THE ROLES OF MARGINALIZATION AND EMPOWERMENT ON INDICATORS OF SYSTEM NAVIGATION AND MENTAL HEALTH FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

by

ROD G. SALGADO

A DISSERTATION

Presented to the Department of Special Education and Clinical Sciences
and the Graduate School of the University of Oregon
in partial fulfillment of the requirements
for the degree of
Doctor of Philosophy

June 2020

DISSERTATION APPROVAL PAGE

Student: Rod G. Salgado

Title: The Roles of Marginalization and Empowerment on Indicators of System Navigation and Mental Health for Parents of Children with Autism Spectrum Disorder

This dissertation has been accepted and approved in partial fulfillment of the requirements for the Doctor of Philosophy degree in the Department of Special Education and Clinical Sciences by:

Laura Lee McIntyre	Chairperson
Wendy Machalicek	Member
Rhonda Nese	Member
Krista Chronister	Institutional Representative

and

Kate Mondloch	Interim Vice Provost and Dean of the Graduate School

Original approval signatures are on file with the University of Oregon Graduate School.

Degree awarded June 2020

DISSERTATION ABSTRACT

Rod G. Salgado

Doctor of Philosophy

Department of Special Education and Clinical Sciences

June 2020

Title: The Roles of Marginalization and Empowerment on Indicators of System Navigation and Mental Health for Parents of Children with Autism Spectrum Disorder

Parents of children with autism spectrum disorder (ASD) may experience stressors in the form of aversion, prejudicial judgement, and discrimination from others for having a child with a disability. These aversive experiences impact their community involvement as well as their mental health. Despite marginalizing experiences, parents may demonstrate psychosocial characteristics, such as empowerment, that promote their community participation. The purpose of this study was to examine the impact of perceived ASD stigmatization and empowerment on the quality of involvement within institutions (e.g., schools) and the relationship of ASD stigmatization with caregiver depression. The sample was comprised of forty-one caregivers of children with ASD between the ages of 7 and 13 years (*M* = 9.54; *SD* = 1.69). Caregiver age ranged from 27 to 55 years (*M* age = 41.02; *SD* = 6.25). Of the sample, 97.6% of parents felt individuals with autism were stigmatized, with 30% reporting ASD stigma has been very or extremely difficult for family functioning. Child adaptive behavior, family income burden, and caregiver depression were all associated with ASD stigmatization. Main findings suggest empowerment significantly predicts family involvement beyond the negative impact of

ASD stigmatization. Perceived difficulty of ASD stigmatization significantly predicts caregiver depression beyond the impact of other forms of discrimination. Given the heightened risk and potential impact of stigmatization for parents of children with ASD, there is a need to understand the underlying psychosocial and systemic mechanisms that may ameliorate or affect the ways in which families interact with their communities.

CURRICULUM VITAE

NAME OF AUTHOR: Rod G. Salgado

GRADUATE AND UNDERGRADUATE SCHOOLS ATTENDED:

University of Oregon; Eugene, Oregon
University of Wisconsin, Madison; Madison, Wisconsin

DEGREES AWARDED:

Doctor of Philosophy, School Psychology, 2020, University of Oregon
Master of Science, Special Education, 2014, University of Wisconsin, Madison
Bachelor of Arts, Psychology, Spanish, 2011, University of Wisconsin, Madison

AREAS OF SPECIAL INTEREST:

Neurodevelopmental Disabilities
Cultural Adaptation of Evidence-Based Practices
Disparities in Service Access for Parents of Children with Disabilities
Testing and Assessment Bias

PROFESSIONAL EXPERIENCE:

Pediatric Psychological Assessor, Child Development and Rehabilitation Center, Eugene, Oregon, 2017-2019

Family Interventionist, Fisher SNAP Lab, University of Oregon, Eugene, Oregon 2017- 2018

Practicum Student and Preschool Transition Specialist, Springfield School District, Springfield, Oregon, 2016-2018

Parent Group Interventionist, Oregon Social Learning Center, Eugene, Oregon, 2015-2018

GRANTS, AWARDS, AND HONORS:

Graduate Teaching Fellowship, University of Oregon, 2014-2019

ACKNOWLEDGMENTS

Thank you first and foremost to my advisor, Laura Lee McIntyre; without her mentorship, ongoing support, and faith in my vision this would not have been possible. Thank you to Wendy Machalicek and Rhonda Nese for their participation and valuable contributions to my committee. Special thanks to my former supervisor and mentor, Krista Chronister, for serving as my institutional representative - our social justice work helped inspire my attention to the deleterious effects of discrimination. Finally, sincerest gratitude to my fellow assessors over the years from the many iterations of the data collection team on the Oregon Early Autism Project – your time and energy has been instrumental to this process and does not go unnoticed. This investigation was supported by a NIH/NICHD grant awarded to Laura Lee McIntyre at the University of Oregon (R01 HD059838-03S1).

DEDICATION

For my parents - whose constant encouragement allowed a little queer brown boy growing up in a small town in Wisconsin the opportunity to dream big.

For everyone who has ever felt marginalized or maligned by society, either as a function of race, culture, sexuality, gender expression, neurodivergence, immigration status or any beautiful combination of the aforementioned – I see you. I feel you. My passion is to continue working towards a world in which our differences are truly celebrated and appreciated. May this only be the beginning.

TABLE OF CONTENTS

Chapter Page

I. LITERATURE REVIEW 1

  Stigmatization for Parents of Children with ASD 1

  Theoretical Framework 3

  Experiences of Parents of Children with ASD 5

  Family Involvement 10

  Empowerment 12

  Research Questions 17

II. METHODOLOGY 21

  Participants 21

  Procedure 21

  Measures 22

    Demographics 22

    Child Functioning 22

    Marginalization 23

    Family Empowerment 25

    Family Involvement 25

    Caregiver Depression 25

III. RESULTS 27

  Analysis Overview 27

    Preliminary Analyses 27

      Question 1 31

Chapter Page

Question 2 35

Question 3 38

Question 4 39

Question 5 41

Question 6 44

IV. DISCUSSION 47

Summary 47

Discussion of Key Findings 49

Limitations 53

Contributions and Future Directions 55

APPENDICES

A. PERCEIVED ASD STIGMATIZATION 57

B. PERCEIVED SOCIODEMOGRAPHIC DISCRIMINATION 58

C. FAMILY INVOLVEMENT QUESTIONNAIRE 60

D. CENTER ON EPIDEMIOLOGICAL STUDIES DEPRESSION 61

E. FAMILY EMPOWERMENT QUESTIONNAIRE 62

REFERENCES CITED 63

LIST OF FIGURES

Figure Page

1. Logic Model 20

LIST OF TABLES

Table Page

1. Demographic Characteristics of the Sample 29

2. Descriptive Information of the Sample 32

3. Bivariate Correlations for ASDD, FES, PDIS, FIQ-E, CES-D, Child Characteristics, and Family Demographics 34

4. Hierarchical Regression Examining Family Empowerment Predicting Family Involvement 39

5. Hierarchical Regression Examining Difficulty of ASD Stigma Predicting Family Involvement 41

6. Hierarchical Regression Examining Empowerment Predicting Family Involvement Beyond Difficulty of ASD Stigma 43

7. Hierarchical Regression Examining Daily Discrimination and Difficulty of ASD Stigma Predicting Caregiver Depression 45

CHAPTER I

INTRODUCTION

Stigmatization for Parents of Children with ASD

Parents of children with autism spectrum disorder (ASD) face incredible parenting stress, which has been examined extensively in the literature (e.g., Davis & Carter, 2008). What is less investigated is the stress that may be experienced as a function of parents' interactions within their communities. In some instances, parents may experience stressors in the form of aversion, prejudicial judgement, and overall prejudicial treatment and discrimination from others for having a child with a disability (Corcoran, Berry, & Hill, 2015; Kinnear, Link, Ballan, & Fischbach, 2016). Apart from stigmatization as a parent of a child with a disability, parents may experience courtesy stigma, or stigmatization felt on behalf of their child with a disability (Green, 2003) and parents of children with ASD may experience more courtesy stigma compared to parents of children with other disabilities (e.g., intellectual disability, physical disability; Werner & Shulman, 2015). Parents of children with a disability may also be more susceptible to experiencing psychological distress (e.g., stress, anxiety, burnout) compared to parents of typically developing children, and parents of children with ASD are particularly vulnerable to presenting with these concerns (Weiss, 2002). Having a child with ASD presents with unique challenges for parents, particularly in public settings, as oftentimes a child with ASD may engage in challenging behaviors but may not appear to have a disability given that they do not have obvious physical differences in their appearance (Corcoran et al., 2015). These fears are not without merit: for example, results from a study by Butler and Gillis (2011) suggest that individuals without ASD held significant levels of stigmatizing beliefs towards individuals with ASD related to idiosyncrasies in social behavior. As such, parents of children with disabilities may fear a stigmatized status for their children that would result in "rejection, mistreatment, social isolation, and loneliness" for their children (Green, 2003, p. 1362).

Families may isolate themselves from potentially beneficial community supports for fear of a negative reaction from others (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). This isolation may serve as a barrier to full participation and involvement within the larger community. A sense of social isolation may be counterproductive in establishing appropriate community or social supports. Research on the relationship of individuals with preexisting mental health conditions and social isolation suggests their community involvement is impacted by the activation of negative schemas (Angermeyer & Matschinger, 2003; Phelan & Link, 1998). Research exploring the relationship of stigmatization and social support for individuals with psychiatric conditions suggests internalized stigmatization is subject to amelioration in the presence of strong social supports within a year of their diagnosis, emphasizing the importance of strong social ties in the face of impactful life circumstances (Mueller, Nordt, Lauber, Rueesch, Meyer, & Roessler, 2006). While a literature review did not yield any direct applications for families of children diagnosed with ASD, it stands to reason that the level of community involvement and quality of community relationships may be mitigated by the additive stress of perceived stigmatization. Apart from being more likely to experience psychological distress, parents of children with ASD may also be more prone to experience childrearing stress and attachment-related anxiety compared to parents of typically developing children (Keenan, Louise, Gray, & Rinehart, 2016).

Overt discriminatory actions and perceived stigmatization may further affect family mental health and well-being by creating a subjective burden that exacerbates overall parental distress (Kinnear, Link, Ballan, & Fischbach, 2016). Promoting positive psychosocial characteristics and/or social and community supports may therefore be invariable in combating potentially deleterious effects perceived stigmatization may add to an already exhausted list of potential stressors experienced by parents of children with ASD.

With that said, there is a dearth of research dedicated to examining the direct impact of perceived disability stigmatization (Ali, Hassiotis, Strydom, & King, 2012) and none that examine perceived stigmatization's effects on the quality of involvement with community supports or institutions (e.g., schools). Given the heightened risk and potential impact of stigmatization for parents of children with ASD, there is a need to understand the underlying psychosocial and systemic mechanisms that may ameliorate or affect the ways in which families interact with their communities (e.g., schools or other service systems).

Theoretical Framework

The myriad of environmental factors (e.g., cultural, institutional, communal, familial) that may interact and influence psychological development can be organized within a nested systemic framework, or ecological systems theory. This model includes five central levels of environmental systems (i.e., chronosystem, macrosystem, exosystem, mesosystem, and microsystem). Each system uniquely interacts to shape the individual experience (Bronfenbrenner, 1979).

Pertinent to the discussion of perceived stigmatization for parents of children with ASD, the macrosystem would house the specific schemas, ideologies, and cultural norms related to having a child with a disability/neurodevelopmental disorder such as ASD. Within the exosystem are the experiences outside of the family's control, for example, the explicit discrimination or marginalization on the basis of ASD related schemas in the macrosystem (e.g., policies and bureaucratic red tape for accessing ASD specific evaluation, barriers to service provision). The mesosystem would be characterized by the interactions between microsystems such as institutional bodies (e.g., health services, school, religious institutions), community supports (e.g., club affiliations, neighborhood), social circles (e.g., peer groups), and families. These microsystems in turn directly impact the individual who may be characterized by their unique dispositions and demographic attributes. Encapsulating all of this is the chronosystem, which describes all nested ecological systems and the individual within the context of sequential events or histories. Related to families of children with ASD this may refer to age of ASD diagnosis, eligibility for Early Intervention (EI) services, incremental changes of the policy landscape, etc. The systemic characterization of ASD related courtesy stigma is consistent with recent research findings suggesting that, if present, perceived stigmatization for having a child with ASD is experienced and transcends across contexts (i.e., school, public, family, friends; Broady, Stoyles, & Morse, 2017).

With that said, the current study focuses on the interactions between variables of the exosystem, mesosystem, and microsystems within the ecological systems model. Particularly of interest are ASD held beliefs within the macrosystem as measured by perceieved stigmatization or discrimination within the exosystem, and its potential impact on the interaction of different microsystems such as family systems and related service systems (e.g., schools). Informed by these various systemic experiences within the environment, it is imperative to also consider the systemic interaction of personal psychosocial characteristics.

Experiences of Parents of Children with ASD

According to the latest monitoring report published in 2018 by the Centers for Disease Control (CDC), the prevalence of ASD in the United States is estimated to be on average 1 in 59; a significant change from early monitoring reports in the 1960's, which estimated ASD prevalence at approximately 1 in 2,000 (2018). Indeed, a much larger number of individuals with ASD are now being identified and served, demystifying what was once considered a rare and very severe condition. However, despite improved screeners and allied medical professional's ASD specific knowledge to promote earlier and accurate identification and overall increased awareness and understanding of ASD in the general public (CDC, 2016; Mandell, Novak, Maytali, & Zubritsky, 2005), research suggests ASD researchers and parents of children with ASD concur that individuals with ASD continue to be stigmatized, and negative effects from stigmatization for individuals with ASD may include being "made to feel inferior, shamed, isolated, or their self-image is damaged" (Fischbach et al., 2015, p. 357).

Characterized by deficits in social functioning, communication, and/or repetitive or stereotyped behaviors (American Psychiatric Association, 2013) children with ASD present unique and diverse challenges for caregivers, which can be perceived negatively by individuals outside of the purview of institutionalized medical knowledge of ASD (Farrugia, 2009). The experience of perceived courtesy stigmatization, particularly as it relates to symptoms of a child's behavioral disorder, may erode the sense of being a 'good parent' (Eaton, Ohan, Stritzke, & Corrigan, 2016). Apart from the courtesy stigma felt on behalf of individuals with ASD, evidence suggests parents of children with ASD oftentimes face stigma themselves for being a parent with a child diagnosed with ASD and may experience a multitude of socially isolating and stigmatizing interactions, including but not limited to: being judged as an ineffective parent for failing to control their child's behavior; corrected for using physical strategies such as restraint for managing escalating behaviors for their child with ASD; or perceived as the causal agent of their child's ASD, as a result of genetic heritability, cold and distancing parenting, or even for vaccinating their child (Corcoran, Berry, & Hill, 2015; Farrugia, 2009; Fischbach et al., 2015; Kinnear, Link, Ballan, & Fischbach, 2016).

