearc.org/document.doc?id=3670>

White, S.W., Elias, R., Salinas, C.E., Capriola, N., Conner, C.M., Asselin, S.B., Miyazaki, Y., Mazefsky, C.A., Howlin, P., & Getzel, E.B. (2016a). Students with autism spectrum

- disorder in college: Results from a preliminary mixed methods: Needs analysis. *Research in Development Disabilities*, 56, 29-40. doi: 10.1016/j.ridd.2016.05.010
- White, S. W., Richey, J. A., Gracanin, D., Coffman, M., Elias, R., LaConte, S., & Ollendick, T. H. (2016b). Psychosocial and computer-assisted intervention for college students with autism spectrum disorder: Preliminary support for feasibility. *Education and Training in Autism and Developmental Disabilities*, 51(3), 307-317.
- Widman, C.J. & Lopez-Reyna, N.A. (2020). Supports for postsecondary students with autism spectrum disorder: A systematic review. *Journal of Autism Developmental Disorders*, <https://doi.org/10.1007/s10803-020-04409-3>
- Wind, Stefanie. (2019). Nonparametric Evidence of validity, reliability, and fairness for rater-mediated assessments: An illustration using Mokken Scale Analysis. *Journal of Educational Measurement*, 56 (3), 478-504.  
<https://doi-org.proxy.cc.uic.edu/10.1111/jedm.12222>
- Wiorkowski, F. (2015). The experiences of students with autism spectrum disorders in college: A heuristic exploration. *The Qualitative Report*, 20(6), 847-863.  
<http://nsuworks.nova.edu/tqr/vol20/iss6/11>

## VITA

**Cheryl J. Widman**

### Education and Qualifications

<b>2017-current</b>	<b>Full-time student</b> College of Education University of Illinois at Chicago	ABD - PhD Candidate in Special Education (expected Spring, 2020)
<b>2013-2014</b>	<b>UIC LEND</b> (Leadership Education in Neurodevelopmental and Related Disabilities)	Pre-doctoral Trainee Fellow
<b>2009-2017</b>	<b>Part-time student</b> College of Education University of Illinois at Chicago	PhD Student in Special Education
<b>2008-2009</b>	<b>Part-time student</b> National Louis University Chicago, Illinois	M.A.T. – Elementary Education (Special Education Minor) Chicago Teaching Fellow Alternative Certification Program (Highly Selective – Admitted 11% of applicants in 2012)
<b>1990-1991</b>	<b>Full-time student</b> University of Illinois at Chicago	B.A. Economics (French Minor)

### National and International Conference Presentations

Widman, Cheryl (2020). *Characteristics of parent participation in the college education of students with Autism Spectrum Disorder*. Oral Presentation: 2º Congresso Internacional Sobre o Transtorno do Espectro Autista: Atualização Clínica e Científica, Rio de Janeiro, Brazil. (forthcoming)

Widman, Cheryl (2019). *Parent participation in the college education of students with Autism Spectrum Disorder*. Oral Presentation: 12<sup>th</sup> International Autism-Europe Congress, Nice, France.

Widman, Cheryl (2018). *Characteristics of parent participation in the postsecondary education of students with Autism Spectrum Disorder – A pilot project*. Oral Presentation: 5<sup>th</sup> World Autism Organisation International Congress, Houston, TX.

Widman, Cheryl (2013). *Cost benefit analysis of a postsecondary education for students with Autism Spectrum Disorder*. Poster: 10<sup>th</sup> International Autism-Europe Congress, Budapest, Hungary.

Widman, Cheryl (2013). *Cost benefit analysis of a postsecondary education for students with Autism Spectrum Disorder*. Oral Presentation: Autism Society National Conference, Pittsburgh, PA.

Widman, Cheryl (2003). *Neurological discrimination and the fight for an appropriate education*. Oral Presentation: 7<sup>th</sup> International Autism-Europe Congress, Lisbon, Portugal.



## Professional Presentations

---

Widman, Cheryl (2014). *Combating Autism reauthorization act policy brief*. Association of University Centers on Disabilities (AUCD) LEND Policy Seminar, Washington, DC.

