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Measurement and Predictors of Mental Health among Parents of Children with Intellectual and Developmental Disabilities

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FLORIDA INTERNATIONAL UNIVERSITY

Miami, Florida

MEASUREMENT AND PREDICTORS OF MENTAL HEALTH AMONG PARENTS
OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

A dissertation submitted in partial fulfillment of

the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

PUBLIC HEALTH

by

Rumi Agarwal

2021

To: Dean Tomás R. Guilarte
R.Stempel College of Public Health and Social Work

This dissertation, written by Rumi Agarwal, and entitled Measurement and Predictors of Mental Health among Parents of Children with Intellectual and Developmental Disabilities, having been approved in respect to style and intellectual content, is referred to you for judgment.

We have read this dissertation and recommend that it be approved.

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Date of Defense: May 28, 2021

The dissertation of Rumi Agarwal is approved.

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Florida International University, 2021

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DEDICATION

Filled with moments of excitement, disappointment, happiness, and anxiety, this doctoral journey would have not been possible without the support from my parents (both birth and in-laws), amazing husband, incredible daughter (who hopes my sense of humor will now return), and my siblings and friends. You have all tolerated my many highs and lows, and still continue to love me! There are no words to express how grateful I am for each of you.

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ABSTRACT OF THE DISSERTATION
MEASUREMENT AND PREDICTORS OF MENTAL HEALTH AMONG PARENTS
OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

by

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Florida International University, 2021

Miami, Florida

Professor Elena Bastida, Co-Major Professor

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Parents of children with intellectual and developmental disabilities (IDD) experience elevated levels of stress, anxiety and other adverse mental health conditions. Despite extensive literature on parental mental health, this research addressed three gaps. First, a systematic review identified the interventions and respective scales used to address and assess stress and anxiety among parents of transition-aged children with autism spectrum disorder (ASD). This was necessary given that the stressors parents experience vary with the age of the child. Of the 11 studies included in the final review, it was evident that most interventions and scales were not aligned with the unique needs and characteristics of this population.

Second, quantitative analysis of the 2017-2018 combined National Survey for Children's Health explored the impact of the health care demands of a child with ASD on the mental health of parents. Health care demands included among others, the time, employment and financial burden that parents experienced. Findings indicated that the mental health of mothers and fathers were associated with differing factors. For example,

among mothers, unfavorable mental health was significantly associated with spending between one to ten hours coordinating care, while among fathers, unfavorable mental health was associated with frustration to obtain services for their child.

Third, using primary data collection, parents of children with IDD (n=176) were recruited to complete an online survey. The study examined parental experiences regarding financial planning and utilization of accounts given the high levels of financial distress these families experience. This study focused on the Achieving a Better Life Experience (ABLE) program, and checking, savings and trust accounts. Several programmatic and personal barriers were identified which hindered planning and utilization. Parents also reported that only 29.5% of their children with IDD had an ABLE account, while rates for checking, savings and special needs trust accounts were also low at 26%, 35% and 13.6%, respectively. Given the impact parental wellbeing has on the child's trajectory, and vice versa, it is imperative to design scales, policies, interventions and programs to address the mental health needs of this parent population.

TABLE OF CONTENTS

CHAPTER	PAGE
CHAPTER 1: INTRODUCTION.....	1
Background.....	1
Research Aims and Methods	5
Theoretical Framework.....	11
References.....	13
CHAPTER 2: MANUSCRIPT 1	23
Abstract.....	23
Background.....	25
Methods.....	33
Results.....	37
Discussion.....	54
Conclusion	62
References.....	63
Tables	80
Figures.....	89
CHAPTER 3: MANUSCRIPT 2	90
Abstract.....	90
Background.....	91
Methods.....	96
Results.....	101
Discussion.....	108
Conclusion	116
References.....	116
Tables	126
CHAPTER 4: MANUSCRIPT 3	132
Abstract.....	132
Background.....	133
Methods.....	137
Results.....	140
Discussion.....	168
Conclusion	176
References.....	176
Tables	182
Figures.....	185

CHAPTER 5: CONCLUSION	187
Summary of Findings and Implications	187
Limitations and Recommendations.....	190
Expected Impact.....	191
VITA.....	194

LIST OF TABLES

TABLE	PAGE
CHAPTER 2: MANUSCRIPT 1	
Table 1. Complete search strategy	80
Table 2. <i>t</i> -distribution calculations	81
Table 3. Quality rating of included studies in review	84
Table 4. Summary characteristics of studies in final review	85
Table 5. Study design of interventions included in the final review	87
CHAPTER 3: MANUSCRIPT 2	
Table 1. Demographic attributes of study sample	126
Table 2. Frequency of mental health and health care demand variables among study sample	127
Table 3. Cross-tabulations of health care demands and demographic variables with maternal and paternal mental health	128
Table 4. Mother's mental health logistic regression – adjusted odds ratio and confidence intervals	130
Table 5. Father's mental health logistic regression – unadjusted odds ratio and confidence intervals	131
CHAPTER 4: MANUSCRIPT 3	
Table 1. Demographic attributes of study sample	182
Table 2. Cross-tabulations of demographic variables and status of having an ABLE account	184

ABBREVIATIONS AND ACRONYMS

ABLE	Achieving a Better Life Experience
ADD	Attention deficit disorder
ADHD	Attention deficit hyperactivity disorder
APSI	Autism Parenting Stress Index
ASD	Autism spectrum disorder
BAI	Beck Anxiety Inventory
BBTP	Building Bridges Triple P
CI	Confidence interval
DASS-21	Depression Anxiety Stress Scale
DD	Developmental disabilities
DD	Developmental delay
FPL	Federal poverty line
ID	Intellectual disability
IDD	Intellectual and developmental disabilities
ILLiad	Interlibrary Loan Internet Accessible Database
LD	Learning disability
LCT	Life course theory
MBCT	Mindfulness-Based Cognitive Therapy
MBP	Mindfulness-Based Program
MBPBS	Mindfulness-Based Positive Behavior Support
MBSR	Mindfulness-Based Stress Reduction

NSCH	National Survey for Children’s Health
OR	Odds Ratio
PASS	Plans to Achieve Self Support
PBS	Positive behavior support
PEERS	Program for the Education and Enrichment of Relational Skills
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSI	Parenting Stress Index
PSS	Parental Stress Scale
PSS-10	Perceived Stress Scale-10
SIPA	Stress Index for Parents of Adolescents
SPSS	Statistical Package for the Social Sciences
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
STAI-S and STAI-T	State and Trait Anxiety Inventory

CHAPTER 1: INTRODUCTION

Background

Developmental disabilities (DD) are a group of heterogeneous disorders, which include, but are not limited to autism spectrum disorder (ASD) and intellectual disability (ID). DD is characterized by difficulties in at least one domain of learning, behavior, and self-care (Zablotsky et al., 2017). In the United States, the prevalence of DD, ASD, and ID among children 3-17 years old in 2016 was almost 7%, 2.8%, and 1.15% respectively (Zablotsky et al., 2017). Among 8-year old children, the prevalence of ASD rose from 1 in 59 in 2014 to 1 in 54 in 2016 (Maenner et al., 2020).

Parents of children with intellectual and developmental disabilities (IDD; a common term in developmental disability literature; National Institutes of Health, 2016) have been shown to experience elevated levels of stress, anxiety, and other adverse mental health outcomes compared to parents of neurotypical children (Al-Yagon & Margalit, 2009; Browne & Bramston, 1998; Gallagher et al., 2008; Piven et al., 1991; Shepherd et al., 2018; Shivers et al., 2019). Numerous studies have examined the stressors these parents face and include among others: Adequacy of social support, the extent of the child's problem behaviors, access to supports and services, employment difficulties, caregiver burden, and financial distress and poverty (Altiere & von Kluge, 2008; Gallagher et al., 2008; Gau et al., 2012; Gray, 2006; Jones et al., 2013; Ludlow et al., 2012; Myers et al., 2009; Nealy et al., 2012; Piven et al., 1991; Lee et al., 2019; Patton et al., 2018; Emerson & Brigham, 2015; Meppelder et al., 2015; Parish et al., 2004).

Some studies have extended the literature base by examining some of these stressors by differences in mental health outcomes among mothers and fathers, and by the age of the child (Davis & Carter, 2008; K. Gray et al., 2014; Griffith et al., 2011; Hastings, 2003; Hayes & Watson, 2013; Samadi et al., 2014; Tehee et al., 2009). While there is some evidence that the stressors among mothers and fathers vary (Allen et al., 2013; Soltanifar et al., 2015), a recent systematic review has drawn attention to the lack of research on fathers (Rankin et al., 2019). Concerning the age of the child, findings in the literature are mixed. Some studies implicate worsening parental mental health as the child grows, while others suggest it improves (Azad et al., 2013; Kousha et al., 2016). Despite this lack of consensus, it is evident that the stressors parents experience is unique to the varying developmental stages of the child. For example, parents of young children worry about delayed development, success in school, friendships, and daily living tasks such as bathing, while parents of transition-aged children worry about the attainment of adult outcomes such as employment, romantic relationships, and the potential for their child to live independently (Koren' et al., 2016; Lee & Shivers, 2019).

Diagnosing and understanding the causes of poor mental health outcomes in this parent population is necessary given the “linked lives” of the parent-child relationship: where a child’s well-being affects parental well-being and vice versa (Barker et al., 2011). Among parents, unaddressed mental health concerns can lower life satisfaction, lead to marital instability, and other poor health outcomes (Bonis, 2016; Reichman et al., 2008). Poor parental mental health can also lead to parents favoring medical treatments rather than behavioral treatments for their child with IDD, given that the latter requires more emotional effort (Moore & Symons, 2009). This can undermine areas of existing

deficits such as behavioral, social, cognitive, and language development (Dardas & Ahmad, 2014). Consequently, these choices can further deteriorate the trajectory for this vulnerable population with regards to academic achievement, employment, and independent living (Brucker & Nord, 2016; Caniglia & Michali, 2018; Laser, 2018; Lauer & McCallion, 2015; Morris et al., 2016; Parish et al., 2010; Salvador-Carulla et al., 2015).

Despite the extensive literature on the stressors and the mental health among families of children with IDD, three areas of interest remain unaddressed. First, given the rising rates of ASD, there has been growing attention to address the unique needs among families and children during the transitional period from adolescence to adulthood (Interagency Autism Coordinating Committee (IACC), 2017). However, intervention studies which aim to assess and address stress and anxiety among parents of transition-aged children with ASD are sparse, and appear to use a plethora of self-report instruments (Cox et al., 2015; Falk et al., 2014; Findler et al., 2016; Samadi et al., 2014). This raises questions regarding the suitability of the intervention and the validity of reported parental stress and anxiety levels. Ensuring that stress and anxiety are accurately captured is especially important given that parents may not project clinically significant levels of parenting stress or depressive symptoms (Davis & Carter, 2008). As such, it is imperative to examine the existing literature and identify the characteristics of interventions and scales being used, to assess fit among parents of transition-aged children with ASD.

Second, it is well established that providing care for a child with ASD is demanding (Marsack-Topolewski & Church, 2019), adding significant time,

employment, and financial burdens on families (Benevides et al., 2019; McManus et al., 2011; Vohra et al., 2014). However, the association between these health care demands and parental mental health has not been examined using nationally representative data. Moreover, no study has considered the differences which may exist between mothers and fathers. By understanding how the mental health of both parents may be impacted differently by time, employment, financial, and other healthcare-related burdens, it may be possible to inform targeted interventions and policies for mothers and fathers respectively.

Third, families of children with IDD experience significant levels of financial hardship (Emerson & Brigham, 2015; Meppelder et al., 2015). To alleviate poverty, reduce financial distress, and improve life outcomes among families and individuals with disabilities (Laser, 2018) the Achieving a Better Life Experience (ABLE) Act was enacted in 2014 (Social Security Administration, 2019). This financial tool was designed to allow individuals with qualifying disabilities to open a tax-free savings account that could be used for disability-related expenses, without losing government benefits to a certain threshold. Despite the potential for the ABLE account to improve financial circumstances, its utilization has been low (Curley, 2020), similar to the utilization of other financial tools such as checking and savings accounts (Goodman & Morris, 2017). No study has yet explored the experience of families of children with IDD in regards to financial planning and utilization of the ABLE account and other financial tools, and the barriers they face which if addressed could improve financial stability and reduce distress.

Given that life expectancy continues to rise into the early 70s for individuals with mild to moderate IDD (Patja et al., 2000) and children often continue to live with their parents into adulthood (Verseghy et al., 2019) there is an urgent need to address parental mental health and its associated stressors. By examining 1) existing scales and interventions to diagnose and address stress and anxiety, 2) the impact of health care demands on mothers and fathers, and 3) the financial planning and utilization experience among these families, we can seek to better understand and extend the literature base. This will help inform meaningful change in self-report instruments, policies, programs, and interventions to improve outcomes for both parents and their child with IDD.

Research Aims and Methods

To address the gaps identified in the literature, this dissertation sets out to examine three distinct aims, each of which utilized a different research methodology: a systematic review, quantitative secondary data analysis, and a cross-sectional survey utilizing primary data collection methods and analyses. The following section presents each aim and their respective methods.

Aim 1

The objective of this study was to identify the characteristics of interventions and the scales used to address stress and anxiety among parents of transition-aged children with ASD. This study utilized a systematic review methodology, which was based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher

et al., 2009) guidelines. Using keywords and controlled vocabulary terms, four electronic databases, PsycINFO, MEDLINE, CINAHL, and Embase were searched for the period 2010 to 2020.

Inclusion criteria for studies in this review were: Intervention studies assessing stress and/or anxiety using a quantitative self-report scale among parents of transition-aged children with ASD. Transition age was defined as 14 to 22 years of age as done similarly in a recent study (Chen et al., 2019). Given that many ASD intervention studies recruit from within a wide age range and do not always provide sufficient demographic details to discern the number of transition-aged children in the study, we statistically estimated this number using *t*-distribution calculations if the information was not available from the manuscript or author. T-distributions rather than normal distribution calculations were used given the small sample sizes (SAS Institute Inc., n.d.) in many ASD intervention studies. To enhance rigor and include studies that may not have explicitly targeted the transition-aged population, studies that were estimated to have at least 50% of children in this age range were included. Studies were limited to the last decade to ensure relevance to the continuously developing field, and were excluded if they measured a mental health outcome other than stress and/or anxiety, used only biomarkers to assess stress and/or anxiety levels, or were a medical intervention. Studies were limited to those published in peer-reviewed journals that met inclusion criteria.

The complete review process was conducted by two reviewers (RA and GW) to minimize bias. Studies included in the final review were examined for methodological rigor using a protocol designed by Hawker, Payne, Kerr, Hardey, and Powell (2002). This critical appraisal tool evaluates nine components of studies which include: 1) abstract and

title, 2) introduction and aims, 3) method and data, 4) sampling strategy, 5) data analysis, 6) ethics and bias, 7) results, 8) transferability/generalizability and 9) implications and usefulness. Each component was assessed using a 4-point Likert scale and was scored and summed (4= good, 3=fair, 2=poor, 1=very poor) resulting in a total quality score for each study (Hawker et al., 2002). Data from all studies included in the final review were extracted by both reviewers and were tabulated on an excel spreadsheet. Reviewers met to discuss discrepancies that arose at all stages of screening and rating until they reached an agreement. Data was analyzed and presented qualitatively to identify the characteristics of interventions and stress/anxiety scales utilized.

Aim 2

The purpose of this study was to examine the health care demands of a child with ASD and its impact on the mental health of mothers and fathers. Specifically, health care demands included the time, financial, and employment burden these caregivers experience in addition to their experience associated with accessing services and their child's levels of independence in respect to daily living skills. The study aimed to answer the following research questions: (1) What is the current mental health status of mothers and fathers of children with ASD? (2) How is the age of the child (0-6, 7-11, 12-17 years old) with ASD associated with the mental health status of mothers and fathers? (3) What is the association between health care demand variables: problems with paying medical bills, changes in a family member's employment status, time spent coordinating and providing home health care, frustration with access to services, and the child's ability to undertake daily activities, on the mental health of mothers and fathers of children?

(4) What are the overall effects of factors related to health care demands, demographics, and secondary conditions on the mental health status of mothers and fathers?

Data from the National Survey of Children's Health (NSCH) 2017 and 2018 combined two-year dataset was used for this quantitative study. The NSCH is a national survey funded and conducted by the Health Resources and Services Administration's Maternal and Child Health Bureau and is administered using both mail and web-based questionnaires. It gathers state and national-level data on the health and well-being of children aged 0-17 years and is weighted to represent the non-institutionalized population of children in the country who are 17 and younger. A total of 52,129 surveys were completed for the 2017 and 2018 combined dataset (weighted n=73,428,760) with 21,599 surveys in 2017 and 30,530 in 2018. For this study, the population of interest was 1,345 children (weighted n=1,850,523) in the combined NSCH dataset who were reported to currently have autism, autism spectrum disorder, Asperger's disorder, or pervasive developmental disorder. The outcome of interest was the mental health of mothers and fathers respectively, while six health care demand variables hypothesized to impact families were identified from the NSCH survey. Several demographic variables and co-occurring developmental disabilities and co-morbidities with ASD were also included in the analysis.

The NSCH 2017 and 2018 combined dataset was imported into the Statistical Package for the Social Sciences (SPSS version 26.0; IBM Corp., 2019) and prepared according to the NSCH Codebook guidelines, which includes adding a sampling weight to allow for complex sampling analysis and setting subpopulations in the sampling plan. Descriptive statistics were used to describe the demographic attributes of the sample and

examine each health care demand variable. As all variables in the study were categorical, chi-square analyses were conducted to examine associations between mother and father's mental health with each of the predictors, demographic variables, and secondary conditions. To account for clustering in the complex survey design (Rao & Scott, 1987) the second-order Rao-Scott adjusted chi-square test statistic was reported which provides an adjusted *F* value. In addition, binary logistic regressions were conducted to determine associations between the mental health status for parents using predictor variables significant from the chi-square analyses. All regression analyses were conducted separately for both mothers and fathers. Odds ratios (ORs) and 95% confidence intervals (CIs) were reported from the binary logistic regression, and the significance level was set at 0.05.

Aim 3

The purpose of this study was to examine the awareness, utilization, facilitators, barriers, and the impact parents of children with IDD report in regards to their experience with financial tools. Specifically, this study focused on the ABLE program and other financial tools such as checking, savings, and trust accounts. The following research questions were examined: 1) What kind of financial planning options are families of children with IDD aware of? 2) Where do families obtain information regarding financial planning options, such as the ABLE program? 3) What barriers or facilitators do families foresee or have experienced in efforts to establish financial stability? 4) What, if any, impact has the ABLE program or other financial accounts had on the child's plans for employment, education, and independent living, and on the mental health of parents? 5)

What is the association between demographic attributes and the utilization of an ABLE account?

Parents of children with IDD were recruited to participate in an online survey (n=176). The eligibility criteria for participation included parents who could 1) read and write English or Spanish, 2) have a child (0 to 26 years old) with IDD, 3) live in the USA, and 4) consent to the study. The age of the child with IDD was limited to the range of 0 to 26 years old to help identify barriers among families with children and young adults, which if addressed could encourage financial planning to begin earlier, thereby allowing the family to benefit from its use longer. The upper age limit was set at 26 to capture the experiences of families as they approached the maximum age for disability onset for ABLE accounts. Parents were recruited for the study via a two-prong sampling approach. First, using convenience sampling a recruitment email (in English and Spanish) was distributed to known disability service providers, organizations, and parents associated with an inclusive postsecondary program (located at the University of the first author) designed for students with IDD. Second, using snowball sampling, parents, service providers, and organizations were requested to share the study details and survey link with all of their contacts and networks.

A consent form and three surveys were designed in English and professionally translated into Spanish. Each survey addressed a specific topic, namely: demographics, general financial circumstances and the ABLE account, and finally, other financial tools such as checking, savings and trust accounts. The survey was developed on REDCap, a Health Insurance Portability and Accountability (HIPPA) compliant platform, where data was also securely stored. A \$10 Amazon e-gift card was emailed to all participants who

completed the survey and who chose to provide an email address. Approval for all materials and procedures was received from the University's Institutional Review Board. Data was downloaded from REDCap into SPSS version 26.0 for analysis. Descriptive statistics were conducted to describe the attributes of the population and analyze responses to the survey questions. Chi-square analyses were conducted to identify associations between demographic variables and the utilization of ABLE accounts. Qualitative data from the open-ended questions were analyzed using reflexive thematic analysis to understand the participant's experiences. This methodology identifies codes and themes guided by the explicit content of the data through an iterative process (Braun & Clarke, 2019). Two reviewers followed the six-step process outlined for thematic analysis.

Theoretical Framework

The life course theory (LCT) posits that social, economic, and environmental factors interact with biological, behavioral, and psychological issues which exert influence and defines outcomes across the course of a person's life (Fine & Kotelchuck, 2010). By extension, this theoretical framework highlights the interdependence among people in important relationships with each other, who as a result, have mutually influential trajectories that extend throughout their lives. As such, the LCT is a suitable framework for this study given the naturally occurring interdependence in a parent-child relationship (Barker et al., 2011; Hutchison, 2005, 2011). The LCT is also a relevant framework to examine the mental health among this parent population, as a recent report

by The Lancet Commission expressed mental health as a “unique product of social and environmental influences, in particular during the early life course, interacting with genetic, neurodevelopmental, and psychological processes and affecting biological pathways in the brain” (Patel et al., 2018, p. 1).

In a seminal paper (Lu & Halfon, 2003), a conceptual framework for the LCT emphasized six concepts: 1) Pathways or trajectories, which highlight that life trajectories can be built or diminished over the life span. Among families with a child with IDD, life trajectories of both the parent and child are impacted from the time of diagnosis, and the response to it over time; 2) Early programming, which states that early experiences or exposures can impact an individual’s future health and development. For parents and children with IDD, any delays in receiving a diagnosis (including parental mental health conditions), and accessing support and interventions can worsen outcomes; 3) Critical or sensitive periods, which are specific moments in time when adverse events can have the greatest impact. Parents of children with IDD are presented with unique challenges across all developmental stages such as childhood, transition-age, and adulthood. As such, age-relevant supports and interventions for both parent and child are necessary; 4) Cumulative impact, indicates how stress over time may have a profound impact on health. Among parents of children with IDD, an accumulation of stress and anxiety can worsen health and other life outcomes for everyone in the family; 5) Risk factors, are those that diminish health and among families of children with IDD include financial distress, difficulties in accessing health care, parent employment, and other healthcare-related burdens; and 6) Protective factors, are those factors that improve life outcomes and contribute to positive development. These include policies and programs such as the

ABLE program which are intended to support the needs of families with children with disabilities.

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CHAPTER 2: MANUSCRIPT 1

Interventions and Scales Addressing and Assessing Stress and Anxiety among Parents of Transition-Aged Children with Autism Spectrum Disorder: A Systematic Review

Abstract

Background: Parents of children with autism spectrum disorder (ASD) report higher levels of stress and anxiety than parents of neurotypical children and other developmental disabilities. Periods of transition, such as the time between adolescence to young adulthood, are especially challenging for parents and their transition-aged child with ASD given the unique stressors of this phase. Since parental wellbeing impacts the trajectory of both the child and parent, interventions specifically designed to target the parental stress and anxiety experienced in this transition stage is crucial.

Objective: To conduct a systematic review to identify the characteristics of interventions and the scales used to address stress and anxiety among parents of transition-aged children with ASD.

Search Methods: Using keywords and controlled vocabulary terms, four electronic databases, PsycINFO, MEDLINE, CINAHL, and Embase were searched for the period 2010 to 2020. Non-English peer-reviewed studies were included. In addition, references of relevant articles were hand-searched.

Data Collection and Analysis: A total of 7903 studies were included in the initial title and abstract screening, which was followed by a full-text review of 261 eligible articles. Only 11 studies met the inclusion criteria: Intervention studies assessing stress and/or

anxiety using a quantitative self-report scale among parents of transition-aged children with ASD. Transition age was defined as 14 to 22 years of age. Characteristics of the population, interventions, and stress/anxiety scale were extracted, and the quality of studies was assessed using an appraisal tool designed by Hawker et al. (2002). Two reviewers screened studies at all stages of the review.

Results: Of the 11 studies, five interventions targeted both parent and child simultaneously, while six targeted only the parents. Interventions broadly focused on either mindfulness (n=5), social functioning through the PEERS program (n=3), or addressed multiple components such as emotional support, social skills, and parent education (n=3). Only two of these studies focused specifically on transition-aged children, and only one intervention addressed transition planning. Five scales were identified assessing stress and/or anxiety and included the Depression, Anxiety and Stress Scale (DASS-21), Perceived Stress Scale (PSS-10), Stress Index for Parents of Adolescents (SIPA), Beck Anxiety Inventory (BAI), and the State and Trait Anxiety Inventory (STAI-S and STAI-T). Nine of the 11 studies had a high quality score.

Limitations: Given the lack of demographic detail in many studies, the number of transition-aged children was statistically estimated using *t*-distributions. In addition, six authors did not reply to the request for missing data and three full-texts remained inaccessible. As such, some studies which could have met inclusion criteria may have been omitted.

Conclusion: Findings highlight the need for suitable instruments and more interventions to support parents of transition-aged children with ASD. Future researchers can use this

review to inform the design, focus of interventions, and selection of measurement tools to ensure they address the unique stressors and needs of this period.

Background

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by challenges in areas such as social interaction, communication, repetitive behaviors, and limited interests. A diagnosis of ASD generally occurs in early childhood and lies within a continuum as symptoms and behaviors can range from mild to severe, and can change over time (American Psychiatric Association, 2013). In the United States, the number of 8-year old children living with ASD has risen from 1 in 59 children in 2014 to 1 in 54 in 2016 (Maenner et al., 2020). At this time, no treatment exists for ASD (Centers for Disease Control and Prevention, 2019) and it is considered to be a lifelong condition (American Psychiatric Association, 2018). Approximately 80% of adults with ASD continue to live with their families after high school (Shattuck et al., 2011) to receive ongoing care and support across their lifespan (Volkmar & Pauls, 2003).

