ASSESSING SERVICE AND SUPPORT DISPARITIES AMONG FAMILIES OF CHILDREN ON THE AUTISM SPECTRUM

by

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A thesis submitted to the Faculty of the University of Delaware in partial fulfillment of the requirements for the degree of Master of Science in Human Development and Family Sciences

Winter 2022

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ACKNOWLEDGMENTS

I am deeply grateful to my advisor, Valerie Earnshaw, for her patience, guidance, and support throughout this project. Her focus and encouragement have been an ongoing inspiration and I am truly honored to have her as a mentor. I am also grateful for my committee members: Dr. Allison Karpyn, Professor Steven Eidelman, and Dr. Sheau Ching Chai, for their guidance and suggestions which no doubt raised the quality of this research.

I am indebted to Dr. Fred Hofstetter, who served as my advisor in the Master of Educational Technology program. His belief in my abilities motivated me to apply to the HDFS program, and I am sincerely thankful for his recommendation and support. Additionally, I would like to thank Dr. Ruth Fleury-Steiner for her support and recommendation. Her family studies class provided me with my first course experience in the HDFS program and reinforced my decision to pursue further study in this area.

Thank you to Dr. Michelle “Sheli” Reynolds, University of Missouri-Kansas City, for connecting me with autism organizations to support participant recruitment for this study. Her support enabled access to a broad reach of diverse participants, and I sincerely appreciate her time and generosity.

Most importantly, I thank my family, especially my husband, Leo, and my four children, Stosh, Gabe, Matt and Lil’ Leo. Their support has made this journey possible, and I am grateful every day for their unyielding love and reassurance.

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ABSTRACT

Families with children on the autism spectrum have critical service and support needs which intensify as their children reach adulthood. Use of autism-related services and social support are related to positive outcomes for children on the spectrum and their caregivers; conversely, gaps in service use and social support, especially as children age, contribute to caregiver stress and family strain. Although research assessing the needs of families with adult children on the spectrum has been limited to date, evidence suggests disparities exist across developmental and racial/ethnic lines. The purpose of this research is to identify disparities in unmet service need and perceived social support among families with adolescent versus adult children on the spectrum living at home and among racial/ethnic minority families as compared to non-minority families. A systemic family development framework is applied to evaluate the influence of unmet service need and social support on the family unit. A cross-sectional, quantitative web-based survey of 122 caregivers recruited through autism agencies and support groups was conducted. Analyses did not identify racial/ethnic and age disparities in unmet service need and social support; however, results revealed that male caregivers perceived more social support and unmet service need than female caregivers, and single caregivers perceived less social support than partnered caregivers. Findings suggest the need for targeted interventions to increase service access for male caregivers and social support access for female and single caregivers.

Chapter 1

INTRODUCTION

Children with Autism Spectrum Disorder (ASD) present with pervasive challenges in communicative, social, and cognitive domains and frequently require support through their lifespan (American Psychiatric Association, 2013; Dudley et al., 2019). As a result, access to autism-related services is critical to promote both the functional outcomes of individuals on the spectrum and the well-being of their caregivers. Additionally, families raising children with ASD confront multiple stressors. These stressors extend well beyond the child to include financial burden, social isolation, and stigma (Lopez et al., 2019). Access to services and social support can alleviate the financial strain of procuring private services, strengthen social networks, and engender a sense of hope (Anderson et al., 2018; Barker et al., 2011; Heiman, 2008). Moreover, insofar as such supports influence caregiver well-being, the benefits of service and social support can have a positive impact on the entire family, as the "linked lives" of caregivers and their children affect the broader context and paths associated with the family life course (Elder, 1994; Laszloffy, 2002).

Though there is ample research documenting positive outcomes associated with service use and social support for families of children on the autism spectrum (Pleet-Odle et al., 2016; Shattuck, 2018; Smith & Anderson, 2014), not all families have access to such services (Anderson et al., 2018). For example, services for children and adolescents on the spectrum are supported by the Individuals with Disabilities Act (IDEA); however, once a child graduates from high school or turns

21, autism-related services are no longer guaranteed (Foden & Anderson, 2011; Smith & Anderson, 2014). As a result, families with adult children with autism may suddenly find themselves without services. This poses immense challenges as families are forced to seek appropriate services on their own (Smith & Anderson, 2014). Additionally, as families with adult children on the autism spectrum move through the life course and formal services are lost, social support becomes particularly critical for aging caregivers (Smith et al., 2012).