ASD and parental distress. Parental self-blame for causing a child's disability may be exacerbated by societal stigma that may link parents with the etiology of their children's disabilities, and ultimately negatively impacts family-well-being (Moses, 2010). Despite no evidence to support the link between vaccinations and ASD, parents of children with ASD may experience the pervasive self-blame and subsequent societal stigmatization from this logic. Regarding internalized beliefs of the etiology of ASD, Fischbach et al. (2015), found a significant number of parents of children with ASD upheld the belief or suspicion that vaccinations were an attributing factor to their child's ASD, and reported they would either hesitate or have hesitated in vaccinating subsequent children.

Parental distress and perceived stigmatization may occur as early as when parents are initially faced with a diagnosis. Parents may report feeling "denial, grief, and disappointment" (Corcoran, Berry, & Hill, 2015, p. 358); and may need to take the time to come to terms and grieve the change in child-rearing and child outcomes from what was expected. Stereotypes of children with ASD and fear of a stigmatized, "atypical" status for a child may cause a heavy emotional load on parents as they wrestle with the implications of an ASD label in a familial and cultural context as well as in relation to system navigation for ASD services and resources (Farrugia, 2009; Russell & Norwich, 2012). Interestingly, research suggests labels alone may have little impact on the stigmatization individuals without ASD feel towards individuals on the autism spectrum. Stigmatization may be restricted to expression of ASD specific symptoms (e.g., stereotypy; Butler & Gillis, 2011). A study by Kinnear and colleagues (2016) found a relationship between ASD related behavioral expressions and both perceived stigmatization and overall reported difficulty in raising a child with ASD. In another study on the usage of ASD "disclosure cards" (i.e., an ASD 'label' is provided in context) for vignettes of children engaging in challenging behavior, participants rated parents as having fewer skill deficits and rated themselves as reacting less negatively to parent-child dyads when provided with the disclosure card stating the child had ASD than when they were not (Austin, Zinke, & Davies, 2016). In a follow-up study, Austin, Galijot, & Davies (2018) found community parent participants presented with parent-child dyads in the context of a disclosure card or disclosure bracelet had reduced negative perceptions of parents of children with ASD compared to a nondisclosure group (e.g., less critical of caregiver, felt reduced need to protect own child and less embarrassment for caregiver). Another study investigating the negative attitudes of an ASD label in the context of updates to diagnostic categorizing for individuals with Asperger's Disorder (AD) found that in a large sample of adults (*N* = 465) who were presented with vignettes describing ASD symptoms with varying qualifiers (i.e., were ascribed either to an ASD, AD, or no label condition) found no significant correlation between ASD label and stigma (Ohan, Ellefson, & Corrigan, 2015). These results are congruent with disability discourse that distinguishes stigmatization relative to medical and social constructs. While parents of children with ASD may still experience stigma on the basis of an ASD label, recent qualitative research reveals parents of children with ASD may actually invoke a medical understanding of ASD in order to protect against a socially constructed view of disability stigma that centralizes unaccommodating social structures (e.g., beliefs of social appropriateness, etc; Manago, Davis, & Goar, 2017). Ergo, while ASD labelling may not consistently explain stigmatization, behavioral symptomology associated with ASD may be a more reliable predictor for perceived negative judgement or stigmatization.

Planning for and having an adult child with ASD may also present with distinctive challenges. Parents may consistently worry about post-secondary outcomes, including accommodations for lifelong care, and whether adequate care and supports can be provided for their child with ASD when they are no longer able to provide said care, thus adding to ongoing stressors (Corcoran et al., 2015). A study by Seltzer and colleagues (2009) found parents of adult children with disability (*M* = 29.9) reported daily presentations of higher stress, negative affect and physical symptoms at midlife age (*M* = 57.4 years) compared to a group of similarly aged parents of typically developing adult children. Research has also suggested stigmatization for having a child with a disability may be a contributor for poorer health outcomes across the lifespan. A recent study by Marsack and Perry (2018) investigating the experiences of lifelong caregivers of adult children with ASD found caregivers faced social exclusion related to the sheer intricacy of their caregiver responsibilities, the impact on daily routines, and ASD specific stigma. In a longitudinal study on parents of individuals with developmental disabilities (DD; *N* = 128) using data from the Survey of Midlife in the United States (MIDUS), authors Song, Mailick, and Greenberg (2018) found stigma was associated with poor health risk for parents. Parents identified as having children with DD at time 1 noted significantly higher levels of stigma (e.g., embarrassment, shame) as well as daily discrimination compared to parents of children without disabilities ten years later at time 2; ten years after that at time 3 these same parents reported poorer health and more chronic ailments. It is apparent the distinct experience of being a caregiver of a child with ASD has lifelong implications and are present from the age of first concern. Parents of children with disabilities are faced with systemic and institutionalized hurdles in promoting positive life outcomes for their children while simultaneously suffering from chronic parental distress (Marsack & Perry, 2018; Song, Mailick, Greenberg, & Hong, 2018; Seltzer et al., 2009). As a mainstay in service delivery for children with ASD, effectively navigating schools and school culture may be imperative for effective service access and promoting overall family well-being and functioning.

Parents and school isolation. Children with ASD are particularly at risk for presenting with behavioral challenges, specifically, externalizing behaviors (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). The perceived stigmatization of parents of children labeled or considered "at risk" for poorer behavior outcomes may hinder their participation (Russell & Norwich, 2012). The behavioral concerns that children with ASD present in school contexts may be particularly severe (e.g., hyperactivity, aggression; Hill et al., 2014; Konst, Matson, Goldin, & Rieske, 2014) and are more likely to be disruptive to overall classroom functioning (McCurdy & Cole, 2014). Parents of children who present with behavioral difficulties may be more likely to miss or pass opportunities to engage with schools (Moore et al., 2016). Moreover, students labeled with disabilities are more likely to experience poorer educational and occupational outcomes when compared to their counterparts in general education (Shattuck, et al., 2012) and children with ASD are at an increased risk for presenting with academic concerns (Keen, Webster, & Ridley, 2016). Some research suggests such disparities for individuals with disabilities may be attributed in part to the effects of labeling theory, or the stigma associated with a disability label (Shifrer, 2013). Hence, chronic societal stressors, such as prejudicial treatment for having a child labeled with a disability corresponding to a behavior phenotype of challenging behavior, may impact participation with school systems. Hence, promoting the involvement of families/parents of children with ASD within schools is critical for positive outcomes for the child and family.

Family Involvement

Family/parental involvement in schools can be defined as the level with which at least one parent is involved in the student's life, specifically in the school context. In practice this can be fluid communication between the teacher and parent, a parent placing a high value on academics and education, and a family's involvement in school activities (Coatsworth, Pantin, & Szapocznik, 2002; Crean, 2004). Levels of parental engagement have been found to be invaluable assets in schools, as it may raise student and teacher expectations and accountability for students (Romero & Ruiz, 2007). Family/parent involvement in schools has been linked to a myriad of benefits for students. For example, higher levels of parent involvement are associated with a more desirable academic performance (Calzada, et al., 2015; Eccles & Harold, 1996; Galindo & Sheldon, 2012), and specifically, this may relate to levels of parental expectation for children's educational achievement (Fan & Chen, 2001). Evidence suggests however, that levels of parent involvement are impacted by both caregivers' psychosocial characteristics (e.g., level of self-efficacy) as well as environmental interactions with their child's teacher (e.g., teacher attitudes, lack of support; Grolnick, Benjet, Kurowski, & Apostoleris, 1997).

Educational involvement for parents of children with ASD. Specific to children with ASD, families of children with ASD who maintain higher levels of educational involvement may demonstrate higher levels of parental self-efficacy and lower levels of distress (Benson, 2015). However, a lack of parental involvement may have adverse effects for families of children with ASD. Parents of children with ASD are at a higher risk for lower involvement in their child's school as well as substandard relationships with their child's teacher (Garbacz, McIntyre, & Santiago, 2016). Research suggests lower levels of family involvement may negatively impact satisfaction in early intervention services as well as success in the transition process of adolescents with ASD (Kramer, 2008; Kraemer, 2012; Popp & You, 2016). Negative experiences in accessing ASD related services may predict family involvement and the quality of parent-teacher relationships (Garbacz, McIntyre, & Santiago, 2016). Evidence based interventions for children with ASD that explicitly include a home-school component have been found to improve the parent-teacher relationship (Garbacz & McIntyre, 2015) which is consistent with research demonstrating parental involvement may result in improved skill generalizability for children with ASD (Burrell & Borrego, 2012). Nevertheless, given the potential myriad of compounding variables affecting parental involvement, parents of children with ASD may choose to home school their children at the risk of furthering isolation and less social and educational support (McDonald, 2011). Examining positive psychosocial attributes that promote effective system navigation is imperative for families of children with ASD.

Empowerment

The potential hindrances to a parent's participation within their child's school resulting from pervasive stigmatization may be influenced by various risk and protective factors. For example, effective psychological coping mechanisms and socio-demographic characteristics of caregivers may counteract caregiver's feelings of distress and impact on community participation (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Lovell & Wetherell, 2018; Lyons, Leon, Roecker-Phelps, & Dunleavy, 2010). Empowerment as a psychological construct, can be defined as a state as opposed to a process, following the conceptual framework of the developers of the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992). As such, empowerment is defined as the ability of an individual or group to act on its own accord in an effort to further a larger degree of control over one's life/lives, and is a dynamic trait readily influenced by interactions with the environment (Singh et al., 1995). Empowerment is continuous to varying degrees, and can be expressed within a family, service system, or larger community/political realm (Koren et al., 1992). Related to parents of children with ASD, evidence suggests higher levels of empowerment may be associated with lower levels of maternal distress (Weiss, MacMullin, & Lunsky, 2015) and higher levels of empowerment may lower levels of crisis in caregivers of children with ASD (Weiss & Lunsky, 2011). In mitigating the psychological distress associated with the strong emotional response parents may experience receiving an ASD diagnosis, a study by Banach, Iudice, Conway, Couse (2010) found increased family participation in community-based resources (e.g., support group, advocacy skills group) was associated with increased levels of empowerment. Research on mothers of children with ASD demonstrated higher reports of parental empowerment may lessen the stress and objective burden of having a child with a disability (e.g., ASD) and increase levels of families' community participation (Burke, Magaña, Garcia, & Mello, 2016). Parents of children with ASD may also report higher levels of empowerment in relation to accessing evidence based ASD interventions such as Applied Behavior Analysis (ABA; Dillenburger, Keenan, Gallagher, & Mcelhinney, 2002), Overall, mounting evidence suggests an interaction between parent empowerment and participation in community-based resources.

Sociodemographic factors and child characteristics. Perceived discrimination as a function of various sociodemographic factors may have adverse effects on psychological functioning. Research from the Midlife in the United States (MIDUS) has yielded several investigations on the effects of perceived discrimination for different marginalized identities. For example, one study demonstrated that for a subset of African American participants (*N* = 592), perceived discrimination was associated with emotional dysregulation in the setting of stressor appraisals and poorer functioning of close relationships (Doyle & Molix, 2014). Relatedly, a different investigation using the MIDUS sample found that perceived discrimination was a negative predictor of overall well-being (e.g., happiness, sense of growth and mastery, perceived autonomy, self-acceptance) for individuals who identified as women (Ryff, Keyes, & Hughes, 2003). Regarding correlations with socioeconomic disadvantage (SED), another study found perceived discrimination partially mediated the relationship between family income and self-reported health (Fuller-Rowell, Curtis, Chae, Ryff, & Freedland, 2018). Hence, caregivers of children with ASD may present with sociodemographic variables resulting in their own unique, additive stigmatization.

With that said, there also appears to be a distinctive experience in the interaction of sociodemographic characteristics and being a parent of a child with ASD. Research continually supports a disparate experience with ASD related services and resources for diverse families, even before an ASD diagnosis is even given (Hidalgo, McIntyre, & McWhirter, 2015); Ijalba, 2016; Liptak, et al., 2008; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell & Novak, 2005; Mandell et al., 2009). For example, in a study examining the sociodemographic differences in parental experience with ASD diagnostic procedures and current services, Hidalgo et al. (2015), found satisfaction varied with levels of education and family income, and satisfaction with pediatric services varied by income. Understanding predictors of perceived ASD specific stigmatization for diverse populations has been a worthwhile endeavor. Zuckerman et al. (2018), conducted an exploratory, cross-sectional study on parental perceptions of community-based ASD stigma in a diverse sample of Latinx and non-Latinx White parents of children with ASD across multiple sites and found higher levels of reported stigma were predicted by ASD service dissatisfaction (i.e., services did not meet needs), the child’s insurance (i.e., public or private), lack of ASD specific knowledge, family composition (e.g., co-parents, siblings with ASD), and ASD symptom severity. These findings add to the extant literature on the uniqueness of ASD specific stigmatization and its interconnectedness with various systems.

In order to gain a fuller appreciation for the role of stigmatization for parents of children with ASD, it is important to consider the intersection of marginalized identities and their additive effects on ASD related stigmatization. These include but are not limited to variables such as: level of education, income, race and ethnicity. For example, related to income, the total health care cost of ASD has risen and, therefore, the cost of quality evidence-based services may be a concern for families (Wang & Leslie, 2010). Research suggests the health care cost of ASD may be significantly more substantial when compared to the health care cost of other disabilities (Tregnango & Cheak-Zamora, 2012). To pay for services not covered by insurance, families may supplement with out-of-pocket expenditures (Young, Ruble, & McGrew, 2009). While there is extant literature to suggest that level of income may play a role in access to quality services and care, there does not appear to be research on the additive effects of low-income stigma on courtesy disability stigma for parents of children with ASD.

Lower levels of formal education may also present as a pertinent risk factor. For example, parents with less educational attainment may feel less efficacious in navigating systems of care for their child with ASD and, if lacking ASD specific knowledge, may be more susceptible to believing and internalizing negative ASD schemas (e.g., the role of vaccinations; Fischbach et al., 2016). Parents with less formal education may also exhibit lower levels of family involvement (Fantuzzo, Tighe, Childs, & Pressley, 2000). Caregivers perceiving higher levels of stigmatization may be less likely to navigate systems (e.g., school systems) efficiently (Green, 2003; Kinnear et al., 2016), and lower level of engagement on the basis of education may be a proxy for more insidious variables (e.g., discrimination on the basis of less formalized education, lacking requisite knowledge to engage, work schedules, etc).

Pervasive disparities continue to exist for racially and ethnically diverse children with ASD. Racially and/or ethnically diverse children with ASD and their families undergo unique experiences in overcoming barriers to services and resources. From increased number of office visits needed for ASD referral compared to White counterparts, biases resulting in older age of diagnosis for ASD compared to White counterparts, distrust in the system coinciding with reticence on using evidence-based practices, and lack of native language usage and support for families of children with ASD during service provision, it's evident total parental distress for having a child with ASD is compounded significantly with racial/ethnic minority status (Ijalba, 2016; Liptak, et al., 2008; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell & Novak, 2005; Mandell et al., 2009) that may contribute to perceived stigmatization. These characteristics may intersect, exacerbating both the objective and subjective burden of having a child with a disability such as ASD putting caregivers at higher risks for community isolation and poorer system navigation.