The Transition Phase

All individuals go through multiple transitions in their life, but one period of particular importance, for individuals with ASD is that spanning from adolescence to adulthood (Wisner-Carlson et al., 2020). This phase can be thought of as a critical or sensitive period as defined by the life course theory (Lu and Halfon, 2003). This is because decisions at this stage can have a significant impact on adult outcomes such as

academic achievement, employment, community participation, and independent living. To ensure that individuals with disabilities have support during this phase, transition services are mandated by the 2004 re-authorization of the Individuals with Disabilities Education Act (IDEA) to enhance the life trajectory (IDEA, 2004).

Unfortunately, outcomes for individuals with ASD remain bleak. Only 58% of these young adults have been shown to have a paid job after high school (which was largely low-pay and part-time), 1 in 4 are socially isolated, only 36% attended college or vocational education, they were less likely to live independently, and over 25% received no services that could support these adult outcomes (Roux et al., 2015). As a result, the 2016-2017 Strategic Plan of the Interagency Autism Coordinating Committee has called for research in areas of inclusion, quality of life, independence, and health across the lifespan, and has specifically addressed the period of transition from adolescence into young adulthood (Interagency Autism Coordinating Committee (IACC), 2017) given the impact of this phase. Although the age range to define the transition period varies, it is generally considered to begin at 14 lasting through 22 years of age (Chen et al., 2019; Suk et al., 2020; U.S. Department of Health and Human Services, 2017).

Recently, several quantitative and qualitative studies have examined this period of transition from the perspective of parents, and findings highlight that this phase is marked by unique stressors that impact quality of life (Lee & Shivers, 2019). During this time, parents take on numerous roles such as advocating, planning, and decision-making (Bianco et al., 2009) while navigating an unchartered, fragmented and complex landscape to ensure continuity of care and services as their child enters adult systems (Federal Partners in Transition Workgroup, 2015) and access switches from a system of

entitlement to eligibility (Cooney, 2002). It has been shown that the quality of the transition planning, and the effort required to plan and find information related to transition decisions are unique stressors to this period and have a cascading effect on parent health and overall wellbeing. Furthermore, as parents begin to age when their child reaches adolescence and young adulthood, they begin to increasingly worry about their child's future and wish to start planning for things such as who will take care of their child once they are gone. Limited financial resources, the need for social support, isolation, parenting efficacy, and the parents' coping style have also been found to be stressors and parent characteristics that adversely influence parent and child outcomes, and the transition experience (Kraemer, 2012; Lounds et al., 2007; Marsack-Topolewski & Graves, 2020; Mason, 2012; Oti-Boadi et al., 2020; Sosnowy et al., 2018; Vogan et al., 2014; Wong et al., 2020; Yu et al., 2018).

The transition phase is also characterized by children with ASD beginning to desire autonomy and asserting their independence (Matsuo et al., 2015; Sosnowy et al., 2018). Parental rights transfer to the student typically at the age of 18, and as a result, the young adult assumes a new role, rights and responsibilities to make financial, medical, educational, employment, and independent living decisions (United States Department of Education, 2017). However, continuing deficits in areas such as communication, social functioning, planning, and taking action inhibit the ability of the transitioning-child with ASD to flourish in an environment that requires interaction and development of new relationships and routines while managing the expectations of the adult world (Wisner-Carlson et al., 2020). Challenging behaviors common in ASD also evolve during this period to include self-injurious behavior, aggression towards others, and elopement

(Mason, 2012; Oti-Boadi et al., 2020; Vogan et al., 2014; Wong et al., 2020; Yu et al., 2018) while additional co-morbidities such as anxiety begin to present themselves (Kaat & Lecavalier, 2015; van Steensel et al., 2011).

Although these stressors appear to mirror challenges experienced by parents of *young* children with ASD, there are critical yet subtle differences between childhood and this transition period. For example, parents of young children with ASD are concerned with understanding their child's *emerging* challenging behaviors, delayed development, success in school, friendships, and daily living tasks such as bathing. Among parents of transition-aged children with ASD however, these challenges evolve into managing *new and persistent* problem behaviors such as aggression, and worries about the attainment of adult outcomes such as employment, romantic relationships, and the potential for their child to live independently (Koren' et al., 2016; Lee & Shivers, 2019). These outcomes are regarded as benchmarks of success in adulthood and are aspirations shared by both parents and their transition-aged children with ASD (Smith et al., 2012; Sosnowy et al., 2018).

Parent Mental Health

A significant amount of research has drawn associations between providing care for a child with ASD and its impact on the caregivers' wellbeing and quality of life. Two commonly examined mental health outcomes among parents in ASD literature are stress and anxiety (Al-Farsi et al., 2016; Conner et al., 2013). This is appropriate given the hallmark characteristics of ASD and its impact on parents since stress is defined as “a response to situations that are threatening, uncontrollable, or unexpected” while anxiety

has been defined as “a persistent anticipation or apprehension about one or more situations to which a person is exposed” (Simon & Corbett, 2013. p.1).

Compared to parents of neurotypical children, parents of children with ASD demonstrate higher levels of stress and anxiety (Baker-Ericzén et al., 2005; Hayes & Watson, 2013; Montes & Halterman, 2007; Padden & James, 2017), and this trend remains even in comparison to parents of children with other disability types (Estes et al., 2013; Valicenti-McDermott et al., 2015). Studies have also examined the effect of the child’s age and developmental stage on parental mental health, although the findings remain mixed. Some studies have demonstrated increasing levels of stress, depression, vulnerability, and poorer health-related quality of life among parents of older children with ASD (Gray et al., 2014; Kousha et al., 2016; Lounds et al., 2007; Tehee et al., 2009). One study compared the caregiving burden of transition-aged children with ASD to that of caring for someone with a brain injury (Lounds et al., 2007) while in another study 60% of parents of 95 transition-aged children reported that worries about the transition period affected their wellbeing and as such reported higher levels of stress (Kraemer, 2012). Some studies, on the other hand, implicate lower levels of depression and anxiety in parents of adolescent children with ASD, but *similar levels of stress* as compared to parents of young children (McStay et al., 2014; Pozo & Sarriá, 2015). Despite conflicting evidence on whether parents experience an improvement or decline in these mental health outcomes as their child ages, it is evident that parents of children and young adults with ASD *continue to experience* stress, anxiety and adverse effects on quality of life across the lifespan (Dizdarevic et al., 2020; Lee & Shivers, 2019).

Interventions

Supporting parents of children with ASD through the various stages of life is imperative given the interdependence of the parent-child relationship on wellbeing and life trajectories as posited in the life course theory (Barker et al., 2011; Lu and Halfon, 2003). As such, unaddressed parental stress and anxiety can have adverse effects on both parents and children (Bones et al., 2019). Among parents, this can have implications on life satisfaction, marital stability, and health outcomes (Bonis, 2016; Reichman et al., 2008) while among individuals with ASD, it can undermine areas of existing deficits such as behavioral, social, cognitive, and language development (Dardas & Ahmad, 2014). In a study with parents of children with ASD, parents experiencing stress and anxiety favored medical treatments versus behavioral recommendations given the emotional effort required in following through with the latter (Moore & Symons, 2009). These choices can deteriorate the trajectory for children with ASD with regard to adult outcomes (Wisner-Carlson et al., 2020). It is therefore crucial that meaningful interventions are designed to address the mental health of parents which can ultimately enhance both parent and child wellbeing (Agbaria, 2020; Sopaul, 2019).

At this time, a vast amount of literature exists on interventions for parents and their young children with ASD (Devescovi et al., 2016; Feinberg et al., 2014; Ingersoll & Wainer, 2013; Keen et al., 2010). There is however, a growing recognition for more targeted intervention studies for parents and transition-aged children with ASD (Benson, 2015; Bones et al., 2019; Karst & Van Hecke, 2012) especially given the increasing number of children with ASD entering adulthood (Smith et al., 2012) and the unique stressors and unrelenting stress and anxiety experienced by parents of this age group

(Cadman et al., 2012; Lee & Shivers, 2019; Smith et al., 2012). Interventions should be designed to address parent outcomes such as stress and anxiety (Bones et al., 2019) given the implications of these conditions on the family system (Karst & Van Hecke, 2012). As such, it is essential to identify the characteristics of the interventions which have been undertaken to date (Maglione et al., 2012; Yoo et al., 2014) to ensure that future studies can build on the existing knowledge and aim to bridge the gap in the transition-age literature, while service providers can access evidence-based interventions to guide program activities.

Stress and Anxiety Scales

Equally important as identifying interventions to address parental stress and anxiety and improve parent-child outcomes, is the necessity to ensure that the scales which have been used to assess changes in these outcomes are valid and reliable. Choosing scales for intervention studies is an important and purposeful decision, which should be aligned with the characteristics of the study's population, the study's purpose, and the utility of the scale (Coster, 2013). For example, some scales are designed specifically for parents of children of certain ages, such as the Parenting Stress Index (PSI; Abidin, 1995) which has been designed to capture stress among parents of children between the ages of 3-months and 10 years old. Unfortunately, a review of the literature indicates that studies sometimes utilize scales that are inappropriate for their population. For example, a systematic review (Hayes & Watson, 2013) found that the PSI has been utilized among parents of children with disabilities, chronic illnesses, and those older than the recommended age range (Fedele et al., 2010; Hastings et al., 2006). Moreover,

some studies omit key details such as the breakdown of disability types within the wide umbrella term of intellectual and developmental disability (IDD; Agbaria, 2020) or the age of the care recipient (Bastanfar et al., 2018) to allow an assessment of the fit of scale to the population. Given the recent attention on the transition period, it is imperative to review the scales currently being utilized in intervention studies to ensure that they are suitable and valid for this recently recognized, yet growing population.

Aim of the Review

A number of systematic reviews have been conducted assessing stress and anxiety scales among non-disability populations (Brunton et al., 2015; Meades & Ayers, 2011; Webb et al., 2018) while some recent systematic reviews have examined interventions for parents of children with ASD (Cachia et al., 2016; Merriman et al., 2020; Rutherford et al., 2019; Shalev et al., 2020). No systematic review to the best of our knowledge, however, has focused on identifying both parent and child interventions that assess stress and anxiety outcomes among parents of transition-aged children with ASD, nor identified the stress and anxiety scales utilized for this population. Thus, given the growing attention in addressing the unique needs during the transition to adulthood, this systematic review aims to 1) identify parent and/or child-targeted interventions that have assessed the effect of the intervention on parent stress and/or anxiety outcomes and 2) review the scales used to measure stress and/or anxiety in these interventions. The PICO (P-Populations/People/Patient/Problem, I-Intervention(s), C-Comparison, O-Outcome) technique was used to frame the research question: What interventions and scales (I) have

been used to address stress and anxiety (O) among parents of transition-aged children with ASD (P)? No comparison group (C) was necessary for this review question.

Methods

The methods of this systematic review were based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009) guidelines.

Study Eligibility Criteria

Inclusion criteria for studies in this review were: Intervention studies assessing stress and/or anxiety using a quantitative self-report scale among parents of transition-aged children with ASD. Transition age was defined as 14 to 22 years of age as done similarly in a recent study (Chen et al., 2019). Given that many ASD intervention studies recruit from within a wide age range and do not always provide stratification of age in their demographics to determine the number of transition-aged children, we statistically estimated this number using *t*-distribution calculations if the information was not available from the manuscript or author. T-distributions rather than normal distribution calculations were used given the small sample sizes (SAS Institute Inc., n.d.) in many ASD intervention studies. To enhance rigor and include studies that may not have explicitly targeted the transition-aged population, studies that were estimated to have at least 50% of children in this age range were included. Studies were limited to the last decade to ensure relevance to the continuously developing field.

Studies were excluded if they measured a mental health outcome other than stress and/or anxiety, used only biomarkers to assess stress and/or anxiety levels, or were a medical intervention. Studies were limited to those published in peer-reviewed journals that met inclusion criteria. Non-intervention studies, conference abstracts, narratives, systematic reviews, case studies, and dissertations were excluded.

Information Source and Search Strategy

Four databases PsycINFO, MEDLINE, CINAHL, and EMBASE were searched electronically by one reviewer on July 5, 2020, for the period 2010 to 2020 using relevant controlled vocabulary, free-text terms, and truncation symbols. Keyword combinations relating to three broad categories were utilized: *anxiety and stress* (Anxi* OR stress* OR distress* OR “emotional availability”), *parent* (Parent* OR mother* OR father* OR family OR families OR maternal OR paternal), and *ASD diagnosis* (ASD OR autis* OR “developmental disabilit*” OR PDD OR Asperger* OR "developmental disorder" OR "childhood disintegrative" OR "pervasive developmental" OR "high functioning autism"). To ensure a comprehensive search of peer-reviewed literature, non-English language studies were included and reference lists of relevant studies were hand searched. The complete search strategy can be seen in Table 1.

Study Selection

Studies were exported to Covidence (a web-based platform for screening of articles for systematic reviews) after duplicates were identified and removed. The complete review process was conducted by two reviewers (RA and GW) to minimize

bias. At the first stage of screening, titles and abstracts were scanned to assess eligibility. If the study was retained for the second stage of screening, the full-text of the study was reviewed. We requested 14 full-texts of articles from the Interlibrary Loan Internet Accessible Database (ILLiad) as they were not accessible via an extensive web-based search. However, full-texts of three studies remained inaccessible (Javad et al., 2018; Sabourin et al., 2013; Sood et al., 2018). Reasons for excluding studies were maintained at the full-text screening stage. Reviewers met to discuss discrepancies that arose at both stages of screening until they reached an agreement. A third reviewer was available to resolve discrepancies if necessary, but this was not required.

Data Collection and Data Items

Data was extracted from each individual study by both reviewers and was tabulated on an excel spreadsheet. This included information on: author(s), year of publication, the country where the study was conducted, sample size of parents and children, age range of children with ASD, estimated/actual percentage of transition-aged children (using *t*-distribution estimates where applicable), name of the intervention, name of the stress and/or anxiety scale(s) and the studies quality score and rating. Authors of studies that had insufficient details in their manuscript to infer the number of transition-aged children or stress/anxiety scale used were contacted using email. A second reminder email was sent to those who did not initially reply. As a result, of the 14 authors originally contacted, six did not respond and could not be included in the screening (Benn et al., 2012; Ede et al., 2020; Elfert & Mirenda, 2015; Hampel et al., 2015; Smith et al., 2012; Whitney & Smith, 2015).

Risk of Bias in Individual Studies

Studies included in the final review were examined for methodological rigor using a protocol designed by Hawker, Payne, Kerr, Hardey and Powell (2002). This critical appraisal tool evaluates nine components of studies which include: 1) abstract and title, 2) introduction and aims, 3) method and data, 4) sampling strategy, 5) data analysis, 6) ethics and bias, 7) results, 8) transferability/generalizability and 9) implications and usefulness. Each component was assessed using a 4-point Likert scale and was scored and summed (4= good, 3=fair, 2=poor, 1=very poor) resulting in a total quality score for each study. Unfortunately, Hawker et al. (2002) did not provide cut-offs for the overall classification of the study's quality rating but stated that a maximum score of 36 reflected a very good study, while the minimum score of 9 indicated very poor methodological quality (Hawker et al., 2002). As such, this study mirrored the parameters utilized in a recent systematic review, which used the same critical appraisal tool: 'high quality' (30–36 points), 'medium quality' (24–29 points), and 'low quality' (9–23 points; Braithwaite et al., 2017). Both reviewers (RA and GW) independently scored and rated each study that qualified for final inclusion. In the event that the overall rating differed between the two reviewers, each of the nine components assessed were discussed until a consensus was reached.

Synthesis of Results

Data was analyzed and presented qualitatively to identify the characteristics of interventions and stress/anxiety scales utilized. No quantitative methods were used to summarize the data.

Results

A total of 261 full-texts were reviewed of which 40 studies were assessed for inclusion based on the 50% criteria for transition-age children with ASD. Reasons for excluding studies were maintained at the full-text stage and can be seen in the PRISMA chart (Figure 1; Moher et al., 2009), but most commonly included a study not targeting the transition-age group. Only 11 studies met this systematic review's final inclusion criteria. Of the 11 studies, five studies were conducted in the USA, two in Canada, and one each in Spain, Australia, Korea, and China. They were published between the years 2014 and 2019. Although all studies in this review were required to meet or exceed the 50% threshold of transition-aged children with ASD, only 2 studies (Singh et al., 2014; Smith et al., 2018) met this criteria at 100% by specifically targeting this age group. Please see Table 2 for *t*-distribution calculations/author responses. Sample sizes in the study ranged from three to 77. Quality assessments indicated that nine studies were of high quality, one of medium quality, and one of low quality. The most common reason impacting quality scores was sampling as many studies did not justify their sample size, had small sample sizes, or did not explain the recruitment source and attrition sufficiently. Please see Table 3 for the quality rating of each study and Table 4 for a summary of the characteristics of studies included in this review.

Interventions

A review of the 11 studies revealed an almost equal distribution among interventions that targeted both parent and child simultaneously (n=5) versus just parents alone (n=6). Of the studies that focused only on parent-targeted interventions, three

studies further limited their focus to just mothers of children with ASD. Interventions were broadly designed to address stressors related to either 1) the child's challenging behaviors, emotional regulation, relationships, and social functioning, or 2) parental wellbeing via mindfulness practices. Only one study (which targeted both parents and children) specifically addressed the needs of children with ASD transitioning to adulthood (Smith et al., 2018). The following section describes the interventions identified in the 11 studies under the following sub-headings: mindfulness, social functioning through the PEERS intervention, and multi-component interventions (Rutherford et al., 2019) addressing social skills, emotional support, and parent education of ASD and transition needs. Please see Table 5 for details on the intervention design of the studies included in this review.

Mindfulness

It was evident that interventions that directly targeted the parent's ability to cope with stress and manage their mental health was a popular strategy. Five of the 11 studies in this review shared this focus. Although they all utilized a mindfulness-based component to do this, each intervention was tailored and unique in characteristics such as the length of the intervention (which ranged from 5-weeks to 40-weeks) and outcomes of interest (in addition to parental stress and wellbeing).

Lunsky et al. (2015) offered 22 parents of adolescents and adults with IDD a 6-week group "*Coping with Stress*" intervention designed to enhance mindfulness and cope with stress. In addition, the intervention aimed to improve mindful parenting, to counter the effects of interacting with an adult child with IDD which can be exhausting and lead

to reactive communications, worsening parent-child relationships. The intervention comprised of components from both the mindfulness-based cognitive therapy (MBCT) and mindfulness-based stress reduction (MBSR) programs, which include training and discussions, meditation practices, and breathing exercises. The ‘loving-kindness meditation’ which is part of MBSR was found to be especially important and relevant to include in the session to address the guilt many of these parents feel in regards to their caregiving, frustration towards their child, or the feeling that they are unable to meet the needs of their child appropriately. To ensure that the intervention addressed the limitations and needs of parents of children with disabilities, the authors adapted the content and delivery based on findings and parent feedback from a pilot study. The number of sessions was increased from four to six, and the time to two hours each to allow families the opportunity to talk and support each other. The requirements for homework were reduced and parents were encouraged to undertake shorter and more frequent practices at home. A planned full-day retreat was also removed from the schedule as parents shared they would be unable to attend this. To accommodate the older group of parents participating in the intervention all session activities were conducted sitting on a chair versus the floor, exercises were simplified, and the voices of the facilitators were louder. The intervention was found to reduce stress in parents from pre- to post-intervention as measured by the stress subscale from the *Depression Anxiety Stress Scale* (DASS-21; Lovibond & Lovibond, 1995), although no significant change was reported in parent mindfulness or mindful parenting (Lunsky et al., 2015).

Ruiz-Robledillo et al. (2015) implemented a pilot “*Mindfulness-Based Program*” (MBP) intervention with six parents of adolescents with ASD (caregivers) and seven

parents of typically developing adolescents (non-caregivers). Both groups of parents participated in a 5-week 9-session program which comprised of meditations, trainings, discussions, and breathing exercises, and were asked to apply and practice what they learned for homework. The aim of the intervention was to improve parental mood (anxiety, negative mood, and feelings of anger), health, and stress. Parental mood and health were assessed using self-report measures, and specific to the focus of this systematic review the study measured levels of state anxiety using the Spanish version of the *State-Trait Anxiety Inventory* (STAI-S; Spielberger et al., 1983). Unique to this mindfulness study was the assessment of stress using a biomarker (cortisol awakening response and afternoon cortisol levels) although this was not the criteria for inclusion. All measures were administered pre and post at session 1 (pre-treatment), session 5 (mid-treatment), and session 9 (post-treatment). Findings indicated that although both groups of parents saw improved depression, somatic symptoms, and general health over the course of the intervention, the caregiver group experienced a greater change. However, anxiety, mood, and stress were improved only when each pre-post session (1, 5, and 9) was evaluated independently versus any statistically significant change in outcomes from the beginning to the end of the intervention (Ruiz-Robledillo et al., 2015).

Singh et al. (2014) undertook a proof-of-concept study with three mothers of transition-aged children with ASD. The intervention “*Mindfulness-Based Positive Behavior Support*” (MBPBS) combined mindfulness-based training with knowledge on how to integrate positive behavior support (PBS). The decision to pair both mindfulness and PBS components was intended to overcome the stress, frustration, fatigue, and attrition parents report when participating in behavioral training programs to manage

challenging behaviors and remembering to implement the strategies they learn consistently with their children. Moreover, MBPBS was designed to support personal transformation (i.e., supporting more than just reductions in parental distress) which would allow mothers to intuitively apply the mindfulness practices when managing challenging behaviors such as aggression, disruption, and lack of compliance with instructions. Mothers attended one pre-session a month prior to the intervention where they learned the basics of meditation and were asked to practice at home. This was followed by 8-sessions over 8-weeks, which taught parents how to apply the MBPBS skills from these sessions during interactions with their child. Mothers were asked to continue their MBPBS practices until week 48 of the intervention. All three mothers received one-on-one training and were assessed before the pre-session (baseline), the first day of baseline, last MBPBS session, and the last day of the 48-weeks. The intervention assessed changes in the child's incidence of aggression, disruptive behaviors, and compliance with instructions (compliance was recorded by both mothers and fathers using an app on their phones). All three outcomes showed statistically significant improvement while mothers were enrolled in the intervention and during the MBPBS practice period. Similarly, parental stress levels measured using the *Perceived Stress Scale-10* (PSS-10; Cohen & Williamson, 1988) also showed statistically significant improvement across the intervention and into the practice phase (Singh et al., 2014).

Singh et al. (2019) conducted a larger-scale MBPBS intervention study using two groups of mothers of adolescents with ASD (n=47) and intellectual disability (ID; n=45). Both groups participated in the MBPBS intervention designed to teach mothers mindfulness-practices which would help them support and manage their child's

challenging behaviors through PBS and reduce their levels of stress. Again, the authors emphasized the need to offer interventions that combined these therapeutic processes to ensure “short-term therapeutic change, as well as longer-term transformational change in the individual” (Singh et al., 2019. p. 2). Both groups of mothers participated in a 40-week study, beginning with a control phase during the first 10-weeks. This was followed by a shorter 3-day training (to minimize inconvenience and burden on parents), and 30-weeks of self-practice while assessments were administered three times (two pre- and one post assessment). Similar to the previous study conducted by the same first author (Singh et al., 2014) mothers in both groups observed their child’s daily aggressive and disruptive behaviors and assessed compliance, which was found to be statistically improved among both ASD and ID groups. In addition, self-report stress levels of mothers as assessed by *Perceived Stress Scale-10* (PSS-10; Cohen & Williamson, 1988) was also significantly reduced among both groups (Singh et al., 2019).

Salem-Guirgis et al. (2019) conducted the “*Mymind*” mindfulness intervention with 23 parents and 23 youth with autism, making it the only mindfulness intervention in this review to offer concurrent sessions to both parent-child dyads. Participants attended 9-sessions over 9-weeks followed by one booster session 9-weeks after the end of the program which encompassed mindfulness content and cognitive behavior therapy. Similar to the other studies discussed above, both groups learned mindfulness-based skills, meditations, breathing exercises, and reviewed practices for homework. In addition, parents in this study were taught how to support their child to reinforce mindfulness practices at home. It was hypothesized that youth with ASD would report improved emotional regulation and autism symptoms, and both groups would experience

enhanced mental health and mindfulness across the intervention. Using a within-subject repeated measures design, the study administered self-report measures at 10-weeks prior to the intervention (baseline assessment), 1-week prior, 1-week post-program, and 10-weeks post-program. Parental mental health was assessed using the *Depression Anxiety Stress Scale* (DASS-21; Lovibond & Lovibond, 1995), however, no significant changes were found in regards to parental depression, anxiety, or stress across the intervention or post-program, although interestingly, there was some improvement during the baseline period which the authors noted as a potential “waitlist effect.” Parents reported improved mindfulness, while youth with ASD experienced enhanced emotional regulation, autism symptoms, and adaptive skills. However, no change in youth mindfulness was evident across any time point (Salem-Guirgis et al., 2019).

Social Functioning – The PEERS Intervention

Of the 11 studies included in this review, three studies directly targeted the persistent challenges related to social functioning, communication, and behaviors common among children with ASD. These studies utilized the “*The Program for the Education and Enrichment of Relational Skills*” (PEERS) intervention (Laugeson & Frankel, 2010) and ranged from 14 to 16-weeks long, and similar to the mindfulness-based interventions examined stress/and or anxiety and other varied parent and child outcomes. All three studies included both parent and child participants in the intervention.

Karst et al. (2015) undertook a randomized control trial with parents and their adolescents with high-functioning ASD (n=64 parent-child dyads, with 32 pairs in the

experimental and waitlist control group respectively). The PEERS intervention is designed to enhance social functioning by providing skills and training about “initiating and maintaining friendships in adolescence” (Karst et al., 2015, p. 757) using a manualized parent-assisted intervention. Both parents and the child attended 14 didactic sessions across 16-weeks, which parent-child dyads participated in separately but simultaneously. Adolescent sessions encompassed homework review of the previous and the upcoming week, delivery of a new lesson (such as handling disagreements, and appropriate use of humor), and active participation through role-play and rehearsals. Parent sessions reviewed the homework assignments their child had already or would be completing in the upcoming week to discuss successes and troubleshoot any concerns, and discussed the contents of that relevant week's lesson. Parent discussions were encouraged to remain within the context of the PEERS program rather than extending to informal support conversations. The intervention focuses on concepts relevant to current social and relationship norms, is delivered in a small group format, and ensures that materials are presented in a manner suitable for individuals with ASD. Parent involvement and participation is an important characteristic of the PEER program for two reasons. First, to ensure that parents can support their child in generalizing the acquired social skills to their day-to-day life during the intervention, and sustain the skills post-intervention. Second, given the interconnectedness of parent and child wellbeing, parent participation aims to address family factors (such as parenting self-efficacy) that influence the child's environment. Using a pre-post assessment, it was expected that parenting self-efficacy would improve while parenting stress as measured by the *Stress Index for Parents of Adolescents* (SIPA; Sheras et al., 1998) and family chaos would

decline. Findings revealed that parenting self-efficacy, family chaos, and stress had observed reductions in the experimental group, although they were not statistically significant.