Race and ethnicity are additional factors influencing service use and social support. For example, researchers have identified lags in autism diagnosis among Black and Latinx children as compared to White children, which often result in delayed access to services (La Roche et al., 2018). Moreover, research reporting differences in perceived social support among minority families has indicated that ethnic minorities show a stronger reliance on informal social support than White families (Zeleke et al., 2019). Differences have been noted in service use, too, suggesting that there are many racial/ethnic differences in both service use and social support (Shattuck et al., 2011).

Access to services and social support is critical for *all* families with children on the spectrum regardless of developmental stage or race; therefore, this research aims to explore whether there are differences in unmet service need and social support among families with children on the autism spectrum depending on the age and race/ethnicity of the child. For this study, unmet service need is defined as services reported as needed but not accessed, and social support is defined as informal social and emotional support provided by friends and family at no cost to the caregiver (Marsack & Samuel, 2017). A systemic family development (SFD) model is used to

conceptualize how autism-related services and social support relate to family well-being at various developmental stages. This model suggests dynamic and reciprocal relationships among family members affect the family unit through the life course; consequently, autism-related services received by any member of the family (i.e., child or caregiver[s]) will ultimately affect the family unit.

Chapter 2

WELLBEING INDICATORS: SERVICE AND SOCIAL SUPPORT

The positive impact of autism-related services and social support for families with children on the spectrum include enhanced caregiver well-being and overall family quality of life (Smith et al., 2012; Marsack & Samuel, 2017). For example, the systemic family development model suggests caregiver well-being is intricately tied to the well-being of the child. Similarly, the well-being of the child enhances that of the caregiver (Laszloffy, 2002). As a result, autism related services benefit the family by improving the functional outcomes of children across many developmental parameters, which ultimately relieves caregiver strain (McStay et al., 2015). Moreover, social support enables families to access informal resources that may otherwise be limited or unavailable. Analysis of unmet service need and social support across developmental and racial/ethnic contexts is necessary to understand the distinct needs and challenges experienced by families of children with autism.

Unmet Service Need

Unmet service need is defined by caregivers' perceptions of autism-related services that are needed but not accessible. For example, needed services may not be accessible if a child with autism "ages out" of the system. That is, while children under age 21 diagnosed with ASD are eligible for services through the Individuals with Disabilities Act (IDEA), they often lose this entitlement when they graduate from high school or turn 21 (American Psychological Association, 2020). At this point,

eligibility must be reestablished. Though each state has different eligibility criteria, the process often involves lengthy assessments and evaluations reviewed by local, state and/or federal agencies whose representatives make the final decision (Foden & Anderson, 2011). Thus, families with adult children with autism may perceive more unmet service need than families with younger children with autism.

Unmet service need may also be impacted by service availability. For instance, though services are generally made available to identified children on the spectrum through state and local agencies, caregivers often incur the burden of locating available services for adult children on the spectrum (Anderson et al., 2018). Further, service availability may be limited by federal, state, and local resources, especially in states where Medicaid funding is low (Smith & Anderson, 2014). This may disproportionately affect minority families as minorities are more likely to have a low income and thus lack access to unfunded, private services (Mather, 2015). Additionally, minority families living in racially segregated neighborhoods, which persist as part of a legacy of institutionalized racism, may have less access to private healthcare services because healthcare agencies are less common in majority-minority neighborhoods (Williams & Collin, 2001).

Social Support

As service use improves outcomes for both individuals on the spectrum and their families, social support, defined as physical and emotional assistance from family and friends provided at no cost to the caregivers, is additionally important in supporting family well-being. Specifically, families with children on the autism spectrum experience stressors and challenges unique to the pervasive nature of the disorder. This strain can affect caregivers' psychological and physical health. For

example, McStay et al. (2015) noted caregivers of children on the spectrum report higher levels of parenting stress, depression, and anxiety than parents raising typical children or children with other disabilities, including Down Syndrome, Cerebral Palsy and Fragile X Syndrome. Additionally, Smith and Anderson (2014) found caregivers of children on the spectrum typically report more health issues than caregivers of children without disabilities. Marsack and Samuel (2017) also noted the strain of parenting a child on the spectrum puts caregivers at higher risk for multiple health problems, including high blood pressure, depression, fatigue, and anxiety.