Given the diverse phenotypic expression of ASD, it is imperative to consider compounding attributes children with ASD may present that may contribute to parents' perceived stigmatization for having a child with ASD, their level of empowerment and subsequent community involvement. As such, research supports a relationship between increased child problem behavior and lower empowerment (Weiss, Cappadocia, MacMullin, Viecil, & Lunsky, 2012; Weiss, MacMullin, & Lunsky, 2015) and, as previously discussed, a relationship between behavioral presentations of ASD (e.g., lower social functioning, increased externalizing behaviors) and negative judgement or stigmatization (Austin et al., 2016; Austin et al., 2018; Butler & Gillis, 2011).

Research Questions

This study aimed to explore the relationship between parents' subjective experience of marginalization and empowerment on mental health and navigation of service systems. Following the logic presented, empowerment, as well as perceived stigmatization for having a child with ASD, may affect the quality of educational engagement by causing more social isolation from community-based systems (i.e., schools) as well as affect overall mental health. A logic model describes the hypothesized associations (Figure 1). The research questions this study will aim to answer are as follows:

1. *To what extent are indicators of marginalization, such as perceived ASD stigmatization and endorsed daily discrimination, or psychosocial traits such as empowerment, related to family characteristics such as child functioning or parent demographics?* It is hypothesized child functioning variables, or adaptive behavior and ASD severity, will be significantly associated with domains ASD stigmatization and empowerment. It is hypothesized parent demographics, or parent education and perceived income burden, will have significant associations with daily discrimination and empowerment.
2. *How do family characteristics (i.e., child functioning or parent demographics), indicators of marginalization (i.e., perceived ASD stigmatization and endorsed*

daily discrimination), and empowerment relate to indicators of family system navigation (i.e., family involvement) and parent mental health (i.e., caregiver depression)? It is hypothesized indicators of marginalization, or perceived ASD stigma and perceive daily discrimination, will be significantly associated with both outcome variables (i.e., family involvement and caregiver depression). It is hypothesized empowerment will be significantly associated with levels of family involvement.

3. *After controlling for family characteristics (i.e., parent demographic and child functioning), does empowerment predict family involvement?* It is hypothesized that empowerment will significantly predict family involvement, above and beyond family characteristics.
4. *After controlling for family characteristics (i.e., parent demographic and child functioning), does perceived ASD stigmatization predict family involvement?* It is hypothesized ASD stigmatization will significantly predict family involvement, above and beyond family characteristics.
5. *After controlling for family characteristics (i.e., parent demographic and child functioning), does empowerment predict family involvement beyond perceived difficulty of ASD stigma?* It is hypothesized empowerment will significantly predict family involvement, even when controlling for both family characteristics and indicators of marginalization.
6. *After controlling for family characteristics (i.e., parent demographic and child functioning), does perceived ASD stigmatization predict caregiver depression beyond endorsed daily discrimination?* It is hypothesized perceived ASD

stigmatization will significantly predict caregiver depression even after controlling for family characteristics and daily discrimination, thus suggesting a unique effect for the phenomenon of courtesy stigma on behalf of a child with a disability.

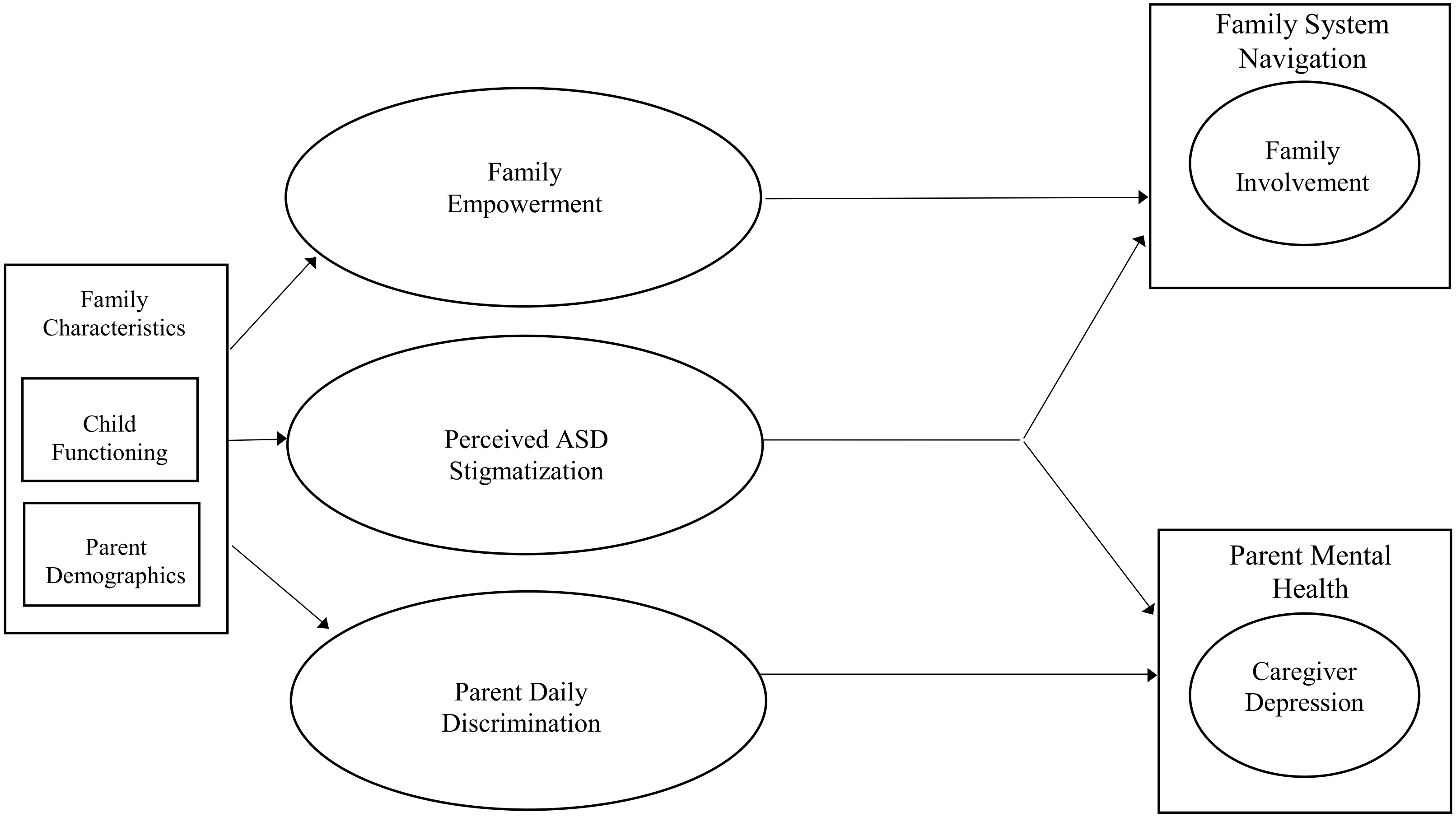


Figure 1. Logic model of proposed study.

CHAPTER II

METHODOLOGY

The data collected for this cross-sectional study is part of the third wave of data collection for a larger exploratory investigation of child, family, and community variables associated with early identification and treatment of ASD, or Oregon Early Autism Project (OEAP- 3; R01HD059838; McIntyre, PI).

Participants

Primary caregivers of children with ASD who participated in the second wave of data collection of the Oregon Early Autism Project were contacted and invited to participate in a third wave of data collection (OEAP-3). Participating OEAP families were previously recruited through local service and resource organizations for families of children with disabilities and school districts in the Pacific Northwest. The current study recruited 41 participants from the Wave 2 sample ($N = 75$), representing slightly more than half of the families who previously participated.

Procedure

Participants were contacted and invited to participate using an invitation letter. A brief telephone interview was completed with interested caregivers to determine whether the family meets inclusionary criteria. Criteria for inclusion included (a) the child has a medical diagnosis of ASD or special education eligibility under the disability category of autism, (b) the child is currently of elementary school-age (i.e., kindergarten through 5th grade), and (c) the child has lived with the primary caregiver for at least one year prior to participation. If inclusionary criteria were met, an overview of the study and participation requirements were described. Once consent for participation was ascertained, a mail home packet was sent to the participant's home and parent interview was completed in person or by phone.

Data for this study was collected from both a mail home packet and subsequent interview. Research assistants scheduled a parent telephone or in-home interview. The interview, conducted by a research assistant, lasted approximately 1 ½ hours. Relevant to this study, the mail home packet included a cover letter, informed consent, and a series of questionnaires on marginalization, empowerment, system navigation, and mental health. During the parent interview, each participant was administered measures on child and family demographic information, service utilization, and standardized psychological assessments of autism severity and adaptive behavior. Parents could elect to participate in an in-person interview or by phone. For their participation, caregivers received a $75 honorarium.

Measures

Demographics. Sociodemographic information was collected via questionnaire as part of the interview with the primary caregiver. Demographic information on both the parent (e.g., age, gender, family income, perceived income burden, level of education, employment status, and caregiver race and ethnicity) and child (age, gender, race/ethnicity, special education eligibility, special education services received, current grade level in school) was collected.

Child functioning. Information describing the child's ASD presentation and functioning was determined using various instruments. In determining the child's overall level of adaptive function and ASD symptom severity, research assistants during the parent interview administered both the Childhood Autism Rating Scale, Second Edition (CARS-2; Schopler, Van Bourgondien, Wellman, & Love, 2010) as well as the Survey Interview Form of the Vineland

Adaptive Behavior Scales – Third Edition (Vineland-3; Sparrow, Cicchetti, & Saulnier, 2016), respectively.

ASD symptom severity. The CARS-2 is a standardized diagnostic tool that produces an ASD symptom severity profile and identifies children with ASD using cutoff scores. A child's ASD symptoms across 15 domains compared to same-age peers. Items are presented on a 7-point scale with higher scores indicating more severe symptoms. The sum of all domains yields an overall symptom severity score which has a range of 15 to 60. Diagnostic cutoff indicating mild ASD is 30, while severe ASD is described as a cutoff score ≥ 38. The CARS-2 has strong internal consistency reliability ($\alpha = .93$; Vaughan, 2011).

Adaptive behavior. The Vineland-3 is a standardized instrument of adaptive behavior that provides standard scores for the communication, daily living skills, and social skills indices and comprise a measure describing overall adaptive functioning, the Adaptive Behavior Composite standard score ($M = 100$, $SD = 15$). Impaired functioning is indicated by a standard score ≤ 69. The internal consistency reliability of the Vineland-3 Survey Interview Form indices and overall composite are as follows: Communication $\alpha = .95$, Daily Living Skills $\alpha = .94$, Socialization $\alpha = .96$, Adaptive Behavior Composite $\alpha = .98$ (Sparrow et al., 2016).

Marginalization. Relevant measures for this study were included in the mail home packet will be the multiple-item scales on stigma for parents of children with ASD (see Appendix A; Kinnear et al., 2016) and well as multiple-item scales from the *Perceived Discrimination* scales of the MIDUS 2 (see Appendix B; Williams et al., 1997).

Perceived stigmatization. ASD stigmatization scales developed by Kinnear and colleagues (2016) were included and will serve as the primary data collection for perceived stigma for having a child with ASD. The related scales, entitled *Parent's Perception of Public*

Stereotypes, describe stereotypes parents believe the public holds about individuals with ASD and have adequate internal consistency reliability. The first stigma scale is entitled, *Competence in Social Roles*, which is a 3-item scale ($\alpha = .84$) that measures ASD specific stereotypes regarding ‘‘marriage’’, ‘‘holding a job’’, and ‘‘living independently.’’ The second stigma scale, entitled, *Autism Causes and Characteristics* contains 5 items ($\alpha = .62$). Parents are asked to respond whether they believed most, some, or only a few people believe: ‘‘Individuals with autism cannot be a good friend because of their autism’’; ‘‘Parents can cause their children’s autism because of their parenting style’’; ‘‘Individuals with autism are ‘mentally ill’’; “Individuals with autism are dangerous or a threat to others”; and “Individuals with autism have intellectual disabilities”. Three single item measures were also included to assess global impacts of stigmatization and difficulty raising a child with ASD. The single-item measures were as follows: “How difficult has the stigma that is often associated with autism been for you and your family?”; “Overall, how difficult would you say it has been for your family to have a child on the autism spectrum?”; and “Do you think individuals with autism are stigmatized?”.

Perceived discrimination. To account for the additive nature of stigmatization, measures on perceived discrimination from the MIDUS 2 will be included in this study (i.e., *Lifetime Discrimination, Daily Discrimination*). The MIDUS 2 *Perceived Discrimination* scales were created to investigate the deleterious effects of racial discrimination in urban areas. Questions ask how often caregivers experience each of the following types of discrimination: “You are treated with less courtesy than other people,” “You are treated with less respect than other people,” “You receive poorer service than other people at restaurants or stores,” “People act as if they think you are not smart,” “People act as if they are afraid of you,” “People act as if they think you are dishonest,” “People act as if they think you are not as good as they are,” “You are called names or insulted," and "You are threatened or harassed"(α = .92; Williams et al., 1997). As previously reviewed, parents of children with disabilities have reported more perceived discrimination on these measures (Song et al., 2018) and in possible conjunction with other marginalized statuses, a holistic view of stigmatization is warranted.

Family empowerment. The Family Empowerment Scale (FES) is a measure of empowerment for families with children who have emotional, behavioral, or mental health concerns. For the purposes of this study, the FES will be provided for parents to fill out in the mail home packet and measures key aspects of caregiver empowerment across domains related to (a) Family, (b) Service System, and (c) Community/Political. Internal consistency reliability ranges from .87 to .88 (see Appendix E; Koren, DeChillo, & Friesen, 1992).

Family involvement. Included in the mail home packet, parents were asked to report their involvement in their child's education using the Family Involvement Questionnaire-Elementary version (FIQ-E; see Apendix C; Manz, Fantuzzo, & Power, 2004). The FIQ-E is a multi-dimensional scale using caregiver report. Parents will rate 46 items using a 4-point scale of increased likelihood of engagement. The FIQ-E yields a composite score comprised of scales measuring (a) Home-Based Involvement (α = .88), (b) School-Based Involvement (α = .84), and (c) Home–School Communication (α = .91).

Caregiver depression. To evaluate caregiver mental health, parents were asked to complete the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). This measure consists of 20 items where the parents indicate how often they experience certain events and symptoms on a 4-point Likert scale. Ratings range from 0 (rarely or none of the time) to 3 (most or all of the time). Items are summed to provide a total score (range 0 – 60) where higher scores indicate more depression symptomology. The CES-D is a reliable and valid screening tool for assessing depression and has been used in a variety of adult and adolescent populations (Hann, Winter, & Jacobsen, 1999; Shinar et al., 1986). The alpha in the current sample is .91.

