ABSTRACT

Mental Health and Aggravation in Mothers of Children with
Autism Spectrum Disorder and a Medical Home:
The Mechanistic Roles of Coping, Social Support, and Health Insurance

Madeline R. Horan, Ph.D.

Mentor: Shawn J. Latendresse, Ph.D.

Mothers of children with autism spectrum disorder (ASD) often report having mental health problems and experiencing aggravation. These maternal outcomes are related to unmet health care needs of children with ASD. One proposed risk factor for differences in maternal outcomes is having a medical home. The disability-stress-coping model of adjustment theorizes that the relationship between risk factors and maternal outcomes, or adaptation, is explained by resistance factors. In the current study, two mediation models were tested to examine the extent to which a medical home is related to maternal outcomes through three proposed mediating constructs: coping, social support, and health insurance. A sample of 988 mothers of children with ASD from the National Survey of Children's Health (NSCH) was utilized in the current study. The results of the multiple mediation models suggest that the relationships between having a medical home and maternal outcomes are largely explained by indirect associations with coping, social support, and health insurance adequacy, but not health insurance type. Additional alternative models were examined to further explore the relationships between having a medical home and maternal adaptations.

Mental Health and Aggravation in Mothers of Children with Autism Spectrum Disorder and a Medical Home: The Mechanistic Roles of Coping, Social Support, and Health Insurance

by

Madeline R. Horan, B.A., M.A.

A Dissertation

Approved by the Department of Psychology and Neuroscience

_____

Charles A. Weaver III, Ph.D., Chairperson

Submitted to the Graduate Faculty of
Baylor University in Partial Fulfillment of the
Requirements for the Degree
of

Doctor of Philosophy

Approved by the Dissertation Committee

_____

Shawn J. Latendresse, Ph.D., Chairperson

_____

Christine A. Limbers, Ph.D.

_____

Annie T. Ginty, Ph.D.

_____

Stacy R. Ryan-Pettes, Ph.D.

_____

Mark C. Kelly, Ph.D.

Accepted by the Graduate School

August 2021

_____

J. Larry Lyon, Ph.D., Dean

Page bearing signatures is kept on file in the Graduate School.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

ACKNOWLEDGMENTS

I would like to express my sincere gratitude to Dr. Shawn Latendresse and Dr. Christine Limbers for their encouragement of this research and my academic career. Thank you to Dr. Annie Ginty, Dr. Stacy Ryan-Pettes, and Dr. Kelly for serving on my dissertation committee. I would also like to thank the Psychology and Neuroscience Department of Baylor University. I am so grateful to be part of a community of brilliant professors and supportive student peers.

DEDICATION

To my incredible, supportive husband, Shawn, and to my little research assistant and daughter, Hadley Rae, who decided that the week before my dissertation defense was the perfect time to be born.

CHAPTER ONE

Introduction

Pediatric Autism Spectrum Disorder (ASD)

ASD is a neurodevelopmental disorder that is characterized by deficits in social communication and the presence of excessively repetitive behaviors (American Psychiatric Association [APA], 2013). ASD is a spectrum disorder, which means it encompasses a wide range of clinical manifestations in the domains of behavior, language, and social skills (Szatmari et al., 2015). ASD is characterized by difficulty initiating and maintaining social communication and inflexibility of behavior or difficulty switching tasks (Gotham et al., 2008; Reszka et al., 2013). Individuals with ASD often experience deficits in verbal and nonverbal communication and display repetitive, stereotypical behaviors (APA, 2013). These characteristics are present in early childhood and impair daily functioning as well as social and academic functioning (APA, 2013; Szatmari et al., 2015).

Estimates of the prevalence of ASD in the United States are between 1% and 2.93% (APA, 2013; Baio et al., 2018; Xu et al., 2019). There has been a rise in the prevalence of ASD since it was first described in the 1940s (Kanner, 1943). The prevalence rates of ASD increased from one in 2500 children before 1985 to one in 150 children in 1992. (Christensen et al., 2016; McDonald & Paul, 2010). The CDC's most recent data from 2016 suggest the prevalence rate is 1 in 54 children (Maenner et al., 2020). The U.S. Department of Education completed studies showing that the rise in

prevalence was attributed to an actual increase in the number of children with ASD rather than increased awareness and different diagnostic criteria (Nevison, 2014). However, other proposed explanations for the increase in prevalence of ASD include differences in community practices for identifying and diagnosing ASD (Maenner et al., 2020) and the lack of standardization in autism screening methods in health care and education settings (Fombonne, 2018; Sheldrick & Carter, 2018). No matter the reason for the rise in prevalence, there are many children with ASD and there is an increased demand for health care services for children with ASD (Chiri & Warfield, 2011).

Health Care Needs of Children with ASD

There is no consensus as to the best treatment for ASD (Hess et al., 2007; National Autism Center, 2015). Among the numerous empirically validated therapeutic approaches used to treat individuals with ASD are behavioral interventions, cognitive behavioral treatments, language training, social skills training, and modeling (National Autism Center, 2015). In addition, certain pharmacological interventions, such as the antipsychotic medications risperidone and aripiprazole, have also been shown to treat the challenging and repetitive behaviors characteristic of ASD (McPheeters et al., 2011). The lack of consensus on the most effective treatments for ASD means that children are often exposed to multiple interventions and treatments in their lifetime. This leads to strain on resources and time for families, schools, and health care professionals (McPheeters et al., 2011; National Research Council, 2001). Further, children with ASD often have comorbid diagnoses, such as epilepsy, intellectual disability, anxiety, and attention-deficit/hyperactivity disorder (ADHD; Baio et al., 2018; Myers et al., 2007; Simonoff et al., 2008). Children may therefore require additional treatments for these comorbidities.

The treatments required for a child with ASD may not be available through their pediatrician. Thus, children with ASD typically see multiple specialists, such as occupational therapists and speech therapists (Brown et al., 2012; Gurney et al., 2006).

The types of services that are needed by children with ASD may be different from those needed by children with other special health care needs, such physical disabilities or chronic illnesses. In a study comparing children with ASD and children with other special healthcare needs, parents of children with ASD reported higher needs for specialty care and therapy services than parents of children with other special health care needs (Chiri & Warfield, 2011). Children with ASD have been shown to need more physician visits, physical therapy, occupational therapy, speech therapy, counseling for behavior problems, and long-term medication treatments than typically developing children (Brown et al., 2012; Gurney et al., 2006). Families of children with ASD need to be able to access these services in order to appropriately address the needs of their child (Perry, 2004).

Children with ASD often have unmet health care needs (Kogan et al., 2008). In a sample of 371 children with ASD, 63% had at least one unmet need for specialty services (e.g., prescription medication, speech therapy, mental health services; Farmer et al., 2014). Compared to children with other special health care needs, children with ASD report higher incidences of unmet health care needs, specifically specialty health services and therapy (Chiri & Warfield, 2011). In a qualitative study of parents of children with ASD, 19% of parents reported that they did not have transparent information about services available and how to access them. Parents also reported that they did not have consistent access to services over time (Hodgetts et al., 2014). Another barrier to

receiving health care that parents have cited is that providers have a lack of skill in treating children with ASD (Chiri & Warfield, 2011).

Children with ASD may also have unmet health care needs based on their insurance coverage and the laws of the state they live in (Wang et al., 2019). Many children with ASD have been covered by public health insurance companies for many years (e.g., the Children's Health Insurance Program [CHIP] has provided coverage for ASD treatments since 1997; Caruso, 2010), but private insurance companies were not required to provide coverage for ASD treatment until recently (Callaghan & Sylvester, 2019). As of August 2019, all 50 states have laws that require coverage for ASD treatments, but in some states there are still limits on the age of the child who has guaranteed coverage and/or limits on the medical costs that insurance companies are required to cover (Autism Speaks, 2019a; Callaghan & Sylvester, 2019). Families of children who live in some of these states with limited coverage may not be able to afford the care their child's needs (Candon et al., 2019). Parents of children with ASD have expressed frustration over the unmet needs of their child (Carbone et al., 2010).