Though parenting stress affects both the physical and psychological health of caregivers, social support can remediate stress and enhance caregiver well-being. For instance, Altiere and von Kluge (2009) studied the stress-relieving benefits of social support on mothers of children with autism and found mothers who reported more social support had fewer illnesses and depressive symptoms. Moreover, Barker et al. (2011) reported an inverse relationship between caregiver stress and access to large social support networks. Further, Marsack and Samuel (2017) studied the effect of informal social support on the perceived quality of life of parents of children with autism and concluded access to informal social support enhanced parents' perceptions of quality of life. Finally, Smith et al. (2012) found social support was directly correlated with caregivers' positive moods. Such findings are important as the SFD model suggests caregiver stress and wellness influence the overall function of the family unit (Altiere & von Kluge, 2009; Laszloffy, 2002).

Chapter 3

DISPARITY GROUPS: AGE AND RACE/ETHNICITY

Both the age of the child on the spectrum and the family's identified race/ethnicity may be related to service needs and social support. Specifically, unmet service need may be greater once a child on the autism spectrum ages out of IDEA (American Psychological Association, 2020). Moreover, differences in autism diagnosis, treatment and service use have been noted among minority families, suggesting obstacles in accessing autism services not typically experienced by White families (Gourdine et al., 2011; La Roche et al., 2018). Differences have been reported in social support, too, with evidence suggesting caregivers of adult children on the spectrum have a stronger need for social support than caregivers of younger children (Smith et al., 2012). Studies have also noted racial/ethnic differences in social support (Shervin & Maryam, 2018; Taylor et al., 2013), though research in this area is limited.

Age

The age of individuals on the spectrum has been shown to be a limiting factor in service eligibility because the entitlements provided through IDEA typically end when children on the spectrum graduate from high school or turn 21 (American Psychological Association, 2020). At this point, families must establish eligibility to gain access to provided services. Even if eligibility is established, many families are overwhelmed by the lack of support at this stage, which makes finding and using services difficult (Anderson et al., 2018). This is especially true for adult children

living at home with their caregivers. For example, Dudley et al. (2019) noted adults with ASD living at home were much less likely to receive services than their counterparts in supported residential facilities. Furthermore, they reported 60% of families caring for adult children on the spectrum claimed they needed more services (p. 565). Similar findings were reported by Anderson et al. (2018). Specifically, they interviewed 20 parents of young adults on the spectrum living at home and found not only were services inadequate for the families and individuals of this population, but most of the participating families claimed they had to bear "the emotional and financial brunt" of finding services and engagement opportunities to meet their adult child's needs (p. S301). A paucity of research in this area confounds the issue. For example, Shattuck et al. (2018) determined limited research in this area is a major factor contributing to the poor understanding of the needs of these families and inadequate service availability for both the caregivers and their adult children on the spectrum.

In addition to service needs, families caring for an adult child with autism have strong social support needs. That is, the strain of raising an adult child on the spectrum is compounded by the stressors inherent in aging which contribute to a need for social support. For example, Barker et al. (2011) reported the stress of parenting a child with ASD persists through the life course, as mothers of adult children with ASD routinely present with elevated stress levels and compromised well-being. Moreover, McStay et al. (2015) noted "pile-up" demands, defined as demands that may be indirectly related to raising a child with ASD, may be greater in families of older children on the spectrum. Smith and Anderson (2014) echoed this finding, and reported stressful events, even if not linked to the child directly, accumulate with age. Changes in the

family course may prove stressful, too, as families realize there will be no end to their caregiver role. Indeed, the SFD model suggests changes in the family course and structure may result in family stress, especially as caregivers lose vital support from their aging parents and other growing children, who may eventually leave the nest (Laszloffy, 2002). Moreover, as caregivers age, the demands of caring for an adult child on the spectrum along with a growing lack of support may contribute to their own emergent health issues (Marsack & Samuel, 2017).

Race/Ethnicity

If gaps in unmet service need and social support are broad among families with adult children on the spectrum, broader still may be the disparities in services noted across racial and ethnic lines. Specifically, gaps in diagnosis and perceived need for services have been noted for minority families as compared to White families, and such disparities may result in unmet service need. For example, though there are no differences in the prevalence of ASD based on race and ethnicity, Latinx and African American children are more likely than White children to be diagnosed at a later age with more symptoms or to be misdiagnosed (Zuckerman, 2014). Additionally, Gourdine et al. (2011) reported African American children required three times the number of healthcare visits than White children before receiving a diagnosis, and typically required services over a longer period of time. Further, results from a nationally representative sample demonstrated Latinx children with ASD were much less likely than White children with ASD to receive school-based therapy services like occupational and physical therapy (Bilaver & Havlicek, 2019). Moreover, they noted both Black and Latinx children were underrepresented in special education. These delays in diagnosis result in obstacles in securing service eligibility. That is, since

these children were not identified, access to autism-related services was delayed or denied.