CHAPTER III

RESULTS

Analysis Overview

This cross-sectional study explored the relationship between parent's perceived stigmatization for having a child with ASD, daily discrimination, mental health, empowerment, family involvement, and parent-teacher relationship. Data analyses included descriptive statistics for all study variables (i.e., means, variance, outliers, and normal distributions), bivariate correlations, mean comparisons, and regression analyses for our main hypotheses, where parent's stigmatization serves as the primary independent variable. Child characteristics (e.g., child's adaptive behavior and ASD severity) and sociodemographic characteristics (e.g., education and income) served as control variables in our main hypotheses. Due to the small sample size for this study (*n* = 41) we used correlational strength to determine clinically meaningful significance.

Preliminary Analyses

First, the distribution of study variables was analyzed to assess for any significant outliers and determine whether data was normally distributed. Table 1 illustrates the distribution of the sample (*n* = 41); no outliers or skew was apparent after the analysis was conducted. Descriptive and demographic data are presented in Table 1 and include either the mean and standard deviation of the demographic variable, or the number and percentage. No violation of assumptions or abnormality were apparent in the data, and thus, no transformations were performed.

Primary caregivers were on average 41.02 years of age (*SD* = 6.25) and 90% identified as female. Of the sample, 87% of caregivers identified as White/Caucasian (*n* = 36). Regarding racial/ethnic diversity within the sample, 2 parents endorsed they were Hispanic/Latino, 1 identified as black, 1 identified as Asian, 1 Native American, 1 Pacific Islander, and 1 endorsed "other" or not otherwise listed. Given the limited racial and ethnic diversity within the sample, analyses investigating group differences by race and ethnicity were not conducted. Slightly more than half of primary caregivers, or 61%, reported working at least part time or were self-employed (*n* = 25). About half of study participants completed a 4-year college degree or higher (*n* = 19). The majority of caregivers, or 95% reported they lived with a spouse or partner. The average household income reported was $63, 151.17 (*SD* = ($37,953.66). The average number of children being supported was 2.56 (*SD* = 1.05).

Study participant's children ranged from 7 to 13 years of age (*M* = 9.54, *SD* = 1.69) and the majority of children were identified as male (*n* = 35, 85.40%) as well as White/Caucasian (*n* = 95.1%). Majority of children were reported as currently receiving special education services (*n* = 40). A majority of children had a medical diagnosis of ASD outside of an educational eligibility (n = 31) and while the average age of ASD diagnosis was 3.36 years (*SD* = 1.80), age of diagnosis ranged from infancy to 7 years of age. Many children reportedly had a second condition outside of ASD (70%) and of those, about a third reported it was Attention Deficit Hyperactivity Disorder (ADHD; 29.30%). The vast majority of the sample has current access to health insurance (98%) and of those, about half (49%) reportedly accessed state issued health insurance or Medicaid.

Table 1

Demographic Characteristics of the Sample

Demographic variable	M (SD) or %
Primary Caregiver and Family	
Age	41.02 (6.25)
% Female	90.02
% Married/ Living with Partner	95.10
% White/Caucasian	87.80
% Black/African American	2.40
% Hispanic/Latino	4.90
% Asian or Pacific Islander	7.32
% Native American	2.40
Annual Household Income in USD	$63,151.17 ($37,953.66)
% Report Not Enough Money/Just Enough	53.7%
% College Degree or Higher	46.34
Total Years of Education Completed	15.46 (2.38)
Number of Children Being Supported	2.56 (1.05)
Child Characteristics	
Age	9.54 (1.69)
% Male	85.40
% White/Caucasian	95.1
Age of ASD Diagnosis	3.36 (1.80)
% Receiving Special Education	97.60
% Enrolled in a School Program	92.70
% with a Secondary Condition	70.07
% with ADHD as Secondary Condition	29.30
% with Other Medical Conditions	36.60
% Regularly Seeing Physician	92.70
% Access to Health Insurance	97.60
% State Insurance/ Medicaid	48.80

Note. ASD = Autism Spectrum Disorder, ADHD = Attention Deficit Hyperactivity Disorder.

Descriptive information on the study variables of interest for the sample is provided in Table 2 and includes the Center on Epidemiological Studies Depression (CES-D), Family Empowerment Scale (FES), Family Involvement Questionnaire, Elementary Version (FIQ-E), Midlife in the United Sates (MIDUS 2), Perceived Discrimination Subscale (PDIS), Childhood Autism Rating Scale (CARS 2), Vineland Adaptive Behavior Scales, Third Edition (VABS 3), as well as questions on demographic information.

On average, caregivers were below the depression threshold of a score of 16 on the CES-D (*M* = 11.51, *SD* = 8.57). However, 12 participants, or 35% of the sample, were at or above the threshold and are at clinical risk for depression. Scores across participants on the CES-D ranged from 0 to 31.

Regarding discrimination, the sample endorsed an average of 10 instances of major discrimination as defined by the PDIS (*SD* = 23.42). While the majority of study participants held the belief individuals with ASD are stigmatized (97.6%), study participants varied in endorsement of specific stigma's related to Stereotypes of Adult Competence (*M* = 6.44, *SD* = 2.01), ASD Causes and Characteristics (*M* = 9.19, *SD* = 2.27), as well as the subjective difficulty of ASD stigma (*M* = 4.07, *SD* = 1.85). Approximately 78% (*n* = 32) endorsed at least some people believe in all items of stereotypes of adult competence, 41.46% (*n* = 17) endorsed at least some people believe in all items of ASD Causes and Characteristics, and 58.54% (*n* = 24) endorsed it has at least been somewhat difficult to both have a child with ASD and be subject to ASD associated stigma for their families.

Regarding satisfaction with services and perceived financial burden, 61% of the sample indicated they were satisfied or very satisfied with their child's services while 80.4% endorsed being satisfied or very satisfied with their child's insurance coverage. Approximately 53.7% endorsed their families did not have enough money or just enough money to get by.

Target children in the sample had an average CARS score of 33.77, falling in the mild/moderate ASD severity range (*SD* = 8.21). Target children's average score on the Adaptive Behavior Composite (ABC) of the Vineland-3 fell in the mild to moderate impairment range (*M* = 68.51, *SD* = 19.99). Subscale score averages in Communication and Socialization were consistent and also fell in the impaired range (*M* = 66.54, *SD* = 26.41; *M* = 63.17, *SD* = 20.71) while Daily Living subscale fell on average within the borderline impaired range (*M* = 77.80, *SD* = 21.46).

Question 1. *To what extent are indicators of marginalization, such as perceived ASD stigmatization and endorsed daily discrimination, or empowerment, related to family characteristics such as child functioning or parent demographics?* Bivariate correlations were conducted to determine the presence and strength of relation between our predictor variables or domains of ASD stigmatization (e.g., Stereotypes of Adult Competence, Stereotypes of ASD Causes and Characteristics, Difficulty of ASD Stigma), perceived daily discrimination, and family empowerment, with our control variables, parent income burden, parent education, child ASD severity, and child adaptive behavior. Results are illustrated in Table 3.

First, regarding associations between our predictor variables, consistent with the logic model in Figure 1, perceived daily discrimination was not significantly associated with perceived ASD stigmatization, suggesting courtesy stigma and perceived stigmatization may function independently of one another (*r* = -.068, *p* = .671; *r* = .161, *p* = .313; *r* = .060, *p* = .708).

Table 2

Descriptive Information of the Sample

Study variable	*M or %*	*SD*
Parent Factors		
CES-D – Depression	11.51	8.75
FES – Total	132.12	17.48
FIQ – Total	2.59	00.45
PDIS – Daily Discrimination	34.44	18.32
Stereotypes of Adult Competence	6.44	2.01
Stereotypes of ASD Causes and Characteristics	9.19	2.27
Difficulty of ASD Stigma	4.07	1.85
% Belief Individuals with ASD Stigmatized	97.6%	
Child Factors		
CARS 2 – Total	33.77	8.21
Vineland-3 – Communication	66.54	26.41
Vineland-3 – Daily Living Skills	77.80	21.46
Vineland-3 – Socialization	63.17	20.71
Vineland-3 – ABC Score	68.51	19.99

Note. CES-D = Center on Epidemiological Studies Depression; FES = Family Empowerment Scale; FIQ-E = Family Involvement Questionnaire, Elementary Version; FSS = Family Support Scale; PDIS = Midlife in the United Sates (MIDUS 2), Perceived Discrimination Subscale; CARS 2 = Childhood Autism Rating Scale; Vineland-3 -ABC Score = Vineland Adaptive Behavior Scales, Third Edition Adaptive Behavior Composite.

Perceived daily discrimination was not significantly associated with family empowerment (*r* = -.092, *p* = .565). Endorsed stereotypes of ASD were not associated with total empowerment (*r* = -.061, *p* = .707; *r* = -.156; *p* = .473) and neither was difficulty of ASD stigma, although approached significance at the *p* = .05 level (*r* =.287, *p* =.069). Notably, Difficulty of Stigma was significantly associated with the Service System subdomain of FES (*r* = 363, *p* = .020).

In regard to variables of child functioning (i.e., ASD severity and adaptive behavior), neither daily discrimination nor empowerment were meaningfully associated with ASD severity or adaptive behavior. ASD severity was also not significantly associated with perceived ASD stigmatization but trended towards significance with the ASD stigma domain, Stereotypes of Adult Competence (*r* = .205, *p* = .198). However, while ASD severity was not related with ASD stigmatization, adaptive functioning was a noteworthy association. Child adaptive behavior was significantly associated with all areas of perceived ASD stigmatization (i.e., Stereotypes of Adult Competence, *r* = -.403, *p* = .009; Stereotypes of ASD Causes and Characteristics, *r* = -.363, *p* = .020; Difficulty of ASD Stigma, *r* = -.416, *p* = .007).

Given the variability in household size and income, perceived financial income was included for analysis in place of gross annual income to capture the subjective and inherent equifinality in the experience of financial burden. Parent demographics (i.e., income and education) were not significantly associated with perceived ASD stigmatization or family empowerment. However, lower levels of education trended towards significance with reported daily discrimination (*r* = -.284, *p* = .072) and perceived income was significantly associated with higher levels of daily discrimination (i.e., more financial burden correlated with higher instances of discrimination; *r* = -.352, *p* = .024).

Table 3

Bivariate Correlations for ASDD, FES, PDIS, FIQ-E, CES-D, Child Characteristics, and Family Demographics

Variables	1	2	3	4	5	6	7	8	9	10
1. Stereotypes of Adult Competence	–									
2. Stereotypes of Causes and Characteristics	**.445****	–								
3. Difficulty of ASD Stigma	**.414****	.187	–							
4. Family Empowerment	-.061	-.156	**.294**	–						
5. PDIS Daily Discrimination	-.068	.161	.060	-.092	–					
6. Family Involvement	-.091	-.226	.259	**.441****	-.234	–				
7. Caregiver Depression	**.381***	.076	**.497****	-.103	-**.384***	-.198	–			
8. Parent Income Burden	-.145	.001	-.104	-.052	**-.352***	.156	**-.505****	–		
9. Parent Education	.030	.149	-.093	-.114	-.284	.050	-.320	**.485****	–	
10. Child ASD Severity	.205	.144	.134	.141	-.002	**.335***	.090	-.097	-.049	–
11. Child Adaptive	**-.403****	**-.363***	**-.416****	-.061	-.096	-.005	-.218	.271	.158	**-.632****

**p* < .05. **p < .01.

Question 2. *How do family characteristics (i.e., parent demographic and child functioning), indicators of marginalization (i.e., ASD stigmatization and daily discrimination), and empowerment relate to indicators of family system navigation (i.e., family involvement) and parent mental health (i.e., caregiver depression)?* Bivariate correlations were conducted to determine strength and direction of the relationship between measures of family characteristics (i.e., parent income burden, parent education, child ASD severity, child adaptive functioning) and indicators of marginalization (i.e., perceived ASD stigmatization and daily discrimination) with outcome variables, family involvement and caregiver depression. Results of the bivariate correlations are represented visually in Table 3.

While higher levels of endorsed ASD stereotypes (i.e., Stereotypes of Adult Competence, Stereotypes of ASD Causes and Characteristics) were trending with lower levels of Total Family Involvement, none of these associations were significant (*r* = -.091, *p* = .570; *r* = -.226, *p* = .155). Interestingly, higher levels of reported ASD Stigma Difficulty was mildly associated with higher levels of the Home-school Communication subdomain of the Family Involvement Questionnaire (*r* = .365, *p* =. 019). While family involvement had a negative trend with daily discrimination, this association was not statistically meaningful (*r* = -.234, *p* = .141). Conversely and consistent with our logic model, empowerment was found to be meaningfully associated with family involvement, such that higher levels of reported empowerment correlated with higher levels of endorsed family involvement (*r* =.441, *p* = .004). Consistent with the logic model, caregiver depression was not found to be associated with empowerment (*r* = -.103, *p*

=.544) and was mildly associated with daily discrimination (*r* = .384, *p* = .019) as well as the ASD stigmatization domain, Stereotypes of Adult Competence (*r* = .381, *p* = .020). A significant positive association was found between caregiver depression and the ASD stigmatization domain, Difficulty of Stigma (*r* = .497; *p* = .002).

Family involvement's association with family characteristics were also explored, with some associations found. As expected, ASD severity was positively associated with total family involvement (*r* = .355, *p* = .032) however, interestingly, adaptive behavior was not (*r* = -.005, *p* = .974). Family involvement was found to be negatively correlated with parent income burden (*r* = -.352, *p* = .024) and not strongly associated with parent education level (*r* = -.284, *p* = .072). Caregiver depression was not meaningfully associated with variables of child functioning (i.e., ASD severity, *r* = .090, *p* =.594; adaptive behavior, *r* = -.218, *p* = .194) nor was it associated with parent education (*r* = -3.20, *p* = .053). Caregiver depression was found to be significantly correlated with parent income burden, such that parents with higher depression scores reported more income burden (*r* = -.505, *p* = .001).

In addition to bivariate correlations using Pearson coefficients, meaningful group differences for family characteristics (i.e., control variables) with predictor and outcome variables were explored using independent sample t-tests. Regarding parent demographics, a statistically significant difference between levels of income burden was found with depression scores (t(35) = 2.85, p = .007), with those reporting their families did not have enough or having just enough money to get by with an average of 15.16 (*n* = 19, *SD* = 8.5) on the CES-D, and conversely those reporting they only worry about extras or never worry about money with an average CES-D score of 7.67 (*n* = 18, *SD* = 7.43).