Effect on Mothers

Mothers experience numerous forms of strain as the primary caregiver for their child with ASD. Mothers are most often the focus of studies of parents of children with ASD because they are usually considered the primary caregivers (Khanna et al., 2010). In a qualitative study of the division of responsibilities of mothers and fathers of children with ASD, mothers spent more time engaging in childcare than fathers while fathers spent more time in paid employment than mothers (Hartley et al., 2014). Mothers and fathers also differentiate on the awareness of the number of their children's support needs

– mothers are more aware of these important support needs than fathers (Hartley & Schultz, 2014). The authors suggest that mothers may be more aware of their child's support needs because they take on a large part of the care of these children. Mothers also expressed that their own support needs were unmet more often than fathers (Hartley & Schultz, 2014).

Mothers of children with ASD experience high levels of parenting stress in studies comparing mothers of children with ASD to typically developing children (Dabrowska & Pisula, 2010) and mothers of children with other disabilities (Hastings, 2008). Some of these comparison groups are mothers of children with Down syndrome (Dabrowska & Pisula, 2010), children with developmental delay (Estes et al., 2009), and other developmental disabilities such as genetic syndromes or psychiatric disorders (Dykens et al., 2014). The elevated risk of poor psychological outcomes has also been supported by meta-analyses (Scherer et al., 2019; Singer, 2006; Yirmiya & Shaked, 2005) and longitudinal studies (Gray, 2002; Hastings et al., 2006). The studies mentioned here suggest that having a child with autism leads to worse maternal outcomes, but an important future direction for studies with these families is examining the reason for differences in outcomes across mothers of children with the same diagnosis and ASD severity. There has been a call for research to elucidate why some mothers of children with ASD display high levels of depression or aggravation and others seem to cope well (Hastings, 2008; Ingersoll & Hambrick, 2011; Weiss et al., 2013). In particular, there has been a call for an empirical model of adjustment for mothers of children with ASD to inform interventions for mothers with poor adaptation (Hastings, 2008). A theoretical

model that can provide a basis for a such an empirical model is the disability-stress-coping model (Wallander et al., 1989).

The Disability-Stress-Coping Model

Maternal adaptation is a complicated phenomenon that is predicted by much more than the child's diagnosis or ASD symptoms. The disability-stress-coping model (Wallander et al., 1989) provides a theoretical framework for understanding this complex relationship between a child's ASD diagnosis and maternal outcomes. The disability-stress-coping model is a risk-resistance model, which emphasizes that, regardless of the disease-specific characteristics, there are individual or family-specific factors that affect the family's adjustment to the disability (Boyer, 2008). Resistance in the context of this model refers to the resources that benefit adaptation in the population of interest (Boyer, 2008). This biopsychosocial model was originally developed as an a priori conceptual model to explain the relationship between risk factors (i.e., disease/disability parameters, psychosocial stressors) and adaptation in children, mediated by resistance factors (i.e., intrapersonal, social-ecological, stress processing; Figure 1.1; Wallander et al., 1989; Wallander & Varni, 1992). Early applications of this model include studies with children with sickle cell disease (Brown et al., 2000), physical disabilities (Wallander et al., 1989), cancer (Katz & Varni, 1988), and intellectual disability (Wallander, 1991). This framework has also been applied to adaptation for mothers of children with physical disabilities (Noojin & Wallander, 1997), rheumatoid arthritis (Manuel, 2001), and cancer (Dolgin et al., 2007). These studies found that mothers of children with these illnesses and disabilities are at a higher risk for distress and other negative adaptations, including impaired mental health and higher risk of parental aggravation. The model identifies risk

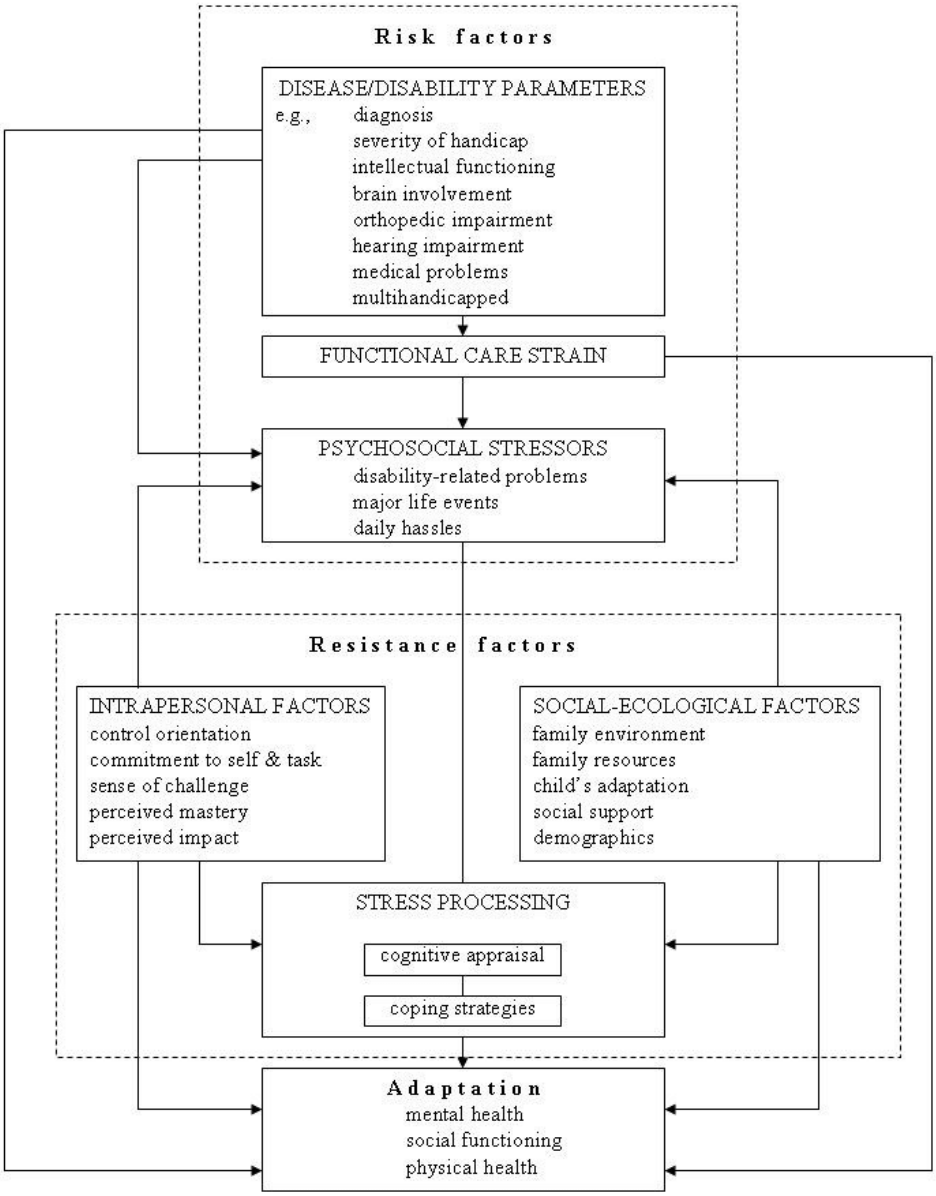

Figure 1.1. Disability-stress-coping conceptual model reproduced from Wallander et al. (1989).

factors related to the child's disease or disability that contribute to maternal outcomes. Additionally, the relationships between risk factors and maternal outcomes are examined through resistance factors that may benefit maternal adjustment to these risk factors (Boyer, 2008). Risk factors, adaptation, and resistance factors are all included in this

single theoretical model because the factors that contribute to adaptive or maladaptive outcomes are part of a complex mechanism, rather than a simple, direct relationship between disease characteristics and family outcomes.