The studies described here document racial and ethnic disparities among minority families with children or adolescents on the autism spectrum. It is unclear, however, if these disparities exist among minority families with *adult* children on the spectrum as research in this area is limited. Some researchers have noted minority families report school services to be more responsive to their needs than formal healthcare services (Zeleke et al., 2019). This has important implications, as when school services are discontinued, families may be forced to rely on services provided through the healthcare system. The challenge here is noted by Gourdine et al. (2011), who found ethnic minorities are *less* likely to seek formal medical treatment, as often "stereotyping, bias, and uncertainty characterized clinician-patient relationships" (p.460). This suggests minority families with children on the spectrum may be reluctant or face additional barriers when seeking formal supports beyond the parameters of the school setting; consequently, it is likely the unmet needs of these families grow as their children age out of IDEA and they are forced to seek formal services elsewhere.

In addition to disparities in service use, minority families may experience differences in social support as well. For example, though research on social support among minority families with children and adult children with autism is limited, Benevides et al. (2016) noted African American parents of children with attention deficit hyperactivity disorder were more likely than White parents to seek help from family members or use religious supports. Further, Taylor et al. (2013) reported African Americans were more likely to provide assistance to their family members

than Whites and were more likely to have daily interactions with extended family members. Moreover, August and Sorkin (2011) studied the effect of social support on the dietary behavioral responses of a diverse sample of adults with diabetes and found Latinx participants received more social support than White participants. Finally, Shervin and Maryam (2018) measured the protective effects of social support on depressive symptoms of African American and White participants and found African American participants benefitted more from the same level of emotional social support. Though these studies were pulled from different research settings, the underlying findings suggest racial and ethnic differences in social support are likely experienced across contexts.

Chapter 4

CURRENT STUDY

Autism spectrum disorder manifests through social, communicative, and cognitive challenges with varying degrees of severity. As a result, families of children on the spectrum report higher levels of stress and have strong service and support needs, and evidence suggests these needs increase as the child ages. Research which focuses on unmet service need and social support needs of families with adult children on the spectrum is limited, even as need in this area is growing. Additionally, past research has had a strong emphasis on racial disparities in ASD diagnosis, treatment, and perceived need, though it is unclear if these disparities change as the child ages. Limitations acknowledged by previous researchers include homogenous samples with narrow age-ranges of children on the spectrum; consequently, the specific needs of families with adult children on the spectrum and families from diverse racial/ethnic backgrounds in terms of service use and social support remain ambiguous.

Given the limitations and paucity of existing research in this area, additional research focusing on the influence of age and race/ethnicity on unmet service need and social support is critical. This research will add to limited knowledge in this area to better inform policy and support targeted interventions for minority families and families with adult children on the autism spectrum. The purpose of this study is to compare unmet service need and social support among minority and non-minority (White) families with adolescent and adult children on the autism spectrum living in

the household. Specifically, this study explores the following questions and hypotheses:

1. Are there age differences in unmet service need and social support experienced by families with children on the autism spectrum? It is hypothesized that there will be age differences in unmet service need and social support, with families of adult children on the spectrum reporting more unmet service need and less social support than families with adolescent children on the spectrum.
2. Are there racial and ethnic differences in unmet service need and social support experienced by families with children on the autism spectrum? It is hypothesized that there will be racial/ethnic differences in unmet service need and social support, with racial and ethnic minority families reporting more unmet service need and more social support than White families.
3. Exploratory aim: Is there an interaction between race/ethnicity and age on unmet service need and social support outcomes? Analyses will explore whether any subgroups (e.g., racial/ethnic minority families with adult children) have greater unmet service need and less access to social support.

Methods

A cross-sectional, quantitative web-based survey of caregivers recruited through autism agencies and support groups was conducted.