Meaningful group differences for income burden on perceived discrimination were also found in the sample (*t*(39) = 3.179, *p* =.003) with those reporting higher income burden endorsing significantly more day to day discrimination (*n* = 22, *M*=20.66, *SD* = 5.42) compared to those reporting little to no income burden (*n*=19, *M* = 15.61, SD = 4.62). Conversely, no significant differences on parent education were found across all variables of interest (college attendance or beyond, *n* = 19). Regarding variables of child functioning, meaningful differences were found in adaptive functioning and perceived ASD stereotypes (*t*(39) = 2.049, *p* =.047) and difficulty of ASD stigma (*t*(39) = 2.043, *p* = .048). Specifically, parents whose children fell in the impaired range on adaptive behavior (i.e., SS <70, *n* = 19) were slightly more likely to endorse ASD stereotypes (*M* = 16.84, *SD* = 3.64) compared to participants whose children's adaptive scores fell in the borderline range and above (i.e., SS >69, *n* = 22, *M* = 14.59, *SD* = 3.39). Similarly, parents whose children fell in the impaired range endorsed more ASD stigma difficulty (*M* = 4.68, *SD* = 1.83) compared to those whose children fell in at least the borderline range of adaptive functioning (*M* = 3.56, *SD* = 1.74). Differences depending on ASD symptom severity were also notable.; Parents of children with greater ASD severity, or who met the "severe" cutoff score of 37 on the CARS-2, reported higher levels of empowerment (*t*(38) = -2.51, *p* = .016, *n* = 16, *M* = 140.25, *SD* = 16.77) when compared to children who reportedly fell below the "severe" ASD symptom threshold (*n* = 25, *M* = 136.79, *SD* = 16.48). Parent of children with greater ASD severity also reported higher levels of family involvement (*t*(38) = -2.415, *p* = .021, *n* = 16, *M* = 2.79, *SD* = .479) when compared to those whose children fell below the "severe" ASD threshold (*n* = 25, *M* = 2.45, *SD* = .402).

Question 3. *After controlling for family characteristics (i.e., parent demographic and child functioning), does empowerment predict family involvement?* To further explore the relation between psychosocial traits and system navigation, a hierarchical regression analysis was conducted to test if empowerment significantly predicted participants' level of family involvement. Results are illustrated in Table 4. The results of the regression indicated family characteristics and empowerment explained approximately 35.4% of the total variance in family involvement (F (5, 35) = 3.832, p = .007). First, in step one, our control variables of parent demographics (i.e., income burden and education) and child functioning (i.e., ASD severity and adaptive behavior) were entered. Combined, family characteristics accounted for approximately 19.9% of the variance in family involvement. Notably, ASD severity was a significant predictor (β = .537, p <.01). Empowerment was entered in step 2 of the model to determine unique variance. When added in the second step, empowerment was found to significantly predicted family involvement, accounting for approximately 15% unique variance above and beyond family characteristics (β = 0.40, p = .006). Consistent with bivariate analysis suggesting a correlation between ASD severity and family involvement, ASD severity continued to be a significant predictor of family involvement in the regression model (β = 0.465, p = .013). The hypothesis, higher levels of empowerment will predict higher levels of family involvement, is supported and is consistent with extant literature demonstrating a meaningful relationship between increased empowerment and higher levels of involvement (Burke, et al., 2016).

Table 4

Hierarchical Regression Examining Family Empowerment Predicting Family Involvement

Variable	*B*	*SE B*	*β*
Model 1			
Constant	1.048	0.713	
Parent Income Burden	0.080	0.095	0.147
Parent Education	-0.008	0.033	-0.042
Child ASD Severity	0.030	0.011	0.537**
Child Adaptive Behavior	0.007	0.005	0.301
F		2.237	
R^2		0.199	
Model 2			
Constant	-0.288	0.797	
Parent Income Burden	0.079	0.087	0.145
Parent Education	0.001	0.030	0.005
Child ASD Severity	0.026	0.010	0.465*
Child Adaptive Behavior	0.006	0.004	0.273
Family Empowerment	0.10	0.004	0.400**
F		3.832	
R^2		0.354	
ΔR^2		0.155	

Note. *$p < .05$. **$p<.01$.

Question 4. *After controlling for family characteristics (i.e., parent demographic and child functioning), does ASD stigmatization predict family involvement?* To further explore the relationship between ASD stigmatization and system navigation, a hierarchical regression analysis was conducted to test if perceived ASD stigma significantly predicted participants' level of family involvement and is illustrated in Table 5. In step one, parent demographics and child functioning variables were entered. In step two, perceived ASD stigmatization (i.e., combined total of ASD stereotypes and subjective appraisal of difficulty of stigma) were entered. The regression model was significant and accounted for approximately 39.1% of the total variance in family involvement (F (6, 34) = 3.633, p = .007). Child ASD severity continued to be a significant predictor of family involvement in the model (β =.594, p < .01). However, while ASD stereotypes were not significant predictors of family involvement (β =-.288, p = .076), stigma difficulty was a meaningful predictor of family involvement (β =.459, p = .005). ASD stigmatization combined accounted for a total of approximately 19.2% unique variance above and beyond family characteristics. The hypothesis, ASD stigmatization predicts family involvement, is partially accepted in regard to the subjective appraisal of the family impact of ASD stigmatization (i.e., ASD Stigma Difficulty) but analyses suggest endorsed ASD stereotypes may not meaningfully impact family involvement.

Table 5

Hierarchical Regression Examining Difficulty of ASD Stigma Predicting Family Involvement

Variable	*B*	*SE B*	*β*
Model 1			
Constant	1.048	0.713	
Parent Income Burden	0.080	0.095	0.147
Parent Education	-0.008	0.033	-0.042
Child ASD Severity	0.030	0.011	0.537**
Child Adaptive Behavior	0.007	0.005	0.301
F		2.237	
R^2		0.199	
Model 2			
Constant	.710	0.801	
Parent Income Burden	0.062	0.085	0.114
Parent Education	0.007	0.030	0.036
Child ASD Severity	0.033	0.010	0.594**
Child Adaptive Behavior	0.009	0.005	0.395
Total ASD Stereotypes	-0.036	0.038	0.459
Difficulty of Stigma	0.113	0.038	0.459**
F		3.633	
R^2		0.391	
ΔR^2		0.192	

Note. **p<.01.

Question 5. *After controlling for family characteristics (i.e., parent demographic and child functioning), does empowerment predict family involvement beyond perceived* *difficulty of ASD stigma?* Given both empowerment and difficulty of ASD stigma were significant predictors of family involvement, additional analysis was conducted to determine the extent to which empowerment would predict family involvement beyond ASD stigma difficulty using a hierarchical regression. The regression model tested accounted for 41.5% of the total variance and significantly predicted family involvement ($F(6, 34) = 4.016$, $p = .004$). In step one, family characteristics were entered, including parent demographics and child functioning variables. Step two saw the inclusion of difficulty of ASD stigma, which accounted for an additional 13.2% unique variance beyond family characteristics ($\beta = .406$, $p = .013$), however, once in step three, the effects of difficulty of ASD stigma were reduced and no longer significant in the model ($\beta =.293$, p = .068). Empowerment was entered and resulted in 8.4% unique variance ($\beta = .313$, $p = .034$). The hypothesis, empowerment will predict significant unique variance beyond family characteristics and difficulty of ASD stigma, is supported.

While the regression model predicting family involvement was significant on the whole, ASD stigma difficulty was no longer significant in step three suggesting ASD stigma difficulty shares sufficient explanatory power with empowerment on family involvement. No further analyses exploring the possible relationship of marginalization and empowerment on system navigation were conducted (e.g., moderation of the relationship between ASD stigma difficulty on family involvement by empowerment).

Table 6

Hierarchical Regression Examining Empowerment Predicting Family Involvement Beyond Difficulty of ASD Stigma

Variable	*B*	*SE B*	*β*
Model 1			
Constant	1.048	0.713	
Parent Income Burden	0.080	0.095	0.147
Parent Education	-0.008	0.033	-0.042
Child ASD Severity	0.030	0.011	0.537**
Child Adaptive Behavior	0.007	0.005	0.301
F		2.237	
R^2		0.199	
Model 2			
Constant	1.03	0.753	
Parent Income Burden	0.070	0.088	0.129
Parent Education	-0.005	0.030	-0.027
Child ASD Severity	0.035	0.011\0	0.625**
Child Adaptive Behavior	0.012	0.005	0.528*
Difficulty of ASD Stigma	0.100	0.038	0.406*
F		3.457	
R^2		0.331	
Model 3			
Constant	-0.677	0.797	
Parent Income Burden	0.072	0.084	0.133
Parent Education	0.001	0.029	0.006
Child ASD Severity	0.030	0.010	0.544**
Child Adaptive Behavior	0.010	0.005	0.443*

Table 6 (continued)

Variable	*B*	*SE B*	*β*
Difficulty of ASD Stigma	0.072	0.038	0.293
Family Empowerment	0.008	0.004	0.313*
F		4.016	
R^2		0.415	
ΔR^2		0.084	

Note. *p<.05. **p<.01.

Question 6. *After controlling for family characteristics (i.e., parent demographic and child functioning), does perceived ASD stigmatization predict caregiver depression beyond endorsed daily discrimination?* The impact of marginalization on parent mental health after controlling for family characteristics was investigated using a hierarchical regression model of analysis. The model was found to meaningfully predict caregiver depression, accounting for 56.5% of the total variance and is illustrated in Table 7 (*F* (7, 29) = 5.377, *p* = .001). In step one, parent demographics and child functioning variables were entered and accounted for 27.6% of the total variance. In step two, daily discrimination was entered, accounting for 5% additional variance to the model and was nonsignificant (*β* = .250, *p* =.138). In step three, ASD stigmatization was entered (i.e., ASD Total Stereotypes and Difficulty of ASD Stigma) and accounted for an additional 23.8% unique variance. Both total endorsed ASD stereotypes and reported difficulty of ASD stigma were predictors of caregiver depression (*β* = .283, *p* =.048; *β* = .465, *p* =.002), with reported stigma difficulty being a statistically stronger predictor below the

.01 level. The hypothesis, ASD stigmatization will predict caregiver depression, is accepted.

Table 7

Hierarchical Regression Examining Daily Discrimination and Difficulty of ASD Stigma Predicting Caregiver Depression

Variable	*B*	*SE B*	*β*
Model 1			
Constant	35.220	14.727	
Parent Income Burden	-4.469	1.806	-0.428*
Parent Education	-0.407	0.619	-0.111
Child ASD Severity	-0.059	0.216	-0.055
Child Adaptive Behavior	-0.061	0.092	-0.137
F		3.056	
R^2		0.186	
Model 2			
Constant	25.838	15.689	
Parent Income Burden	-3.658	1.848	-0.350
Parent Education	-0.222	0.619	-0.060
Child ASD Severity	-0.095	0.213	-0.088
Child Adaptive Behavior	-0.087	0.092	-0.196
Daily Discrimination	0.423	0.277	0.250
F		3.011	
R^2		0.327	
Model 3			
Constant	-7.490	15.598	

Table 7 (continued)

Variable	*B*	*SE B*	*β*
Parent Income Burden	-2.867	1.550	-0.274
Parent Education	-0.533	0.528	-0.145
Child ASD Severity	0.031	0.180	0.028
Child Adaptive Behavior	0.077	0.087	0.173
Daily Discrimination	0.481	0.232	0.284*
ASD Stereotypes Total	.708	0.342	0.283*
Difficulty of Stigma	4.056	1.204	0.465**
F		5.377	
R^2		0.592	
ΔR^2		0.265	

Note. *p<.05. **p<.01.

CHAPTER IV

DISCUSSION

Summary

This exploratory, cross-sectional study sought to investigate the impact of marginalization and empowerment, considerate of contextual family characteristics, on variables of system navigation and caregiver mental health for parents of children with ASD. While prior research has investigated the impact of daily discrimination on stress for parents of children with disabilities (Song et al., 2018), as well as the impact of disability specific courtesy stigma on appraised difficulty raising a child with ASD (Kinnear et al., 2015), a review of existing literature did not yield any studies that have investigated the impact of disability specific courtesy stigma on parent mental health. Similarly, extant literature suggests a relationship between feelings of empowerment and indicators of system navigation (i.e., involvement; Burke et al., 2018) however, none have investigated the impact factors of marginalization (e.g., disability specific courtesy stigma) may have on levels of involvement.

A sample of 41 caregivers with children currently diagnosed with ASD between the ages of 7 to 13 was recruited. In this study, we were interested in exploring the relationship family characteristics, such as parent demographics and child functioning, may have with empowerment as well as with indicators of perceived marginalization (i.e., ASD stigmatization, daily discrimination). Specifically, family characteristics of interest were parent's perceived income burden, parent's education level, child's adaptive behavior and child's ASD symptom severity. The relations between family characteristics and parent mental health, or caregiver depression, as well as system navigation, or family involvement, were also explored. In our analyses on indicators of family investigation, we investigated whether ASD stigmatization predicted empowerment after accounting for family characteristics, whether empowerment predicted parent's family involvement after accounting for family characteristics, and finally the degree to which empowerment predicted family involvement above and beyond ASD stigmatization. In our analyses of indicators of mental health, we examined whether ASD stigmatization predicted caregiver depression after accounting for family characteristics, whether daily discrimination predicted caregiver depression after accounting for family characteristics, and finally whether ASD stigmatization predicted caregiver depression above and beyond daily discrimination.

Findings suggest parent's perceived income burden was meaningfully associated with reported experiences of daily discrimination and depression, with parents noting having "not enough money" or "just enough money to get by" significantly more likely to endorse greater instances of daily discrimination and more likely to report depressive symptoms. Child's adaptive behavior was significantly related to all areas of perceived ASD stigmatization (i.e., Stereotypes of Adult Competence, Stereotypes of Causes and Characteristics, and Difficulty of Stigma), with parents whose children were in the impaired range of adaptive functioning were significantly more likely to endorse ASD stigma. Curiously, parents whose children had ASD symptom severity in the "severe" range were more likely to endorse traits characteristic of empowerment as well as report higher levels of involvement. Pearson correlation coefficients confirmed no significant relationship between our predictor variables (i.e., empowerment, daily discrimination, and ASD stigmatization) and no significant relationship between our outcome variables (i.e., family involvement and caregiver depression). Consistent with our hypothesis, empowerment was a significant predictor of family involvement. ASD stigmatization was only partially predictive of family involvement, in that only difficulty of stigma, not endorsed stereotypes, was significant. Further analyses suggest empowerment significantly predicts family involvement, even after accounting for perceived difficulty of ASD stigma, parent demographics, and child functioning. Finally, despite a mildly significant correlation, caregiver depression was not significantly predicted by daily discrimination, but was mildly predicted by perceived ASD stereotypes and significantly predicted by difficulty of ASD stigma after accounting for parent demographics and child functioning.