Another study by Schiltz et al. (2018) examined the effects of the PEERS intervention on youth with ASD and their parents (n=77) using a subsample from another randomized control trial of the PEERS study which did not assess parent outcomes (Schohl et al., 2014). As discussed above with Karst et al. (2015) parent-child dyads attended concurrent but separate sessions. The purpose and aims were the same with the goal to enhance social skills, with parent sessions focusing on how they can support their child at home in developing and sustaining the skills learned. The intervention consisted of 14-sessions (covering the same content as Karst et al., 2015) over 14-weeks. In addition to assessing the impact of the intervention on parent depression and anxiety using a pre-post assessment, the authors examined the association between the child's challenging behaviors and parental stress (as measured by the *Stress Index for Parents of Adolescents*; Sheras et al., 1998), depression and anxiety and the influence of these factors on parental involvement (defined as "frequency of parent-child interactions and parental awareness of events and activities in their child's life"; Schiltz et al., 2018, p. 1170) controlling for social skills. Findings confirmed the effect of challenging behaviors on stress and depression, and parental involvement. Although the effect of the intervention on levels of parental stress were not measured, the intervention lowered parental depression but was only modestly significant, with no statistically significant change in levels of anxiety as measured by the *Beck Anxiety Inventory* (BAI; Beck & Steer, 1990; Schiltz et al., 2018).

A culturally-adapted version of the PEERS intervention was conducted in South Korea by Yoo et al. (2014). Although the overall structure and elements of the original manualized intervention were retained as explained in detail above, the authors adapted and revised the content of the 14-sessions for relevance to Korean youth (such as jokes, common social networking sites, and teen activities). Using a randomized control pre-post intervention and 3-month follow-up design, 23 parent-child dyads participated in the intervention group with another 24 dyads in the delayed treatment control group. Both self-report and observational data were used to assess outcomes from this intervention. Teens with ASD in the intervention group demonstrated statistically significant improvement in “social skills knowledge, interpersonal skills, and play/leisure skills” (Yoo et al., 2014, p. 145) in addition to a reduction in ASD and depressive symptoms. Parental depression reduced significantly from pre to post for the experimental group. State and trait anxiety of parents was measured using the *State-Trait Anxiety Index* (STAI-S and STAI-T; Spielberger et al., 1983) and revealed a statistically significant reduction in state anxiety among mothers of the intervention group. At 3-month follow-up, no significant maintenance effects were detected (Yoo et al., 2014).

Multi-Component Interventions – Social Skills, Emotional Support, and Parent Education

Three studies in this review offered interventions encompassing multiple components within their sessions. This included skills for managing challenging behaviors, emotional support for parents, training on managing emotions, and parent education on topics such as knowledge about ASD and transitions. Two studies targeted only the parent while one study included both parent and child in the intervention.

Zu et al. (2019) designed an intervention to address emotional management and enhance social skills training for mothers of children with ASD. Mothers from two different cities, Shanghai (n=8) and Taichung (n=8) participated in a 12-week semi-structured intervention and attended one 90-minute session a week. The intervention focused on providing mothers in the two groups a forum to share feelings and experiences, have discussions and support each other. In addition, each week a new topic was covered such as an improved understanding of ASD, availability of social services, holding realistic expectations for children with ASD, managing marital relationships, and seeking social support from others. One session specifically focused on teaching mothers how to promote social skills among their children utilizing the PEERS method. Zu et al. (2019) did not provide details on what aspects of the extensive PEERS topics were covered in the one-day session dedicated to social skills training. Furthermore, unlike the other studies described earlier which used the PEERS intervention, Zu et al. (2019) only included parents in the intervention. A unique aspect of this intervention, however, was the evaluation of the mothers' speech patterns, as mothers may use negative language in response to their child's challenging behaviors, which can lead to spiraling and worsening parent-child responses. The study recorded and transcribed the discussions mothers engaged in during the 12-sessions and analyzed the text using TextMind and LIWC software. Over the three stages of the study (early, middle and late) and across both groups "frequency of positive emotional words increased and negative emotional words decreased" (Zu et al., 2019, p. 1). Maternal depression and anxiety were assessed at weeks 0, 6, and 12. Depression levels were significantly decreased across both groups and throughout the intervention, while anxiety as measured by the Chinese version of the

Beck Anxiety Inventory (BAI; Beck & Steer, 1990) was reduced but not statistically significant. Although children were not part of the intervention, they were assessed for autism symptoms. These were reduced throughout the intervention which the authors contributed to the improved maternal positive speech, depression, and anxiety levels (Zu et al., 2019).

Mazzucchelli et al. (2018) conducted a pilot study to assess the feasibility of the “*Building Bridges Triple P*” (BBTP) manualized intervention. The BBTP was designed to specifically target the unique needs of parents of adolescents with ASD by providing training and education in the following areas: a) enhancing parent understanding of their teenager’s behaviors, b) building skills to teach their child appropriate behaviors and manage challenging behaviors (such as dealing with risky behaviors), and c) encouraging their child to be socially engaged. Parents (n=9) participated in five group sessions and three telephone sessions, for a total of eight-sessions lasting 11.5 hours. Group sessions were designed to provide parents peer support while telephone sessions were intended to address the individual needs of families. To further tailor the intervention to the needs of each family, participating parents were asked to identify a target behavior in their adolescent they desired to change, and a percentage for improvement that would signify the accomplishment of their goal. Behaviors that parents selected to change in their adolescent included “spending less time on the computer or iPad, going to bed and not using electronic devices by 9 pm, and talking positively to siblings” and “appropriately seeking Mum’s company” (Mazzucchelli et al., 2018, p. 52). All except one parent reported an accomplishment of their goal by the end of the program. It was also expected that parent-report of their adolescent behavior, emotional and social problems would

improve, along with positive changes in parent outcomes of parenting self-efficacy, discipline style and depression, stress, and anxiety which was measured using the *Depression Anxiety Stress Scales-21* (DASS-21; Lovibond & Lovibond, 1995). Using a pre-post assessment at baseline, post-intervention and at 3-month follow-up, findings indicated an improvement in adolescent behavior, and all parental outcomes at post-intervention and statistically significant improvement at 3-month follow-up for all outcomes except for parental anxiety.

Smith et al. (2018) designed an intervention called “*Transitioning Together*” after an extant review of the literature, and feedback from focus groups and a small pilot study. The refined manualized intervention specifically targeted the period of transition, ensuring that the needs of families and their adolescents with ASD leaving high school and approaching adulthood were met. Prior to the commencement of the intervention, parent-child dyads, and any invited family members attended private “joining sessions” (Smith et al., 2018, p. 6) designed to build rapport and discuss goals for participating in the intervention. Once joint sessions were completed for all families, parents and adolescents attended 8-weekly sessions held concurrently but in separate rooms. Parent sessions addressed content related to ASD in adulthood, planning for postsecondary education and employment, impact of ASD on the family, effects of the environment on the individual with ASD, strategies to manage behaviors, problem-solving, community involvement, legal issues such as guardianship and trusts, and the impact of ASD on parental wellbeing. An important component of all the sessions was providing parents an opportunity for social support. Sessions attended by the adolescent covered social skills, goal-setting, and similar to the parent sessions, problem-solving. Using a randomized

waitlist control design, 16 parent-child dyads participated in the intervention group while 25 were part of the control group. Using a pre-post intervention assessment, parent depression, stress, and problem-solving skills were measured. Parent-child relationships were measured by quality, burden, expressed emotion about their child related to positivity, happy/proud, warmth, and criticism, while adolescent outcomes were related to social interactions, autism symptoms, and social engagement. Parents in the intervention group showed statistically significant pre-post improvement in depression and problem-solving, but no change in stress as measured by the *Perceived Stress Scale-10* (PSS-10; Cohen & Williamson, 1988) and parent-child relationships. Change in adolescents' autism symptoms were not significant pre-post in the intervention group, although social interactions and social engagement increased significantly.

Stress and Anxiety Scales

A total of five different scales were used to assess parental stress and/or anxiety in the reviewed studies. Five studies only assessed stress; three studies only measured anxiety; while three studies assessed both stress and anxiety. The section below highlights the characteristics of each of the five scales utilized.

Depression, Anxiety and Stress Scale – 21 (DASS-21; Lovibond & Lovibond, 1995)

The DASS-21 contains three subscales to assess depression, anxiety, and stress. Each subscale comprises seven questions for a total of 21 questions. Using a 4-point scale (0 = “Did not apply to me at all” to 3 = “Applied to me very much”) participants report on how they felt over the past week. The DASS-21 was utilized by three studies within

this review, with two studies using the full scale (Mazzucchelli et al., 2018; Salem-Guirgis et al., 2019) and one only using the stress subscale (Lunsky et al., 2015). Internal consistency for the subscales in the studies ranged from good to excellent (0.70 to 0.94). However, Mazzucchelli et al. (2018) reported questionable internal consistency for the stress scale at 0.69. Two studies (Lunsky et al., 2015; Salem-Guirgis et al., 2019) pointed out that it was possible that the scales used were not sensitive enough to assess changes in participants from pre-post intervention. Lunsky et al. (2015) also noted that perhaps utilizing alternate stress scales such as the Parental Stress Scale (PSS; Berry & Jones, 1995) or the Parenting Stress Index (PSI; Abidin, 1995) may be a more useful measure. They elaborated that the Isolation subscale of the Parenting Stress Index would be especially useful to assess the impact of interventions that provide parental support on feelings of isolation.

Perceived Stress Scale-10 (PSS-10; Cohen & Williamson, 1988)

The PSS-10 assesses the perceived level of stress in the past month and measures the frequency with which participants find their lives to be unpredictable, overloaded, and uncontrollable. The scale uses a 5-point scale (0 = “Never” to 4 = “Very often”) to provide a total score of general life stress, with higher totals indicating greater levels of stress. Three studies utilized the PSS-10 in this review (Singh et al., 2014, 2019; Smith et al., 2018) with two studies reporting good internal consistency of 0.8 and higher (Singh et al., 2019; Smith et al., 2018) while the third reported no psychometric properties for the PSS-10 specific to the current study (Singh et al., 2014). The use of the PSS-10 was questioned by Smith et al. (2018) given that this scale measures general life stress rather

than stress related to parenting an adolescent with ASD. As such, the authors also suggested that the use of the Parenting Stress Index (PSI; Abidin, 1995) or the Questionnaire on Resources and Stress (Konstantareas et al., 1992) may be a more suitable and sensitive measure.

Stress Index for Parents of Adolescents (SIPA; Sheras et al., 1998)

The SIPA is a 90-item scale that identifies areas of stress with regard to three specific components arising from parent-adolescent interactions. The Adolescent Domain assesses stress experienced by a parent as a result of his/her adolescent life, while the Parent Domain measures stress arising from interactions with the adolescent, and finally, the Adolescent-Parent Relationship Domain determines stress arising from the perceived quality of the parent-adolescent relationship. Scores from each of these are summed to provide a Total Parenting Stress score. The SIPA is designed specifically for parents of adolescents between the ages of 11 to 19 years. Two studies in this review used this scale (Karst et al., 2015; Schiltz et al., 2018) and both reported strong internal consistency of 0.95. Although Karst et al. (2015) used the SIPA, they pointed out the need to further examine the effect of the PEERS intervention on stress “with an increased sample size and/or use of a more sensitive measure (perhaps an ASD-focused instrument)” (Karst et al., 2015. p. 761). Similarly, Schiltz et al. (2018) referred to the need for more measures that are validated for an ASD sample.

Beck Anxiety Inventory (BAI; Beck & Steer, 1990)

The BAI assesses levels of anxious symptoms an individual experienced over the past month. The 21-items have four Likert scale options (0 = “Not at all” to 3 = “Severely - it bothered me a lot”) which when summed provides a total score indicating minimal, mild, moderate, or severe levels of anxiety. Two studies used the BAI in this review (Schiltz et al., 2018; Zu et al., 2019) with one using the Chinese version of the scale (Zu et al., 2019). However, only Schiltz et al. (2018) reported a psychometric property for the current study, an internal consistency value of 0.87. They also expressed concern on the limitations of the BAI due to the “specific components of anxiety that the BAI measures,” which may not reflect the worry or rumination that parents of adolescents with ASD may experience (Schiltz et al., 2018, p. 1176).

State and Trait Anxiety Inventory (STAI-S and STAI-T; Spielberger et al., 1983)

The STAI-S and STAI-T are each 20-item scales that measure two different types of anxiety. The STAI-S measures state anxiety which assesses temporary feelings of anxiousness at the current moment while the STAI-T measures trait anxiety, which determines the stable levels of anxiety an individual experiences. Participants self-report using a 4-point Likert scale (0 = “Nothing” to 4 = “Plenty”). One study in this review used only the STAI-S administered using the Spanish version (Ruiz-Robledillo et al., 2015) and reported a satisfactory internal consistency of 0.62. A second study in this review used both the STAI-S and STAI-T in the Korean form (Yoo et al., 2014) and reported good internal consistency for both scales at 0.84.

Discussion

This systematic review aimed to examine the current state of literature with regard to transition-aged children with ASD. Specifically, the purpose was to identify interventions that targeted the unique stressors of this critical period in life and the respective scales used to assess stress and/or anxiety outcomes among the parents of these children. Despite the vast literature base which was reviewed, only 11 studies met the inclusion criteria of which only two studies specifically targeted the transition-age group (Singh et al., 2014; Smith et al., 2018). It was evident from the review that most ASD interventions continue to focus on young children and their families with ASD. Although the investment in early childhood research and interventions have contributed to improved outcomes among children with ASD, it is crucial to prioritize interventions targeting the transition years into adulthood to support better outcomes in both parents and their children with ASD across the lifespan (Wisner-Carlson et al., 2020).

Intervention Areas

All interventions in this review focused on parental stress and/or anxiety outcomes given the implications of parental wellbeing on the family system. Interventions however differed in the pathway by which they addressed stress and/or anxiety. Some studies targeted these outcomes directly through secondary engagement strategies for coping (Piazza et al., 2014) such as mindfulness training. Interventions utilizing secondary engagement are especially necessary for this population given that the many problems they face in regards to parenting a child with ASD may not always have immediate solutions (Lunsky et al., 2015). Moreover, such interventions help parents

develop acceptance of their situation (Piazza et al., 2014). Other studies in this review targeted parental stress and/or anxiety by focusing on indirect factors and utilizing primary engagement strategies (Piazza et al., 2014). Interventions using primary engagement strategies address the stressors which have the potential to be managed, reduced, and alleviated through planning and problem-solving (Piazza et al., 2014) such as skills to actively cope with the child's challenging behaviors, social functioning, and transition planning. Although five studies targeted indirect factors, most focused on social functioning, and only one study focused on transition planning.

Given that parents of young adults with ASD are overwhelmed with worry about their child's future and wish to plan and make decisions (Marsack-Topolewski & Graves, 2020; Oti-Boadi et al., 2020) it is imperative that interventions address this stressor. A recent cross-sectional study among parents of transition-aged children with ASD found that the quality of transition planning has a significant influence on the family's quality of life, parental mental health, and the transition experience (Wong et al., 2020). As such, future interventions should prioritize transitional support, which includes access to quality information related to resources and services such as Medicaid and Vocational Rehabilitation. Parental training in areas such as problem-solving and learning how to make plans are also imperative (Marsack-Topolewski & Graves, 2020; Resch et al., 2012; Russa et al., 2014; Wong et al., 2020). Family readiness should also be addressed by disseminating information on topics such as transfer of rights at adulthood and FERPA laws (*Family Educational Rights and Privacy Act (FERPA)*, 2018) to ensure clarity and prevent misunderstandings during the transition process (Martinez et al., 2012). This is especially important given the inability of many parents to step back and

hold high expectations from their child, which can impede the child's progress and outcomes (Agarwal et al., 2020). Interventions should also emphasize parent education (Preece & Trajkovski, 2017) in regards to ASD across the lifespan and the expectations for care over the life course. Embedding social support for parents in all interventions should be a priority. Although some studies in the review included this component, it is evident that parents of this age group, in particular, seek and need social support which has a direct impact on mental wellbeing (Mason, 2012; Resch et al., 2012; Tuohy & Yazdani, 2016).

Findings from this review highlighted the popularity of interventions which targeted the social deficits and challenging behaviors among children with ASD. It was interesting, however, that only one study included children in the mindfulness intervention, despite the high rates of anxiety among this age group (Kaat & Lecavalier, 2015; van Steensel et al., 2011) and its potential to improve behaviors, ASD symptoms, and emotional regulation (Salem-Guirgis et al., 2019). Also missing in the findings from this review is the need to target the development of independent living skills among transition-aged children. Deficits in these areas of daily living have been shown to elicit great parental stress and have the potential to be improved through timely and age-appropriate interventions (Ponton et al., 2019). Given that children with ASD continue to live with their aging parents (Shattuck et al., 2011) it is essential that interventions are designed to reduce the caregiving burden on parents by supporting mastery of independent living skills.

Study Design

It is evident that intervention research targeting the unique needs of this group should be prioritized, and a push for more rigorous study designs is necessary to build a robust evidence-base for transition interventions. Only three studies were randomized controlled trials (Karst et al., 2015; Smith et al., 2018; Yoo et al., 2014) and few had control groups. Moreover, most study assessments were designed as simple pre-posts with only two studies that included a follow-up assessment at 3-months post-intervention (Mazzucchelli et al., 2018; Yoo et al., 2014). Although the overall quality rating of these studies were high, they scored lower in the sampling category given the small size they used (studies ranged from 3 to 77 parents). In addition, the interventions appeared to target parents and their children with high functioning autism. Given the spectrum within which ASD can lie, it is imperative for interventions to target the different functioning levels of ASD (Roberts et al., 2011) and narrower age groups to ensure that the unique needs of each life stage are addressed (Salem-Guirgis et al., 2019). Our findings reveal that research on young adults between the *specific ages* of 18 and 22 is even more sparse with only three studies that included participants within this age group (Salem-Guirgis et al., 2019; Singh et al., 2014; Zu et al., 2019).

A number of parent and family outcome variables were assessed in the studies examined in this review such as parenting self-efficacy, family chaos, mindfulness, and parental involvement in addition to stress and anxiety. The nature of the intervention and the additional outcomes to be measured, is an important point of consideration for future studies, as many parent characteristics such as self-efficacy mediate or moderate the effect of parental wellbeing (Pickard & Ingersoll, 2017). It has been shown, for example,

that parenting efficacy is associated with the transition experience and parent health (Wong et al., 2020). Moving forward, intervention studies will want to continue targeting and assessing these additional parent and family characteristics. As such, interventions should be designed to include both parents and child, which has multiple benefits. First, as discussed extensively in the PEERS intervention, it allows parents to reinforce and generalize the skills their child learns beyond the intervention and into the natural environment (Karst et al., 2015). Second, family-centered interventions acknowledge the effect of parent education, support, and training on parent wellbeing and its cascading effects on the family (Smith et al., 2018; Smith & Anderson, 2014).

Interventions should also carefully consider the length of the intervention and the commitment expected from parents to ensure that they can have a meaningful impact (Salem-Guirgis et al., 2019) without adding to the burden already experienced by these families (Karst & Van Hecke, 2012). Finally, interventions should be tailored to the needs of the parent population. Given that parents of transition-aged children with ASD may be older, it is necessary for future studies to keep limitations and preferences of the age group in mind, similar to the efforts undertaken by Lunsky et al. (2015).

Stress and Anxiety Scales

In addition to well-designed interventions targeting direct and indirect factors, there is a need for valid and reliable assessments of stress and anxiety outcomes in parents given that the stressors faced by parents of children with ASD and even more specifically, transition-aged children with ASD are unique. However, none of the five scales identified in this review were designed for parents of children with ASD or even

disabilities in general, and all but one (the STAI-S/STAI-T; Spielberger et al., 1983) were noted by the authors as a possible limitation to their findings. Studies shared that the scales were likely not sensitive enough to capture changes in this parent population, and referenced the need for instruments that were specific to the ASD population.

For example, Smith et al. (2018) pointed out that the use of the Perceived Stress Scale (PSS; Cohen & Williamson, 1988) may not have been appropriate given that it measures general life stress rather than parenting stress related to raising a child. While many scales have been developed to assess stress among the parent population, such as the Parental Stress Scale (PSS; Berry & Jones, 1995) and the Parenting Stress Index (PSI; Abidin, 1995) which are commonly used in ASD studies (Davis & Carter, 2008; Samadi et al., 2014; Wang et al., 2013), they focus on constructs such as “child distractibility or demandingness” (Abidin, 1995; Silva & Schalock, 2012) and not the unique and complex constructs which could capture the stress in parents raising a child with ASD (McStay et al., 2014; Silva & Schalock, 2012). Moreover, the PSI is designed for parents of children aged 3-months to 10 years of age (Abidin, 1995). It is concerning that two authors (Lunsky et al., 2015; Smith et al., 2018) in this review (who used a scale not designed for parents – DASS-21 and the PSS-10 respectively) suggested the use of the PSI as an alternative to enhance sensitivity. Although, choosing a scale designed for parents would be more suitable, the transition age range of the participants in their respective studies and the intended age group of the PSI scale would not be aligned.

In 2012, the Autism Parenting Stress Index (APSI; Silva & Schalock, 2012) was developed to capture the specific stressors associated with caring for a child with ASD. The measure consists of 13-items and covers three domains of parenting stress: “core

social disability, difficult-to-manage behavior, and physical issues” and is ranked on a 5-point scale (“Not stressful,” “Sometimes creates stress,” “Often creates stress,” “Very stressful on a daily basis,” or “So stressful that sometimes we feel we cannot cope”). The initial psychometric assessment was conducted with children under the age of 6 and allows clinicians to understand where parents may need additional support in regards to parenting skills. The scale also allows an examination of intervention effects on parental stress levels. Although this scale is specific to the parents of children with ASD, it has been psychometrically assessed among parents of *young children* with ASD. It is possible that none of the studies in this review utilized the APSI given the transition-age of their study population. However, future studies may wish to psychometrically assess the suitability of this scale for older children with ASD.

Scales used to assess anxiety in this review were also designed for the general population. Although the STAI-S was used in two studies and the STAI-T in one (Ruiz-Robledillo et al., 2015; Yoo et al., 2014) only state anxiety demonstrated any improvement during interventions. This is to be expected given that state anxiety measures the temporary and short-term change in anxiety levels. Even in the study with a 3-month follow-up that assessed trait anxiety (Yoo et al., 2014), there was no significant change in these levels. This may imply that the intervention was not able to maintain its effectiveness over time, or may signal the need for more sensitive instruments for this population. Similarly, the BAI also does not assess for worry sufficiently or capture rumination which is commonly experienced among parents of children with ASD (Schiltz et al., 2018).

It is imperative that the selection of measurement scales is guided by the population, purpose, and utility of the measure. Failing to do so even in the most rigorously designed interventions may lead to the study being unable to detect changes in outcomes, or lead to inaccurate findings (Coster, 2013). This is especially important given the differing characteristics of children with and without disabilities, and how that impacts interactions between children and parents (Dardas & Ahmad, 2014; Zaidman-Zait et al., 2010). Currently, stress scales have been designed for the general population, parents, parents of children with varying disabilities, and even parents of young children with ASD. However, there is a need to design stress and anxiety measurement tools that are specific to the constructs and stressors relevant to the life stage (Rutherford et al., 2019) of the *older* child with ASD if we hope to accurately assess the effectiveness of interventions on parent mental wellbeing. Researchers should refrain from using scales based on their popularity and/or ease of administration. The fit of constructs to the targeted population should not be overlooked, which could lead to validity concerns (Shadish et al., 2002). At this time, in the absence of measures designed for parents of older-aged children with ASD, researchers should at least consider scales intended for parents of children with ASD or parents in general.

Strengths and Limitations

This systematic review adhered to PRISMA guidelines, hand-searched relevant reference lists, included non-English literature and contacted authors for missing information to minimize publication and selection bias. However, there are limitations that may have led to the exclusion of some important intervention studies and respective

scales from the findings. First, although studies were limited to one decade from 2010 to 2020 to ensure relevance to the continuously progressing ASD field, studies prior to 2010 may have been omitted. Second, gray literature was excluded which would impact publication bias. Third, given the wide age ranges of children and the lack of detail in manuscripts related to age we had to estimate (using *t*-distribution calculations) the number of children within our transition-age criteria to determine if the intervention study included this specific group. As a result of this estimate and the decision to include studies based on a 50% cutoff, studies may have been excluded or included. Moreover, although 14 authors of studies with insufficient details were contacted with two reminder emails, we did not hear back from six authors (Benn et al., 2012; Ede et al., 2020; Elfert & Mirenda, 2015; Hampel et al., 2015; Smith et al., 2012; Whitney & Smith, 2015). Similarly, we requested 14 full-texts from ILLiad as they were not accessible via an extensive web-based search. However, full-texts of three studies remained inaccessible (Javad et al., 2018; Sabourin et al., 2013; Sood et al., 2018).

Conclusion

There is growing awareness for the need for ASD research to span beyond childhood and specifically, the awareness to examine the critical period of transition (U.S. Department of Health and Human Services, 2017; Wisner-Carlson et al., 2020) given its impact on adult outcomes for the individual with ASD and family wellbeing. Our findings highlight the gap which exists in regards to this specific group and identifies areas for consideration in regards to intervention focus, study design, and selection of

measurement tools. Future researchers can use this review to inform the design of their interventions which are aligned with the unique stressors of this period and the needs of the family.