Widman, Cheryl (2014). *Characteristics of academically successful postsecondary students with Autism Spectrum Disorder*. Illinois LEND Poster Symposium, Chicago, IL.

## Publication

---

Widman, C. & Lopez-Reyna, N. (2020). Supports for postsecondary students with autism spectrum disorder: A systematic review. *Journal of Autism and Developmental Disorders*, <https://doi.org/10.1007/s10803-020-04409-3>

## Awards

---

University of Illinois President's Research in Diversity Travel Assistance Award, Spring, 2019

UIC William E. Albin & Charlotte C. Young Doctoral Fellowship Award, 2019

UIC Graduate School Travel Award, 2013 & 2018

UIC Graduate Student Council Travel Award, 2018

Goodlow Magnet School Community Service Award - 2010

## Postsecondary Teaching Experience

---

Teaching Assistant (instructor of record): Fall, 2019 Special Education 410 - Exceptional Learners (online course)

Teaching Assistant Intern: Fall, 2017: Special Education 410 - Exceptional Learners (online course)

## Teaching Experience

---

<b>2019 - present</b>	<b>Teaching Assistant/Instructor of Record</b>	<b>University of Illinois at Chicago</b>
<b>2016 – 2017</b>	<b>Middle Grades Special Education Teacher (ELA Reading/Math)</b> Chicago Teaching Fellow Urban Educator	<b>Leif Ericson Scholastic Academy</b> -Chicago Public Schools
<b>2015-2016</b>	<b>In-service Special Ed Mentor</b> National Louis University	<b>In-service Special Ed Mentor</b> National Louis University
<b>2012-2016</b>	<b>Middle Grades Special Education Teacher (ELA Reading/Math)</b> Chicago Teaching Fellow Urban Educator	<b>Earle STEM Academy (formerly Goodlow Magnet School)</b> Chicago Public Schools
<b>2008 - 2012</b>	<b>Middle School Math Teacher</b> Chicago Teaching Fellow Urban Educator	<b>Goodlow Magnet School -</b> Chicago Public Schools

### **Credentials and Endorsements**

---

Active Professional Education License (#1850313): K-9 (2013-2023)

Learning Behavior Specialist 1 (Illinois cross-category endorsement)

Middle School Teaching Endorsements:

Mathematics

Social Science

Foreign Language - French

### **Memberships**

---

Association on Higher Education and Disability (AHEAD)

Autism-Europe

Autism Society

Council for Exceptional Children (CEC)

International Society for Autism Research (INSAR)

The Arc of Illinois

World Autism Organisation

### **Services to the Department and Field**

---

The Arc of Illinois Executive Board Member – Development Committee, 2019 – present

State of Illinois Autism Task Force Partner – 2019 - present

Special Ed Department Representative to the UIC Graduate Student Council, 2017 – present

Think College Credentials in Higher Education Affinity Workgroup Member, 2019 - present

Volunteer at Grupo Salto (working with children with autism as a volunteer) 2013-2014

Professional Development Workshop: *Using continuous formative assessment with at-risk children*. Goodlow

Magnet School (Chicago Public Schools), 2011.

Professional Development Workshop: *Research projects for middle school students using APA 6th edition*. Goodlow

Magnet School (Chicago Public Schools), 2010.

Goodlow Magnet School Middle Grades Department Chair, 2009-2010

Goodlow Magnet School Faculty Local School Council Member: Recording Secretary, 2009-2011

Goodlow Magnet School Professional Personnel Leadership Committee (PPLC) Chair/Recording Secretary, 2009-2011

Goodlow Magnet School Leadership Committee (ILT), 2010-2011, 2015-2016.

### **Autism Identification and Interventions**

---

Autism Diagnostic Observation Schedule (ADOS): training and implementation through LEND

Picture Exchange Communication System (PECS): training through LEND

Applied Behavior Analysis (ABA): training through LEND and professional development with implementation in my Special Education classroom

Pivotal Response Treatment (PRT): training through LEND

Positive Behavior Interventions and Support (PBIS): extensive utilization of Sprick's CHAMPS and

Evidence Based Behavioral Strategies (EBBS) protocols in my Special Education classroom

---