Risk Factors

Simply having a diagnosis with a chronic illness or physical condition puts children and parents at risk for maladjustment (Wallander & Varni, 1992). However, there are other related risk factors that theoretically contribute to the family's adjustment. The risk factors that were included in the disability-stress-coping model focus on disease and disability parameters (e.g., disease severity, medical problems, comorbidities), functional independence, and psychosocial stressors related to their illness (Wallander et al., 1989). The psychosocial stressors are factors that are both specific to the disease, such as daily hassles of mobility or additional transportation to medical treatment, and in general, such as starting middle school or making friends (Wallander & Varni, 1992). These general psychosocial stressors may be exacerbated by disease-specific parameters. For example, adolescents starting middle school are faced with stressors such as navigating a new school environment and establishing new friendships, but these may be more difficult to confront if a child is in a wheelchair or has to miss many days of school for medical treatment. These risk factors affect the adaptation of children and parents. For mothers of children with chronic illnesses, their child's disease severity, need for specialty health care services, and functional dependence impact their adaptations (Wallander & Noojin, 1995). Maternal adaptation is more affected by psychosocial stress related to their child's disability than the child's functional dependence or disability parameters (Wallander et al., 1990).

Adaptations

The disability-stress-coping model was first developed out of an interest to examine the factors that contribute to variations in adjustment (e.g., child behavior, social competence) across children with chronic physical disorders (Wallander et al., 1989). The researchers found that the majority of children with one of six chronic physical illnesses had no difference in adaptation compared to norms for children their age. Some exhibited behavioral and social competence issues and only few reached clinical levels of maladaptation (Wallander et al., 1989). When this model was applied to mothers of children with physical disabilities, maternal adaptation was defined as mental health, physical health, and social functioning (Wallander et al., 1990). In the early applications of the conceptual model, there were few significant direct relationships between risk factors and adaptation in children (Wallander et al., 1989). This led to more studies assessing the indirect effect of disease and disability parameters on adaptation through resistance factors.

Resistance Factors

As associations between disease characteristics and adaptation are not necessarily straightforward, a benefit of examining these relationships through the disability-stress-coping model of adjustment is that investigators can explore potential explanations for why mothers of children with the same underlying disease factors often manifest very different outcomes (Boyer, 2008). The complicated nature of psychological adaptation is reflected in the mediating resistance factors in the disability-stress-coping model. The resistance factors in the model are generally divided into three types: stable person factors, socio-ecological factors, and stress processing (Wallander et al., 1989). Stable

person factors include intrapersonal factors such as temperament, competence, and perceived mastery. Examples of socio-ecological factors are family financial resources, social support, and family psychological resources. Stress processing was defined based on the cognitive transactional model of stress and coping in which people appraise a situation as stressful and then manage, or cope with, the particular parts of the situation they appraised as stressful (Lazarus & Folkman, 1984). Wallander and colleagues found that disease parameters did not always directly predict child adaptation, but instead a multivariate model that included social-ecological, stress, and intrapersonal factors was a better fit for children with different chronic illnesses (Wallander et al., 1989). Other theoretical models such as the caregiving stress process model (Aneshensel et al., 1995) and the caregiving process and caregiver burden model (Raina et al., 2004) built off this multivariate approach. For the current study, the multivariate disability-stress-coping model is the theoretical basis for examining the indirect relationship between having a medical home and constructs of maternal adaptation through related explanatory constructs.

Proposed Models

Based on the disability-stress-coping model, the first proposed model of the current study examined the relationship between having a medical home and maternal mental health, both directly and indirectly, through three constructs: coping strategies, social support, and health insurance. See Figure 1.2 for the proposed mediation model. The second proposed model of the current study examined the relationship between having a medical home and maternal aggravation, both directly and indirectly, through

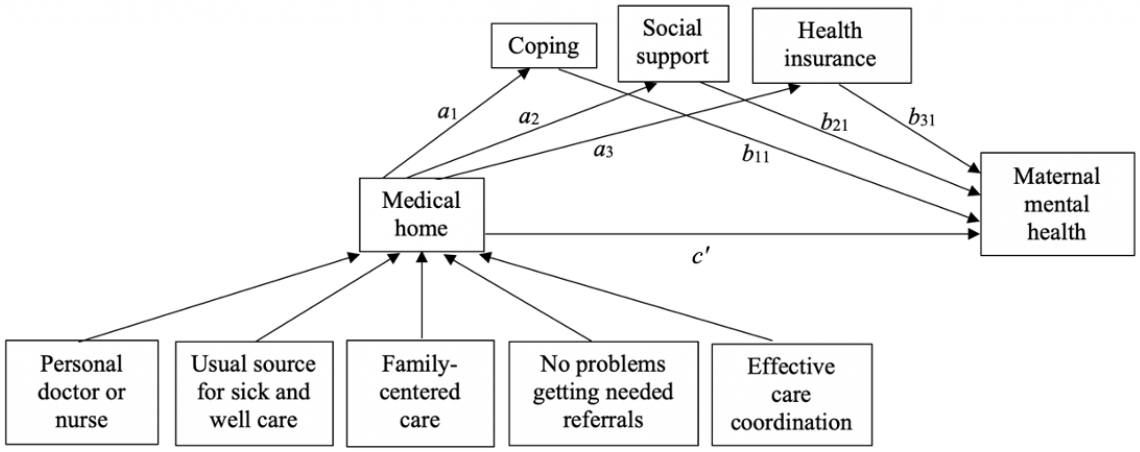

Figure 1.2. Proposed model of the relationship between having a medical home and mothers' mental health, mediated by coping, social support, and health insurance.

the same three constructs. See Figure 1.3 for the proposed mediation model. The relationship between medical home status and maternal outcomes is theoretically impacted by all three of these explanatory factors through a complex mediation mechanism rather than through a single direct mechanism. For example, parents with supportive social relationships are more likely to have healthy patterns of coping (Feeney & Collins, 2014; Zaidman-Zait et al., 2018). Each of these constructs is related to having a medical home (*a* paths in Figures 1.2 and 1.3), maternal mental health (*b* paths in Figure 1.2), and maternal aggravation (*b* paths in Figure 1.3).

The disability-stress-coping model indicates that the mechanism underlying the relationships among these variables should be modeled through mediation. In mediation models, the association between having a medical home and maternal outcomes would be explained, at least in part, by the three resistance factors: coping, social support, and health insurance. There are many alternative models that may explain the mechanism underlying the association between having a medical home and maternal outcomes. Testing alternative models that represent different patterns of relationships among the

variables may fit the data better (MacCallum et al., 1993; Wu & Zumbo, 2008). The correct model is a theoretical property of the population, so choosing the correct model is often not possible. Instead, the best fitting model is chosen based on theory, empirically tested relationships in the literature, and indirectly tested through model fit indices (McCoach et al., 2007; Wu & Zumbo, 2008). It is seldom done, but it is valuable to test alternative models a posteriori to examine the other mechanisms that may explain the relationships among the variables (Vandenberg & Grelle, 2009; Wu & Zumbo, 2008). By testing alternative models, confirmation bias about the correct model is reduced and researchers can place more confidence in the relationships they find among the variables (Vandenberg & Grelle, 2009).

Lack of a Medical Home as a Risk Factor for Maternal Outcomes

A study based on the disability-stress-coping model reported four areas of concern that contributed to maternal adaptation: medical and legal concerns, concerns for the child, concerns for the family, and concerns for the self (Wallander & Noojin, 1995).