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<https://doi.org/10.2224/sbp.8013>

Tables

Table 1. Complete search strategy

Database	Search Strategy
Medline Proquest	(MESH.EXACT("Burnout, Psychological") OR MESH.EXACT("Anxiety") OR MESH.EXACT("Psychological Distress") OR MESH.EXACT("Stress, Psychological") OR Anxi* OR stress* OR distress* OR "emotional availability") AND (MESH.EXACT("Single Parent") OR MESH.EXACT("Mothers") OR MESH.EXACT("Fathers") OR MESH.EXACT("Parents") OR Parent* OR mother* OR father* OR family OR families OR maternal OR paternal) AND (MESH.EXACT("Developmental Disabilities") OR MESH.EXACT.EXPLODE("Child Development Disorders, Pervasive") OR ASD OR autis* OR "developmental disabilit*" OR PDD OR Asperger* OR "developmental disorder" OR "childhood disintegrative" OR "pervasive developmental" OR "high functioning autism")
PsycINFO	(MAINSUBJECT.EXACT("Caregiver Burden") OR MAINSUBJECT.EXACT("Psychological Stress") OR MAINSUBJECT.EXACT("Stress") OR MAINSUBJECT.EXACT("Anxiety") OR MAINSUBJECT.EXACT("Distress") OR Anxi* OR stress* OR distress* OR "emotional availability") AND (MAINSUBJECT.EXACT("Fathers") OR MAINSUBJECT.EXACT("Family") OR MAINSUBJECT.EXACT.EXPLODE("Single Parents") OR MAINSUBJECT.EXACT("Adoptive Parents") OR MAINSUBJECT.EXACT("Mothers") OR MAINSUBJECT.EXACT("Parents") OR Parent* OR mother* OR father* OR family OR families OR maternal OR paternal) AND (MAINSUBJECT.EXACT.EXPLODE("Autism Spectrum Disorders") OR ASD OR autis* OR "developmental disabilit*" OR PDD OR Asperger* OR "developmental disorder" OR "childhood disintegrative" OR "pervasive developmental" OR "high functioning autism")
CINAHL	Anxi* OR stress* OR distress* OR "emotional availability" OR (MM "Anxiety") OR (MM "Stress, Psychological") OR (MM "Caregiver Burden") AND Parent* OR mother* OR father* OR family OR families OR maternal OR paternal OR (MM "Parents") OR (MM "Adoptive Parents") OR (MM "Biological Parents") OR (MM "Fathers") OR (MM "Mothers") OR (MM "Parents of Disabled Children") AND ASD OR autis* OR "developmental disabilit*" OR PDD OR Asperger* OR "developmental disorder" OR "childhood disintegrative" OR "pervasive developmental" OR "high functioning autism" OR (MM "Asperger Syndrome") OR (MM "Autistic Disorder") OR (MM "Pervasive Developmental Disorder-Not Otherwise Specified") OR (MM "Developmental Disabilities")
Embase	('anxiety'/de OR 'caregiver burnout'/de OR 'family stress'/de OR 'distress syndrome'/de OR 'emotional stress'/de OR anxi* OR stress* OR distress* OR 'emotional availability') AND (adoptive AND 'parent'/de OR 'mother'/de OR 'father'/de OR 'family'/de OR 'parent'/de OR parent* OR mother* OR father* OR family OR families OR maternal OR paternal) AND ('autism'/de OR 'asperger syndrome'/de OR 'childhood disintegrative disorder'/de OR 'pervasive developmental disorder not otherwise specified'/de OR 'developmental disorder'/de OR asd OR autis* OR 'developmental disabilit*' OR pdd OR asperger* OR 'developmental disorder' OR 'childhood disintegrative' OR 'pervasive developmental' OR 'high functioning autism')

Table 2. *t*-distribution calculations

Author (Year)	Parents (n)	Child (n)	Age Range	Mean	SD	For 22: X = age limit - mean	For 14: X = age limit - mean	df= sample -1	TDIST: less than 22	TDIST: less than 14	T-DIST Final Value	% range 14 to 22
Bourke-Taylor et al. (2019)	36	36	5 - 19	10.1	4	11.9	3.9	35	1.00	0.9997	0.0002	0.02
Choque et al. (2017)	NR	150	7 - 17	12.05	2.61	9.95	1.95	149	1.00	0.9734	0.0265	2.65
	NR	146		11.59	2.66	10.41	2.41	145	1.00	0.9913	0.0086	0.86
Clifford & Minnes (2013)	20	20	2 - 22	9.32	4.83	12.68	4.68	19	1.00	0.9999	0.000	0.01
	25	25	3 - 17	9.81	4.14	12.19	4.19	24	1.00	0.9998	0.000	0.02
Corona et al. (2019)	NR	25	12 - 17	13.8	1.52	8.2	0.2	24	1.00	0.5784	0.422	42.16
Dykens et al. (2014)	243	243	2 - 54	10.85	7.53	11.15	3.15	242	1.00	0.9990	0.001	0.09
Ferraioli & Harris (2013)	15	15	NR	NR	NR	-	-	-	-	-	-	6.6*
Fung et al. (2018)	33	33	3 - 20	10.4	4.4	11.6	3.6	32	1.00	0.9994	0.001	0.05
Ghoneim (2018)	30	30	3 - 18	7.36	2.98	14.64	6.64	29	1.00	0.9999	0.000	0.00
Gika et al. (2012)	11	11	4.5 - 17	7.5	NR	14.5	6.5	10	1.00	0.9999	0.000	0.00
Hall et al. (2016)	42	42	3 - 16	11.63	0.06	10.37	2.37	41	1.00	0.9887	0.011	1.13
	28	28		11.21	1.19	10.79	2.79	27	1.00	0.9952	0.005	0.48
Hwang et al. (2015)	6	6	8 - 15	11.16	NR	10.84	2.84	5	0.99	0.9818	0.018	17*
Johnson et al. (2014)	32	32	0 - 19	10.3	5.1	11.7	3.7	31	1.00	0.9995	0.000	0.04
Jones et al. (2018)	21	21	4 - 16	10.53	3.16	11.47	3.47	20	1.00	0.9987	0.001	0.12
Jonsson et al. (2019)	NR	23	8 - 17	13.04	2.58	8.96	0.96	22	1.00	0.8262	0.174	17.37
	NR	27		12.63	2.83	9.37	1.37	26	1.00	0.9087	0.091	9.12
Karst et al. (2015)	32	32	11 - 16	14.1	1.3	7.9	-0.1	31	1.00	0.4604	0.540	53.95
	32	32		13.4	1.5	8.6	0.6	31	1.00	0.7235	0.276	27.64
Kuhlfthau et al. (2020)	51	51	2 to >17	NR	NR	-	-	-	-	-	-	29.4*

Lunsky et al. (2018)	29	40	3 - 20	10.4	4.36	11.6	3.6	39	1.00	0.9995	0.000	0.04
Lunsky et al. (2017)	26	26	16 - 40	22.7	5.4	-0.7	-8.7	25	0.245	0.000	0.245	24.52
	24	24	17 - 38	22.7	6	-0.7	-8.7	23	0.24	0.000	0.245	24.55
Lunsky et al. (2015)	22	22	NR	21.1	7.1	0.9	-7.1	21	0.81	0.000	0.811	81.08
Martin et al. (2019)	137	137	3 - 28	9.7	4.57	12.3	4.3	136	1.00	0.9999	0.000	0.00
Mazzucchelli et al. (2018)	9	6	12 - 16	15.14	1.53	6.86	-1.14	-	-	-	-	66.7*
McConkey & Samadi (2013)	28	28	3 - 17	7.82	4.86	14.18	6.18	27	1.00	0.9999	0.000	7*
Moss et al. (2014)	not reported	26	8 - 17	11.74	2.53	10.26	2.26	25	1.00	0.9836	0.016	1.64
Radley et al. (2014)	not reported	3	10 - 14	12.4	NR	9.6	1.6	2	0.99	0.8746	0.120	33*
Ridderinkhof et al. (2018)	74	45	8 - 19	13.03	2.72	8.97	0.97	44	1.00	0.8313	0.169	16.87
Ruble et al. (2018)	36	36	2.3 - 15	6.9	3.9	15.1	7.1	35	1.00	0.9999	0.000	0.00
Ruiz-Robledillo et al. (2015)	Caregiver: 6 Non-caregivers: 7	6	NR	15	6.48	7	-1	5	0.999	0.1816	0.818	81.79
Salem-Guirgis et al. (2019)	23	23	12 - 23	15.65	2.57	6.35	-1.65	22	1.00	0.0565	0.943	94.34
Samadi et al. (2013)	37	37	3 - 17	8.2	2.92	13.8	5.8	36	1.00	0.9999	0.000	8.6*
Schultz et al. (2018)	77	NR	11 - 16	13.58	1.46	8.42	0.42	-	-	-	-	54.54*
Schultz et al. (2012)	16	16	11 - 14	12.68	1.36	9.32	1.32	15	1.00	0.8966	0.103	10.33
	10	10		12.62	1.13	9.38	1.38	9	1.00	0.8995	0.100	10.04
Singh et al. (2019)	ASD: 47	47	13 - 17	15.15	NR	6.85	-1.15	46	1.00	0.1280	0.872	87.20
	ID: 45	45	13 - 17	15.56	NR	6.44	-1.56	44	1.00	0.0629	0.937	93.70
Singh et al. (2020)	65	65	9 - 14	12.17	1.62	9.83	1.83	64	1.00	0.9640	0.036	3.60
	65	65		11.8	1.65	10.2	2.2	64	1.00	0.9842	0.016	1.57
	65	65		11.95	1.68	10.05	2.05	64	1.00	0.9777	0.022	2.22

Singh et al. (2014)	3	3	15 - 19	16.66	NR	5.33	2.66	-	-	-	-	100*
Smith et al. (2018)	16	16	14 - 17	15.56	0.73	6.44	-1.56	-	-	-	-	100*
	25	25		15.36	1.19	6.64	-1.36	-	-	-	-	100*
Spruin et al. (2018)	9	11	10 - 16	12.7	2.12	9.3	1.3	10	1.00	0.8886	0.111	11.14
Verschuur et al. (2019)	13	13	8 - 14	11.2	2.2	10.8	2.8	12	1.00	0.9919	0.008	0.80
	13	13	3 - 11	6.11	3.2	15.89	7.89	12	1.00	0.9999	0.000	0.00
Wright et al. (2015)	38	38	2 - 16	8.76	2.86	13.24	5.24	37	1.00	0.9999	0.000	0.00
	24	24		9.25	4.08	12.75	4.75	23	1.00	0.9999	0.000	0.00
Yoo et al. (2014)	NR	23	12 - 18	14.04	1.64	7.96	-0.04	22	1.00	0.4842	0.516	51.58
	NR	24		13.54	1.5	8.46	0.46	23	1.00	0.6750	0.325	32.49
Zu et al. (2019)	8	8	4 - 20	11.75	2.32	10.25	2.25	7	1.00	0.9704	0.030	2.96
	8	8		14.13	5.07	7.87	-0.13	7	0.99	0.4501	0.550	54.98

NR – Not reported

* actual percentage of transition-aged children as reported in study or author response to email

Table 3. Quality rating of included studies in review

Author (Year)	Title and Abstract	Introduction and Aims	Method and Data	Sampling	Data Analysis	Ethics and Bias	Findings and Results	Transferability / Generalizability	Implication Usefulness	Total Score	Quality Rating
Karst et al. (2015)	4	4	4	3	4	4	4	3	3	33	High
Lunsky et al. (2015)	4	4	3	3	3	4	3	3	4	31	High
Mazzucchelli et al. (2018)	4	4	3	2	3	4	4	3	3	30	High
Ruiz-Robledillo et al. (2015)	4	3	4	2	4	3	4	2	4	30	High
Salem-Guirgis et al. (2019)	4	4	3	3	4	4	4	3	3	32	High
Schiltz et al. (2018)	3	3	2	2	4	2	4	2	3	25	Medium
Singh et al. (2019)	3	3	3	3	4	4	4	4	4	32	High
Singh et al. (2014)	4	3	4	4	4	4	4	4	3	34	High
Smith et al. (2018)	4	4	4	4	4	4	4	3	3	34	High
Yoo et al. (2014)	4	4	4	3	4	4	4	3	4	34	High
Zu et al. (2019)	2	2	2	3	3	2	3	2	2	21	Low

Table 4. Summary characteristics of studies in final review

Author (Year)	Country	Parent (n)	Child participant / recipient (n)	Age range of child	% of children 14 to 22 years old ^a	Name of intervention	Stress and/or anxiety scale	Quality score - Rating
Karst et al. (2015)	USA	EXP: 32 WL: 32	EXP: 32 WL: 32	11 - 16	EXP: 54% WL: 27.6%	PEERS	Stress Index for Parents of Adolescents	33 - High
Lunsky et al. (2015)	Canada	22	22	Not reported	81.08%	Coping with stress: A mindfulness group for families of teens or adults with developmental disabilities	Stress subscale from the Depression Anxiety Stress Scale	31 - High
Mazzucchelli et al. (2018)	Australia	9	6	12 – 16	66.7% ^b	Building Bridges Triple P	Depression Anxiety Stress Scales – DASS-21	30 - High
Ruiz-Robledillo et al. (2015)	Spain	Caregivers of ASD: 6 Non-caregivers: 7	Children with autism/Asperger's: 6	Not reported	81.79%	MBP: Mindfulness-Based Program	State Anxiety Inventory (Spanish)	30 - High
Salem-Guirgis et al. (2019)	Canada	23	23	12 – 23	94.34%	MYMind	Depression, Anxiety, and Stress Scale - DASS-21	32 - High
Schiltz et al. (2018)	USA	77	Not reported	11 – 16 ^c	54.54% ^d	PEERS	Stress Index for Parents of Adolescents & Beck Anxiety Inventory	25 - Medium
Singh et al. (2019)	USA	ASD: 47 ID: 45	ASD: 47 ID: 45	13 – 17	ASD: 87.18%	MBPBS: Mindfulness-Based Positive Behavior Support	Perceived Stress Scale-10	32 - High
Singh et al. (2014)	USA	3	3	15-19	100% ^b	MBPBS: Mindfulness-Based Positive Behavior Support	Perceived Stress Scale-10	34 - High

Smith et al. (2018)	USA	EXP: 16 WL:25	EXP:16 WL:25	14 - 17	100% ^b	Transitioning Together	Perceived Stress Scale-10	34 - High
Yoo et al. (2014)	South Korea	EXP: 23 WL: 24	EXP: 23 WL: 24	12 - 18	EXP: 51.58% WL: 32.5%	PEERS – Korean Version	State and Trait Anxiety Inventory	34 - High
Zu et al. (2019)	China	Shanghai: 8 Taichung: 8	Shanghai: 8 Taichung: 8	4 – 20	Shanghai: 2.96% Taichung: 54.98%	Psychoeducational intervention: social skills training (PEERS) & knowledge about ASD	Beck Anxiety Inventory (Chinese)	21 - Low

EXP: Experimental group; WL: Waitlist control group; ^aEstimate from *t*-distribution calculation, unless noted otherwise; ^bActual value from manuscript; ^cValue derived from parent study; ^d Value derived from author response

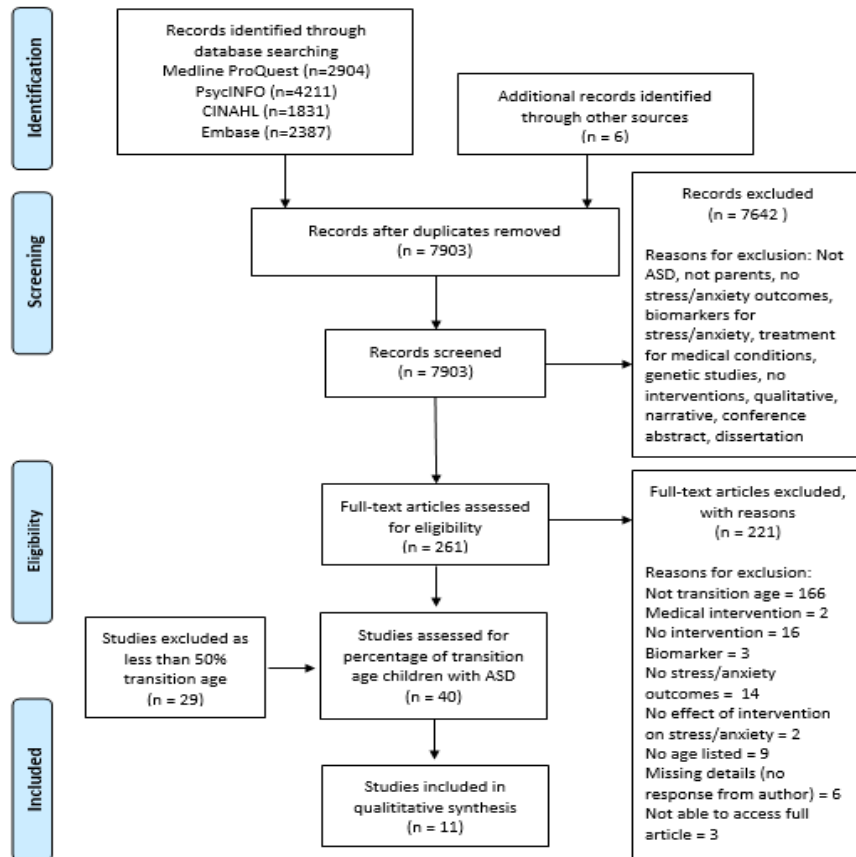
Table 5. Study design of interventions included in the final review

Author (Year)	Intervention Participant	Duration/Length	Design	Assessments	Outcomes of Interests	Unique Components
Mindfulness: Secondary Engagement Strategy						
Lunsky et al. (2015)	Parent (mothers & fathers)	6-weeks (6-sessions; 2 hours each)	Single group; no control	2 (pre and post)	Mindfulness, mindful parenting and stress	Adapted to older parents
Ruiz-Robledillo et al. (2015)	Parent (mothers & fathers)	5-weeks (9 sessions; 2 hours each)	Two groups (caregivers and non-caregivers)	3 (pre-mid-post)	Anxiety, mood and anger, health and stress	Stress measured through cortisol markers
Salem-Guirgis et al. (2019)	Parent (mothers and fathers) & Child	9-weeks (9 sessions; 1.5 hours each) + 1 booster session (9-weeks post-program)	Single group; no control	4 (2 pre and 2 post)	Mindfulness, parent-depression, stress and anxiety and youth emotion regulation and autism symptoms	Both parent and child included in a mindfulness intervention
Singh et al. (2019)	Parent (only mothers)	40-weeks (10-week control period, followed by 3-sessions held over 3 consecutive days and 30-weeks of practice)	Two groups; no control (ASD and ID)	3 (2 pre and 1 post)	Maternal stress levels and aggressive, disruptive and compliance behaviors among children	Two components of intervention: mindfulness and support for challenging behaviors in children
Singh et al. (2014)	Parent (only mothers)	48-weeks (1 pre-training session followed by 4-weeks of practice, then 8 sessions over 8-weeks followed by meditation practices at home)	Single group; no control	4 (2 pre and 2 post)	Maternal stress levels of mothers, and aggressive, disruptive and compliance behaviors among children	One-on-one training; Two components of intervention: mindfulness and support for challenging behaviors in children; 100% transition age
Social Functioning: Primary Engagement Strategy						
Karst et al. (2015)	Parent (mothers and fathers) & Child	16-weeks (14-sessions; 1.5 hours each)	Two groups (intervention and waitlist control); Randomized control trial	2 (pre and post)	Family chaos, parenting stress, and parenting self-efficacy	Small groups

Schiltz et al. (2018)	Parent (mothers and fathers) & Child	14-weeks (14-sessions; 1.5 hours each)	Two groups (intervention and waitlist control); Randomized control trial	2 (pre and post)	Child's challenging and social behaviors, parental stress, depression and anxiety and parental involvement	Small groups
Yoo et al. (2014)	Parent (mothers and fathers) & Child	14-weeks (14-sessions; 1.5 hours each)	Two groups (intervention and waitlist control); Randomized control trial	3 (1 pre and 2 post including one at 3-month follow-up)	Teens social ability, ASD symptomology, depression, anxiety and behavioral problems. Parental depression, state and trait anxiety	Culturally adapted PEERS intervention in Korean
Multi-Component: Primary Engagement Strategy						
Mazzucchelli et al. (2018)	Parent (mothers and fathers)	8-weeks (8-sessions; 11.5 hours total)	Single group; no control	3 (1 pre and 2 post including one at 3-month follow-up)	Adolescent problem behaviors; parent dysfunctional disciplining styles; parent depression, anxiety and stress	In-person and phone sessions; parents identify a goal they want to achieve
Smith et al. (2018)	Parent (mothers and fathers) & Child	8-week (8 sessions plus 2 pre-intervention family joining sessions)	Two groups (intervention and waitlist control)	2 (pre and post)	Parent depression, general life stress, and problem-solving, parent-child relationships (quality, burden, happy/proud, warmth, positive remarks, criticism) and adolescent outcomes (social interactions, autism symptoms and social engagement)	Focus on transition period; parents identify goals in joining sessions; 100% transition age
Zu et al. (2019)	Parent (only mothers)	12-week (12-sessions; 1.5 hours each)	Two groups; no control	3 (pre-mid-post)	Parents positive/negative language, depression, anxiety and child's ASD symptoms	Speech patterns of mothers

Figures

Figure 1. PRISMA flowchart



From: Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, 6(7), e1000097. <https://doi.org/10.1371/journal.pmed.1000097>

CHAPTER 3: MANUSCRIPT 2

Health care demands of a child with autism and its impact on the mental health of mothers and fathers: A quantitative analysis using the NSCH 2017-2018 combined dataset

Abstract

Background: The health care needs of a child with autism spectrum disorder (ASD) adds significant demands on caregivers. Although the time, financial, and employment burden these caregivers experience have been previously examined, this study extends the existing literature base by assessing the impact of these demands on the mental health of parents, and how they may be associated differently between mothers and fathers.

Method: Multiple health care demand variables and their associations with parental mental health were quantitatively examined using the National Survey for Children's Health 2017-2018 combined dataset. Chi-square and binary logistic regression analyses were separated by both mothers and fathers of children with ASD.

Results: Findings indicated that the mental health of mothers was significantly associated with spending between one to ten hours coordinating care, and having a child whose ability to complete daily activities was moderately or consistently affected. Inadequate insurance and being non-Hispanic black/other/multi-racial was also significantly associated with unfavorable mental health. Among fathers, unfavorable mental health was significantly associated with frustration to get services for their child, and

interestingly, having a family member who *did not* stop work, cut hours, or took a leave of absence.

Conclusions: Gender roles may explain some of the differences in the way health care demands uniquely impacts the mental health of mothers and fathers. Findings from this study can help prioritize policy changes given the significant needs of this population and their families. In addition, these findings bring to light the invisible effects of structural and ASD-related challenges on parental mental health in the policies, services, and interventions that are designed.

Background

The increasing prevalence of autism spectrum disorder (ASD) among 8-year old children in the United States (from 1 in 59 in 2014 to 1 in 54 in 2016; Maenner et al., 2020) has called attention to the effects and needs of this lifelong condition for both children and their caregivers (Dudley & Zwicker, 2014; Matson et al., 2016). This is especially important given the hallmark features of ASD which affect communication, interests, social interactions (American Psychiatric Association, 2013), and the ability to complete daily living skills (Cruz-Torres et al., 2020). Moreover, individuals with ASD are frequently diagnosed with co-occurring developmental disabilities such as intellectual disability, learning disability, attention deficit hyperactivity disorder and developmental delay, and mental health conditions such as anxiety and depression (Levy et al., 2010). These heighten the responsibility and complexity of caregiving (Marsack-Topolewski &

Church, 2019) which is most commonly provided by families across the lifespan (Volkmar & Pauls, 2003).

To support the extensive healthcare needs of individuals with ASD, they need access to multiple and simultaneous age-appropriate services such as educational, vocational, and specialized health care (Kamp-Becker et al., 2017). Unfortunately, much of these services are missing or fragmented making it challenging and frustrating for caregivers to access the services they need (Brewer, 2018; Crossman et al., 2020; Shivers et al., 2019; Williams-Caldwell, 2012) which invariably leads to considerable time spent on coordinating care (Parker & Killian, 2020). These responsibilities also affect the choices parents make regarding their own employment, with many, up to 57.1% of families in one study (Kogan et al., 2008) choosing to leave work or reduce hours to provide home care (Rogge & Janssen, 2019). These indirect costs (frustration with accessing services, time spent coordinating and providing care, and effects on employment) heighten the strain families experience as a result of increased *direct* costs. These arise from the expenses associated with the frequent utilization of various healthcare providers, and necessary services, equipment and diets (Cummings et al., 2016; Dudley & Zwicker, 2014; Gurney et al., 2006). Consequently, many families report a greater financial burden in regards to caring for their child with ASD (Rogge & Janssen, 2019).

It is not surprising that studies have shown that parents of children with ASD have worse mental health outcomes such as stress, anxiety, and depression compared to parents of neurotypical children (Hayes & Watson, 2013; Padden & James, 2017) and those with other disabilities (Estes et al., 2013; Valicenti-McDermott et al., 2015).

Stressors examined include the child's level of daily living skills and independence, which is a significant challenge in the ASD population, and influences the trajectory for adult outcomes (Marsack-Topolewski et al., 2021; Tillmann et al., 2019). A few studies examining the mental health of parents have extended their research by exploring differences between mothers and fathers. This is especially relevant given the unique gender roles among parents, where mothers, to a large extent, remain the primary caregiver (ten Hoopen et al., 2020) while fathers are generally considered to be the financial provider (Ang & Loh, 2019). In a study of 124 participants, mothers and fathers were assessed for predictors of stress related to the symptoms of ASD. Interestingly, the father's levels of stress was predicted by challenges in the child's cognitive and sensory levels, while mothers' stress levels were associated with deficits in the child's social skills (Allen et al., 2013) which are characteristics of ASD impacting daily living activities. In another study with parents of children with ASD aged 2 to 12 years old, findings highlighted that stress levels of fathers were associated with the severity of ASD, while overall, mothers were more stressed than fathers (Soltanifar et al., 2015). A recent systematic review, however, concluded that there is insufficient research on fathers of children with ASD, despite the potential for them to positively impact the family structure and be equally involved as mothers (Rankin et al., 2019).