Discussion of Key Findings

The first and second research questions of the study sought to explore the existence and strength of meaningful associations from parent demographics and child functioning with study variables. Working within the ecological framework, it stands to reason participant behavior, subjective experiences, and overall wellbeing would be in part impacted by contextual factors in the environment shaping their identities. Parent demographic variables of interest included income burden and level of education, while child functioning variables included adaptive behavior and ASD severity. Analyses conducted included Pearson correlation coefficients as well as independent sample t-tests to compare meaningful group differences in the sample. As evident from the descriptive analysis, participants were largely homogenous in regard to race (88% White/Caucasian) and gender (90% female). Hence, these demographics characteristics, while they have demonstrated strong associations with study variables per extant literature (e.g., race and gender on daily discrimination, Fuller-Rowell, et al., 2018) were not included for analysis given limited variability in the sample to detect significance. Almost half of the sample completed at least a 4-year college degree, the average household size being about 4.5 (*SD* = 1.78), and the average annual household income was $63,151.17. To compare, the Department of Health and Human Services has set the federal poverty line at $25,750 for a family of four in the continental United States (DHHS, 2019). Analyses mostly found no significant correlations or meaningful differences for parent demographics and the study variables; however, income burden was significantly associated with both perceived daily discrimination and depression. Socioeconomic disadvantage continues to be related with reported discrimination, which is not only consistent with prior research (e.g., Fuller-Rowell, et al., 2018), but also may suggest economic burden uniquely influences discriminatory experiences even in an otherwise homogenous sample of caregivers of children with ASD. Unsurprisingly, it was not necessarily the amount of money that affected the sample's wellbeing, but rather, income in the setting of financial burden, that appeared associated with psychological distress. Given the known variability in the cost of ASD on parents dependent on child needs and access as well as the variability in service coverage and availability (Parish, Thomas, Williams, & Crossman, 2015), it stands to reason that reported financial burden, as opposed to gross income alone, would better encapsulate the unique economic strain and subsequent adverse effects on the mental health of parents of children with ASD. Child functioning, both ASD severity and level of adaptive behavior, was not associated with caregiver depression, which is inconsistent with longstanding research demonstrating child functioning significantly impacts parent mental health (e.g., Ingersoll & Hambrick, 2011). A surprising finding with variables of child functioning was the significant association between higher levels of ASD severity, and not adaptive behavior, with higher levels of family involvement. This finding is inconsistent with research suggesting parents of children with higher developmental risk report less family involvement (Garbacz, et al., 2016). However, the growing presence of evidence-based practices in ASD specific services and/or need to coordinate school supports with home, may influence parents' motivation to be increasingly involved in their child's school. Another surprising finding was the lack of association between ASD symptom severity and measures of perceived ASD stigmatization, given existing albeit limited research on parent negative appraisals of "autistic" traits (Johnson, Filliter, and Murphey, 2009). However, given impairments in adaptive behavior were significantly related with larger endorsements of ASD stigmatization, it would seem discrepancies in environmental functioning from same aged peers, and perhaps not "classic" ASD specific symptoms, that largely inform societal and even parental misconceptions of ASD (e.g., degree of overall impairment in social functioning as opposed to stemming behaviors, echolalia, etc). As such, the differential diagnosis of severe cases of ASD from intellectual disability is a particularly heady task, even for skilled clinicians (Matson & Williams, 2013) and it stands to reason non-clinicians (e.g., parents) may have difficulties making these distinctions as well.

The next set of research questions sought to explore the degree to which positive psychosocial traits, such as empowerment, may impact family involvement when accounting for family characteristics and possible effects of ASD stigmatization. No prior research has investigated the potential deleterious effects of perceived ASD stigmatization on family involvement, and bivariate correlations support these constructs existing separately and being nonrelated. Beyond confirming perceived difficulty of ASD stigma and empowerment impacted family involvement in separate models, findings suggest empowerment remains a significant predictor of family involvement beyond perceived difficulty of ASD stigma. In other words, despite the subjective appraisal of the negative impact ASD stigmatization may have on a caregiver's family, psychosocial traits such as empowerment impacted degree of family involvement. Given the decrease in predictive power in the regression model for difficulty of ASD stigmatization once empowerment was accounted for, possible moderation of empowerment between stigma difficulty and family involvement was deemed unnecessary for this study. As documented in prior research suggesting positive relationships between empowerment and school involvement for families of children with ASD (Burke, Rios, Garcia, & Magaña, 2018), our findings suggest degree of system navigation is impacted by positive psychosocial traits even when controlling for variability in child functioning and parent demographics and potential implicit negative appraisal of child disability status.

The last research question explored the impact of indicators of marginalization on parental mental health. Consistent with bivariate correlation analyses suggesting a relationship between daily discrimination and caregiver depression, our regression model of analysis suggests perceived discrimination mildly predicts caregiver depression. This finding further contributes to research indicating discrimination predicts mental health above and beyond socioeconomic disadvantage (Kessler, Mickelson, & Williams, 1999). The unique impact of perceived ASD stigmatization on parent mental health was of particular interest for this study, and findings from regression analyses suggest perceived

ASD stigmatization, particularly, difficulty of ASD stigma, significantly impacts parent mental health beyond both sociodemographic characteristics and other experiences of discrimination. Specifically, perceived stigmatization accounted for an additional 26.5% of unique variance on caregiver depression. Findings support a burgeoning body of literature on the deleterious effects of marginalization on the overall well-being for parents of individuals with disabilities (e.g., Song, et al., 2018) and, critical to our sample population, contribute to the dearth of research investigating disability specific stigma and its negative impact on the quality of life for parents of children with ASD (Kinnear, et al., 2015). Moreover, findings suggest that while the promotion of empowerment may impact family involvement independent of perceived stigmatization or discrimination, negative disability appraisals may still have significant adverse effects on mental health for parents of children with neurodevelopmental disabilities.

Limitations

While the implications of this exploratory study meaningfully elucidate the possible impact of positive psychosocial traits and compounded marginalization on system navigation and mental health, findings should be considered within the parameters of its limitations.

The recruited sample size (*n* = 41) is a considerable weakness and hindered the available methods of statistical analyses due to inadequate power to detect statistical significance. Given sampling constraints, future research should replicate this study bolstering efforts in recruitment. Specifically, proximity to an academic medical center within an urban center may provide a larger convenience sample and concurrently address limitations in participant diversity, particularly when considering cultural and racial diversity. Further, the racial and ethnic homogeneity in our sample may in part explain the limited associations observed between daily discrimination and our outcome variables, caregiver depression and family involvement. Some unintended selection criteria of the caregivers include English proficiency, English literacy, and the time and resources to facilitate study participation. Prior research findings indicating a relationship between daily discrimination and mental health may be detecting the unique experiences of intersecting marginalized identities (i.e., adverse mental health effects of discrimination exacerbated by experiences of multiple demographic and contextual factors; Keyes, 2009). Additionally, measures used to describe our outcome variables are inherently culturally and contextually restricted. For example, cross cultural validation studies of the CES-D have had mixed results, with some research indicating endorsement of depressive symptoms may be affected by cultural biases (e.g., Lee, et al., 2011). Unique contexts for caregivers of children with ASD, and potentially intersecting identities, might lend itself to a mental health profile not fully captured by a single measure of depression, or the CES-D. Family involvement within schools may look inherently different for diverse populations, and the measure does not necessarily capture racialized or culturally bound practices within education settings that may provide undue barriers to caregivers (Brown, Souto-Manning, & Laman, 2010) or ableist practices in less knowledgeable public schools that may discourage involvement for parents of children with disabilities (McDonald, 2011).

Lastly, attention should also be given to the limitation of disability stigmatization measures, which may be bound by culture, geography, and time. To this effect, this study found variability in internal consistency within the Stereotypes of ASD Causes and

Characteristics domain, as suggested by bivariate correlation coefficients ranging from $r = .255$ to $r = .590$. In contrast, coefficients within items under the Stereotypes of Adult Competency domain ranged from $r =.837$ to $r =.892$. Cronbach's alpha scores were calculated and consistent with interitem correlations (i.e., Stereotypes of Adult Competence, $\alpha = 0.84$; Stereotypes of ASD Causes and Characteristics, $\alpha = 0.62$). These findings suggest the ASD stereotype measures used, originally developed by Kinnear, et al.., (2015), require revision and further validation to ensure generalizability and relevancy. Intra-subtest scatter may be indicative of collective "debunking" or disproval of certain stereotypes over others (e.g., "parents cause their children's autism because of their parenting style"). Shared beliefs on ASD are bound to shift or vary as a function of demographics, awareness of ASD, increased availability of evidence-based practices, and access to quality information regarding ASD.

Contributions and Future Directions

The main benefit from this explanatory, cross sectional study was to gain a deeper understanding of psychosocial characteristics promoting system navigation in the face of compounded perceived marginalization and caregiver distress. While this study demonstrated the deleterious effects of ASD stigmatization on caregiver mental health, it also demonstrated the advantageous effects feelings of empowerment can have on family involvement.

Identifying and continuing research on perceived stigmatization as a significant contributor to parent's mental health may help elucidate complexities in family participation, particularly for families of children with disabilities. Families possess unique narratives that can prove invaluable for educators, practitioners, and school staff providing sustentative services to families. The further investigation into the impact of stigmatization and empowerment on family involvement may create insight in informing engagement strategies for school and community systems for families of children with disabilities, building on limited research of advocacy programs for parents of children with ASD (e.g., Burke et al., 2016). Empowerment may be critical in lessening the negative effects that greater societal stressors for having a child with a disability, such as chronic discrimination, may have on school outcomes and overall family well-being. If empowerment is further conceptualized as both an inherent quality and developable skill, parent education and support programs can identify the innate strengths of families and take a strengths-based approach in promoting positive outcomes for parents of families with developmental disabilities and ASD. In a proactive and holistic approach, which takes into account the mechanisms affecting the well-being of caregivers of children with disabilities, practitioners and educators can help alleviate undue stress by validating the stigmatizing interactions and isolating consequences of societal discrimination. Service providers can then hope to indirectly influence positive behavioral and academic outcomes for students with disabilities by promoting family involvement and parental wellbeing and ultimately change dominant paradigms within community systems that negatively and unfairly stereotype families of children with disabilities.

APPENDIX A

PERCIEVED ASD STIGMATIZATION

1. Individuals with autism will never be able to___. Do you think most people believe that, some people believe that, or only a few people believe that?

	Most people	**Some people**	**A few people**
a. Hold a job	○	○	○
b. Live independently	○	○	○
c. Marry	○	○	○

2. Do most people, some people or a few people believe ___ ?

	Most people	**Some people**	**A few people**
a. Individuals with autism cannot be a good friend because of their autism	○	○	○
b. Parents can cause their children's autism because of their parenting style	○	○	○
c. Individuals with autism are 'mentally ill'	○	○	○
d. Individuals with autism are dangerous or a threat to others	○	○	○
e. Individuals with autism have intellectual disabilities	○	○	○

3. How difficult has the stigma that is often associated with autism been for you and your family?

○ Extremely ○ Very ○ Somewhat ○ A Little ○ Not at all

4. How difficult has it been for your family to have a child on the autism spectrum?

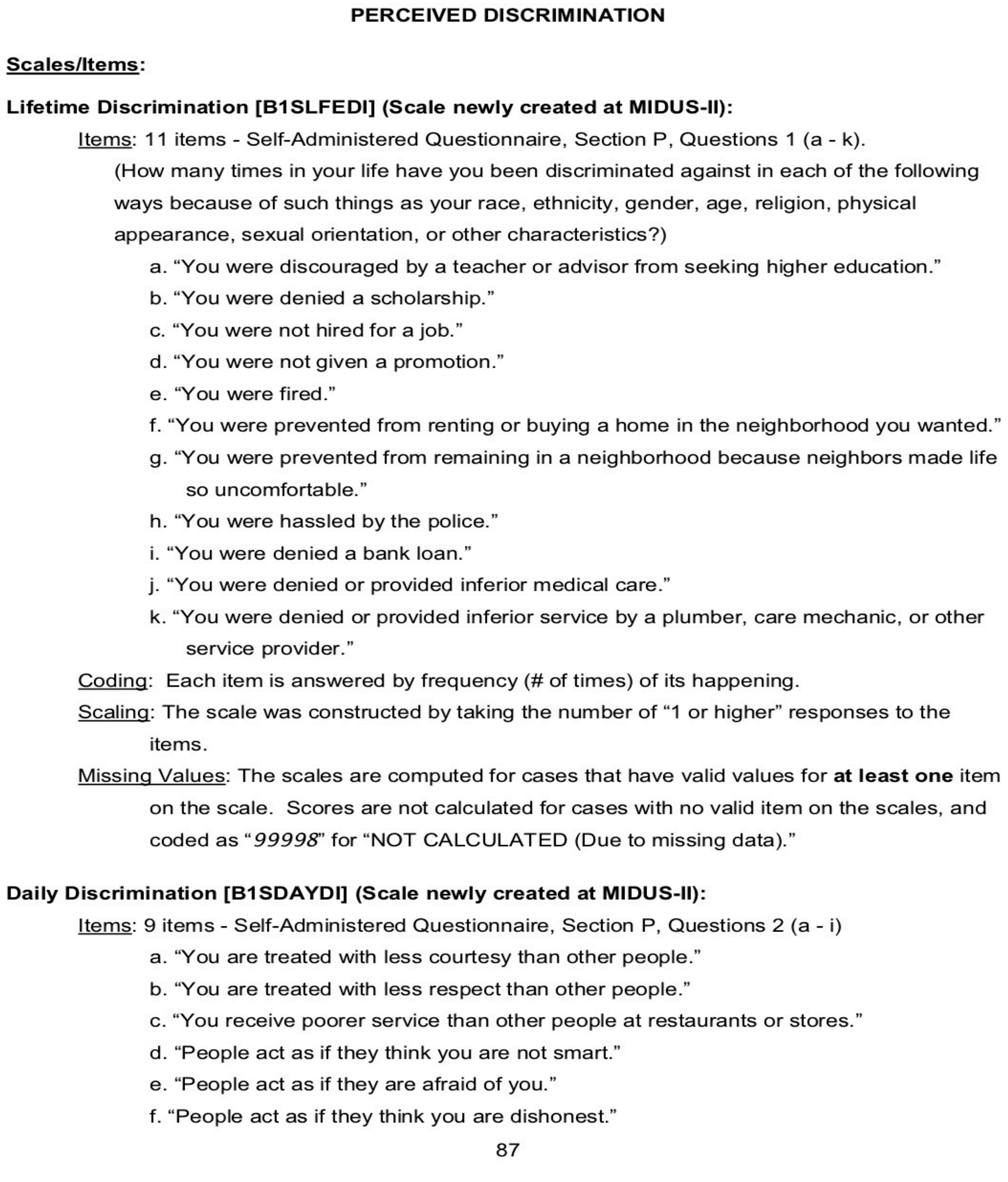
○ Extremely ○ Very ○ Somewhat ○ A Little ○ Not at all

5. Do you think individuals with autism are stigmatized?

○ Definitely yes ○ Probably yes ○ Probably no ○ Definitely no

APPENDIX B

PERCIEVED SOCIODEMOGRAPHIC DISCRIMINATION



PERCEIVED DISCRIMINATION

Scales/Items:

Lifetime Discrimination [B1SLFEDI] (Scale newly created at MIDUS-II):

Items: 11 items - Self-Administered Questionnaire, Section P, Questions 1 (a - k).