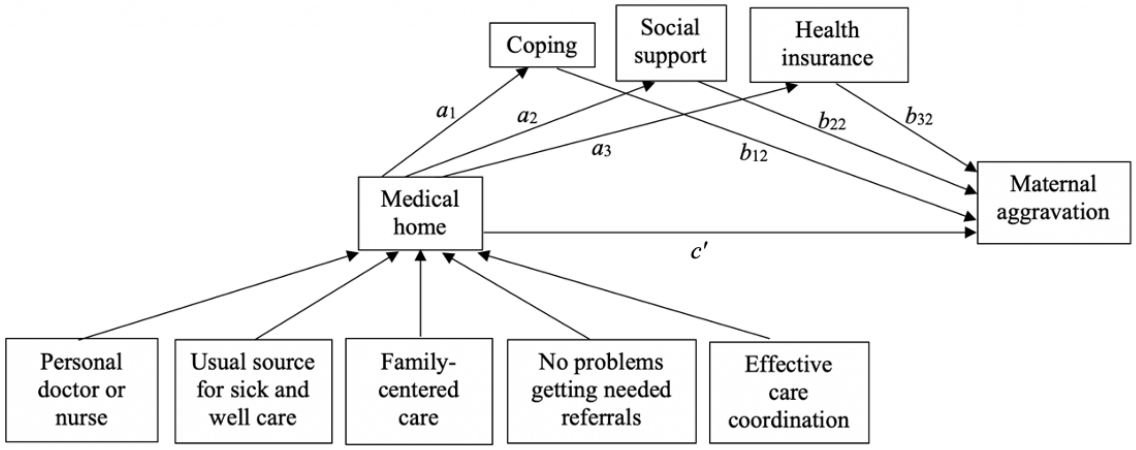

Figure 1.3. Proposed model of the relationship between having a medical home and mothers' parental aggravation, mediated by coping, social support, and health insurance.

Many of these concerns are addressed through the child having a medical home. The American Academy of Pediatrics (AAP) defines a medical home as medical care for children that has the seven components listed in Appendix A (AAP, 1992; Homer et al., 2008). The medical care should be delivered by physicians who provide primary care services as well as facilitate all aspects of the child's health and well-being. The physician should have a partnership with the family characterized by trust and respect. (AAP, 1992; AAP, 2002). A medical home can have a physician associated with a number of locations, such as physicians' offices, hospital outpatient clinics, school-based clinics, community health centers, and health department clinics (AAP, 2002). The emphasis of the definition of a medical home is not the location, but the approach to providing comprehensive, continuous, accessible care to children from infancy to young adulthood (See Appendix A; AAP, 1992; AAP, 2002). There is a clear link between children lacking a medical home and having a greater number of unmet healthcare needs that worsen disease outcomes (Farmer et al., 2014; Golnik et al., 2011; Kogan et al., 2008).

Not having a medical home can hinder the health and well-being of children and their families (AAP, 2002). In a review of the outcomes related to having a medical home for children with special health care needs, including children with ASD, there was a positive association between having a medical home and desired outcomes, such as better health status, timeliness of care, family centeredness, and improved family functioning (Homer et al., 2008). Specifically, children with ASD who did not have a medical home had more unmet health care needs, particularly for specialty services, than children with

ASD who had a medical home (Farmer et al., 2014). These specialty services (e.g., speech therapy, occupational therapy) have been shown to improve health outcomes for children with ASD (Kuhlthau et al., 2017; Rogers & Vismara, 2008). A lack of these services impacts the disease parameters, such as severity, outlined in the risk factors portion of the disability-stress-coping model (Figure 1.1).

Parents often experience frustration and stress when they assume the responsibilities of coordinating care and special services for their child with ASD (Carbone et al., 2010). Treatments for children with ASD can be prescribed and administered through many different offices (e.g., educational services, medical therapies, county services, etc.) and the treatment plan is likely to change over time (Golnik et al., 2011). The frustration and confusion these cause for parents can be in part alleviated through having a medical home that provides coordinated care for the families (Carbone et al., 2010; Farmer et al., 2014). For families of children with ASD, having a medical home also decreases financial and time burdens (Kogan et al., 2008). When parents of children with ASD are part of a shared decision-making process with health care professionals, consistent with the medical home model, they report higher satisfaction (Frosch & Kaplan, 1999; Golnik et al., 2011; Roter & Hall, 1992) and confidence in managing their child's ASD (Clark et al., 1998; Golnik et al., 2011).

Maternal Adaptations

The disability-stress-coping model shows how risk factors lead to maternal adaptation. Maternal adaptation includes outcomes such as mental health, physical health, and social functioning (Wallander et al., 1990). Two different adaptations that are prevalent in the literature from mothers of children with chronic illnesses are mental

health and aggravation. It was previously shown that these outcomes in mothers of children with ASD are affected by their children having a medical home (Cohen & Limbers, 2019; Limbers et al., 2020).

Maternal mental health. One important adaptation for mothers of children with ASD is mental health (Benson, 2006; Taylor & Warren, 2012; Totsika et al., 2011). Maternal mental health is the state of internal equilibrium specific to the role and responsibilities of being a mother (Karimzadeh et al., 2017). Maternal mental health is often operationalized via measures of anxiety, depression, and/or symptoms of distress (Hock & Schirtzinger, 1992). The association between maternal mental health and child adjustment is bidirectional (Baker et al., 2003). Mothers with poor mental health may impact their child's well-being; conversely, children with poor adaptation may be difficult and display problem behaviors which would lead to increased issues with maternal mental health (Farmer & Deidrick, 2006).

There are numerous studies documenting how disease specific characteristics of ASD impact maternal mental health. Greater ASD symptom severity in the child has been linked to increased maternal depression (Bromley et al., 2004; Ingersoll & Hambrick, 2011). In a study of 68 mothers of children with ASD, researchers found that ASD severity was positively associated with maternal depression (Benson, 2006). In another study, researchers found that maternal psychopathology was positively related to their child's ASD severity (Tomeny, 2017). Sawyer et al. (2010) found that mothers of children with ASD who felt more time pressure experienced more mental health problems, but the amount of time they spent caring for their child was not related to increased mental health problems. The time pressure associated with caring for a child

with ASD could be alleviated by having a medical home with coordinated care efforts (Homer et al., 2008).

The relationship between children with ASD having a medical home and maternal mental health is a more recent topic of scientific inquiry. In a national sample of children in the United States with ASD, mothers of children with a medical home reported better maternal mental health (Limbers et al., 2020). A similar positive relationship has also been shown in children with diabetes (Cohen & Limbers, 2019) and children with general chronic health conditions (Farmer et al., 2011). The mechanisms of this relationship are unclear and have not been studied (Limbers et al., 2020). Having a medical home improved parental satisfaction and maternal mental health, and effective care coordination seemed to be one of the most important factors of having a medical home in this relationship (Farmer et al., 2011; Limbers et al., 2020). These studies had methodological limitations, such as small sample size (Farmer et al., 2011), and no study to date has assessed potential explanatory variables in the relationship between having a medical home and maternal mental health.

Maternal aggravation. Another maternal adaptation that is impacted by the lack of a medical home is maternal aggravation. This is the frustration and stress mothers experience specifically related to caring for their children (Macomber & Moore, 1999). In the United States, nationally and at the state level, there was an increase in parental aggravation from 1997 to 2007 (Murphey et al., 2014). Maternal aggravation is a subdomain of parenting stress (Blumberg et al., 2005), but it was developed to reflect the attitude a parent has rather than a cognitive appraisal that would fall under the stress processing resistance factor in the disability-stress-coping model (see Figure 1.1). In this

way, maternal aggravation is another maternal adaptation illustrated as an outcome in the disability-stress-coping model, not a resistance factor.

Maternal aggravation is affected by family stressors (Anderson Moore & Vandivere, 2000), including having a disorder such as ASD. Parents of children with ASD are at a heightened risk of experiencing parental aggravation (Hock & Ahmedani, 2012; Mancil et al., 2009; Montes & Halterman, 2007; Zablotsky et al., 2013). This higher risk may be attributed to difficulty obtaining a diagnosis of ASD, characteristics of the child (e.g., problem behaviors), and/or a lack of social support (Dunn et al., 2001). Parents of children with ASD were more likely to have high parental aggravation than parents of children with developmental problems other than ASD, parents of children with special health care needs without developmental problems, and parents of children without special health care needs (Schieve et al., 2007).