Existing literature has also assessed the mental health of parents by the age of the child (Dovgan & Mazurek, 2019; McStay et al., 2014; Pozo & Sarriá, 2015) given that levels of caregiving burden may change as the child's needs evolve (Hanson & Hanline, 1990; Ludlow et al., 2012). One longitudinal study examined stress among mothers of children with (n=94; ASD, Down Syndrome, and cerebral palsy) and without

developmental disabilities (n=125) and found that maternal stress was high during early childhood (between the ages of 3 to 5) but declined during middle childhood (between the ages of 6 to 13; Azad et al., 2013). On the other hand, some studies have found worse mental health conditions among older children with ASD (Gray et al., 2014; Kousha et al., 2016). At this time, findings appear to be mixed on the effect of the child's age on parental mental health, although they appear to implicate worse mental health outcomes among *mothers of young children* with ASD (Ang & Loh, 2019; Jones et al., 2013; Samadi et al., 2014).

Examining the mental health and predictors of mental health among parents of children with ASD is critical as its effects can be seen on the health and marital satisfaction for parents (Bonis, 2016; Reichman et al., 2008). Moreover, unfavorable parental mental health can have a cascading impact on the life trajectory of children with ASD given that the wellbeing of family members are linked and interdependent (Barker et al., 2011). In line with the life course theory (Fine and Kotelchuck, 2010), it is clear that the biological and developmental demands of caring for a child with ASD can impact economic, social, behavioral, and psychological factors among children and parents, thereby altering the course of their lives.

A few studies have used nationally representative data from *older* versions of the National Survey of Children's Health (NSCH) to examine the mental health of these parents by factors such as ASD severity (Schieve et al., 2011), coping supports (Zablotsky et al., 2013) and the effect of ASD complexity on the health care experience (Parker & Killian, 2020). Other studies (also using older versions of the NSCH dataset) have not examined mental health but have assessed *family impact* variables as the

outcome of interest which include the *financial, employment, and time burden* families experience. For example, one study has assessed these variables among children with ASD (Benevides et al., 2019), another has examined them among families with children with developmental disabilities (McManus et al., 2011) while another has compared the burden between families with a child with ASD, to other developmental disabilities and mental health conditions (Vohra et al., 2014).

Despite this literature, no study to the best of our knowledge has used nationally representative data to examine how the financial, employment and time burden for families (family impact variables) with children with ASD impacts the mental health of the parents, nor examined the effects of those stressors on both mothers and fathers independently. This study extends the definition of *family impact* to include frustration with accessing services and the effect of the child's condition on daily activities and utilizes these variables as *predictors* for mental health outcomes, and as such, refers to these variables as *health care demands*. By expanding the definition of family impact and identifying any differences that may exist between mothers and fathers, interventions and policies can be targeted to support these families and children to a greater extent. Moreover, although each health care demand variable is structural or an ASD-specific challenge that should be addressed in their own right, examining their association with parental mental health is equally important given their invisible effect on a potentially faster downward trajectory for the family.

Current Study

This study aims to examine the multiple facets of a parent's life impacted by the health care demands posed by caring for a child with ASD and its effect on the mental health of both mothers and fathers. The study aimed to answer the following research questions: (1) What is the current mental health status of mothers and fathers of children with ASD? (2) How is the age of the child (0-6, 7-11, 12-17 years old) with ASD associated with the mental health status of mothers and fathers? (3) What is the association between health care demand variables: problems with paying medical bills, changes in a family member's employment status, time spent coordinating and providing home health care, frustration with access to services, and the child's ability to undertake daily activities, on the mental health of mothers and fathers? (4) What are the overall effects of factors related to health care demands, demographics, and secondary conditions on the mental health status of mothers and fathers? We hypothesize that mothers of children with ASD will have less favorable mental health than fathers; mothers and fathers of younger children (0 to 5 years old) will have worse mental health than parents of older children; and that all health care demand factors will be positively associated with unfavorable mental health outcomes among both mothers and fathers.

Methods

Participants and Procedures

Data from the National Survey of Children's Health (NSCH) 2017 and 2018 combined two-year datasets was used for this quantitative study. The NSCH is a national

survey funded and conducted by the Health Resources and Services Administration's Maternal and Child Health Bureau and is administered using both mail and web-based questionnaires. It gathers state and national-level data on the health and well-being of children aged 0-17 years and is weighted to represent the non-institutionalized population of children in the country who are 17 and younger. Using random sampling, an invitation to participate in an initial screener is mailed to households. An adult who has knowledge of the child's health is asked to complete the screener online or via paper identifying all children under the age of 17 in the household. Adults who proceed to complete the survey, are asked to focus on the health of one child who is randomly selected. As such, only one child from each eligible household is the subject of the adult's survey. A total of 52,129 surveys were completed for the 2017 and 2018 combined dataset (weighted $n=73,428,760$) with 21,599 surveys in 2017 and 30,530 in 2018. For this study, the population of interest was 1,345 children (weighted $n=1,850,523$) in the combined NSCH dataset who were reported to currently have autism, autism spectrum disorder, Asperger's disorder, or pervasive developmental disorder.

Measures

This study examined the relationship between several independent variables hypothesized to be associated with the mental health status of mothers and fathers of children with ASD. Keeping relevance for policy and clinical implications in mind, and to increase sample sizes within categories some variables and response options were collapsed and recoded.

Dependent Variables

The outcome of interest was the mental health of mothers and fathers respectively. Two separate questions were asked in the survey: “If this child’s mother lives in the household, what is the status of the mother’s mental and emotional health, in general?” and “If this child’s father lives in the household, what is the status of the father’s mental and emotional health, in general?” The three original response options “Excellent or very good”, “good”, and “fair or poor” was collapsed into two categories as done in a previous study (Zablotsky et al., 2013). This included (1) Less favorable mental health which reflected the “fair or poor” response, and (2) More favorable mental health, which combined “excellent or very good” and “good” responses.

Independent Variables

Health Care Demands: A total of six variables hypothesized to impact families as a result of health care demands, and associated with the mental health of mothers and fathers were identified from the NSCH survey. Healthcare-related financial strain was assessed from the question “During the past 12 months, did your family have problems paying for any of this child’s medical or health care bills?” This was regrouped into two responses (1) Had problems paying medical bills, and (2) Did not have problems paying medical bills or had no medical/health-related expenses. Impact on the parents' employment was analyzed from the question “During the past 12 months, have you or other family members left a job, taken a leave of absence, or cut down on the hours you work because of this child’s health or health conditions?” This was categorized into two groups: (1) Family member left a job, took a leave of absence or reduced hours or both, and (2)

Employment not affected. The time burden of coordinating and providing care was derived from two questions “In an average week, how many hours do you or other family members spend arranging or coordinating health or medical care for this child?” and “In an average week, how many hours do you or other family members spend providing health care at home for this child?” Responses to both these questions were recoded to retain three responses (1) 11 or more hours per week, (2) 1 to 10 hours per week, and (3) Less than 1 hour per week. The experience of accessing services was derived from “During the past 12 months, how often were you frustrated in your efforts to get services for this child?” which was regrouped to (1) Usually/always/sometimes frustrated, and (2) Never frustrated. The final question “Does this child have health conditions that consistently and often greatly affect their daily activities during the past 12 months?” was categorized as (1) Daily activities consistently/moderately affected and, (2) Daily activities never affected.

Demographic Variables: Several demographic variables were included in the analysis.

These included: age of the child with ASD (0-5 years old, 6-11 years old, and 12-17 years old); race/ethnicity of the child (Hispanic, non-Hispanic White, non-Hispanic Black/other/multi-racial); sex of the child; household poverty level as assessed by the federal poverty level (FPL; less than 199% FPL, 200% to 399% FPL, or 400% FPL or greater); insurance adequacy (current insurance is inadequate/and or had a gap in coverage in the past year, or current insurance is adequate and continuously insured in the past year) and the highest level of education of the adult (less than high school, high school or GED, or more than high school).

Secondary Conditions: Frequently co-occurring developmental disabilities and co-morbidities with ASD were included in the analysis. A categorical variable was created to indicate the number of co-occurring developmental disabilities the child with ASD currently had. This included intellectual disability (ID), attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD), learning disability (LD), and developmental delay (DD). Responses were coded as “One or no other co-occurring developmental disability” and “2 to 4 other co-occurring developmental disabilities”. Similarly, a variable was created to indicate if the child had co-occurring anxiety or depression. This was coded into “One or no co-occurring mental health condition” and “2 co-occurring mental health conditions”.

Data Analysis

The NSCH 2017 and 2018 combined dataset was imported into the Statistical Package for the Social Sciences (SPSS version 26.0; IBM Corp., 2019) and prepared according to the NSCH Codebook guidelines, which includes adding a sampling weight to allow for complex sampling analysis and setting any subpopulations in the sampling plan. Given that the focus of this study was the population of children with autism, this was set as the subpopulation in the sampling plan. Descriptive statistics (such as frequency and percent) were used to describe the demographic attributes of the sample and examine each health care demand variable. As all variables in the study were categorical, chi-square analyses were conducted to examine associations between mother and father’s mental health with each of the predictors, demographic variables, and secondary conditions. To account for clustering in the complex survey design (Rao &

Scott, 1987) the second-order Rao-Scott adjusted chi-square test statistic was reported which provides an adjusted F value.

Binary logistic regressions were conducted to determine associations between the mental health status for parents using the predictor variables significant from the chi-square analyses. Odds ratios (ORs) and 95% confidence intervals (CIs) were used to report results, and the significance level was set at 0.05. To test for the multicollinearity assumption in logistic regressions, tolerance levels for all health care demand variables were examined using SAS software version 9.4. All tolerance values were higher than 0.1, indicating no collinearity.

Results

Sample Characteristics

The sample of children with ASD was primarily male (78.1%) and non-Hispanic Whites (42.8%). Most children were between the ages of 6 to 11 years old (45.2%), followed closely by the 12 to 17 years old age group (42.6%). More than half of the children with ASD had between two to four co-occurring developmental disabilities (69.2%), while almost a third of the sample had both (depression and anxiety) co-occurring mental health conditions (29.3%). Family demographics indicate that most parents had more than a high school education (64.2%), the household poverty level was 199% or less for over half of the families (56.2%), and almost 40% of the children had inadequate insurance, and/or the child had a gap in their coverage in the past 12 months.

Please see Table 1 for demographic details, unweighted counts, and weighted percentages.

The characteristics of the sample in regards to the health care demand variables and the mental health of mothers and fathers are depicted in Table 2. Approximately 13% of children had parents who reported that they spent 11 or more hours per week *coordinating* health or medical care, while 31% reported that they spent 11 or more hours per week *providing* health care at home for their child. Most frequently, however, parents spent between 1 to 10 hours coordinating and providing care (45.2% and 44.6% respectively). Almost 50% of children had parents who were frustrated in the effort it took to get services for their child, 28.5% had a family member who had left a job, took a leave of absence or reduced work hours or both, while almost 18% had problems paying the child's medical or health care bills. An overwhelming 83.4% of parents reported that their child's condition moderately or consistently affected their daily activities.

Current Mental Health Status of Mothers and Fathers

The mothers of 89.5% of children with ASD reported being in favorable mental health, while 10.5% were reported to have less favorable mental health. Fathers of children with ASD had slightly better mental health with 92.2% reported having favorable mental health with only 7.8% having unfavorable mental health. Please see Table 2 for these frequencies.

Association Between Independent Variables and Mental Health Outcomes

To examine the association between independent variables (demographics, secondary conditions, and health care demand variables) and the mental health of both mothers and fathers, chi-square tests of independence were conducted (see Table 3 for all cross-tabulations depicting the unweighted counts and weighted percentages). The following section separates the findings by the two outcomes of interest: mother's mental health and father's mental health.

Mother's Mental Health

First, the relationship between all demographic and secondary condition variables, and the mental health of mothers were examined. Race/ethnicity was statistically significant (adjusted $F(1,848, 2311.970) = 6.322, p < .005$) which indicated that among those with less favorable mental health, a greater proportion were families who were from the non-Hispanic blacks/other/multi-racial group (19.4%) compared to Hispanics (4.4%) and non-Hispanic Whites (10.9%). Insurance adequacy (adjusted $F(1,1251) = 4.309, p < .05$) was also statistically significant. Among mothers with less favorable mental health, 15.3% reported inadequate insurance or a gap in coverage compared to only 7.5% among mothers who reported adequate and continuous insurance. The gender of the child and number of co-occurring developmental disabilities were found to be marginally statistically significant (adjusted $F(1,1251) = 3.811, p = .051$ and adjusted $F(1,1251) = 3.736, p = 0.053$ respectively). Mothers of a female child with ASD had less favorable mental health compared to mothers of males with ASD (17.7% versus 8.3%), while mothers of a child with two to four other co-occurring developmental disabilities

also had less favorable mental health compared to mothers of children with ASD who had one or no other developmental disability (12.9% versus 6.9%). These results demonstrate that there is a statistically significant difference in the mental health of mothers of children with ASD by race/ethnicity and insurance adequacy.

In regards to the specific research question related to how the age of the child is associated with mental health, no statistically significant association was found between maternal mental health and the child's age (adjusted $F(1.986, 2484.938) = .309, p = .732$), although cross-tabulated frequencies indicate that mothers of 6 to 11-year-olds with ASD have less favorable mental health (11.8%) compared to mothers of 0 to 5 and 12 to 17 year old's (7.6% and 9.9% respectively). Specifically, the findings illustrate that mental health worsens when a child enters the 6 to 11 age group, but improves when they enter the 12 to 17 age group (although not to the same level as when the child is 0 to 5 years old).

Second, the relationship between health care demand variables and maternal mental health was examined. This analysis indicated a statistically significant difference in the mental health of mothers by the following variables: the time spent coordinating health care in an average week (adjusted $F(1.928, 2411.454) = 6.570, p < .005$), frustration with the effort to get services for the child (adjusted $F(1, 1251) = 5.523, p < .05$), problems paying for the child's medical or health care bills (adjusted $F(1, 1251) = 5.549, p < 0.05$), and the effect of the condition on daily activities (adjusted $F(1, 1251) = 8.258, p < .005$). Families who reported spending between one to ten hours coordinating care per week had less favorable maternal mental health (21.7%) compared to those who spent less than 1 hour (7%) or 11 or more hours (6.2%) coordinating health care for their

child. As expected, families that were usually or sometimes frustrated in the effort it took to get services had more mothers with unfavorable mental health (14.5%) compared to those who were not frustrated in getting services (6.8%). Similarly, families who reported having problems paying for their child's medical bills had higher levels of unfavorable mental health among mothers (19.8%) compared to those who did not have medical expenses or had no problems paying (8.2%). The effect of the child's condition on daily activities and maternal mental health was also evident from the cross-tabulated frequencies. Among mothers with less favorable mental health, a greater proportion were those whose child's daily activities were moderately or consistently affected (11.7%) compared to mothers of children whose daily activities were never affected (3.3%).

Father's Mental Health

Similar to the findings for mothers, the mental health of fathers was not significantly associated with the age of the child with ASD (adjusted $F(1.255, 1570.050) = 1.663, p = .198$). Cross-tabulated frequencies mirror that of mothers and indicate that fathers of 6 to 11-year-olds with ASD have less favorable mental health (10.8%) compared to fathers of 0 to 5 and 12 to 17-year-olds (2.2% and 5.9% respectively). Only two health care demand variables were found to be associated with fathers using chi-square analyses. First, a statistically significant difference was found in the mental health of fathers in respect to frustration with efforts to get services for the child (adjusted $F(1, 1251) = 4.927, p < .05$). Similar to the mental health of mothers, families who were usually or sometimes frustrated with accessing services had a higher frequency of unfavorable mental health among fathers (12.2%) compared to families who were never

frustrated with accessing services (3.9%). A statistically significant association was also evident between fathers' mental health and if they or another family member had stopped, cut down on work hours, or taken a leave of absence because of the child's health condition (adjusted $F(1, 1251) = 8.149, p < .005$). Interestingly, cross-tabulated frequencies indicate *worse* mental health among participants who responded that employment or hours were *not* affected (9.8%) compared to those who reported that they or someone in the family did leave a job, cut hours, or took a leave of absence (2.4%).

Overall Effects of Independent Variables on Mental Health Outcomes

Binary logistic regressions were undertaken to assess the effect of statistically significant variables from the chi-square analyses on the likelihood that mothers and fathers of children with ASD would report that they have less favorable mental health.

Mother's Mental Health

The logistic regression model for mothers contained seven independent variables (paying medical bills, time spent coordinating care, frustrated to get services, gender of child, race/ethnicity, insurance adequacy, and the number of co-occurring developmental disabilities). As shown in Table 4, families who reported spending 1 to 10 hours a week coordinating care, were almost two and half times more likely to report less favorable maternal mental health than those who spent less than 1 hour per week on coordinating care (AOR: 2.41, 95% CI: 1.19, 4.86). In addition, the odds of Hispanic and non-Hispanic White families to report unfavorable maternal mental health was 18% and 36% the odds of non-Hispanic Black/other/multi-racial families to report unfavorable mental

health (AOR: 0.18, 95% CI: 0.07, 0.48) and (AOR: 0.36, 95% CI: 0.17, 0.75) respectively. Families who reported having inadequate insurance or having a gap in coverage were two and half times more likely to report less favorable maternal mental health than those who had adequate insurance and no gaps in coverage (AOR: 2.53, 95% CI: 1.17, 5.47).

It is important to note that the variable assessing the effect of the condition on daily activities was omitted from the above logistic regression model, despite being statistically significant in the cross-tabulations. This decision was made because the OR and 95% confidence interval were not available due to a small sample size in an initial regression model, which included this variable. However, given the interest of this study in this specific variable, a simple logistic regression was undertaken with just this predictor. As such, an unadjusted weighted odds ratio for the effect of the condition on daily activities can be reported and was found to have marginal statistical significance (OR: 3.82, 95% CI: 1.44, 10.15, $p = 0.07$). This indicated that participants who reported that the child's daily activities were consistently or moderately affected by their condition, were almost four times more likely to report less favorable mental health than those whose daily activities were never affected.

Father's Mental Health

Chi-square analyses indicated that two health care demand variables were significantly associated with a father's mental health (frustrated with efforts to get services and a family member having to stop employment, cut hours, or take a leave of absence). When both these variables were added to a single logistic regression model, an

odds ratio and 95% confidence interval was not available for the variable frustrated to get services, due to a small sample size. As such, it was necessary to assess each of these two variables in separate weighted logistic regression models and report unadjusted odds ratios. Findings (see Table 5) depict that a family member having to alter aspects of their employment was a significant predictor for father's mental health (OR: 0.23, 95% CI: 0.08, 0.69). This means that the odds of families who had someone change their employment status to report unfavorable paternal mental health was 23% the odds of families who did not have anyone change their employment status and report unfavorable mental health. Essentially, the OR for changes to employment status suggests that compared to a family where someone had a change in employment status, families with no changes to employment status were more likely to report unfavorable mental health compared to reporting that they had favorable mental health. Frustration with accessing services was also a significant predictor for fathers' mental health (OR: 3.39, 95% CI: 1.09, 10.55). This indicates that participants who reported that they were usually or always frustrated with accessing services were almost three and a half times more likely to report unfavorable mental health than those who reported that they were never frustrated with accessing services.

Discussion

The purpose of this study was to examine how the health care demands of caring for a child with ASD impacts the mental health of both mothers and fathers. Although previous studies using large national datasets have examined the financial, employment

and time burden among families of children with ASD and other comparison groups, none have assessed their impact on parental mental health. Moreover, they have not examined mothers and fathers separately, nor included access to services and effects of the condition on daily living activities in their analyses. Understanding the impact of these health care demands and how they may be associated with the mental health of both mothers and fathers differently is crucial to tailor policies and interventions for the appropriate parent, and to prevent a downward spiraling trajectory for everyone in the family.

In line with existing literature (Ang & Loh, 2019; Soltanifar et al., 2015), findings from our study indicate that mothers of children with ASD are in poorer mental health compared to fathers (10.5% less favorable mental health among mothers versus 7.8% among fathers) although it is evident that this is only by a slight margin. This may be indicative of evolving gender roles where fathers are beginning to be more involved with providing care (Williams, 2008) and as such, the effect of the parent's gender on mental health is also diminishing. In addition, the age of the child with ASD was not found to be significantly associated with the mental health of either parent. This is in agreement with a study that assessed only mothers of children ages 3 to 16 years old (n=140) which concluded that age did not affect stress levels and family quality of life (McStay et al., 2014). Our finding however is interesting, given that *most* existing research *has* found differences by age, and differ only in regards to whether parents of younger aged children with ASD are more or less stressed than parents of older children with ASD (Azad et al., 2013; Gray et al., 2014; Kousha et al., 2016). A review of the cross-tabulations from this study indicates that mental health does vary by age. Both mothers and fathers of children

with ASD who were between 6 to 11 years old had less favorable mental health than parents of children in the younger (0 to 5 years) or older (12 to 17 years) age groups. Although not statistically significant, these findings remind us that the stressors parents face do evolve as the child grows, and the period between 6 to 11 years old may be especially critical and challenging. This could be attributed to the fact that this is the period when children are generally diagnosed with autism or Asperger syndrome (average age of 5.5 years and 11 years respectively), and as a result, parents are more likely seeking post-diagnosis support which has shown to be highly unsatisfactory (Crane et al., 2016).

By separating the analyses by mothers and fathers, this study was also able to identify the stressors unique to both parents respectively, which would be expected given the varying roles parents play in their family unit. Among mothers, their mental health was significantly associated with four health care demand variables (time spent coordinating healthcare, frustrated to get services, problems paying bills, and effect of the condition on daily activities), and demographic and secondary condition variables: race/ethnicity, insurance adequacy, gender and number of co-occurring developmental disabilities. Further analyses to assess which of these variables were a significant predictor of mothers mental health narrowed this down to time spent coordinating care (specifically, coordinating care for one to 10 hours a week), race/ethnicity, insurance adequacy, and the effect of ASD on the child's daily activities (which was marginally significant). Among fathers, only two health care demand variables were both significantly associated and predictive of mental health (frustrated to get services, and a family member left a job, cut hours, or took a leave of absence).

Caring for a child with ASD requires tremendous effort and coordination to ensure services from varying healthcare providers, therapists, and supports are received (McBain et al., 2020). In this study, most caregivers (45.2%) spent between one to 10 hours coordinating care while a previous study using an older NSCH dataset found that caregivers of children with ASD were spending 10 or more hours per week (Vohra et al., 2014). This finding in itself is optimistic, possibly indicating that coordinating care has become easier as a result of more integrated and improved services and/or perhaps the availability of online information and scheduling options. However, mothers who spent one to 10 hours coordinating care in this study were more likely to have worse mental health than mothers who spent more than 11 hours coordinating care. It is important to consider why this may be the case. It is plausible that spending between 1 to 10 hours a week on coordinating care may limit a mother's opportunity from engaging in employment or other desired activities since mothers of children with ASD who are employed have been found to work approximately 20 hours a week (Cidav et al., 2012). As such, there may be a level of disappointment among these mothers. Among mothers who spend more than 11 hours coordinating care, it is possible that employment or participating in other activities is not even considered a feasible option, and as such, there is less disappointment and a lower impact on mental health.

The amount of time families spend coordinating care may be linked to the insufficient supports and fragmented services families encounter when accessing healthcare for their child, which can lead to frustration and stress (Russa et al., 2014; Vohra et al., 2014; Williams-Caldwell, 2012). Our findings are in alignment with a previous study, which reported that parents who were frustrated with being able to access

services for their child had poorer mental health (Resch et al., 2012). Although mothers appear to be impacted by the time spent coordinating care, it is necessary to consider why frustration with accessing services is significant for only fathers' mental health. Perhaps as suggested in the literature on gender roles, it is because fathers of children with ASD see “themselves as advocates fighting obstructive services to access appropriate care” (Burrell et al., 2017, p. 1135) and as such, are more affected by the barriers they face in accessing the care needed.

It is well established that families caring for children with ASD experience a greater financial burden as a result of increased healthcare expenses. As such, they would welcome additional income coming in from all family members working (Kogan et al., 2008; Vohra et al., 2014). Unfortunately, having to balance caring for a child with ASD and employment responsibilities leads to many family members reducing or stopping employment, contributing to lost productivity and monetary losses which a family bears over their lifetime (Montes & Halterman, 2008; Rogge & Janssen, 2019). Consequently, it would be expected that when family members have to stop work or cut hours it would have an adverse impact on mental health. Contrary to this expectation, however, findings from this study implicate that the mental health of fathers is *better* when someone in the family stopped work, cut hours or took a leave of absence. This is also in contrast to a previous study, which found that among parents of children with developmental problems, being employed was a predictor for better mental health, possibly linked to parents having an opportunity to engage in activities outside of providing care (Ha et al., 2008). It is possible that in our study, the improved mental health among fathers is explained by them feeling relieved, grateful, and less guilty knowing that someone in the

family was able to use their time to provide more care for the child. It would be interesting if the NSCH survey collected data on which specific family member changed their employment status. For example, if the data indicated that mothers altered their employment status more frequently than fathers, it may further explain why the mental health of fathers would improve.

A child's level of daily functioning abilities invariably has an impact on the primary caregiver who has to ensure that any gaps in these everyday activities are filled (Marsack-Topolewski et al., 2021). Given that mothers remain to be the primary caregiver, it is not surprising to find that they are more likely to have worse mental health if their child is consistently unable to complete daily activities independently. This finding is in line with a study of 34 parents of adolescents (Ponton et al., 2019), and another study with 162 parents of toddlers with ASD (Green & Carter, 2014) which reported that daily living skills and level of independence were associated with levels of parental stress. The effect on mental health is likely exacerbated given that adaptive functioning is also associated with success in adult outcomes (Tillmann et al., 2019).

Adequacy of insurance has also shown to be a concern among families of children with ASD (Vohra et al., 2014) despite the mandates by all states and the District of Columbia requiring health insurance companies to cover autism-related health care services (American Speech Language Hearing Association, 2021). Despite these laws, parents continue to face challenges as some insurance plans are exempt from this mandate (Mandell et al., 2016). In addition, it is possible that families struggle with finding providers covered through their existing insurance given the limited supply of healthcare providers which support ASD, such as child psychiatrists, pediatricians, and

board-certified behavioral analysts (McBain et al., 2020). Disparities in regards to race and ethnicity and various ASD outcomes have also been well documented in the literature (Benevides et al., 2019; Heron et al., 2020; Magaña et al., 2012; Walsh et al., 2017), and findings from this study indicate that Hispanics and non-Hispanic Whites parents of children with ASD have better mental health outcomes than non-Hispanic Black/other/multi-racial groups. This is in agreement with previous studies which have also found that African American and Asian American parents have higher levels of stress than other racial and ethnic groups (Delambo et al., 2011; Kim et al., 2020; Williams et al., 2019).