Participants and Procedures

Participants in this study were caregivers of individuals diagnosed with ASD living at home. A national web-based survey was posted on social media sites which cater to the target population as well as conducted via email, and 122 caregivers were

recruited from local and national autism support groups and organizations. Only caregivers who had a child with a formal diagnosis or classification of autism spectrum disorder between the ages of 16-30 who has lived at home for the past 12 months were included. Additionally, participants needed to be able to read and comprehend English and have access to a computer or mobile device to complete the web-based survey.

Measures

Independent variables included race and ethnicity, categorized as nonminority (White) and minority, and the age of the individual diagnosed with ASD, categorized as persons aged 21 to 30 defined as "adult" and those aged 16 through 20 defined as "adolescent". Dependent variables included perceptions of unmet service need and perceived levels of social support. Unmet service need was defined as caregivers' perceptions of autism-related services that are needed but not accessible. Social support was defined as physical and emotional assistance from family and friends provided at no cost to the caregivers. Other demographic variables were measured as co-variates.

Demographics

Race, ethnicity, gender (based on the 2020 U.S. Census definitions) and state of residence of the primary caregiver, the caregiver's spouse/partner as well as the individual on the spectrum were measured. Race was measured based on the 2020 U.S. Census definitions and was categorized as White (non-minority) and minority (non-White). The age of the individual on the spectrum was also measured, where individuals aged 16-20 were defined as "adolescent" and those aged 21-30 were

defined as “adult”. In addition, the living arrangement, educational and vocational status of the individual with autism, as well as the caregivers’ and caregivers’ spouse’s/partner’s educational status, vocational status, and household income were measured. The primary caregiver provided confirmation of an ASD diagnosis or classification.

Perceptions of Unmet Service Need

Perceived unmet service need was measured using questions modified from the 2012 *Oklahoma Autism Needs Assessment Survey* and the *2011 Survey of Pathways to Diagnosis and Services*. The first survey was developed by the Oklahoma Autism Network to assess service and support needs among caregivers of children diagnosed with ASD, and its use has been deemed appropriate by the Oklahoma Family and Interagency Council (The Oklahoma Family and Interagency Autism Council, 2013). The *2011 Survey of Pathways to Diagnosis and Services* was used as part of the National Longitudinal Transition Study-2 (NLTS2) in which a nationally representative sample of students receiving special education services were followed for ten years to better understand their experiences as they transitioned from adolescence to early adulthood (National Longitudinal Transition Study-2, n.d.). Participants were asked whether they perceive that they needed, had available to them, or have used services within a series of 9 service categories including: respite, recreation, medical, therapeutic, psychological, daily living support, supported employment, family counseling, family training and adolescent and adult day services. Reported unmet service need in each category was scored as “1”, and scores ranged from 0 (indicating no unmet service need) to 9 (indicating unmet need in every

category). Scores were summed with higher scores indicating greater unmet service need.

Perceived Social Support

Perceived social support was measured using the *ENRICHD Social Support Instrument* (ESSI), a 7-item survey originally designed to measure perceived social support in cardiac patients; however, researchers have determined it is a reliable and valid measure to assess perceived social support among caregivers with adult children on the spectrum (Marsack & Samuel, 2017). Four items were rated on a 5-point scale, with "1" specifying "none of the time" and "5" specifying "all of the time", and 3 items were measured on a dichotomous scale (yes/no). Answers were summed to determine the total score (Cronbach's alpha=0.74). Scores ranged from 7-26, with higher scores indicating stronger perceptions of social support.

Analysis

First, descriptive statistics were explored, including means and standard deviations of perceived ASD-related unmet service need and social support among minority and nonminority (White) families and families with a child with ASD between the ages of 16-20 or 21-30. To address research questions 1 and 2, univariate and separate multivariable regression analyses were conducted including race and age of the child with ASD as predictors of social support, and univariate and multivariable Poisson regression analysis including race and age of the child with ASD as predictors of unmet service need. Control variables included the income, education, and gender of caregiver. To address research question 3, a moderation analysis using PROCESS was conducted (Hayes, 2017).

Chapter 5

RESULTS

Participant Characteristics

Participant characteristics are described in Table 1. The sample consisted of 122 caregivers with more female than male participants. There were 101 participants identifying as White, and 21 participants identifying as non-White or racial/ethnic minority. Most participants were college educated and were employed at least part-time. Four percent of the participants reported an income of less than 26,000 annually. The mean age of the participants' child for whom the survey was completed was 20.44, with 85 children identified by their caregivers as White and 28 identified as a non-White racial/ethnic minority

Table 1 Participant Characteristics (N=122)

Characteristic	M	SD	%	n
Caregiver				
Age	52.03	9.27		
Race				
White			81.5	101
Other			16.9	21
Education (College Degree and Above)			71	88
Employment (Full-time)			79	63.7
Gender				
Men			8.9	11
Women			88.7	110
Relationship Status				
Partnered			69.4	86
Single			25	31

Table 1 Participant Characteristics continued.