Parental aggravation is associated with the child with ASD not having a medical home. In a study of children with special health care needs, not specifically ASD, parents of children with a medical home were less likely to report increased parental aggravation than those without a medical home (Arauz Boudreau et al., 2012). In a study with a sample of parents of children with ASD from the 2007 National Survey of Children's Health (NSCH), increased parental aggravation was associated with lack of a medical home (Schieve et al., 2011). Parents of children with ASD had higher parental aggravation when the child with ASD had recent special care needs than when the child with ASD did not have recent special health needs (Schieve et al., 2007). This relationship has been examined and established, but resistance factors as indirect

explanatory variables of this relationship have not been explored, as with maternal mental health.

Resistance Factors

Based on the disability-stress-coping model, the first proposed model of the current study examined the relationship between having a medical home and maternal mental health, both directly and indirectly, through three constructs: coping strategies, social support, and health insurance. The second proposed model of the current study examined the relationship between having a medical home and maternal aggravation, both directly and indirectly, through the same three constructs. Coping strategies, social support, and health insurance are all included in both models because there is a cumulative effect of experiencing multiple family and environmental risks (Baron-Lee et al., 2015). Each of these constructs is related to having a medical home (*a* paths in Figures 1.2 and 1.3), maternal mental health (*b* paths in Figure 1.2), and maternal aggravation (*b* paths in Figure 1.3).

Coping strategies. One of the possible resistance factors in the relationship between having a medical home and maternal mental health is the mother's coping strategies. Lazarus and Folkman (1984) describe coping as the process by which a person manages the particular parts of the person-environment relationship they appraised as stressful. The relationship between having a medical home and coping has been studied in children with special health care needs, but not specifically with parents of children with ASD. In a study of parents in the United States, parents of children who reported they were not coping well had lower incidence of having a medical home (Baron-Lee et

al., 2015). This relationship was also examined in a different sample of children in the United States and parents reported better coping with the demands of parenthood when their child had a medical home compared to parents who reported their child did not have a medical home (Arauz Boudreau et al., 2012). In another study of children with special health care needs, children who had a medical home were more likely to have parents who reported that they were coping well (Drummond et al., 2012). Parents who reported that medical care was family-centered, specifically, reported better coping (Drummond et al., 2012). Studies that have focused on the relationship between the child having a medical home and maternal coping (path a_1 in Figures 1.2 and 1.3) have included children with ASD in the sample of children who have special health care needs (e.g., Drummond et al., 2012), but there are no studies that have examined this relationship specifically in families of children with ASD.

Additionally, there is evidence that coping can impact maternal mental health (path b_{11} in Figure 1.2; Major, 2003). In Lazarus and Folkman's book (1984) detailing their transactional model of stress and coping, they emphasize that coping processes affect adaptational outcomes. They specifically remark that "what we usually mean by mental and physical health are tied up with the ways people evaluate and cope with the stresses of living" (Lazarus & Folkman, 1984). This relationship between coping mechanisms and mental health is reflected in the stress processing resistance factor of the disability-stress-coping model (Wallander et al., 1989). Positive coping strategies have been associated with better maternal mental health in mothers of children with intellectual disabilities (Adams et al., 2018), low birthweight (Weiss & Chen, 2002), and cancer (Barrera et al., 2004). There is evidence supporting the relationship between

coping and mental health for mothers of children with ASD. (Benson, 2010; Dunn et al., 2001; Major, 2003; Zablotsky et al., 2013). In a study using the 2007 iteration of the NSCH, researchers found that coping buffered the relationship between ASD severity and parent mental health (Zablotsky et al., 2013). Benson (2010) looked more specifically at different coping styles in mothers of children with ASD. He found that avoidant coping was associated with higher depression and anger and cognitive reframing was associated with better maternal well-being. In a latent profile analysis of parents of children with ASD, different profiles emerged based on coping styles (Zaidman-Zait et al., 2018). Parents in profiles characterized by reduced or disengaged coping strategies had the highest psychological stress two years later. The relationship between coping and maternal mental health is empirically and theoretically established, so it is appropriate to include coping as a mediating construct in the proposed model (Figure 1.2).

Lazarus and Folkman (1984) also discuss coping in the context of social functioning. They suggest that relationships are able to endure the occasional poor coping strategy employed by one party in the relationship, but over the long term, inappropriate or ineffective coping strategies will lead to misunderstandings and frustration. Maternal aggravation is the frustration mothers feel in their relationship with their child (Macomber & Moore, 1999). Coping has been associated with parental aggravation specifically in parents of children with ASD (path b_{12} in Figure 1.3). In a study of children with ASD in Spain, the engagement coping style had a significant indirect effect on the relationship between ASD symptoms and parenting stress (Miranda et al., 2019). Adaptive coping strategies were associated with decreased parenting stress in a study of parents with ASD (Hastings & Johnson, 2001). The link between coping and parenting

stress follows Lazarus and Folkman (1984) transactional model of stress and coping. Since parental aggravation is a subdomain of parenting stress (Blumberg et al., 2005), it is possible that coping mediates the relationship between having a medical home and parental aggravation.

Maternal social support. Another construct in the proposed mediation models is maternal social support. Social support is the perception or experience of being cared for by others (Wills, 1991). Romantic partners or spouses, friends, relatives, coworkers, and community groups can all be sources of social support (Allen et al., 2002). Social support can come in different forms: informational support, instrumental support, and emotional support (Taylor, 2011). Informational social support is helping someone understand a stressful event and their available resources or coping strategies. Instrumental support is providing financial resources, goods, services, or other tangible assistance. Emotional support is providing nurturing and reassurance to a person to remind them that they are valuable (Taylor, 2011). Maternal social support is perceiving or experiencing these types of social support in the context of raising children (Wiles et al., 2019).

Having a medical home has been shown to decrease the mothers' need for social support (path a_2 in Figures 1.2 and 1.3). A review of the outcomes associated with having a medical home used a conceptual model to guide their article search and one of the theoretical long-term outcomes of having a medical home was social support as a subdomain of family functioning (Homer et al., 2008). In a study with families of children with special health care needs in rural areas of the Midwest in the United States, a medical home was introduced as an intervention to assist families in navigating the health care system (Farmer et al., 2005). Child health services, satisfaction with health

services, family functioning, and child functioning were all assessed before and after the implementation of a medical home, and the researchers found that parents, 98% of whom were mothers, reported less need for social support after the intervention (Farmer et al., 2005). A similar result was found when medical homes were provided for adolescent mothers and their children (Cox et al., 2012). There is evidence that parents of children with ASD seek information for services through ASD-specific support groups (Cole et al., 2017; Mandell & Salzer, 2007). This implies that parents seek social support from other parents of children with ASD to obtain information that could be given through a medical home.

In addition to the evidence in the literature that having a medical home is related to social support for mothers, there is an established relationship between social support and maternal mental health. There is strong evidence for the relationship between social support and maternal mental health (path b_{21} in Figure 1.2). Social support has been linked to improved mental and physical health for decades (House et al., 1988; Taylor, 2011). In a longitudinal study, mothers who perceived higher levels of support from the child's father when they gave birth and mothers who experienced increased levels of support over time reported fewer mental health problems five years after their child was born (Meadows, 2011). Social support is also related to better mental health in mothers receiving welfare (Siefert et al., 2000), single mothers (Cairney et al., 2003), mothers of preterm infants (Younger et al., 1997), and mothers of children on ventilators (Kuster & Badr, 2009). Social support has been associated with better maternal mental health in mothers of children with ASD. In a nationally representative study of mothers of children with ASD in the United States, mothers with emotional and neighborhood social support

were at a lower risk for poor mental health, especially for mothers who had children with the greatest ASD impairments (Zablotsky et al., 2013). Low levels of social support from family members were associated with higher psychological distress in mothers of children with ASD (Bromley et al., 2004). In general, there is a positive relationship between the level of mental health problems and available social support (Cohen & Wills, 1985; Dunn et al., 2001; Dunst et al., 1986; Horton & Wallander, 2001; Sawyer et al., 2010). The abundance of literature provides evidence that social support should be included as an explanatory construct in the currently proposed models.