Looking ahead, it is evident that poor mental health is a concern among these parents and its stressors need to be addressed. National employment policies should consider the impact of caring for a child with disabilities in supporting flexible hours and providing child care to encourage parent employment. At the same time, it is crucial that coordinated services, that are easily accessible and covered through insurance without gaps in coverage, are facilitated. Efforts should be made to increase the supply of healthcare workers serving individuals with ASD, given the rising rates of ASD prevalence (McBain et al., 2020). Moreover, interventions should focus on enhancing adaptive functioning skills at an early age. It may also be necessary for providers to screen parents of children with ASD for mental health conditions and refer them to support groups and treatment as necessary. Ultimately, given the lifelong nature of ASD, and the interdependence among family members, it is crucial that policies and programs are directed across the lifespan, support both parents and individuals with ASD, and target all social, economic, and environmental risk factors to support a healthy family

trajectory (Fine and Kotelchuck, 2010, Lu and Halfon, 2003). Substantial structural changes need to be made to ensure that the growing number of families caring for children with ASD are supported holistically.

Limitations and Future Directions

Despite the use of a large nationally representative dataset, there are a few limitations to this study that should be considered when reviewing the findings. First, the NSCH survey is cross-sectional in design, and as such is not able to infer causality. In this study, it is possible that mothers and fathers had pre-existing mental health conditions which contributed to the employment, financial, and time burden they experienced. Future studies examining the predictors of mental health outcomes among parents of children with ASD may seek to use a longitudinal survey, with an assessment at baseline. This design would also allow a better understanding of changes in health care demands, needs across the lifespan, and highlight how the mental health of one parent may affect the others'. Second, all the data collected in the survey, including autism-specific information is based on self-report. As a result, there may be some bias, especially in regards to rating one's mental health condition. Furthermore, the survey was designed to allow the survey participant to assess their own and the *other* parent's mental health, if both parents lived in the same household. These possible biases could explain the reportedly high rates of *favorable* mental health among parents. It is also possible that a single question assessing mental health among parents may not accurately capture psychological wellbeing nor the differences which exist between stress, anxiety, and depression. It is also important to acknowledge the small sample sizes within groups

when examining the subpopulation of ASD and parents' mental health. This inhibited the study from running regression models with all independent variables and as such limited the models to only those variables significant from the chi-square analyses and the report of unadjusted odds ratio for some. Looking ahead, the NSCH survey may want to consider sampling a higher number of children with ASD, and specifically more fathers.

Conclusion

This study set out to examine how the health care demands arising from caring for a child with ASD impacts the mental health of mothers and fathers. Findings from this study suggest that mothers and fathers are impacted by unique health care demands which may be explained by existing gender roles. Furthermore, this study highlights health care demands which are the most stressful for parents, and as such should be prioritized and addressed in policy and service. The findings also act as a reminder to consider the invisible effects of policies on the mental health of caregivers, which despite being a potential by-product of structural challenges, should also be addressed *directly* through parent screenings and mental health interventions.

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Tables

Table 1. Demographic attributes of study sample

	Unweighted count	Weighted %
Gender		
Male	1057	78.1
Female	288	21.9
Age		
0-5 years	164	12.1
6-11 years	465	45.2
12-17 years	716	42.6
Race/ethnicity		
Hispanic	176	34.4
Non-Hispanic white	900	42.8
Non-Hispanic black/other/multi-racial	269	22.8
Household poverty level		
199% FPL or less	502	56.2
200 to 399% FPL	408	22.9
400% FPL or greater	435	20.9
Insurance adequacy		
Insurance is inadequate and/or had gap in coverage	532	38.1
Insurance is adequate and continuously insured	807	61.9
Caregiver education		
Less than high school	34	11.9
High school or GED	201	23.9
More than high school	1110	64.2
Co-occurring developmental disability		
1 or no other developmental disability	378	30.8
2 to 4 other co-occurring developmental disabilities	785	69.2
Co-occurring mental health conditions		
1 or no other mental health condition	475	70.7
2 mental health conditions	207	29.3

Table 2. Frequency of mental health and health care demand variables among study sample

	Unweighted count	Weighted %
Time spent coordinating care		
11 or more hours per week	49	13.2
1 to 10 hours per week	321	45.2
Less than 1 hour per week	348	41.5
Time spent providing care		
11 or more hours per week	207	31.0
1 to 10 hours per week	292	44.6
Less than 1 hour per week	193	24.4
Frustrated in efforts to get services		
Usually/sometimes frustrated	675	49.2
Never frustrated	661	50.8
Family member left a job, took leave of absence or cut hours		
Left job or took leave of absence or both	380	28.5
Employment not affected and no leave of absence taken	947	71.5
Problems paying medical bills		
Had problems paying bills	273	17.9
Did not have problems paying bills or had no medical expenses	1060	82.1
Effect of condition on daily activities		
Daily activities moderately or consistently affected	1065	83.4
Daily activities never affected	161	16.6
Mother's mental health		
Less favorable mental health	143	10.5
More favorable mental health	1055	89.5
Father's mental health		
Less favorable mental health	58	7.8
More favorable mental health	882	92.2

Table 3. Cross-tabulations of health care demands and demographic variables with maternal and paternal mental health

	Mothers					Fathers					
	Weighted % (Unweighted count)					Weighted % (Unweighted count)					
	Less favorable mental health		More favorable mental health		<i>p</i> - value	Less favorable mental health		More favorable mental health		<i>p</i> - value	
Time spent coordinating care											<i>.152^a</i>
11 or more hours	6.2	(9)	93.8	(37)		2.4	(2)	97.6	(34)		
1 to 10 hours	21.7	(52)	78.3	(233)		22.7	(23)	77.3	(186)		
Less than 1 hour	7	(40)	93	(272)		6	(15)	94	(234)		
Time spent providing care											<i>.978</i>
11 or more hours	13.4	(35)	86.6	(155)		3.1	(11)	96.9	(126)		
1 to 10 hours	12.8	(39)	87.2	(222)		13.7	(20)	86.3	(188)		
Less than 1 hour	12.2	(22)	87.8	(151)		10	(7)	90	(122)		
Frustrated in efforts to get services											<i>.019</i>
Usually/sometimes frustrated	14.5	(89)	85.5	(516)		12.2	(29)	87.8	(437)		
Never frustrated	6.8	(53)	93.2	(534)		3.9	(29)	96.1	(440)		
Family member left a job, took leave of absence or cut hours											<i>.160</i>
Left job or took leave of absence or both	15	(57)	85	(284)		2.4	(17)	97.6	(234)		
Employment not affected and no leave of absence taken	8.7	(85)	91.3	(760)		9.8	(40)	90.2	(640)		
Problems paying medical bills											<i>.019</i>
Had problems paying bills	19.8	(44)	80.2	(212)		6.3	(16)	93.7	(174)		
Did not have problems paying bills or had no medical expenses	8.2	(98)	91.8	(836)		8.1	(42)	91.9	(700)		
Effect of condition on daily activities											<i>.004</i>
Daily activities moderately or consistently affected	11.7	(120)	88.3	(834)		8.2	(49)	91.8	(689)		
Daily activities never affected	3.3	(13)	96.7	(125)		7.5	(5)	92.5	(113)		
Age											<i>.732</i>
0-5 years	7.6	(15)	92.4	(133)		2.2	(5)	97.8	(114)		
6-11 years	11.8	(56)	88.2	(360)		10.8	(21)	89.2	(300)		

12-17 years	9.9	(72)	90.1	(562)		5.9	(32)	94.1	(468)	
Race/ethnicity					.002					.406
Hispanic	4.4	(21)	95.6	(136)		10.6	(12)	89.4	(105)	
Non-Hispanic white	10.9	(96)	89.1	(711)		4.5	(39)	95.5	(615)	
Non-Hispanic black/other/multi-racial	19.4	(26)	80.6	(208)		9.7	(7)	90.3	(162)	
Household poverty level					.106					.228
199% FPL or less	10.7	(64)	89.3	(362)		10.4	(24)	89.6	(236)	
200 to 399% FPL	14.9	(51)	85.1	(313)		7.3	(18)	92.7	(279)	
400% FPL or greater	5.4	(28)	94.6	(380)		3.5	(16)	96.5	(367)	
Insurance adequacy					.038					.267
Insurance is inadequate and/or had gap in coverage	15.3	(78)	84.7	(414)		5.2	(23)	94.8	(354)	
Insurance is adequate and continuously insured	7.5	(65)	92.5	(638)		9.4	(35)	90.6	(527)	
Caregiver education					.676^a					.077
Less than high school	9	(4)	91	(21)		-	(0)	100	(12)	
High school or GED	9.1	(20)	90.9	(138)		20.7	(5)	79.3	(101)	
More than high school	11.2	(119)	88.8	(896)		5.1	(53)	94.9	(769)	
Gender of child					.051					.479
Male	8.3	(102)	91.7	(834)		8.4	(46)	91.6	(689)	
Female	17.7	(41)	82.3	(221)		5.6	(12)	94.4	(193)	
Co-occurring developmental disability					.053					.343
1 or no other developmental disability	6.9	(41)	93.1	(303)		5.5	(12)	94.5	(265)	
2 to 4 other co-occurring developmental disabilities	12.9	(90)	87.1	(600)		10	(40)	90	(477)	
Co-occurring mental health condition					.512					.501
1 or no mental health condition	10.1	(55)	64.6	(380)		13.6	(25)	86.4	(305)	
2 to 4 mental health conditions	17.5	(40)	82.5	(138)		8.6	(14)	91.4	(109)	

^a Fisher's Exact Probability Test reported if cell size less than 5

Table 4. Mother’s mental health logistic regression – adjusted odds ratio and confidence intervals

	Less favorable mental health	
	AOR	95% CI
Paying medical bills		
Problems paying medical bills	1.52	0.66-3.49
No problems paying bills/no medical expenses	-	-
Time coordinating care		
11 or more hours per week	0.88	0.27-2.86
1 to 10 hours per week	2.41*	1.19-4.86
Less than 1 hour per week	-	-
Frustrated to get services		
Usually/sometimes frustrated	0.88	0.39-1.99
Never frustrated	-	-
Gender of child		
Male	0.47	0.20-1.09
Female	-	-
Race/ethnicity		
Hispanic	0.18**	0.07-0.48
Non-Hispanic white	0.36*	0.17-0.75
Non-Hispanic black/other/multi-racial	-	-
Insurance adequacy		
Inadequate/gap in coverage	2.53*	1.17-5.47
Adequate/no gap in coverage	-	-
Co-occurring DD		
1 or no other DD	0.68	0.30-1.53
2 to 4 other DD	-	-

Note: Reference category: More favorable mental health.

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.

* $p < .05$.

** $p < .005$.

Table 5. Father’s mental health logistic regression – unadjusted odds ratio and confidence intervals

	Less favorable mental health	
	OR	95% CI
Frustrated to get services		
Usually/sometimes frustrated	3.39*	1.09-10.55
Never frustrated	-	-
Family member left a job, took leave of absence or cut hours		
Left job or took leave of absence or both	0.23*	0.08-0.69
Employment not affected and no leave of absence taken	-	-

Note: Reference category: More favorable mental health.

Abbreviations: OR, odds ratio; CI, confidence interval.

* $p < .05$.

CHAPTER 4: MANUSCRIPT 3

Financial planning and utilization among parents of children with intellectual and developmental disabilities: An exploratory study

Abstract

Background: Families of children with intellectual and developmental disabilities (IDD) experience significant levels of financial hardship, which has implications on outcomes for the child, family, and parental mental health. Participating in financial planning activities and utilization of financial tools such as the Achieving a Better Life Experience (ABLE) program have the potential to alleviate poverty and improve life outcomes. Unfortunately, current rates of banking and usage of ABLE accounts are low among individuals with disabilities, and no existing study has examined this phenomenon among families of children with IDD.

Method: Parents of children with IDD (n=176) residing in the United States completed an online survey to explore rates of financial planning and utilization, in addition to the barriers, facilitators, and impact parents experience in the process of opening and managing ABLE, checking, savings and trust accounts. Quantitative analyses included frequencies and chi-square associations, while open-ended responses were analyzed using thematic analysis.

Results: Parents of children with IDD worry about their child's financial future, however, paradoxically, are not engaging in financial planning. Findings revealed that rates of

banking and utilization of all financial tools are low among this population. Only 29.5% of children had an ABLÉ account, 26% had a checking account, 35% had a savings account, and only 13.6% had an established special needs trust. Several programmatic and personal barriers were identified which hindered financial planning and utilization. These findings can help inform immediate programmatic changes and long-term policy considerations.

Conclusions: This novel study offers insight into the financial planning experience of families with children with IDD. It is imperative that we support greater utilization of financial tools among these families, to decrease levels of poverty, improve parental mental health, and improve outcomes for families and individuals with IDD.

Background

Families of children with intellectual and developmental disabilities (IDD) experience significantly high levels of financial distress (Emerson & Brigham, 2015; Meppelder et al., 2015; Parish et al., 2004) which is exacerbated by having to provide care and cover expenses for adult children living at home, who largely remain unemployed (Piazza et al., 2014; Pryce et al., 2017; Vincent et al., 2020). According to the American Community Survey, the percentage of working-age adults with disabilities who live in poverty is more than double that of individuals without disabilities (26% compared to 10%; Goodman & Morris, 2017). This financial hardship impacts parental mental health (Lee et al., 2019; Patton et al., 2018), which can adversely influence the treatments parents choose for their child (Dardas & Ahmad, 2014; Wilson et al., 2018).

Moreover, financial strain limits the ability of individuals with IDD to access necessary services such as housing, transportation, education, and health, which consequently impacts opportunities for competitive employment (Brucker & Nord, 2016; Caniglia & Michali, 2018; Laser, 2018; Lauer & McCallion, 2015; Morris et al., 2016; Parish et al., 2010; Salvador-Carulla et al., 2015), and the overall life trajectory for both parents and children.

With an increasing prevalence of developmental disabilities, affecting almost one in every six children in the United States as of 2017 (Zablotsky et al., 2019), and life expectancy continuing to rise into the early 70s (Patja et al., 2000), the urgency to support families in financial distress across the lifespan is crucial. Through participation in planning activities, there are opportunities to enhance quality of life (Hewitt et al., 2013), which includes the creation and utilization of financial plans and tools. Unfortunately, financial planning specifically related to banking activities remains low among individuals with disabilities. In 2011, 18.9% of individuals with a disability (compared to 7.4% for people without disabilities) were unbanked, referring to having a checking or savings account, which only decreased slightly to 18.1% in 2017 (compared to 5.7% for people without disabilities). Furthermore, less than 40% of families with disabilities saved for emergencies, of which 18% were more likely to save at home or with family or friends rather than use a bank account (Goodman & Morris, 2017).

A few studies have attempted to understand long-term planning behaviors among families of children with IDD. In one study, long-term planning was found to involve largely “aspirational” discussions, rather than definitive actions (Burke et al., 2018, p. 96) while another study found family planning efforts lacked specificity (Bowey &

McGlaughlin, 2007). Among individuals with disabilities, studies have reported that the ability to make financial decisions and access services is impeded by limitations in knowledge and skills (Caniglia & Michali, 2018), while reasons for being unbanked included fear of losing social security benefits, insufficient funds to keep in an account, and high account fees (Goodman & Morris, 2017).

The introduction of the Achieving a Better Life Experience (ABLE) Act in 2014 allowed individuals with disabilities (with an onset prior to age 26) to open an ABLE account (Social Security Administration, 2019). This account is designed to encourage savings for disability-related expenses, which can enhance vocational achievements, financial independence, economic growth, and quality of life (Laser, 2018; Morris et al., 2016). The ABLE program has been considered a, "down payment on freedom" as it allows individuals with disabilities to breakthrough poverty by contributing to saving goals and investment without losing government benefits up to a certain threshold (Laser, 2018, p. 810). Unfortunately, the adoption of the ABLE program has been slow since its enactment seven years ago. Despite the ability of almost 8 million Americans with disabilities to access tax-free income (Morris, 2019), only 56,632 accounts have opened as of December 2019 (Curley, 2020). It is not evident from existing literature if this slow rate of adoption is a result of the many pitfalls critics have associated with the ABLE program such as limits on age and yearly contributions (Hershey et al., 2017a; Rephan & Groshek, 2016), or myths which surround the program such as the loss of Medicaid, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) benefits if the account exceeds \$2,000 (Ulisky, 2019).

Given the low rates of banking and utilization of ABLE accounts among individuals with disabilities, and the impact financial instability can have on outcomes for families and their children with IDD across the lifespan, it is necessary to explore parental experiences related to financial planning. No studies, to the best of our knowledge, have explored the reasons which could explain the low rates of utilization, nor have they examined the rates of banking and ABLE accounts specifically among families of children with IDD. Moreover, no study has examined the impact financial planning and utilization, can have on employment, education, and independent living outcomes for children with IDD, and parental mental health. An understanding of parent's perceptions is especially important to identify any gaps in disseminated information and within policies and programs. Bridging these gaps could improve utilization of financial accounts which can be seen as protective factors, and fulfill their intended purpose of improving life outcomes, and diminish the risk of financial distress.

As such, the present study sought to understand the financial planning experience among families of children with IDD, with an additional focus on the ABLE program. Specifically, the following research questions were examined: 1) What kinds of financial planning options are families of children with IDD aware of? 2) Where do families obtain information regarding financial planning options, such as the ABLE program? 3) What barriers or facilitators do families foresee or have experienced in efforts to establish financial stability? 4) What, if any, impact has the ABLE program or other financial accounts had on the child's plans for employment, education, and independent living, and on the mental health of parents? 5) What is the association between demographic attributes and the utilization of an ABLE account?

Methods

Participants

Parents of children with IDD were recruited to participate in an online study from October 2020 through December 2020. A total of 176 surveys were collected, which is an acceptable sample size given the exploratory nature of this study (Jones et al., 2003). The eligibility criteria for participation included parents who could 1) read and write English or Spanish, 2) have a child (0 to 26 years old) with IDD, 3) live in the USA, and 4) consent to the study. The age of the child with IDD was limited to the range of 0 to 26 years old to help identify barriers among families with children and young adults, which if addressed could encourage financial planning to begin earlier, thereby allowing the family to benefit from its use longer. The upper age limit was also set at 26 to capture the experiences of families as they approached the maximum age for disability onset for ABLE accounts.

Procedure

An exploratory cross-sectional study design using an online survey was utilized. Parents were recruited via a two-prong sampling approach. First, using convenience sampling, a recruitment email (in English and Spanish) with study details and a survey link was distributed widely to disability service providers and organizations with whom the study team had prior contacts. In addition, parents of children who were currently/previously enrolled in an inclusive postsecondary program designed for students with IDD (18 to 26 years old), located in the University of the first author were sent an email to participate in the survey. Second, using snowball sampling, parents,

service providers, and organizations were asked to share the study details and survey link *via email* with all of their own contacts and networks. The recruitment email specifically requested that the survey link not be posted on any social media site to prevent bots and spam respondents from accessing the link, which is likely given the monetary incentive associated with participation. Flyers for the study were also translated in both English and Spanish which included a QR code and were attached to all recruitment emails.

Participants who clicked on the survey link were directed to REDCap, a Health Insurance Portability and Accountability (HIPPA) compliant platform where the survey was developed, and where data was securely stored. The survey link was enabled with the reCAPTCHA feature which attempts to distinguish between humans and bots, thereby protecting websites from abuse. A \$10 Amazon e-gift card was emailed to all participants who completed the survey and who chose to provide an email address, which was the only identifiable information collected. Approval for all materials and procedures was received from the University's Institutional Review Board.

Measures

A consent form and three surveys were designed in English and professionally translated into Spanish using a certified translation service company, to allow respondents the option to choose their language of preference. All surveys utilized multiple-choice, Likert scale, and open-ended questions and aligned with the research questions. Participants were first directed to choose their preferred language, followed by the consent page which provided study details and required them to checkboxes to confirm that they met the eligibility criteria and consented to the study. If they were

eligible, they proceeded to survey one, which asked demographic questions about the parent and child (for example, “what is your current marital status” and “how old is your child”). If the parents selected that their child’s age was 27+ the parent was exited out of the survey. Eligible parents were automatically directed to survey two, which asked a few general financial questions, followed by specific questions related to the ABLE program (for example, “have you heard of the ABLE program”). Upon completion of survey two, parents proceeded to survey three which asked about the utilization of other financial tools such as checking, savings, and trust accounts (for example, “how easy or difficult was it to create a checking/savings account?”), and Social Security programs their child may have used. At the end of survey three, parents were given the option to provide an email address.

A significant amount of skip-logic was incorporated into survey two, to capture the perspectives of three different groups in regards to the ABLE program. The three groups categorized participants based on responses to two questions: “Have you heard of the ABLE program?” with two response options “yes or no” and “Does your child have an ABLE account?” with three response options “yes, no and not sure.” Please see Figure 1 for an overview of these groups.

Data Analysis

Data was downloaded from REDCap into the Statistical Package for Social Sciences (SPSS Version 26.0; IBM Corp., 2019) for analysis. The data was checked for normality and both the parent's age and the child’s age were found to not be normally distributed (Kolmogorov-Smirnov value $p = 0.048$ and $p = 0.00$ respectively). In

addition, a review for outliers identified one record where the parent's age was listed as '4', and as such, this was set as missing. Descriptive analyses were conducted to describe the attributes of the population and analyze responses to the survey questions. Chi-square tests were conducted to identify associations between demographic variables and the utilization of ABLE accounts. Fisher's exact tests were conducted and reported when the expected cell size was less than five.

Qualitative data from the open-ended questions were analyzed using reflexive thematic analysis to understand the participants' experiences. This methodology identifies codes and themes guided by the explicit content of the data through an iterative process (Braun & Clarke, 2019). Eleven surveys had short open-ended responses in Spanish, which were translated into English by a Spanish-speaking team member. Two reviewers followed the six-step process outlined for thematic analysis which included familiarization with the data, generation of initial codes, identifying and defining themes, and writing up of the results. Any discrepancies in the themes were discussed until a consensus was reached.

Results

Quantitative Findings

Sample Demographics

A total of 176 parents participated in the survey of which the majority resided in Florida (84.1%). Most participants were mothers (83%). Parents ranged between the ages of 24 and 68 years old ($M = 45.92$, $SD = 10.37$), and almost 81% were White and about

24% were Hispanic or Latino. Most parents were employed at the time of the survey (61.4%), however, among those who were not employed, approximately 35% stated that their job was affected by COVID-19. Almost 70% of participants were married, and over 60% of the children were living with both parents. Approximately 37% of the parents had a 2-year associate degree or less, and 34% had a household income between \$50,000 and \$74,999. In response to a question asking about their current financial situation, about 32% of parents reported that they lived comfortably, followed by about 31% sharing that they met their basic expenses and had a little leftover, almost 27% stated that they were just meeting their basic living expense, while 5% did not have enough money to meet basic living expenses. Another 5% chose not to answer this question.

The average age of the child as reported by parents was 12.44 (SD = 7.78) and the four most frequently reported IDD diagnosis among children in the survey included: Down syndrome (39.2%), autism spectrum disorder (35.2%), intellectual disability, and developmental delay (both 27.8% respectively). Approximately 28% of these children received SSI benefits, 9% received SSDI benefits and 44% received Medicaid. Please see Table 1 for demographic details. Parents were also asked if they had heard of the Plans to Achieve Self Support (PASS) program offered by the Social Security Administration (SSA) which aims to help individuals with disabilities pursue or return to employment (Social Security Administration, 2019). Almost 88% reported that they had not heard of PASS. However, when asked if they would be interested to learn more about the program given that it helps set money aside for specific work goals, almost 61% of parents who had not heard of PASS shared they would be interested to learn more. Utilization of this program was low in this sample, with only one participant who identified their child

having used PASS. Over 14% responded that they had not used PASS as their child's disability limits this.

Knowledge, Awareness and Source of Information Regarding Financial Options

Participants in the survey were asked about their awareness regarding various financial tools. In regards to the ABLE program specifically, 57.4% responded that they had heard about it. Among these parents, knowledge about the ABLE program was low. Almost 30% were not sure or did not know (referred to as 'did not know' hereafter) what the ABLE program was about, 20.8% did not know who is eligible for the program, almost 48% did not know what expenses it could cover, and almost 37% did not know what the advantages of having an ABLE account are. Parents who had heard of the ABLE program reported that the source of their information included: a disability service provider or organization (41.6%) such as The Arc and the Down Syndrome Foundation of Florida, followed by a parent who had a child with a disability (24.8%), and a disability event (20.8%) such as the Family Café (an annual event in Orlando, Florida) and Buddy Walk. Almost 15% of parents also heard about the ABLE program from family and friends, the ABLE National Resource Center, and the internet. None of the participants stated that their source of ABLE information was the SSA.

Over 80% of parents in the survey were aware of a checking and savings account (84.1% and 82.4% respectively), followed by stock investments (59.7%) and a special needs trust (50.6%). Very few participants were aware of a pooled-income trust (10.8%) while almost 7% stated that they were not aware of any of these financial options. The source of information for these financial tools was most frequently reported to come from

banks (55%), family and friends (40.2%), and financial advisors (28.7%). Around 20% of parents heard about these options from another parent who had a child with a disability, disability service providers, the internet, and their legal advisor. Approximately 7% heard of them from their child's school, while only a handful of parents had heard of these from the SSA (5.5%).

Utilization, Barriers and Facilitators for Financial Planning and Accounts

A parent's attitude, self-efficacy, and ability to make financial decisions and plans were assessed, as these factors could facilitate or hinder the utilization of financial tools. About 60% of parents were very confident or fairly confident that they were making the best choices to manage their money, savings, and investments. Conversely, almost 40% were only slightly confident or not at all confident. Almost all the parents (94.9%) stated that it was very or fairly important for them to secure their child's financial future, and approximately 80% of parents had thought about what they could do to secure their child's financial needs since their diagnosis. However, only half of the parents (51.1%) had a specific financial plan or schedule to save or invest for their child's future. This is interesting, given that most parents (70.7%) reported that they began to actively think about their child's financial future between the time their child was born until when the child was around five years old.