Child				
Age	20.44	3.85		
Race				
White			68.5	85
Other			22.6	28
Outcomes				
Unmet Service Need	2.10	2.2		
Social Support	17.2	4.52		

Note. Percentages may not total 100 due to missing data. Unmet service need was measured on a scale of 0-9, with 9 indicating greatest unmet service need. Social support was measured on a scale of 7-26, with higher scores indicating more perceived support.

Social Support

Table 2 includes results of univariate and multivariable analyses predicting social support. The results demonstrate the child's race/ethnicity and age are not associated with access to social support. Results reveal an association between caregiver gender and access to social support, however, with female caregivers perceiving less support than male caregivers. Results reveal an association between caregiver relationship status and access to social support, with single caregivers perceiving less support than partnered caregivers. Results of the multivariable analysis confirmed child race/ethnicity and age are not associated with perceived social support. Additionally, results of the multivariable analysis confirmed an association between caregiver gender and social support, with female caregivers reporting less support than male caregivers. Additionally, results of the multivariable analysis confirmed an association between caregiver relationship status and social support, with single caregivers reporting less support than partnered caregivers. The final

analysis suggested that the association between child age and access to social support is not moderated by child race/ethnicity.

Table 2 Social Support

Characteristics	Univariate Model				Multivariable Model				Moderation Model			
	B	*SE*	*Beta*	*p-value*	*B*	*SE*	*Beta*	*p-value*	*B*	*SE*	*Beta*	*p-value*
Child Age: 21 and older	0.87	0.85	0.09	0.31	0.95	0.92	0.10	0.30	0.02	0.13	0.02	0.87
Child Race +Ethnicity: Minority	-0.26	0.98	-0.03	0.79	0.62	1.00	0.06	0.54	0.57	1.05	0.05	0.59
Child Age * Race									0.07	0.31	0.02	0.83
Parent Income:												
0-26k	-2.88	2.07	-0.13	0.17	-0.29	2.16	-0.01	0.89	-0.67	2.15	-0.03	0.76
27-50k	-1.49	1.01	-0.14	0.14	0.44	1.05	0.04	0.68	0.41	1.08	0.04	0.70
Parent Education:												
College Degree	0.04	0.96	0.01	0.97	-0.42	1.01	-0.04	0.68	-0.54	1.02	-0.05	0.60
Parent Gender:												
Woman	-3.50	1.41	-0.23	0.01	-3.19	1.38	-0.21	0.02	-3.23	1.4	-0.22	0.02
Parent Age	-0.01	0.05	-0.01	0.91	-0.01	0.05	-0.01	0.95	0.12	0.05	0.02	0.83
Parent Relationship Status:												
Single	-3.89	0.88	-0.38	<.001	-4.50	0.99	-0.44	<.001	-4.49	1.02	-0.44	<.001
Constant					21.01	2.96		<.001	20.8	3.22		<.001

Unmet Service Need

Table 3 lists results of unmet service need measured by the number of services reported as needed but not accessed, categorized by race, gender, and relationship status. Table 4 includes results of univariate and multivariable analyses predicting unmet service need. Results of the univariate analysis suggest the child's race/ethnicity and age are not associated with unmet service need. Results suggest an association between caregiver gender and unmet service need, however, with male

caregivers perceiving more unmet service need than female caregivers. Results of the multivariable analysis confirmed child race/ethnicity and age are not associated with unmet service need. The final analysis suggested that the association between child age and unmet service need is not moderated by child race/ethnicity.