There is also evidence that social support should be included as a resistance factor in the mediation model between having a medical home and parental aggravation because parents of all children who have social support at work or in other contexts outside their immediate family may have reduced parental aggravation (Moore & Ehrle, 1999). Mothers who perceive they have more social support from friends and family have less distress and hostility in their parent-child interactions (Bonds et al., 2002; Green et al., 2007). In a longitudinal study of first-time mothers, mothers who had more perceived social support also reported less parental distress and aggravation (Levy-Shiff et al., 1998). There is also empirical evidence for the relationship between maternal social support and maternal aggravation in mothers of children with ASD (path b_{22} in Figure 1.3; Benson & Karlof, 2008; Gray, 2003). Specifically, increased parental aggravation was associated with lack of emotional support (Schieve et al., 2011). In a study of children with ASD in Spain, confident social support was significantly associated with parenting stress (Miranda et al., 2019). Boyd (2002) conducted a selective review that supports a relationship between lack of social support and increased parenting stress and

aggravation in mothers of children with ASD. A recent study of parents of adolescents with ASD reported that there were not simple relationships between child problem behaviors and/or ASD symptom severity and parent aggravation (Dieleman et al., 2018). The article concluded with a recommendation that social support be researched as a possible explanation for this relationship. It is clear that more social support is associated with decreased parenting aggravation, making social support an appropriate explanatory variable in the proposed model.

Health insurance. The third resistance factor included in the proposed models is health insurance. In general, insurance coverage is the major determinant of whether children have access to health care (Edmunds & Joel Coye, 1998). Access to a medical home is affected by health insurance status (Strickland et al., 2009). There is also evidence that having a medical home may lead to more stable health insurance, suggesting that the relationship between these two variables may be bidirectional (Ghandour et al., 2011; Watson et al., 2020). Having a medical home facilitates access to information regarding types of health insurance available to families, specifically through the care coordination component, which has been shown to reduce out-of-pocket costs for parents and decrease parent's time away from work to coordinate those services themselves (Ghandour et al., 2011). Many parents and their children receive insurance benefits from the parents' employers, and more stable employment leads to fewer gaps in insurance (Watson et al., 2020). Mothers of children with ASD reduced their hours worked per week by 16%, on average, compared to mothers of children without ASD (McCall & Starr, 2018). Fathers also reduced their hours worked per week in this study, but by a smaller margin. These changes in employment hours can affect the parents', and

therefore their dependents', eligibility for their employer's health insurance. Caregivers of children with ASD were more likely to avoid changes in their employment to keep their health insurance than caregivers of children with other special health care needs (Watson et al., 2020).

The relationship between having a medical home and health insurance has been established (path a_3 in Figures 1.2 and 1.3). Care provided through a medical home costs less money and is often more effective than care provided through emergency departments, walk-in clinics, and other urgent care centers (AAP, 2002). The health care team in a medical home provide information on the types of health insurance available to children with ASD (AAP, 2002). This allows parents to make informed decisions about the type of health insurance their child should be enrolled in: private or public (Tippy et al., 2005). Historically, expanded approaches to health care, such as a medical home, have been more likely to be financed by public health insurance than by private insurers (Edmunds & Joel Coye, 1998; Parish et al., 2015; Wang et al., 2012). Health insurance plans that allow patients and their families to choose any provider typically have very limited coverage of the supportive therapies required for children with chronic illnesses (Edmunds & Joel Coye, 1998).

For children with ASD, supportive therapies include speech therapy, occupational therapy, physical therapy, and sensory integration therapy among other possible therapies (Centers for Disease Control and Prevention [CDC], 2019). Most managed care plans, provided by the employers, provide preventive and primary care benefits for children, but they differ in the extent to which specialty pediatric services are covered (Edmunds & Joel Coye, 1998; Peele et al., 2002). There are, however, mixed results in the difference

between public and private insurance for access to services for children with ASD (Liptak et al., 2008; Parish et al., 2015; Young et al., 2009). For example, one study found no difference in the access to services or types of services used between privately and publicly insured children with ASD (Young et al., 2009). However, this study was limited to children in Kentucky and the authors recommend that future research include a measure of medical home as a more comprehensive measure of access to care.

While studies have been done that examine the impact that health insurance has on having a medical home, few studies have examined parent's perception of the adequacy of their child's health insurance and its relationship with having a medical home. Most studies that examine the relationship between having a medical home and health insurance or financial burden use objective measures, such as out-of-pocket costs, type of health insurance, and family income (Liptak et al., 2008; Parish et al., 2015). In addition to the objective costs of having a chronic illness, the subjective perception of a patient's financial situation is part of the financial toxicity or financial burden that families experience (Zafar & Abernethy, 2013). This has been studied much less often than objective costs of illness in patients with cancer (Santacroce et al., 2019; Zafar & Abernethy, 2013), chronic kidney disease (Medway et al., 2015), and developmental disabilities (Murphy et al., 2007). One qualitative study of parents of children with ASD did not specifically mention the children having a medical home, but the parent's perception of their financial situation was associated with access to care and the parents' experience with the ASD service delivery system (Moodie-Dyer et al., 2014). Having a medical home may predict a mother's subjective view that their child has adequate health insurance. As part of the comprehensive component of the medical home, the physician

should provide information on the different types of health insurance available to the child (AAP, 2002). This may influence the mother's perception of the adequacy of her child's health insurance and provide more information that may allow her to change her child's health insurance to a more appropriate health insurance plan (Tippy et al., 2005).

Having health insurance for their children can alleviate poor mental health outcomes for mothers (Conger et al., 1992; Shalowitz et al., 2006). Finances and insurance status may lead directly and indirectly to anxiety, depression, posttraumatic stress, and other types of parental mental health (Brown et al., 2008). The association between a child's health insurance status and maternal outcomes, including maternal aggravation, has been recently described in a conceptual model for families of children with cancer (Santacroce & Kneipp, 2018). For mothers of children with ASD, their child's health insurance can impact their mental health (path b_{31} in Figure 1.2). In a study of mothers of children with ASD, there was a trend for mothers of children without health insurance to have poor mental health (Zablotsky et al., 2013). The positive effect of the child's health insurance on maternal mental health has been studied in mothers of children with asthma (Shalowitz et al., 2006) and ADHD (Lesesne et al., 2003), but not ASD specifically. However, the association between having a medical home and child's health insurance for children with ASD provides evidence that this is an appropriate resistance factor in the relationship between having a medical home and maternal mental health.

Parents report that having health insurance for their children reduces their aggravation (Institute of Medicine Committee on the Consequences of Uninsurance, 2002). Health insurance for the entire family is associated with a decrease in parental

stress and aggravation because parents do not have to worry as much about unexpected health costs (Schmit & Matthews, 2017). Parents who struggle with accessing health insurance for their children, such as immigrant families, report high levels of parental aggravation (Yu & Singh, 2012). For children with ASD, increased parental aggravation has been associated with lack of health insurance (path b_{32} in Figure 1.3). Schieve et al. (2011) found that for parents of children with ASD, high aggravation was associated with a lack of health insurance and lack of a medical home. In study of mothers of children with ASD, there was a trend for mothers of children with health insurance to have higher parenting stress (Zablotsky et al., 2013). The literature specifically examining the relationship between health insurance type and adequacy is lacking for parents of children with ASD. However, the established relationship between having a medical home and child's health insurance support the addition of health insurance as an explanatory variable in the proposed model.