Similarly, the child's attitude and interest in personal finances and related competence were also assessed. Only about 16% of children were reported to show an interest in being involved in planning or managing their own accounts. Approximately 19% were not interested, 41% were too young, while 24% were reportedly not showing

an interest as a result of disability limitations. Parents also shared how confident they felt about their child's ability to manage money. Almost 22% of parents indicated that they were not confident at all, 23% indicated that they felt slightly or fairly confident, while only about 2% were very confident. The remaining 54% of parents reported that either their child was too young or their disability limits this.

The following sections highlight the findings of the study in respect to the utilization, barriers, and facilitators for the following financial accounts: 1) ABLE accounts, and 2) Checking, savings, special needs trust, and pooled income trusts (referred to as trusts hereafter). The first three sections relate to the ABLE program (Groups 1, 2 and 3 as seen in Figure 1), and the last section presents the findings for other financial options. A small percentage (1.7%, n=3) of the participants stated that they had heard of the ABLE program but were not sure if their child had an account. These participants were directed to survey three on other financial accounts and did not complete any further questions related to the ABLE program.

ABLE Group 1: Of the 176 survey respondents, only 52 parents (29.5%) had heard of the ABLE program and had an account for their child. The top three concerns and questions parents most frequently had prior to opening the ABLE account included: what the money in the account could be used for (almost 56%), what would happen to the money in the account in the event of death (42.3%), and would the account affect the child's SSI/SSDI benefits (almost 33%). The top three personal concerns that parents had before opening an ABLE account included: not being sure that they would have sufficient money left over to contribute to the account (42.3%), concerns that no one else in the

family or friends would make contributions to the account, and concerns about their own or their child's ability to make financial decisions such as choosing investment options (almost 31% each respectively). Most parents took it upon themselves to research the answers to their questions and concerns (almost 86%). Some contacted the state ABLE office (23.1%) or asked a trusted friend or family member for help to answer their concerns (17.3%).

All of these parents took the initiative to set up the ABLE account themselves, and only six of these parents consulted with their adult child when opening it. In most cases, parents did not consult with their child as the child was either too young (55.8%) or the child's disability limited this option (25%). Most frequently, parents in this group did not use any help to open the ABLE account (80.8%). If they did, it was most frequently received from the state ABLE program (9.4%) or a financial planner (3.8%). In line with these findings, almost 85% of parents shared that it was easy or very easy to open an ABLE account, while only 5.8% said it was difficult or very difficult. Approximately 10% stated that the experience was neutral. Almost all parents (98.1%) were responsible for managing the account, with only one parent who reported that the parent and child managed the account together. A little over 69% of parents shared that it was easy or very easy to manage an ABLE account, while about 2% said it was very difficult. Approximately 30% stated that the experience was neutral.

ABLE Group 2: Among the survey respondents, 46 parents (26.1%) had heard of the ABLE program but did not have an account for their child. Parents shared their top three reasons for why they chose to not open an account which included: they were not sure of

the real benefit of having an ABLE account (32.6%), not being sure what the money in the account could be used for, and if the child was eligible for an ABLE account (26.1% each). The top three personal concerns which kept parents from opening an account included not having the time to find out more about the program (54.3%), not sure that there would be enough money to contribute to the account (41.3%), and concerns that no family or friends would contribute to the account (21.7%).

Despite these concerns, almost all the parents believed that an ABLE account could be useful to support their child. Parents reported that they believed the account could be somewhat helpful or very helpful to pay for educational expenses (84.8%), employment expenses (89.1%), building an emergency fund (93.4%), independent living expenses (93.5%), health expenses (95.7%), and building long-term savings for the child (97.8%). As such, almost 72% of parents stated that they would be interested in learning more about the ABLE program. These parents most frequently reported that they would prefer to hear about the ABLE program from their state ABLE program or representative (33.3%), a disability service provider/organization, or their financial planner (18.2% each respectively). In respect to the communication method they would prefer, most parents stated that email (45.5%), a recorded webinar (24.2%), or a live webinar with opportunities for questions and answers (15.2%) would be the most desirable.

ABLE Group 3: There were 75 parents (42.6%) of all survey participants who reported that they had not heard of the ABLE program. Upon selection of this response, the survey directed them to a short description of the ABLE program which also briefly explained the eligibility criteria. This was followed by additional survey questions. After reading

the description, 61.3% (n=46) of parents stated that they would be interested in learning more about the program, 21.3% said they were not interested at this time, while 17.3% said they were not interested. Almost 85% of the parents who were interested in the program reported that based on the description they read, they felt their child may be eligible for an account. Parents could select their top three concerns or questions that came to their mind after reading the ABLE description. Most frequently, parents wanted to know how much the monthly fees were for an ABLE account (37%) if their child would meet eligibility requirements (28.3%), and what would happen to the money in the account in the event of death (26.1%). The top three personal concerns were that they had not heard more about the program from other people, agencies, and service providers (52.2%), were concerned about their own or their child's ability to make financial decisions (50%), and they were unsure if there would be enough money left over to contribute into an ABLE account (47.8%). An overwhelming 91.3% stated that they were somewhat likely or very likely to make an effort to find answers to the concerns and questions they had. When these parents were asked what their top three uses of an ABLE account would be if they had one, similar to parents in group 2, about 76% stated they would use it to build long-term savings for the child's future. They would also use it for independent living expenses (54.3%) followed by building an emergency fund (47.8%). Parents shared that their top three preferred sources to hear more about the ABLE program would be from a state ABLE program/representative (32.6%), disability service providers/organizations (26.1%), and/or families who have an ABLE account (21.7%). Exactly half of the parents (50%) stated they would like to receive more information via email, a one-on-one-meeting (19.6%), and/or regular mail (10.9%).

Other Financial Accounts: To assess utilization of financial accounts other than ABLE, parents who were aware of other financial accounts (n=164) were asked if their child currently had, or had access to any of the following: checking, savings, special needs and pooled income trusts, and stock investments. The majority of parents within this group stated that their child did not have any of these financial accounts (38.4%). However, almost 30% of children had a checking account (28%), and close to 40% had a savings account (37.8%). About 15% had a special needs trust (14.6%) and 6% had stock investments (6.1%). Almost 8% stated that their child had another account such as a 529 prepaid college plan, while no parent stated that their child had a pooled income trust.

The experience of opening a checking and savings account was explored among those who responded that their child had either of these accounts (n=87). Most accounts were opened as a result of parents taking the initiative to set up this account for their child, and only 23% of parents said that their adult child was consulted in the process. Almost half of these parents noted that their child was too young to permit this involvement (49.4%) or their disability limited this (21.8%). Parents shared the top three concerns and questions they had before opening the checking/savings account. Most frequently, parents were concerned if the account would affect SSI/SSDI benefits (36.8%), if it would affect Medicaid benefits (33.3%), and how much the monthly fees for the account would be (28.7%). Concerns arising from a personal nature which parents most frequently reported included: the ability of the parent or child to make financial decisions (54%), not sure that there would be enough money to contribute to the account (36.8%), and not being sure they could find someone to help answer questions (21.8%). Most parents researched the answers to their programmatic questions on their own

(67.8%), spoke to someone from the financial institution (32.2%), or asked a trusted friend or family member (27.6%). Opening the checking/savings account was reported as being easy or very easy by almost 83% of the parents, with almost 53% sharing that they received help to open the account from someone at the financial institution. Parents were also largely responsible for managing the checking/savings account (88.5%) with about 87% reporting that managing the account is easy or very easy.

Among parents who reported that their child had a special needs trust, 25% stated that the process to open it was difficult or very difficult, 50% stated this was neutral while only 25% stated the process was easy. Interestingly, the experience with managing trusts was different, with 25% reporting it is difficult, 29.2% stating it is neutral, while 45.8% sharing that it is easy or very easy.

Please see Figures 2 and 3 for an overview of the six most frequently reported programmatic and personal concerns parents had about ABLE accounts (separated by Groups 1, 2, and 3) and checking/savings accounts to illustrate differences and similarities among groups.

Impact of Financial Accounts on Families and Children

The majority of parents with an ABLE account for their child (Group 1; n=52) reported that their top three reasons for opening an ABLE account was to build long-term savings for their child's future (almost 83%), followed by providing funds to support their child's independent living expenses such as rent and groceries (51.9%), and setting money aside for emergencies (almost 33%). Almost 62% of the participants found the account very helpful for building a long-term savings account for the future of the child,

followed by almost 52% reporting that it was very helpful for building an emergency fund. Interestingly, the ABLE account was not used for educational, employment, independent living, or health care expenses by the majority of these account holders (94.2%, 94.2%, 90.4%, and 82.7% respectively). Overall, almost 80% of parents agreed that the ABLE account served the purpose they expected it to, while 17% were not sure. Only about 4% of parents reported that the ABLE account did not serve the purpose they expected.

Parents were also asked if they noticed any changes in their child if the child was using the ABLE account. Only two parents stated that their child was taking more initiative and was motivated to learn and grow. Most respondents stated that their child was too young at this time to notice any changes in them (approximately 44%), while others stated that their child's disability limits the ability to identify changes (almost 38%). All other parents shared no changes were apparent in their child. Of the parents who reported that their child had a checking or savings account, the majority shared that the account was very or somewhat helpful in providing the child independence through the use of a debit card for daily living expenses (71.4%). Using these accounts was also helpful to build long-term savings for the child's future (56.3%), building an emergency fund (49.4%), and paying for independent living expenses (48.2%). Children who used their checking/savings account were reported to be more self-confident (8%), more motivated, and taking the initiative to learn and grow (12.5%).

To assess the impact of financial concerns on mental health, parents responded to the question "Do you worry, feel stressed or anxious thinking about your child's financial future?" Approximately 11% of the parents stated never or rarely, about 39% reported

sometimes while 50% of parents shared that they were often or always worried, stressed, or anxious.

Associations Between Demographic Variables and Utilization of ABLE Accounts

To examine if any statistically significant associations exist between demographic variables and utilization of ABLE accounts, cross-tabulations and chi-square tests of independence were conducted. Please see Table 2 for all cross-tabulation results.

Race approached marginal significance, $p = .057$ in relation to the utilization of ABLE accounts. Cross-tabulated frequencies indicated that more Whites had an ABLE account ($n=47$) compared to Black or African American participants ($n=5$). The age of the child was also marginally significant, $p = .054$. Frequencies illustrate that children between the ages of 21 to 26 had the highest percentage of ABLE accounts (70.8%) followed by children between the ages of zero to five years old (57.1%). Ethnicity was statistically significant, $p = .011$ with findings indicating that families who were not Hispanic or Latino had a higher proportion of ABLE accounts (59%) compared to Hispanic or Latino families. These results demonstrate that there is a statistically significant difference between the utilization of an ABLE account by ethnicity. There was no statistically significant association between the utilization of an ABLE account and the parent's household income, level of education, marital status, and living situation of the child.

Qualitative Findings

Analyses of open-ended questions led to the identification of six themes: 1) Barriers to *opening* financial accounts, 2) Facilitators to *opening* financial accounts, 3) Barriers to *managing* financial accounts, 4) Facilitators to *managing* financial accounts, 5) Recommended changes to ABLE programs, and 6) The impact of financial accounts. Themes related to opening and managing accounts were separated, as they are two distinct stages in respect to financial planning and management.

Theme 1: Barriers to Opening Financial Accounts

This theme describes the concerns and questions that parents had during their experience with opening or considering to open an ABLE, checking, savings, or trust account. This theme has two sub-themes: 1) Program barriers highlight the concerns that stem from the characteristics of the financial account itself, and 2) Personal barriers which highlight concerns arising from personal circumstances and characteristics of parents.

Program Barriers: Several concerns related to the actual components of the ABLE program were raised by parents from all three groups. Parents appeared to be unclear on what the correct age to open an ABLE program should be. Some stated that they would open it when the child was older as it would be more relevant for their needs at that time, while others questioned what the advantage of opening the account when the child was younger would be. Parents were also worried about the level of risk associated with an ABLE account arising from the fact that investments could lose value, that the political

landscape could lead to changes in the rules of the program, and, overall if an ABLE account was a safe option. Other programmatic concerns parents shared included: what would happen to the funds in the ABLE account if something happened to the child (for example, could claims be made for Medicaid repayment), what the program fees are, can child support be deposited into the account after the child turns 18, why ABLE is not able to issue a debit card if there are two guardians for the child and challenges with finding trained representatives to answer questions related to a 529 rollover plan. Questions related to eligibility for an ABLE account were a common concern among parents who had not heard of the ABLE program. Specifically, parents were not sure if attention deficit hyperactivity disorder (ADHD) was an eligible disability, or if you had to be an SSI beneficiary to qualify. Parents shared that they needed more information about the eligibility criteria. An additional programmatic concern voiced by parents from all three ABLE groups was related to what the advantage of having an ABLE account was compared to any other account. Specifically, parents questioned what the benefits of an ABLE account were if the rate of return was the same as other savings accounts, or how the ABLE account was different from the Florida 529 prepaid account. A few quotes from parents which capture some of these concerns are presented below:

[My] child is young now and I don't see much benefit [to opening an ABLE account]. It might be tax free [sic] but if the interest is a typical savings rate of less than 1%, it wouldn't make much difference anyway.

Parent from Group 3

We opened the account and have not added funds except what we put in to open the account. I'm still not sure this is the best vehicle for my daughter to save. I don't like all the rules that apply. *Parent from Group 1*

We have 2 guardians for our child (both parents). Most ABLE accounts can't issue [a] debit card if there are 2 guardians. *Parent from Group 1*

Opening the account itself was easy. However, I had a direct FL-Prepaid-to-ABLE account rollover, and no one could help me with that. It was like the ABLE reps [representatives] had never heard of a 529 rollover, and it is a tax sensitive [sic] thing, so I had to know the facts. Ultimately, I contacted [blinded name], the director [of ABLE Florida], for help. He connected me with a [representative] who could help, which was great, but the lack of educated [representatives] was unfortunate. *Parent from Group 1*

One parent expressed an interesting point of view about why there was a need to have a separate or different type of savings account for individuals with disabilities:

I would make the ABLE account be ANY account owned by [or] for a qualified individual. Why must my son with an intellectual disability have extra requirements and limitations on where he can save his money? Why

shouldn't a regular checking, savings or investment account qualify? I don't understand why someone who has an intellectual disability or any disability needs to be more capable and more informed than the average person to participate in society. Disabled people already have a disability. Needing to store money in a particular organization seems like an extra legislation-induced disability. *Parent from Group 1*

Parents also expressed programmatic concerns related to opening checking and savings accounts. Similar to the concerns expressed above, parents were not sure about banking fees, and who would have control of the account if something happened to the parent. In addition, parents shared they were worried about the process to transfer the account to the child when they turned 18 years old, and the ability of their child to make financial decisions. It was also evident that parents were concerned if funds in the account would affect their child's eligibility for benefits. This latter concern was shared by almost all parents who also had a trust account. Among parents who had an established trust, it was clear that a lot of detailed information was required such as what they were, the benefits of having a trust, the costs to set them up, and who would manage the trust.

When she [child with IDD] gets older will the checking account affect her ability to get SSI and Medicaid?

Personal Barriers: At a personal level, parents expressed that opening an ABLE account was challenging given the lack of sufficient funds and worries about how to make the best investment decisions. There was also a clear need among parents for easily accessible information about the ABLE program, and the opportunity to receive ABLE advice and assistance.

We hope to get ourselves to a point where we can open and grow an ABLE [account] but our financial situation is such that we don't have the money to do so. *Parent from Group 2*

[I would like] better [and] easier to understand information that is accessible. I asked at my bank [about the ABLE program] and they had no idea what I was talking about. *Parent from Group 2*

Parents also reported that opening an ABLE account required time and money which was a significant personal barrier. Many parents stated that they did not currently have the time to think about the ABLE program or time to set it up. Moreover, they shared that they needed someone to explain how the ABLE program fits with other financial options available and eligibility for benefits, which would add to the costs of opening an ABLE account.

[I need] someone to help with the process that can provide advice regarding the workings of the ABLE account, in conjunction with a trust,

social security benefits, Medicaid, etc., so that I can be fully informed to utilize resources effectively. *Parent from Group 2*

Similarly, time and costs were also reported barriers for opening trust accounts. Parents shared that trusts were expensive to open as they required an attorney, which they had to spend time finding, and that a significant amount of paperwork was involved in the establishment of a trust.

It took us years to save for this expense [creating a trust]. It's very expensive. It also took much effort to assign all of [the] assets to the trust and to set up the life insurance to fund the trust upon our death.

[Challenges with setting up a trust included:] Gathering all info [information], getting an attorney, [and] getting all parties together.

Theme 2: Facilitators to Opening Financial Accounts

This theme describes the factors that supported parents with opening an ABLE, checking, savings, or trust accounts. This theme has two sub-themes. First, program facilitators highlights the factors that stem from the characteristics of the account itself. The second sub-theme, personal facilitators highlights personal attributes which supported the opening of financial accounts.

Program Facilitators: Parents reported that the website for the ABLE program was quite easy to use and understand, and representatives on the phone and via email were helpful. In addition, the ABLE program was easier to understand compared to some other financial programs. Moreover, parents expressed that the limited options available for investment choices in the ABLE program was desirable, as it made decision-making easier.

[The] online platform is easy to manage and customer service is available to me.

The Florida website and hard copy information [for the ABLE program] was well written. More importantly, it is an easy program to understand. It is not like an IRA or other tax advantage [sic] savings plan that uses pre-taxes [sic] dollars and has age base[d] withdrawal rules. I have not made any withdrawals. I have not had to call customer service.

It is very easy to open an ABLE account. The website is very straightforward, contributions are made automatically each month and the options for investing are spelled out well so they are easily understood.

Similarly, parents who reported that their child had a checking or savings account shared that opening an account online was easy to do. Checking and savings accounts could also easily be transferred to a child when they turned 18, which parents shared

made it easy for their child to have access to an account. Moreover, staff at the bank were very helpful and worked with the SSA to set up the account appropriately.

[I] went to the bank and customer service was very helpful.

SSI [SSA] provided paperwork so setup at the bank was easy.

Personal Facilitators: At a personal level, parents shared that talking with someone who has experience with ABLE accounts was very helpful in opening one.

I had an experienced friend help with the process.

Having someone walk us through the process made it easy.

In respect to opening a checking or savings account, many parents shared that since they already had an existing account and relationship with a bank, opening this account for their child was exceptionally easy. It was evident that parents with established trust accounts for their child had made the necessary effort to secure their child's financial future and benefits, especially for when parents would pass away. These parents took the initiative to research their questions themselves, and sought the help of lawyers and financial advisors to establish trusts.

[A trust was created] to provide [a] financial future for [my] child while preserving benefits.

I created the Special Needs Trust for my son in the case of my death.

We used a lawyer who specializes in special needs trusts who walked us through it.

Theme 3: Barriers to Managing Financial Accounts

This theme describes the concerns parents had arising from their experience with managing their financial accounts. In respect to the ABLE account, parents had concerns regarding the lack of control over where and how the money was invested and the limitations in respect to the amount of money that could be deposited. Although some parents stated that setting up the gift-giving option (the ABLE program allows the account holder to invite other friends and family to contribute directly into the account) was relatively easy, some parents expressed that this was difficult. In addition, some parents were unclear about how withdrawals from the account should be handled, and how tax forms should be prepared. It was also shared by one parent, that they did not know how to ensure that their child's expenses could be kept separate and withdrawn from the ABLE account when the family shopped together.

It is currently easy to manage the account since my son is 7 and does not need to routinely access the account. It [sic] we were to need it frequently, the hardest part

would be keeping his expenses separate from the rest of the family's expenses.

We buy things for him at the same places and times that we buy for the rest of the family.

It's been very easy to deposit and change the investment option. I am somewhat intimidated on how to withdraw the money, so I haven't even attempted it. I have not applied for the debit card option yet...if it's available.

Easy online platform. Finding where to allow others to make contributions is challenging.

[I have] concerns about tax consequences but withdrawals and deposits are easy.

Some parents shared that managing a trust account was challenging as they always had to be alert about changes in their lives that would require updating their trust, and the laws and rules associated them. Although most families had hired a lawyer or financial planner to open and manage the trust, concerns related to taxes and laws were evident.

[Need to be aware of] accounting rules, fiduciary rules, and disbursement rules (to maintain public benefits).

We have to continually think about the trust to insure [sic] all of our accounts and assets are included in the trust.

Theme 4: Facilitators to Managing Financial Accounts

This theme describes what facilitated the management of financial accounts. Overall, parents stated that managing an ABLE account was relatively easy as the website was clear and navigating it was simple. As such, parents were able to access the accounts readily. Contrary to the experience of some parents, a few noted that depositing and withdrawing funds was straightforward while setting up gift-giving was also easy.

I have only recently begun withdrawing money from the account each money. Depositing and withdrawing money is straightforward. I have [not] had to fill out tax forms yet.

The website is easy to navigate, and all the info needed to maintain the account is laid out in an easy to read [sic] format.

Interestingly, in respect to the management of a trust account, most parents stated that they did not need to spend any time managing it after the initial set-up, as the trust would become active upon their passing. The following quote captures the sentiments of parents:

All the work to form the trust is done, now it is just waiting to be used.

Theme 5: Recommendations for ABLE Programs

This theme describes the suggestions parents made regarding the ABLE program to increase awareness and to make them easier to open and manage. Findings were categorized under two sub-themes: 1) Program components, which highlights recommendations regarding features of the ABLE program itself, and 2) Information and support, which describes the type of support parents need.

Program components: It was evident that parents would like to see an increase in the contribution and lifetime limits imposed on ABLE accounts. Many parents also commented on the need for more control over investment decisions, and that having the option of prepaid spending cards (with ABLE funds) would be useful to give to their child for spending. It was also suggested to allow the gifting link to be more customizable, with perhaps a personal photo a parent could use.

[I would like to] be able to have options of how the money is invested.
Have more flexibility of how the funds are used to benefit my daughter.

[A] prepaid card for withdrawals sounds interesting, as I would like my child to have access to SOME of the money, so he can practice buying things, like a Slurpee or a t-shirt he wants, but NOT have access to the whole account. If I could somehow remotely program him to have \$25 week [sic] credited to his card, that would be awesome.

My account is already linked and I can transfer money with just a click and entering the amount to contribute. The links for gifting are easy to share with family and others who may want to contribute, but I'd like to be able to customize the gift link with a picture.

Information and Support: Parents reported the need for more information about the ABLE program, such as the uses and limitations of the account. In addition, they wanted more support to help manage and answer questions as they arose, and resolve account issues. One parent suggested the following in regards to more information and support:

Have a recorded webinar on how an individual is managing their account for monthly living.

Theme 6: Impact of Financial Accounts

This final theme discusses the impact that having a financial account such as an ABLE, checking, savings, or a trust account had on families. Findings reflected two distinct areas of impact, which have been presented as sub-themes: 1) Emotional wellbeing, and 2) Independent living skills.

Emotional Wellbeing: Having an ABLE account had an impact on how parents felt. Many parents reported feeling good and more secure knowing that they had money set aside for their child, which could be used in the event of an emergency or after their death. It was also important for the parents to know that the funds would not impact their

child's eligibility for Medicaid and SSI benefits. One parent shared an example of how the ABLÉ account created a sense of relief, as the funds were able to support a health care expense. However, many parents remained concerned that they did not have enough saved in the account. Interestingly, many parents shared that they could not comment on the impact of the ABLÉ account on their lives yet, as they had not used the account.

We haven't used the account yet. We contribute monthly and hope it will be utilized with discretion and that it will be helpful.

[I feel] happier knowing that we are saving for his future without him losing Medicaid or SSI [benefits] as he becomes an adult.

I feel a little more secure that she has an account that no one can use for any other purposes than for her personal needs. I worry that there isn't enough money in it!

I feel as a mom [I am] more relieved that this [ABLE account] can help with my sons [sic] life. He needed a hearing aid that insurance or even agencies won't help [acquire]. [Because he has] the ABLÉ United [account, he was able] to save [and] buy his own hearing aid which made us all happier. Thank you.

The impact on families from having a child that had a checking, savings, or trust account mirrored the findings from above. Parents with checking/savings accounts were happy that their child had the money for emergencies. Among parents who had an established trust account for their child, parents felt more secure, less anxious, and relieved about their child's financial future especially for when they would no longer be around. One parent was concerned that it was not fully funded, while another expressed worry regarding the management of multiple trusts especially when parents were divorced. The following quotes capture the sentiments of parents with established trusts for their child:

[Having a trust makes me feel] good. The problem of multiple trusts and who pays for what expenses and how to coordinate expenditures is very challenging and problematic. Divorced couples with multiple trusts will have a challenging time with this.

It takes away financial worry, or worry that my child will be left open to fraud or huge tax bill after my passing.

[I feel] better than before we had it, but anxious because it is not fully funded.

Independent Living Skills: This sub-theme describes the impact of financial accounts on the child's independent living skills. Specifically, it describes the growth and concerns

parents shared in regards to money management skills among their children. Parents of children with access to an ABLER, checking, or savings account shared that their child was learning to be independent by using a debit card and having access to funds. They were also happy that these accounts allowed their child to learn basic financial skills such as budgeting and savings, and managing their accounts.

[I am] confident that my child is learning to use a debit card and [the] responsibility of managing the account. That is, knowing what is on the account and how much is available for spending.

I like knowing that he is developing some basic understanding of the use of bank accounts.

I am happy he can use the ATM card and shop for food and other small items he likes. He does need supervision on how much to spend.

The child is depositing his own money into the account from birthday gifts from grandparents. He is building the habit of growing savings.

However, some parents were concerned about their child's ability to use the checking/savings account, or make sound financial decisions as a result of poor money management skills or limitations arising from their disability.

I opened the checking account before the ABLE account, hoping I could teach my child how to use a debit card, but I feel it is too difficult for him, so the account sits dormant with about \$200 of his Christmas money in it.

I am happy he has an account, but it makes me scared that he knows about money and could take money out he does not have, even after he has been instructed and educated about it.

I'm worried about the future and if they can safely handle their finances.