Table 3 Participant Characteristics and Service Need

Race/Ethnicity n=103			Gender n=102		Relationship Status n=103	
Services Needed	White % (n)	Minority % (n)	Female % (n)	Male % (n)	Single % (n)	Partnered % (n)
0	24.3 (25)	6.8 (7)	26.5 (27)	4.9 (5)	5.8 (6)	25.2 (26)
1	15.5 (16)	3.9 (4)	14.7 (15)	3.9 (4)	3.9 (4)	15.5 (16)
2	12.6 (13)	2.9 (3)	13.7 (14)	1.9 (2)	7.8 (8)	7.8 (8)
3	9.7 (10)	1.9 (2)	11.8 (12)	0	2.9 (3)	8.7 (9)
4	5.8 (6)	0	5.9 (6)	0	.97 (1)	4.9 (5)
5	6.8 (7)	0	6.9 (7)	0	0	6.8 (7)
6	2.9 (3)	.97 (1)	3.9 (4)	0	.97 (1)	2.9 (3)
7	3.9 (4)	0	3.9 (4)	0	.97 (1)	2.9 (3)
8	0	.97 (1)	.98 (1)	0	0	.97 (1)
9	0	.97 (1)	.98 (1)	0	.97 (1)	0
Total	84	19	91	11	25	78

Table 4 Unmet Service Need

Characteristics	Univariate Model				Multivariable Model				Moderation Model		
	B	*SE*	*Beta*	*p-value*	*B*	*SE*	*Beta*	*p-value*	*B*	*SE*	*p-value*
Child Age: 21 and older	0.24	0.14	1.27	0.10	0.22	0.17	1.24	0.20	-0.20	0.05	0.69
Child Race +Ethnicity: Minority (nonwhite)	0.10	0.16	1.1	0.55	0.02	0.18	1.02	0.91	0.01	0.19	0.95
Child Age * Race									-0.02	0.05	0.69

Table 4 Unmet Service Need continued.

Parent Income											
0-26k	-0.50	0.29	0.61	0.10	-0.18	0.34	0.84	0.60	-0.24	0.33	0.47
27-50k	0.04	0.17	1.04	0.81	0.21	0.19	1.23	0.27	0.18	0.19	0.33
Parent Education											
College Degree +	0.21	0.15	1.23	0.16	0.08	0.18	1.08	0.66	0.07	0.18	0.69
Parent Gender											
Woman	-1.14	0.36	0.32	0.00	-1.09	0.37	0.34	0.01	-1.11	0.37	0.00
Parent Age					-0.01	0.01	1.00	0.95	-0.001	0.01	0.95
Parent relationship Status											
Single	-0.06	0.16	0.94	0.68	-0.13	0.18	0.88	0.47	-0.12	0.10	0.53
Intercept	0.59	0.11	1.81	<.001	0.75	0.64	2.11	0.24			

Chapter 6

DISCUSSION

This study did not detect age or racial/ethnic differences in unmet service need and social support access among families with adolescent or adult children on the autism spectrum. These results conflict with findings from previous studies, which suggest age and racial/ethnic differences exist in both unmet service need and perceived social support (Anderson et al., 2018; La Roche et al., 2018). It is possible that the services measured, including education and healthcare services, may not have been perceived as *needed* by the families in this study. For example, the majority of families in this study identified as White. Benevides et al. (2016) found that White caregivers identified a need for therapy services less frequently than minority caregivers, and researchers suggested minority families may be more likely to seek treatment based on functional outcomes. Additionally, families of adult children on the autism spectrum are more likely to seek and access services independently, without the support of state and local agencies (Anderson et al., 2018). Thus, these families may not have perceived services procured on their own as "needed", even as access to these services demand substantial time and financial resources.

Differences in perceived social support among racial and ethnic minorities and among families with adult children on the spectrum were also not detected in this study, although current research suggests such differences may exist (Lopez et al., 2019; Benevides et al., 2016). This study measured access to perceived social support. It is possible the true disparity lies not in perceived social support per se, but in the

social networks accessible by White and minority families and families with adult children on the spectrum. For example, Gourdine et al. (2011) found that minority families gained greater satisfaction from informal social supports and friendship networks than White families. Moreover, since the age range of the caregivers' children was rather narrow (i.e., 16-30), differences in perceived social support may not become apparent until later in the life course. A study which expands the child age range beyond 30 may provide insight into potential disparities experienced as adult children with autism and caregivers' age.

Although there were no racial/ethnic and age differences identified in perceived unmet service need and social support, results suggest caregiver *relationship status* is related to perceived social support. Specifically, single caregivers perceived less social support than partnered caregivers. This finding suggests the social networks of single caregivers may be limited. For example, as partnered caregivers have access to the social networks of their partners (e.g., in-laws, friends, etc.) single caregivers may lack such access; consequently, this may lead to a loss of social networks which may limit a single caregiver's access to social support. Further, time may be a limiting factor in a single caregiver's ability to create, expand and access existing social networks. Research focusing on specific support needs and barriers experienced by single caregivers raising children on the autism spectrum is practically nonexistent, and more research is needed to gain a better understanding of the unique needs of this population.