Child and Household Characteristics as Covariates

There is evidence that there are differences in maternal outcomes based on characteristics of their children and households, which indicates that these characteristics may be important covariates in the current models. A previous study of the relationship between having a medical home and maternal outcomes included child age, sex, and household poverty as covariates (Limbers et al., 2020), so these three variables were chosen as covariates in the current models. The clinical manifestation and health care needs of children with ASD change as children age, which influence the experience of mothers raising children with ASD (McGovern & Sigman, 2005; Shattuck et al., 2007). In one study of mothers of children with ASD, having a younger child was associated

with higher levels of maternal stress (Duarte et al., 2005). Boys are approximately four times more likely than girls to be diagnosed with ASD (Baio et al., 2018). This may be based on diagnostic bias toward the ways ASD manifests in boys or better adaptation to ASD symptoms in girls (Dworzynski et al., 2012). Sex differences in the clinical manifestation of ASD may influence maternal outcomes. In the general population, maternal factors, such as coping, social support, and maternal warmth have been shown to be affected by household poverty (Klebanov et al., 1994; Radey & McWey, 2021). In mothers of children with ASD, less favorable mental health and high stress were both more likely in mothers living below the poverty line (Zablotsky et al., 2013). Differences in these three variables could possibly confound the relationships among having a medical home, maternal adaptations, and resistance factors.

Other child characteristics that have been associated with maternal outcomes are race/ethnicity, adverse childhood experiences (ACEs), age at ASD diagnosis, and ASD severity. Studies have shown differences in maternal mental health (Zablotsky et al., 2013) and parental aggravation (Schieve et al., 2011) based on child's race. ACEs have also been associated with worsened health conditions and higher costs of care (Bethel et al., 2014; Chartier et al., 2010; Florence et al., 2013; Smith & Smith, 2010). There are differences in parental aggravation based on the parent rating of ASD severity (Schieve et al., 2011). ASD severity was also associated with family-centered care and parental aggravation in a study of parents of children with ASD (Simpson et al., 2021). The age at which a child is diagnosed with ASD can also impact parent outcomes. Delays in receiving a diagnosis can result in increased parent dissatisfaction and stress (Cohen, 2006; Moh & Magiati, 2012; Schall, 2000). While they are not specifically of interest in

the current models, these variables may also confound the relationships among having a medical home, maternal adaptations, and resistance factors.

Current Study

Based on the theoretical disability-stress-coping model of adjustment to chronic disorder (Wallander et al., 1989) and the empirical literature on children with ASD having medical homes, maternal mental health, and maternal aggravation, the current study included analysis of two proposed models. First, the current study examined possible mediating variables (coping, social support, and health insurance) in the relationship between the child having a medical home and mother's mental health in mothers of children with ASD. Second, the current study also examined possible mediating variables (coping, social support, and health insurance) in the relationship between having a medical home and parental aggravation in mothers of children with ASD. It was hypothesized that there would be a significant, positive total effect of having a medical home on improved maternal mental health. It was also predicted that there would be a significant, negative total effect of having a medical home on increased parental aggravation. Furthermore, it was hypothesized that these total effects of a medical home on both maternal mental health and parental aggravation in mothers of children with ASD would operate, at least in part, through significant indirect effects on maternal coping, social support, and/or health insurance when examined through the proposed multiple mediation frameworks.

CHAPTER TWO

Methods

Participants

The NSCH is a cross-sectional, national survey of children's health and well-being. The most recent survey was conducted in 2017 and 2018 (Child and Adolescent Health Measurement Initiative [CAHMI], 2009). Invitations to complete the survey were mailed to households and parents were asked to complete a screener if interested in participating in the survey. Based on the screener, one child was randomly selected per household and a parent completed the survey for this child. Parents were able to complete the survey either online or on paper. In the 2017 and 2018 iteration of the NSCH, 52,129 surveys were completed by caregivers across the United States. For the current study, the participants were limited to parents who reported that they have a child with ASD (n = 1,440). Mothers are defined as biological, adopted, step, or foster mothers. Fathers and other caregivers (n = 416) were excluded from the sample of parents of children with ASD. Children whose mothers responded "Uninsured" when asked about their child's current health insurance status were excluded from the study to guarantee that findings were due to patient-centered medical home status access and not lack of health care in general. The final sample consisted of 988 mothers of children with ASD and health insurance.

Measures

Maternal Mental Health

A single item was used in the NSCH to assess maternal mental health. Mothers were asked to rate their mental and emotional health, in general, on a scale from 1 (excellent) to 5 (poor). Responses were reverse scored so that higher scores indicate better perceptions of maternal mental health. This item has been widely used as an indicator of mothers' perception of their mental health in other studies (Cohen & Limbers, 2019; Limbers et al., 2020; Linares et al., 2020; Whitehead, 2017). Single-item measures of self-rated mental health have been widely used in health research; in a review of these single-item measures, they were associated with multi-item measures of mental health, overall health, and health service satisfaction (Ahmad et al., 2014).

Maternal Aggravation

The Aggravation in Parenting Scale (Blumberg et al., 2005) was used to assess maternal aggravation. This measure was derived from the Parental Stress Index (Abidin, 1997) and the Parental Attitudes about Childrearing scale (Easterbrooks & Goldberg, 1984). The original Aggravation in Parenting Scale had four items: How much time during the past month have you:

- felt your (child/children) much harder to care for than most?
- felt your (child/children do) things that really bother you a lot?
- felt you are giving up more of your life to meet your (child/children's) needs than you ever expected?
- felt angry with your (child/children)?

Mothers were asked to respond to each of these with one of four response categories: all of the time, most of the time, some of the time, or none of the time. The cultural validity of the Aggravation in Parenting Scale is limited among Spanish speaking parents, and removal of the third item (felt you are giving up more of your life to meet your child's needs than you ever expected) improved the measure (Oster et al., 2002). This item was removed in the 2007 administration of the NSCH and has not been included in subsequent surveys, including the 2017/2018 iteration (Blumberg et al., 2009). The Aggravation in Parenting Scale has been used in previous research (Hock & Ahmedani, 2012; Schieve et al., 2007; Schieve et al., 2011) as well as in the National Survey of America's Families (NSAF) in 1997, 1999, and 2002 (Ehrle & Moore, 1997).

Medical Home

The NSCH developed an operational definition of medical home based on the seven components of a medical home described in the policy reports written by the AAP (CAHMI, 2009). The seven components of a medical home (accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective) were used in the development of the medical home measure in the NSCH, but the survey's methodology did not allow for measuring the concept of medical home directly (CAHMI, 2019). For example, the cross-sectional nature of the data collection did not provide an adequate way of asking about the continuity of care (CAHMI, 2009). Based on the survey's methodological limitations and the survey authors' interpretation of the concept of a medical home, the NSCH measured five key components of a medical home: having a personal doctor or nurse, a usual source for sick care, family-centered care, problems getting referrals when needed, and effective care coordination when

needed (CAHMI, 2019). Families have a medical home if the mothers indicated that the child received adequate care on the first three components: having a personal doctor or nurse, and a usual source for sick care, family-centered care. If children required referrals or care coordination, the mothers must have also indicated that the child met the criteria on those components to qualify as having a medical home. For example, a child may receive all care from a primary care physician and would not need referrals or care coordination. In this case, the child would only have to meet the criteria for the first three components to have a medical home. If a child does require referrals and does not meet the criteria for this component, then the child would not have a medical home even if they met the criteria for the first three components. See Figure 2.1 for a visual representation of the criteria children must have met to have a medical home. This method of assessing whether or not a child has a medical home has been used in previous studies of families of children with ASD (Cheak-Zamora & Farmer, 2015; Kogan et al., 2008; Sobotka et al., 2016).