(How many times in your life have you been discriminated against in each of the following ways because of such things as your race, ethnicity, gender, age, religion, physical appearance, sexual orientation, or other characteristics?)

a. "You were discouraged by a teacher or advisor from seeking higher education."
b. "You were denied a scholarship."
c. "You were not hired for a job."
d. "You were not given a promotion."
e. "You were fired."
f. "You were prevented from renting or buying a home in the neighborhood you wanted."
g. "You were prevented from remaining in a neighborhood because neighbors made life so uncomfortable."
h. "You were hassled by the police."
i. "You were denied a bank loan."
j. "You were denied or provided inferior medical care."
k. "You were denied or provided inferior service by a plumber, care mechanic, or other service provider."

Coding: Each item is answered by frequency (# of times) of its happening.

Scaling: The scale was constructed by taking the number of "1 or higher" responses to the items.

Missing Values: The scales are computed for cases that have valid values for **at least one** item on the scale. Scores are not calculated for cases with no valid item on the scales, and coded as "*99998*" for "NOT CALCULATED (Due to missing data)."

Daily Discrimination [B1SDAYDI] (Scale newly created at MIDUS-II):

Items: 9 items - Self-Administered Questionnaire, Section P, Questions 2 (a - i)

a. "You are treated with less courtesy than other people."
b. "You are treated with less respect than other people."
c. "You receive poorer service than other people at restaurants or stores."
d. "People act as if they think you are not smart."
e. "People act as if they are afraid of you."
f. "People act as if they think you are dishonest."

g. “People act as if they think you are not as good as they are.”

h. “You are called names or insulted.”

i. “You are threatened or harassed.”

Coding: 1 Often; 2 Sometimes; 3 Rarely; 4 Never.

Scaling: The scale is constructed by calculating the **sum** of the values of the items. Items were reverse-coded so that high scores reflect higher standing in the scale. For an item with a missing value, the mean value of completed items is imputed.

Missing Values: The scales is computed for cases that have valid values for **at least five** items on the scale. The scale score is not calculated for cases with fewer than five valid items on the scales, and coded as “98” for “NOT CALCULATED (Due to missing data).”

Psychometrics:

Daily Discrimination [B1SDAYDI]:

Sample (N)	Alpha	Mean	Std. dev
M2 Total Sample (3970)	.92	12.81	4.44
M2 Main RDD Sample (1775)	.92	12.96	4.52
M2 Twin Sample (1187)	.92	12.75	4.48
M2 Sibling Sample (627)	.91	12.53	4.16

Sources:

*The perceived discrimination questions were developed by one of the authors for use in a study of racial discrimination in Detroit (Williams et al., 1997). The questions were based largely on the results of previous qualitative studies of discrimination (Essed, 1991; Feagin, 1991). – from *Kessler et. al. (1999) [see below]*

Williams, D. R., YU, Y., Jackson, J. S., & Anderson, N. B. (1997). Racial differences in physical and mental health: Socioeconomic status, stress and discrimination. *Journal of Health Psychology*, 2, 335-351.

Studies using the scales:

Kessler, R. C., Mickelson, K. D., & Williams, D. R. (1999). The prevalence, distribution, and mental health correlates of perceived discrimination in the United States. *Journal of Health and Social Behavior*, 40, 208-230.

Ryff, C. D., Keyes, C. L. M., & Hughes, D. L. (2004). Psychological well-being in MIDUS: Profiles of ethnic/racial diversity and life-course uniformity. In O. G. Brim, C. D. Ryff & R. C. Kessler (Eds.), *How healthy are we?: A national study of well-being at midlife.* (pp. 398 - 422). Chicago: Univ. of Chicago Press.

References:

Essed, P. (1991). *Understanding everyday racism*. Newbury Park, California: Sage.

Feagin, J. R. (1991). The continuing significance of race: Anti-black discrimination in public places. *American Sociological Review,* 56, 101-116.

APPENDIX C

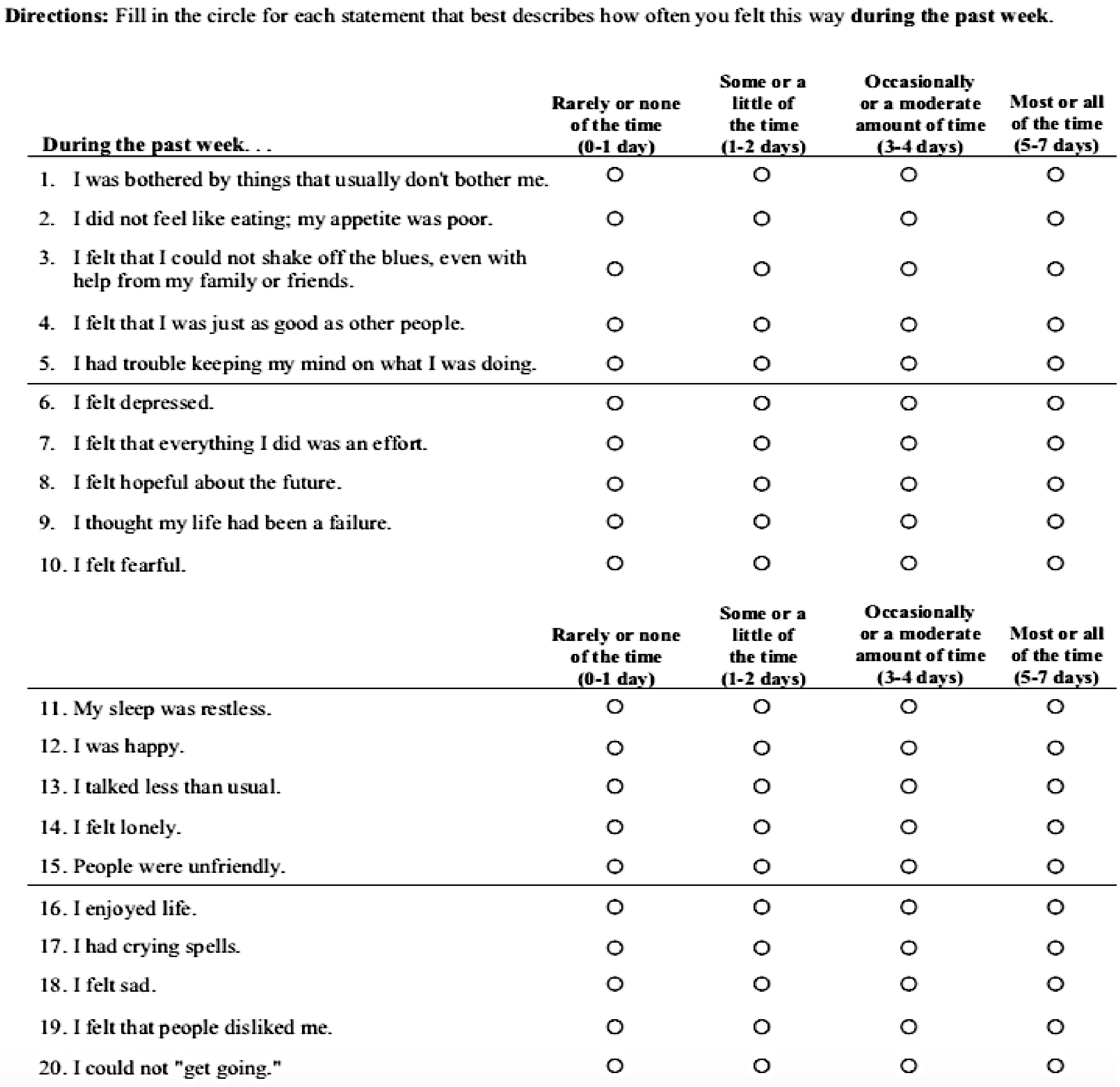
FAMILY INVOLVEMENT QUESTIONNAIRE

Family Involvement Questionnaire – Elementary Version

	Rarely	*Sometimes*	*Often*	*Always*
1. I attend conferences with the teacher to talk about my child's learning or behavior.	1	2	3	4
2. I contact the teacher or principal to get information.	1	2	3	4
3. I talk to my child's teacher about his/her daily school routine.	1	2	3	4
4. I limit my child's TV and video watching.	1	2	3	4
5. I review my child's school work.	1	2	3	4
6. I take my child to the public library.	1	2	3	4
7. I suggest classroom activities and school trips to the teacher.	1	2	3	4
8. I attend parent workshops or training offered by my child's school.	1	2	3	4
9. I talk to my child's teacher about the classroom rules.	1	2	3	4
10. I take my child to school in the morning.	1	2	3	4
11. I keep a regular morning and bedtime schedule for my child.	1	2	3	4
12. I praise my child for his/her school work in front of the teacher.	1	2	3	4
13. I share stories with my child about when I was in school.	1	2	3	4
14. I take my child to places in the community to learn special things (museum, church.)	1	2	3	4
15. I call the teacher if I am concerned about things that my child tells me about school.	1	2	3	4

APPENDIX D

CENTER ON EPIDEMIOLOGICAL STUDIES DEPRESSION



Directions: Fill in the circle for each statement that best describes how often you felt this way **during the past week.**

During the past week. . .	**Rarely or none of the time (0-1 day)**	**Some or a little of the time (1-2 days)**	**Occasionally or a moderate amount of time (3-4 days)**	**Most or all of the time (5-7 days)**
1. I was bothered by things that usually don't bother me.	○	○	○	○
2. I did not feel like eating; my appetite was poor.	○	○	○	○
3. I felt that I could not shake off the blues, even with help from my family or friends.	○	○	○	○
4. I felt that I was just as good as other people.	○	○	○	○
5. I had trouble keeping my mind on what I was doing.	○	○	○	○
6. I felt depressed.	○	○	○	○
7. I felt that everything I did was an effort.	○	○	○	○
8. I felt hopeful about the future.	○	○	○	○
9. I thought my life had been a failure.	○	○	○	○
10. I felt fearful.	○	○	○	○

	Rarely or none of the time (0-1 day)	**Some or a little of the time (1-2 days)**	**Occasionally or a moderate amount of time (3-4 days)**	**Most or all of the time (5-7 days)**
11. My sleep was restless.	○	○	○	○
12. I was happy.	○	○	○	○
13. I talked less than usual.	○	○	○	○
14. I felt lonely.	○	○	○	○
15. People were unfriendly.	○	○	○	○
16. I enjoyed life.	○	○	○	○
17. I had crying spells.	○	○	○	○
18. I felt sad.	○	○	○	○
19. I felt that people disliked me.	○	○	○	○
20. I could not "get going."	○	○	○	○

APPENDIX E

FAMILY EMPOWERMENT QUESTIONNAIRE

Directions: Below are a number of statements that describe how a parent or caregiver of a child with autism spectrum disorder may feel about his or her situation. For each statement, please fill in the circle that best describes how the statement applies to you.

	Not True At All	**Mostly Not True**	**Somewhat True**	**Mostly True**	**Very True**
1. I feel that I have a right to approve all services my child receives.	○	○	○	○	○
2. When problems arise with my child, I handle them pretty well.	○	○	○	○	○
3. I feel I can have a part in improving services for children in my community.	○	○	○	○	○
4. I feel confident in my ability to help my child grow and develop.	○	○	○	○	○
5. I know the steps to take when I am concerned my child is receiving poor services.	○	○	○	○	○
6. I make sure that professionals understand my opinions about what services my child needs.	○	○	○	○	○
7. I know what to do when problems arise with my child.	○	○	○	○	○
8. I get in touch with my legislators when important bills or issues concerning children are pending.	○	○	○	○	○
9. I feel my family life is under control.	○	○	○	○	○
10. I understand how the service system for children is organized.	○	○	○	○	○
11. I am able to make good decisions about what services my child needs.	○	○	○	○	○
12. I am able to work with agencies and professionals to decide what services my child needs.	○	○	○	○	○
13. I make sure I stay in regular contact with professionals who are providing services to my child.	○	○	○	○	○
14. I have ideas about the ideal services system for children.	○	○	○	○	○
15. I help other families get the services they need.	○	○	○	○	○
16. I am able to get information to help me better understand my child.	○	○	○	○	○

REFERENCES CITED

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with Autism, Down Syndrome, or Fragile X Syndrome. American Association on Intellectual and Developmental Disabilities, 109(3), 237–254.

Ali, Afia, Hassiotis, Angela, Strydom, Andre, & King, Michael. (2012). Self-stigma in people with intellectual disabilities and courtesy stigma in Family carers: A systematic review. *Research in Developmental Disabilities: A Multidisciplinary Journal, 33*(6), 2122-2140.

Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury Park, CA: Sage.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: Author.

Austin, J., Galijot, R., & Davies, W. (2018). Evaluating Parental Autism Disclosure Strategies. *Journal of Autism and Developmental Disorders, 48*(1), 103-109.

Austin, J., Zinke, V., & Davies, W. (2016). Influencing Perception About Children with Autism and their Parents Using Disclosure Cards. *Journal of Autism and Developmental Disorders, 46*(8), 2764-2769.

Banach, M., Iudice, J., Conway, L., & Couse, L. (2010). Family Support and Empowerment: Post Autism Diagnosis Support Group for Parents. *Social Work with Groups, 33*(1), 69-83.

Benson, P. R. (2015). Longitudinal effects of educational involvement on parent and family functioning among mothers of children with ASD. *Research in Autism Spectrum Disorders*, *11*, 42–55. http://doi.org/10.1016/j.rasd.2014.11.011

Broady, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. *Health & Social Care in the Community*, *25*(1), 224–233. https://doi-org.libproxy.uoregon.edu/10.1111/hsc.12297

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*(7), 513–531. doi: 10.1037/0003-066X.32.7.513

Brown, Sally, Souto-Manning, Mariana, & Laman, Tasha Tropp. (2010). Seeing the Strange in the Familiar: Unpacking Racialized Practices in Early Childhood Settings. *Race, Ethnicity and Education, 13*(4), 513-532.

Burke, M., Rios, K., Garcia, M., & Magaña, S. (2018). Examining differences in empowerment, special education knowledge, and family–school partnerships among Latino and White families of children with autism spectrum disorder. *International Journal of Developmental Disabilities,* 1-7.

Burke, M., Magaña, S., Garcia, M., & Mello, M. P. (2016). Brief Report: The Feasibility and Effectiveness of an Advocacy Program for Latino Families of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *46*(7), 2532–2538. http://doi.org/10.1007/s10803-016-2765-x

Burrell, T. L., & Borrego, J. (2012). Parents' Involvement in ASD Treatment: What Is Their Role? *Cognitive and Behavioral Practice*, *19*(3), 423–432. http://doi.org/10.1016/j.cbpra.2011.04.003

Butler, Robert C., & Gillis, Jennifer M. (2011). The Impact of Labels and Behaviors on the Stigmatization of Adults with Asperger's Disorder. *Journal of Autism and Developmental Disorders, 41*(6), 741-749.

Calzada, E. J., Huang, K.-Y., Hernandez, M., Soriano, E., Acra, C. F., Dawson-Mcclure, S., … Brotman, L. (2015). Family and Teacher Characteristics as Predictors of Parent Involvement in Education During Early Childhood Among Afro-Caribbean and Latino Immigrant Families. *Urban Education*, *50*(7), 870–896. http://doi.org/10.1177/0042085914534862

CDC. (2016). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012, *65*(3).