Strengths and Limitations

Research assessing unmet service need and social support among ethnically diverse families and families with adult children on the spectrum is scant, even as an

increasing number of people of all races/ethnicities on the autism spectrum age out of the system. This study adds to existing research and raises new questions surrounding the diverse perceptions of single and partnered caregivers and suggests single caregivers may have less access to social support than partnered caregivers, identifying a need for further work in this area. This study is limited by a relatively small nonrepresentative convenience sample; consequently, findings are specific to this sample. A larger, nationally representative sample would enable researchers to generalize findings to the broader population. For example, although gender differences were detected, the small number of men in the study (n=11) prohibited any firm conclusions regarding gender differences. A larger sample with more men could provide insight into gender differences in social support and service needs. Additionally, because a cross-sectional design was used, results reflect a "snap-shot" of families in various stages of the life course rather than assessing perceptions overtime. Longitudinal studies would address this limitation and provide a more accurate picture of the service and support needs of these families as they move through the life course. Finally, the quantitative measures used to detect perceived social support disparities among single caregivers do not provide insight into why these disparities exist. Qualitative methods characterizing the perceived cause of support disparities as described by affected families could elaborate on these findings and offer insight to support more targeted interventions

Conclusions

Families of children on the autism spectrum report considerable needs in both autism related services and social support, and recent research suggests disparities in unmet service need and social support may exist among racial and ethnic minorities

and families of adult children on the autism spectrum. Although the results of this study did not reflect these disparities, policies addressing potential disparities are necessary to ensure service equity and support for all families caring for children and adult children on the autism spectrum. Policies are particularly needed as the service and support needs of these families are increasing. For example, over the next decade, approximately 70,700 to 116,000 teens will age out of autism related school-based services per year (Autism Statistics and Facts, 2021). This suggests a strong need for policies which support vocational services for growing children on the spectrum, respite services for their aging caregivers, and equal access to services for these diverse families.

Although this study did not identify racial/ethnic and age disparities in unmet service need and social support, results identified potential differences in social support between single and partnered caregivers. To address these potential disparities, policy makers should invite the participation of single caregivers in local, state, and federal advisory councils. This will ensure single caregivers have a voice in creating policy to better addresses their diverse service and support needs. In addition, training for support professionals should include increasing sensitivity to the support needs of single caregivers, and agencies that employ these professionals should consider recruiting single caregivers to add to their support teams if single caregivers are not already represented. Finally, local, state, and federal agencies, along with support professionals and family advocates, must coordinate their efforts to promote targeted interventions for *all* families with children on the autism spectrum. This will ensure the unmet service and support needs of each affected family, regardless of

race/ethnicity, developmental stage, gender, or relationship status is addressed and supported through the life course.

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Appendix

IRB/HUMAN SUBJECTS APPROVAL

Institutional Review Board
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DATE:	August 3, 2020
TO:	Ethel Sticinski, PhD
FROM:	University of Delaware IRB
STUDY TITLE:	[1614896-1] Master's Thesis
SUBMISSION TYPE:	New Project
ACTION:	DETERMINATION OF EXEMPT STATUS
EFFECTIVE DATE:	August 3, 2020
REVIEW CATEGORY:	Exemption category # *(2)*

Thank you for your New Project submission to the University of Delaware Institutional Review Board (UD IRB). According to the pertinent regulations, the UD IRB has determined this project is EXEMPT from most federal policy requirements for the protection of human subjects. The privacy of subjects and the confidentiality of participants must be safeguarded as prescribed in the reviewed protocol form.

This exempt determination is valid for the research study as described by the documents in this submission. Proposed revisions to previously approved procedures and documents that may affect this exempt determination must be reviewed and approved by this office prior to initiation. The UD amendment form must be used to request the review of changes that may substantially change the study design or data collected.

Unanticipated problems and serious adverse events involving risk to participants must be reported to this office in a timely fashion according with the UD requirements for reportable events.

A copy of this correspondence will be kept on file by our office. If you have any questions, please contact the UD IRB Office at (302) 831-2137 or via email at hsrb-research@udel.edu. Please include the study title and reference number in all correspondence with this office.

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