Discussion

This novel study set out to examine the awareness, utilization, facilitators, barriers, and impact parents of children with IDD report in regards to their experience with financial tools. Specifically, this study focused on the ABLE program and other financial accounts such as checking, savings, and trusts. Overlap in many qualitative and quantitative findings helped reinforce several encouraging results which were identified. It was apparent that awareness of ABLE, checking and savings accounts were relatively high, and among parents who had these accounts, it was commonly being used to build long-term savings for the child's future and an emergency fund. This is extremely important given the high costs of disability-related expenses which span across the

lifetime (Lunsky et al., 2019), and to support a positive individual and family trajectory. The impact of having an account was also desirable, as parents reported better emotional health knowing that their child's future was more secure after they had passed away. Benefits of having and accessing an account were also reported among children with IDD who had an opportunity to develop independence while simultaneously learn money management skills, allowing them to experience and align with the societal expectations of young adulthood. These findings fit the framework of the life course theory by highlighting the interaction between economic, environmental, and social factors, and psychological, and behavioral outcomes (Fine and Kotelchuck, 2010). Moreover, it illustrates the interdependence between a parent's wellbeing and that of their children (Hutchison 2005, 2011).

Despite these encouraging findings, the study draws attention to the glaring gaps which need to be bridged if we hope for improved financial security and pathways across the lifespan among families and their children with IDD. Utilization of all financial tools relative to the overall study sample (n=176) was low. Only 29.5% of children had an ABLE account, 26% of children had a checking account, 35% had a savings account, and only 13.6% had a special needs trust. Given that the majority of parents with financial accounts reported that opening them (except for trusts) was easy and straightforward, it is clear that programmatic and personal barriers hinder more families from participating in financial planning for their child.

Clearly, the majority of parents in this study had contemplated their child's financial future and believed that securing it was important. Despite this desirable attitude and intention towards financial planning, only half of the parents in this study had

enacted a specific plan for their child. This is concerning given that financial planning has been associated with self-rated health and depression (Weida et al., 2020). It is not surprising then, that almost 90% of parents in this study expressed worry, stress, and anxiety thinking about their child's financial future. This lack of planning can be contributed to the lack of confidence in respect to managing money and the ability to make financial decisions, as reported in the findings and illustrated in Figure 4.

Another reason, common to all groups in this study, and aligned with previous literature, was the concern that there would be insufficient funds to contribute towards an account (Burke et al., 2018; Goodman & Morris, 2017). While many parents in this study reported not being able to make ends meet with their household income, it is also possible that parents do not understand how to budget and save to contribute towards an account. In the case of the former, it is essential to support policies and programs that allow families who live in financial hardship to break past the cycle of poverty (Parish et al., 2010) such as the ABLE program. In the case of the latter, it is essential that we “build people’s capacities to improve their financial situation” (Weida et al., 2020, p. 11), which should include training and workshops on financial planning and management, which are relevant for families of children with IDD. It may even be necessary for government agencies to include regular financial planning and consultations as an automatic benefit to these families at critical junctures, such as within two years of diagnosis. This will ensure that parents participate in specific, goal-oriented financial planning efforts (Lee et al., 2019) starting when their child is young and that parents who need support and assistance (such as those without financial literacy) are not left behind. Similar to providing financial training to parents, it may be necessary to prioritize money management

training among individuals with IDD. Parents of some children expressed that they did not have the confidence in their child's ability to handle their own accounts. To promote independent living among adults with IDD and decrease the stress and worry among families, educational systems should emphasize this crucial life skill in their curriculum (Agarwal et al., 2020; Caniglia & Michali, 2018; Miller et al., 2018).

One of the advantages of an ABLE account is the potential for family and friends to contribute towards disability-related expenses so that the child is not solely dependent on government support, yet at the same time does not risk losing their government benefits (Hershey et al., 2017b). Parents from all three ABLE groups in this study, however, expressed concerns that no one else would contribute to the account. This is a troublesome finding, as it suggests that these families are perhaps not receiving the level of social support they need. The benefits of a strong social support system on parental mental health and life satisfaction have been well established (Halstead et al., 2018; Lu et al., 2018; Patton et al., 2018) and as such, this concern should be addressed. Ensuring that parents understand the need to include friends and family in discussions about future plans for their child is imperative. To ensure that parents are not left socially isolated, healthcare providers and social workers may consider distributing information designed specifically for the extended support system. This could include information about the disability itself, and suggestions for meaningful ways they may provide support, such as financial contributions. This may enhance awareness for the family's needs, increase sensitivity and the necessary support.

To increase planning efforts and utilization of financial accounts, it is also essential to address the programmatic barriers reported by parents. For example, parents

from all three ABLE groups were not sure what the real benefit of an ABLE account was, while parents from Group 1 and the checking/savings group were concerned about how funds in the account could impact eligibility for SSI, SSDI, and Medicaid benefits. It is also interesting to find that over 50% of the parents who have an ABLE account (Group 1) were *initially* not sure what the money in the account could be used for. These barriers and others can be quickly and largely resolved through clear messaging, enhancing awareness, and distributing information widely (Lee & Burke, 2020). ABLE programs should develop easy-to-understand informational material which explicitly explains the unique benefit of an ABLE account versus other accounts, eligibility criteria, impact on government benefits, fees, the right age to open an account, what expenses the account can cover (which emphasizes its use beyond a savings account), and risks of having an account. For example, in regards to risks, one parent in this study shared that the changing political climate and its impact on program policies can deter families from participating in programs such as the ABLE account. Similar worries were reported in a previous study where families worried how changes in the state's budget would affect the availability of disability services (Burke et al., 2018). This is a concern that should be addressed by ABLE programs. If this risk exists, it should be clearly communicated.

In the longer-term, ABLE programs should consider advocating for the need to increase contribution limits and the age limit for onset of disability beyond 26. Previously, the developmental period and cut-off for developmental disabilities was 22. However, in the most recent edition of the Diagnostic and Statistical Manual for Mental Disorders (DSM-5), the American Psychiatric Association (2013) has left the cut-off age for the developmental period to the discretion of the clinician (American Psychiatric

Association, 2013; Tasse, 2016). As such, given that a diagnosis for IDD could arrive beyond the age of 26, and costs for healthcare continue to rise, this is a change that should be considered. Additional considerations for ABLE programs include offering prepaid debit cards to account holders and a more customizable gifting experience.

It is also evident from both qualitative and quantitative findings that parents need someone to help answer questions and provide advice and support when making financial decisions. Although the ABLE program is intended to allow individuals even without a financial planning background to open and manage their own accounts, there is an inherent risk associated with this. As suggested by Hershey et al. (2017a), “A key pitfall of ABLE account DIY management is that an unsophisticated owner who is not knowledgeable about tax law dynamics could inadvertently create investment results that exceed account limitations and open the beneficiary to penalties and the loss or suspension of certain public benefits” (Hershey et al., 2017a, p.73). Although ABLE programs already offer access to ABLE representatives and parent volunteers to help answer questions, it may be necessary to increase this presence and the level of guidance offered.

Unlike the recommendation from the report by Goodman et al. (2017) to disseminate financial curriculum and planning information via the SSA (Goodman & Morris, 2017), this study finds that awareness efforts and distribution of information would be more impactful if undertaken by state ABLE programs. In addition, support from disability organizations, financial planners, and families with an existing ABLE account should be harnessed. Information should be made available via email, regular mail, recorded and live webinars, and one-on-one meetings. Particular attention should be

paid to ensuring that families from underrepresented groups, including Hispanic and Latino families and individuals are reached through this effort. Given that many parents in the study began to think about their child's financial future between the ages of birth and five years old, this may be an opportune time to intervene. However, since an IDD diagnosis may be confirmed later, and parents have evolving priorities over the lifespan (for example, some parents in this study shared that they were "not interested to learn more *at this time*"), it is imperative that parents receive updated information periodically so that the lack of information does not impede or delay the ability to take action when ready.

Among parents with an existing ABLÉ account, parents shared that they opened the account with the intent that it could be useful for building savings, emergency funds, and independent living expenses. However, most parents used the account primarily for building a savings account, but not for independent living, employment, educational, or other disability-related expenses. This could be due to the concerns regarding withdrawals and completing tax forms, which have led to many families not actively using the account. ABLÉ programs should ensure greater clarity on the various expenses the account can be used for to maximize the benefits from an ABLÉ account and offer step-by-step support to enhance account management. Ultimately, a key benefit of the ABLÉ program is its intent to provide individuals with disabilities greater autonomy in their lives, by offering an account with tax-benefits that is easy to open, access, and manage for disability-related expenses (Rephan & Groshek, 2016). To ensure that these benefits are realized, it is imperative that the above barriers and suggestions are considered. Improved planning efforts and utilization of financial tools such as an ABLÉ

account have the potential to improve the mental health of parents. Moreover, it can ensure that individuals with disabilities, such as those with IDD, benefit from financial services which allow savings, enhance employment opportunities, and improve economic inclusion (Goodman & Morris, 2017).

Limitations

This study has a few limitations, which should be noted when interpreting the findings. First, the sample size is small, and most participants resided in the state of Florida. As a result, the generalizability of the findings is limited. In addition, the small groups within demographic variables limited the ability to undertake a regression analysis. As such, future studies should aim for a larger sample size ideally with national representation across race and ethnicity groups. Given the cross-sectional design, the study is unable to infer causality, while the sampling design and gift card incentive, creates the likelihood of volunteer bias. Also, there is the possibility of social desirability bias given the personal nature of the financial questions. Despite these limitations, however, this study offers a unique insight into the financial experience of families with children with IDD, especially in regards to the different groups within the ABLE program, and checking, savings, and trust accounts. As such, this allows a more targeted approach in addressing the needs of each group.

Conclusion

This exploratory study helps to increase our understanding of what factors facilitate and hinder the utilization of financial tools among families of children with IDD. It is clear that utilization has a positive impact on the life trajectory of both parents and their children. Perhaps with clearer and readily accessible information, better financial self-efficacy, and improved support utilization rates will improve, and positive effects of financial planning on education, employment, health, and independent living outcomes will be seen.

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Tables

Table 1. Demographic attributes of study sample

	Overall sample (N=176)	
	N	%
Parent's age* - Range, <i>M (SD)</i>	24 – 68, 45.92 (10.37)	
Child's age - Range, <i>M (SD)</i>	0 – 26, 12.44 (7.78)	
State of residence		
Florida	148	84.1%
Tennessee	7	4%
Oregon	5	2.8%
Other states	16	9.1%
Parent Gender		
Female	146	83%
Race		
White	142	80.7%
Black or African American	20	11.4%
Other	9	5.1%
Prefer not to answer	5	2.8%
Ethnicity		
Hispanic or Latino	43	24.4%
Not Hispanic or Latino	128	72.7%
Prefer not to answer	5	2.8%
Currently employed		
Yes	108	61.4%
No	68	38.6%
If not employed, was job affected by COVID-19?		
Yes	24	35.3%
No	44	64.7%
Household Income		
<49,999	54	30.7%
50,000 – 74,999	59	33.5%
>100,000	53	30.1%
Prefer not to answer	10	5.7%
Highest level of education		
Two-year associate degree or less	65	36.9%
Bachelor's degree	60	34.1%
Master's/Doctoral/Professional degree	51	29%
Current marital status		

Married	122	69.3%
Widowed/Divorced/Separated	36	20.5%
Never married	18	10.2%
Child's living situation		
With one parent	48	27.3%
With both parents	110	62.5%
In an extended family	12	6.8%
Other	6	3.4%
Child's IDD diagnosis**		
ADHD	41	23.3%
ASD	62	35.2%
Behavioral Disorders	22	12.5%
Cerebral Palsy	15	8.5%
Developmental Delay	49	27.8%
Down Syndrome	69	39.2%
Fetal Alcohol Spectrum Disorders	1	0.6%
Hearing Impairment	11	6.3%
Intellectual Disability	49	27.8%
Language & Speech Disorders	42	23.9%
Learning Disorder	28	15.9%
Tourette Syndrome	1	0.6%
Vision Impairment	12	6.8%
Other	14	8%
Government programs/services child receives**		
SSI	49	27.8%
SSDI	16	9.1%
Medicaid	78	44.3%
VR agency funds	10	5.7%
HUD housing	5	2.8%
SNAP	22	12.5%
529 Prepaid college plans	10	5.7%
FAFSA	4	2.3%
Social Security programs	1	0.6%
Other	8	4.5%
None of the above	62	35.2%

* One missing value

** Does not add to 176 or 100% as participants could select multiple responses

ADHD: Attention-Deficit/Hyperactivity Disorder; ASD: Autism Spectrum Disorder; SSI: Supplemental Security Income; SSDI: Social Security Disability Insurance; VR: Vocational Rehabilitation; HUD: Housing and Urban Development; SNAP: Supplemental Nutrition Assistance Program; FAFSA: Free Application for Federal Student Aid

Table 2. Cross-tabulations of demographic variables and status of having an ABLE account

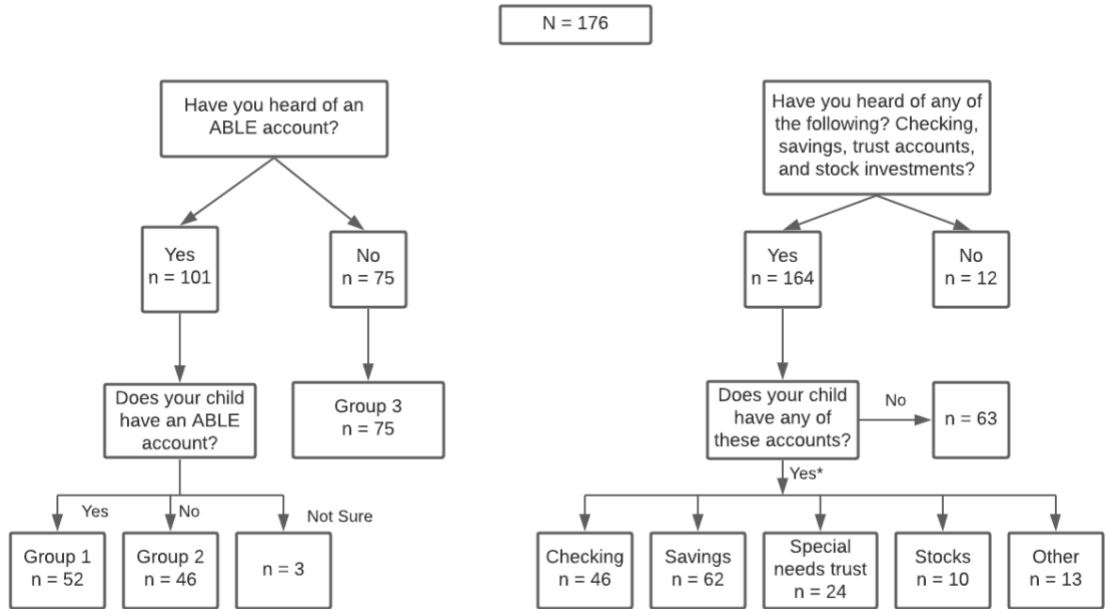
	Does your child have an ABLE account?				<i>p</i> -value
	No/Not Sure		Yes		
	Count	(%)	Count	(%)	
Race					.057*
White	40	46%	47	54%	
Black or African American	3	37.5%	5	62.5%	
Other	2	100%	0	-	
Prefer not to answer	4	100%	0	-	
Ethnicity					.011*
Hispanic or Latino	16	72.7%	6	27.3%	
Not Hispanic or Latino	32	41%	46	59%	
Prefer not to answer	1	100%	0	-	
Household Income					.431
<49,999	15	62.5%	9	37.5%	
50,000 – 74,999	13	44.8%	16	55.2%	
>100,000	18	46.2%	21	53.8%	
Prefer not to answer	3	33.3%	6	66.7%	
Highest level of education					
Two-year associate degree or less	19	61.3%	12	38.7%	.210
Bachelor's degree	16	47.1%	18	52.9%	
Master's/Doctoral/Professional degree	14	38.9%	22	61.1%	
Current marital status					.732
Married	35	47.3%	39	52.7%	
Widowed/Divorced/Separated	10	47.6%	11	52.4%	
Never married	4	66.7%	2	33.3%	
Child's living situation					.934
With one parent	13	50%	13	50%	
With both parents	31	47%	35	53%	
In an extended family	3	50%	3	50%	
Other	2	66.7%	1	33.3%	
Child's Age					.054*
0 to 5	9	42.9%	12	57.1%	
6 to 10	10	50%	10	50%	
11 to 15	11	78.6%	3	21.4%	
16 to 20	12	54.5%	10	45.5%	
21 to 26	7	29.2%	17	70.8%	

Note: Fisher's Exact Test reported when cell size is less than 5

*Significant or marginally significant at the 0.05 level

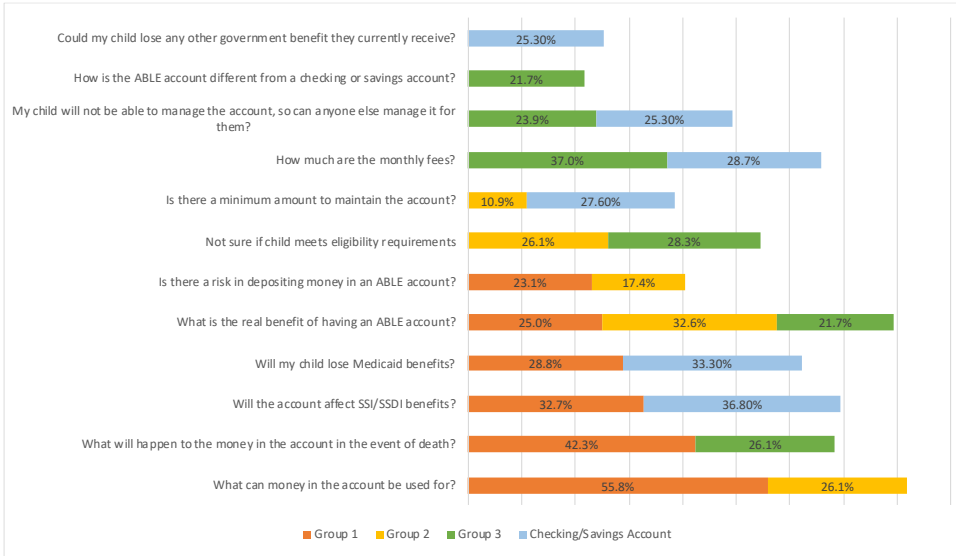
Figures

Figure 1. Overview of awareness and utilization of ABLE accounts and other financial tools



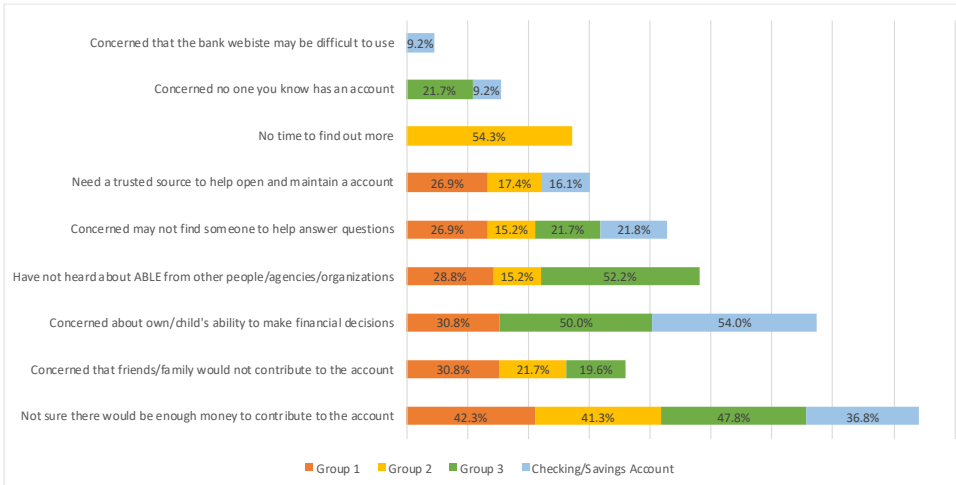
*Does not add to 164 as parents could select multiple responses

Figure 2. Top six programmatic concerns and questions of each group



Note: Does not add to 100% within groups as parents could select multiple responses.

Figure 3. Top six personal concerns of each group



Note: Does not add to 100% within groups as parents could select multiple responses.

CHAPTER 5: CONCLUSION

Parents of children with IDD experience significant levels of stress, anxiety, and other adverse mental health outcomes (Lee & Shivers, 2019; Shepherd et al., 2018). Given that their wellbeing and that of their children are inextricably linked (Barker et al., 2011; Hutchison, 2005, 2011), understanding and addressing parental mental health is crucial. As such, this dissertation focused on addressing three gaps, which have the potential to improve mental health among this population of parents.

Summary of Findings and Implications

Manuscript 1 aimed to examine the current state of literature concerning transition-aged children with ASD. Specifically, by using a systematic review methodology, the study intended to identify interventions that targeted the unique stressors during this critical period in life, and the respective scales used to assess stress and/or anxiety outcomes among the parents of these children. Despite the vast literature base reviewed, only 11 studies met the inclusion criteria. Interventions broadly focused on either mindfulness (n=5), social functioning through the PEERS program (n=3), or addressed multiple components such as emotional support, social skills, and parent education (n=3). Only two of these studies focused specifically on transition-aged children, and only one intervention addressed transition planning. It was evident from this review that most ASD interventions continue to focus on young children and their families with ASD. Five scales assessing stress and/or anxiety were also identified

through the review and included the Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995), Perceived Stress Scale (PSS-10, Cohen & Williamson, 1988), Stress Index for Parents of Adolescents (SIPA; Sheras, Abidin and Konold, 1998), Beck Anxiety Inventory (BAI; Beck & Steer, 1990), and the State and Trait Anxiety Inventory (STAI-S and STAI-T; Spielberger et al., 1983). However, none of the scales used were designed for parents of children with disabilities. Moreover, all but one scale (the STAI-S/STAI-T) were noted by the authors of studies in this review as a possible limitation to their findings, by stating that the scales were likely not sensitive enough to capture changes in this parent population. They also expressed the need for instruments that were specific to the ASD population. Future researchers can use this systematic review as a starting point to inform the design of their interventions (including instrument selection), to ensure they address the unique stressors and needs of the transition period.

Manuscript 2 aimed to examine how health care demands from caring for a child with ASD impacts the mental health of both mothers and fathers, using a nationally representative dataset. Findings indicated that the mental health of mothers was significantly associated with spending between one to ten hours coordinating care, and having a child whose ability to complete daily activities was moderately or consistently affected. Inadequate insurance and being non-Hispanic Black/other/multi-racial was also significantly associated with unfavorable maternal mental health. Among fathers, unfavorable mental health was significantly associated with frustration to get services for their child, and interestingly, having a family member who *did not* stop work, cut hours, or took a leave of absence. Gender roles may explain some of the differences in the way health care demands uniquely impacts the mental health of mothers and fathers. Findings

from this study can help *prioritize* policy changes given the significant needs of this population and their families. As such, these findings draw attention to the invisible effects of structural and ASD-related health care challenges on parental mental health in the policies, services, and interventions that are designed.

Manuscript 3 set out to examine the awareness, utilization, facilitators, barriers, and impact parents of children with IDD report in regards to their experience with financial tools. Specifically, this study focused on the ABLE program and financial tools such as checking, savings, and trust accounts. Several encouraging results were identified. It was apparent that awareness of ABLE, checking and savings accounts were relatively high, and among parents who had these accounts, it was commonly being used to build long-term savings for the child's future and an emergency fund. This is extremely important given the high costs of disability-related expenses, which span across the lifetime (Lunsky et al., 2019). The impact of having an account was also desirable, as parents reported better emotional health knowing that their child's future was more secure after they had passed away. Benefits of having and accessing an account were also reported among children with IDD who had an opportunity to develop independence while simultaneously learning money management skills. Despite these encouraging findings, the study found that utilization of all financial tools relative to the overall study sample (n=176) was low. Only 29.5% of children had an ABLE account, 26% of children had a checking account, 35% had a savings account, and only 13.6% had a special needs trust. Several programmatic and personal barriers were identified which hindered financial planning and utilization. These findings can help inform immediate programmatic changes and long-term policy considerations, which could enhance the

utilization of financial tools among these families, and consequently, decrease levels of poverty, improve parental mental health, and improve outcomes for individuals with IDD.

Limitations and Recommendations

This dissertation addressed three gaps in IDD literature using relevant research methods. However, as with all studies, some limitations should be noted. For manuscript 1, many studies did not provide sufficient demographic detail to discern the number of transition-aged children in the study. As such, the number within this population was statistically estimated using *t*-distributions. In addition, six authors did not reply to the request for missing data and three full-texts remained inaccessible. Moreover, studies were limited to one decade from 2010 to 2020, and gray literature was excluded. As such, there is the potential for publication bias and the risk that some studies which could have met inclusion criteria may have been omitted. Given the unique stressors parents of transition-aged children with ASD face, our findings highlight the need for more intervention research in regards to this specific group and the development of valid and reliable measurement tools.

For manuscript 2, we are unable to infer causality given the cross-sectional nature of the dataset. Furthermore, the use of one question to assess mental health may not accurately capture psychological wellbeing nor the differences which exist between stress, anxiety, and depression. The use of self-report may have also contributed to bias, while the small sample sizes within groups limited our statistical analyses. Future studies

examining the predictors of mental health outcomes among parents of children with ASD may seek to use a longitudinal survey, with an assessment at baseline, and other methods besides self-report to collect data. Also, studies may want to consider sampling a higher number of children with ASD, and specifically more fathers.

For manuscript 3, the sample size was small, and most participants resided in the state of Florida. As a result, the generalizability of the findings is limited. Also, the small groups within demographic variables limited the ability to undertake a regression analysis. As such, future studies should aim for a larger sample size ideally with representation across racial and ethnic groups. Given the cross-sectional design, the study is unable to infer causality, while the sampling design and gift card incentive, creates the likelihood of volunteer bias. Moreover, there is the possibility of social desirability bias given the personal nature of the financial questions. Future studies may wish to consider qualitative or longitudinal studies to further explore financial planning among this parent population, and overcome some of these limitations.

Expected Impact

Findings from this dissertation have the potential to make a major contribution to the literature and the field of IDD. Given the lifelong nature of an IDD diagnosis and the care parents must continue to provide, a life course approach to addressing parental mental health is also needed. By examining measurement tools, interventions, health care demands, and financial planning which encompassed varying age groups of children with IDD, there is an opportunity to enhance the way with which mental health among these

parents is approached. Ultimately, a deeper understanding of parental mental health has the potential to enhance the life trajectory for parents, families, and individuals with IDD through decreased levels of poverty, improved health, and access to education, employment, and independence.

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