Coatsworth, J. D., Pantin, Hi., & Szapocznik, J. (2002). Familias Unidas: A family-centered ecodevelopmental intervention to reduce risk for problem behavior among Hispanic adolescents. *Clinical Child and Family Psychology Review*, *5*(2), 113–132. JOUR. Retrieved from 10.1023/A:1015420503275

Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: A systematic review and meta-synthesis. *J Intellect.Disabil.*, (1744–6309 (Electronic)). http://doi.org/10.1177/1744629515577876

Crean, H. F. (2004). Social support, conflict, major life stressors, and adaptive coping strategies in Latino middle school students: An integrative model. *Journal of Adolescent Research*, *19*(6), 657–676. JOUR. Retrieved from 10.1177/0743558403260018

Davis, N., & Carter, A. (2008). Parenting stress in mothers and fathers of toddlers with Autism Spectrum Disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*(7), 1278-1291.

Dillenburger, K., Keenan, M., Gallagher, S., & McElhinney, M. (2002). Autism: Intervention and parental empowerment. *Child Care in Practice, 8*(3), 216-219.

Doyle, D., & Molix, L. (2014). Perceived discrimination as a stressor for close relationships: Identifying psychological and physiological pathways. *Journal of Behavioral Medicine, 37*(6), 1134-44.

Eccles, J. S., & Harold, R. D. (1996). Family involvement in children's and adolescents' schooling. In A. Booth & J. F. Dunn (Eds.), *Family–school links: How do they affect child outcomes?* (pp. 3–34). Mahwah, NJ: Lawrence Erlbaum Associates.

Eaton, K., Ohan, J., Stritzke, W., & Corrigan, P. (2016). Failing to Meet the Good Parent Ideal: Self-Stigma in Parents of Children with Mental Health Disorders. *Journal of Child and Family Studies, 25*(10), 3109-3123.

Fan, X., & Chen, M. (2001). Parental involvement and students' academic achievement: A meta-analysis. *Educational Psychology Review, 13*(1), 1–22. doi:10.1023/A:1009048817385

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health and Illness*, *31*(7), 1011–1027. http://doi.org/10.1111/j.1467-9566.2009.01174.x

Fantuzzo, J., Tighe, E., & Childs, S. (2000). Family Involvement Questionnaire: A multivariate assessment of family participation in early childhood education. *Journal of Educational Psychology, 92*(2), 367-376. doi: 10.1037/0022-0663.92.2.367

Fischbach, R. L., Harris, M. J., Ballan, M. S., Fischbach, G. D., Link, B. G., Charman, T., … Sivberg, B. (2015). Is there concordance in attitudes and beliefs between parents and scientists about autism spectrum disorder? *Autism*, *6*(4), 207–214. http://doi.org/10.1177/1362361315585310

Fuller-Rowell, T., Curtis, D., Chae, D., Ryff, C., & Freedland, K. E. (2018). Longitudinal health consequences of socioeconomic disadvantage: Examining perceived discrimination as a mediator. *Health Psychology, 37*(5), 491-500.

Garbacz, S. A., & McIntyre, L. L. (2015). Conjoint Behavioral Consultation for children with autism spectrum disorder. *School Psychology Quarterly, 31*(4), 450–466. doi: 10.1037/spq0000114

Garbacz, S. A., McIntyre, L. L., & Santiago, R. T. (2016). Family involvement and parent–teacher relationships for students with autism spectrum disorders. *School Psychology Quarterly, 31*(4), 478–490. doi: 10.1037/spq0000157

Green, S. E. (2003). “What do you mean ‘what’s wrong with her?’”: Stigma and the lives of families of children with disabilities. *Social Science and Medicine*, *57*(8), 1361–1374. http://doi.org/10.1016/S0277-9536(02)00511-7

Grolnick, W. S., Benjet, C., Kurowski, C. O., & Apostoleris, N. H. (1997). Predictors of parent involvement in children’s schooling. *Journal of Educational Psychology, 89*(3), 538–548. doi: 10.1037/0022-0663.89.3.538

Hidalgo, N., McIntyre, L., & McWhirter, E. (2015). Sociodemographic differences in parental satisfaction with an autism spectrum disorder diagnosis. *Journal of Intellectual & Developmental Disability, 40*(2), 1-9.

Ijalba, E. (2016). Hispanic Immigrant Mothers of Young Children With Autism Spectrum Disorders: How Do They Understand and Cope With Autism? *American Journal of Speech-Language Pathology*, 1–14. http://doi.org/10.1044/2015

Ingersoll & Hambrick. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 337-344.

Johnson, Shannon A., Filliter, Jillian H., & Murphy, Robin R. (2009). Discrepancies between Self- and Parent-Perceptions of Autistic Traits and Empathy in High Functioning Children and Adolescents on the Autism Spectrum. *Journal of Autism and Developmental Disorders,39*(12), 1706-1714.

Keen, D., Webster, A., & Ridley, G. (2016). How well are children with autism spectrum disorder doing academically at school? An overview of the literature. *Autism: The International Journal of Research and Practice, 20*(3), 276–294. doi: 10.1177/1362361315580962

Keenan, B., Newman, L., Gray, K., & Rinehart, N. (2016). Parents of Children with ASD Experience More Psychological Distress, Parenting Stress, and Attachment-Related Anxiety. *Journal of Autism and Developmental Disorders, 46*(9), 2979-2991.

Keyes, C. L. M. (2009). The Black-White paradox in health: Flourishing in the face of social inequality and discrimination. Journal of Personality, 77(6), 1677-1706.

Kessler, R., Mickelson, K., & Williams, D. (1999). The Prevalence, Distribution, and Mental Health Correlates of Perceived Discrimination in the United States. *Journal of Health and Social Behavior, 40*(3), 208-230.

Kim, E. M., Sheridan, S. M., Kwon, K., & Koziol, N. (2013). Parent beliefs and children’s social-behavioral functioning: The mediating role of parent-teacher relationships. *Journal of School Psychology*, *51*(2), 175–185. http://doi.org/10.1016/j.jsp.2013.01.003

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives. *Journal of Autism and Developmental Disorders*, *46*(3), 942–953. http://doi.org/10.1007/s10803-015-2637-9

Konst, M. J., Matson, J. L., Goldin, R., & Rieske, R. (2014). How does ASD symptomology correlate with ADHD presentations? *Research in Developmental Disabilities, 35*(9), 2252–2259. doi: 10.1016/j.ridd.2014.05.017

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, *37*(4), 305–321. http://doi.org/10.1037/h0079106

Kraemer, B. (2008). Transition for youth with autistic spectrum disorder: School preparation, family involvement and outcomes. *Journal Of Intellectual Disability Research, 52*, 713.

Kraemer, B. (2012). Family involvement and impact during the period of transition for youth with ASD. *Journal Of Intellectual Disability Research, 56*(7-8), 734.

Lee, Jung Jae, Kim, Ki Woong, Kim, Tae Hui, Park, Joon Hyuk, Lee, Seok Bum, Park, Jin Woo, . . . Steffens, David C. (2011). Cross-cultural considerations in administering the center for epidemiologic studies depression scale. *Gerontology, 57*(5), 455-61.

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Frver, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Children's Health. *Journal of Developmental and Behavioral Pediatrics*, *29*(3), 152–160.

Lovell, & A. Wetherell. (2018). Caregivers' characteristics and family constellation variables as predictors of affiliate stigma in caregivers of children with ASD. *Psychiatry Research, 270*, 426-429.

Lyons, Amy M., Leon, Scott C., Roecker Phelps, Carolyn E., & Dunleavy, Alison M. (2010). The Impact of Child Symptom Severity on Stress among Parents of Children with ASD: The Moderating Role of Coping Styles. *Journal of Child and Family Studies, 19*(4), 516-524.

Manago, Davis, & Goar. (2017). Discourse in Action: Parents' use of medical and social models to resist disability stigma. *Social Science & Medicine, 184*, 169-177.

Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities*, *11*(2), 110–5.

Matson, J., & Williams, L. (2013). Differential diagnosis and comorbidity: Distinguishing autism from other mental health issues. *Neuropsychiatry, 3*(2), 233-243.

McCurdy, E. E., & Cole, C. L. (2014). Use of a peer support intervention for promoting academic engagement of students with autism in general education settings. *Journal of Autism and Developmental Disorders, 44*(4), 883–893. doi: 10.1007/s10803-013-1941-5

McDonald, J., & Lopes, E. (2014). How parents home educate their children with an autism spectrum disorder with the support of the schools of isolated and distance education. *International Journal of Inclusive Education, 18*(1), 1–17. doi: 10.1080/13603116.2012.751634

Moore, K. J., Garbacz, S. A., Gau, J. M., Dishion, T. J., Brown, K. L., Stormshak, E. A., & Seeley, J. R. (2016). Proactive Parent Engagement in Public Schools: Using a Brief Strengths and Needs Assessment in a Multiple-Gating Risk Management Strategy. *Journal of Positive Behavior Interventions*. http://doi.org/10.1177/1098300716632590

Moses, T. (2010). Exploring parents' self-blame in relation to adolescents' mental disorders. *Family Relations*, *59*(2), 103–120. http://doi.org/10.1111/j.1741-3729.2010.00589.x

Mueller, Nordt, Lauber, Rueesch, Meyer, & Roessler. (2006). Social support modifies perceived stigmatization in the first years of mental illness: A longitudinal approach. *Social Science & Medicine,62*(1), 39-49.

Ohan, J., Ellefson, S., & Corrigan, P. (2015). Brief Report: The Impact of Changing from DSM-IV 'Asperger's' to DSM-5 'Autistic Spectrum Disorder' Diagnostic Labels on Stigma and Treatment Attitudes. *Journal of Autism and Developmental Disorders, 45*(10), 3384-3389

Popp, T. K., & You, H. (2016). Family Involvement in Early Intervention Service Planning: Links to Parental Satisfaction and Self-Efficacy. *Journal of Early Childhood Research, 14*(3), 333-346.

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied psychological measurement*, *1*(3), 385-401.

Romero, A., & Ruiz, M. (2007). Does Familism Lead to Increased Parental Monitoring?: Protective factors for Coping with Risky Behaviors. *Journal of Child & Family Studies*, *16*(2), 143–154. JOUR. Retrieved from 10.1007/s10826-006-9074-5

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology and Psychiatry*, *17*(2), 229–245. http://doi.org/10.1177/1359104510365203

Ryff, C., & Hughes, D. (2003). Status inequalities, perceived discrimination, and eudaimonic well-being: Do the challenges of minority life hone purpose and growth? *Journal of Health and Social Behavior, 44*(3), 275-291.

Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics, 119*, S114–S121. doi: 10.1542/peds.2006-2089Q

Seltzer, M., Almeida, D., Greenberg, J., Savla, J., Stawski, R., Hong, J., & Taylor, J. (2009). Psychosocial and biological markers of daily lives of midlife parents of children with disabilities. *Journal of Health and Social Behavior, 50*(1), 1-15.

Semke, C. A., Garbacz, S. A., Kwon, K., Sheridan, S. M., & Woods, K. E. (2010). Family involvement for children with disruptive behaviors: The role of parenting stress and motivational beliefs. *Journal of School Psychology*, *48*(4), 293–312. http://doi.org/10.1016/j.jsp.2010.04.001

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *PEDIATRICS*, *129*(6), 1042–1049. JOUR. http://doi.org/10.1542/peds.2011-2864

Shifrer, D. (2013). Stigma of a label: educational expectations for high school students labeled with learning disabilities. *Journal of Health and Social Behavior*, *54*(4), 462–80. http://doi.org/10.1177/0022146513503346

Singh, N. N., Curtis, W. J., Ellis, C. R., Nicholson, M. W., Villani, T. M., & Wechsler, H. a. (1995). Psychometric Analysis of the Family Empowerment Scale. *Journal of Emotional and Behavioral Disorders*, *3*(2), 85–91. http://doi.org/10.1177/106342669500300203

Song, J., Mailick, M. R., Greenberg, J. S., & Hong, J. (2018). The lifelong health effects of parenting a child with developmental or mental health problems. In C. D. Ryff & R. F. Krueger (Eds.), The Oxford handbook of integrative health science. New York: Oxford University Press.

Song, J., Mailick, M. R., & Greenberg, J. S. (2018). Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma. Social Science & Medicine, 217, 152-158.

Tregnago, Megan K., & Cheak-Zamora, Nancy C. (2012). Systematic review of disparities in health care for individuals with autism spectrum disorders in the United States. *Research in Autism Spectrum Disorders, 6*(3), 1023-1031.

Vickers, H. S., & Minke, K. M. (1995). Exploring parent–teacher relationships: Joining and communication to others. *School Psychology Quarterly, 10*(2), 133–150. doi: 10.1037/h0088300

Wang, Li, & Leslie, Douglas L. (2010). Health Care Expenditures for Children with Autism Spectrum Disorders in Medicaid. *Journal of the American Academy of Child & Adolescent Psychiatry, 49*(11), 1165-1171.

Weiss, J. a., Cappadocia, M. C., MacMullin, J. a., Viecili, M., & Lunsky, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism*, *16*(3), 261–274. http://doi.org/10.1177/1362361311422708

Weiss, J. A., & Lunsky, Y. (2011). The Brief Family Distress Scale: A Measure of Crisis in Caregivers of Individuals with Autism Spectrum Disorders. *Journal of Child and Family Studies*, *20*(4), 521–528. http://doi.org/10.1007/s10826-010-9419-y

Weiss, J. A., MacMullin, J. A., & Lunsky, Y. (2014). Empowerment and Parent Gain as Mediators and Moderators of Distress in Mothers of Children with Autism Spectrum Disorders. *Journal of Child and Family Studies*, *24*(7), 2038–2045. http://doi.org/10.1007/s10826-014-0004-7

Weiss, M., J. (2002). Hardiness and Social Support as Predictors of Stress in Mothers of Typical Children, Children with Autism, and Children with Mental Retardation. *Autism: The International Journal of Research and Practice, 6*(1), 115-30.

Werner, S., & Shulman, C. (2015). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *Journal of Intellectual Disability Research, 59*(3), 272-283.

Williams, D., Yan Yu, Jackson, & Anderson. (1997). Racial Differences in Physical and Mental Health: Socio-economic Status, Stress and Discrimination. *Journal of Health Psychology, 2*(3), 335-351.

Wong, C., Odom, S. L., Hume, K. A., Cox, C. W., Fettig, A., Kurcharczyk, S., et al. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. Journal of Autism and Developmental Disorders. Advance online publication. doi: 10.1007/s10803-014-2351-z

Young, April, Ruble, Lisa, & McGrew, John. (2009). Public vs. Private Insurance: Cost, Use, Accessibility, and Outcomes of Services for Children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders, 3*(4), 1023-1033.

Zuckerman, K., Lindly, O., Reyes, N., Chavez, A., Cobian, M., Macias, K., . . . Smith, K. (2018). Parent Perceptions of Community Autism Spectrum Disorder Stigma: Measure Validation and Associations in a Multi-site Sample. *Journal of Autism and Developmental Disorders, 48*(9), 3199-3209.