Coping

A single item was used in the NSCH to assess coping. Mothers were asked "How well do you think you are handling the day-to-day demands of raising children?" The three response options were 1 (very well), 2 (somewhat well), and 3 (not very well or not very well at all). Higher scores indicate worse perceptions of coping. This item has been used to assess maternal coping in other studies (Montes & Halterman, 2007; Zablotsky et al., 2013).

Social Support

A single, dichotomous item was used to assess social support. Mothers were asked whether or not their children were "living with parents who have someone that could turn to for day-to-day emotional support with parenting or raising children." This item has previously been used in research of parents with ASD (Montes & Halterman, 2007; Schieve et al., 2007; Schieve et al., 2011).

Health Insurance

Health insurance was assessed with two constructs: type of current health insurance and adequacy of current insurance. Mothers were asked to indicate the type of health insurance their child had. The response options were "Public health insurance only," "Private health insurance only," and "Public and private insurance." Public health insurance is Medicaid, Medical Assistance, or any kind of government assistance plan for those with low income or disability. Private health insurance is insurance through an employer or union, coverage purchased directly through an insurance company, TRICARE or other military health care, insurance through the Affordable Care Act, or other private insurance. For the current study, this nominal variable was recoded into two dummy variables using orthogonal contrasts. In the first dummy variable, "Public health insurance" was coded as -1, "Private health insurance" was coded as -1, and "Public and private insurance" was coded as 2 so that children who had both public and private health insurance was compared to children who had either private or public health insurance. In the second dummy variable, "Public health insurance" was coded as -1, "Private health insurance" was coded as 1, and "Public and private insurance" was coded as 0 so that

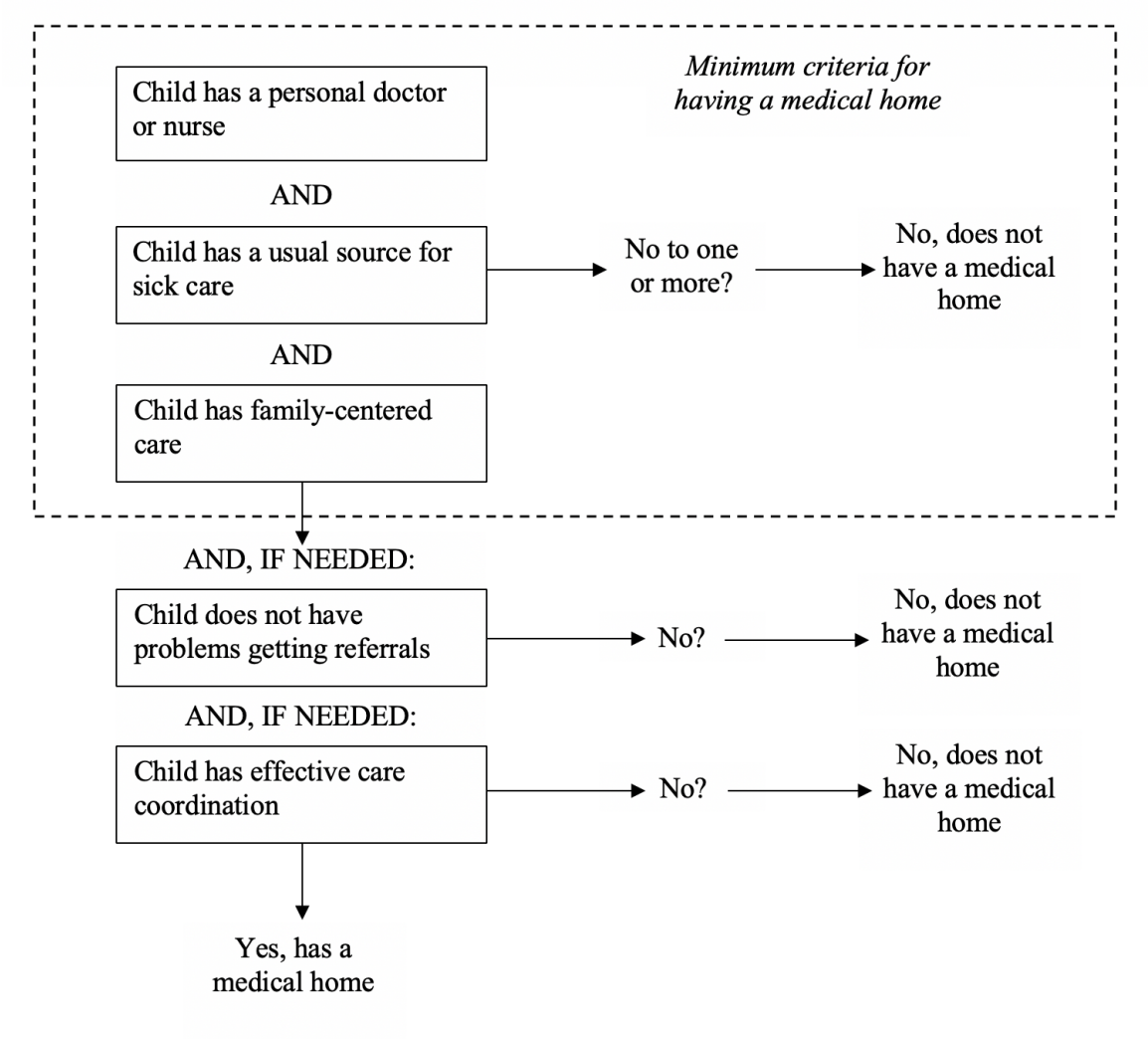

Figure 2.1. Measurement of medical home from National Survey of Children's Health 2017/18 adapted from CAHMI (2009)

children who had public health insurance was compared to children who had private health insurance.

Adequacy of health insurance was assessed with five items: (1) current health insurance coverage, (2) whether coverage is sufficient to meet the child's needs, (3) how much they paid out-of-pocket for child's health care, (4) how often are these costs reasonable, and (5) whether insurance allows the child to see needed health care providers. Adequate insurance is defined by the following criteria: child currently has

health insurance coverage, benefits usually or always meet child's needs, benefits usually or always allow child to see needed providers, and families have either no out-of-pocket expenses or out-of-pocket expenses are usually or always reasonable. Children must meet all four of these criteria to have adequate health insurance, so the adequacy of health insurance variable is a dichotomous variable. These measures of health insurance have been used in previous studies (Karpur et al., 2018; Thomas et al., 2016; Zhang & Baranek, 2016).

Covariates

Several sociodemographic variables will be included as covariates in the model. These include child age, sex, and household poverty, consistent with a previous study using the 2011-2012 iteration of the NSCH (Limbers et al., 2020). Child age was reported in years. Household poverty level was assessed based on the federal poverty level (FPL) and U.S. Census guidelines. Families were categorized as 0-99% FPL, 100-199% FPL, 200-399% FPL, or 400% FPL or greater.

Other child characteristics were included in descriptive statistics of participant characteristics and analyses of alternative models. These variables are race/ethnicity, ACEs, age at diagnosis, and diagnosis severity. Mothers reported their child's/ethnicity as white, non-Hispanic; Hispanic; multi-race, non-Hispanic; black, non-Hispanic; Asian, non-Hispanic; American Indian or Alaska Native, non-Hispanic; or Native Hawaiian and other Pacific Islander, non-Hispanic. Race and/or ethnicity have been used as covariates in other studies of children with ASD (Hock & Ahmedani, 2012; Montes & Halterman, 2007). Mothers responded whether or not the following nine ACEs were true for their child: it was hard to cover basics on the family's income; parent was divorced or

separated; parent had died; parent had served time in jail; saw or heard parents slap, hit, kick, or punch one another in the home; was a victim of violence or had witnessed neighborhood violence; lived with anyone who was mentally ill, suicidal, or severely depressed; lived with anyone who had a problem with drugs or alcohol; and treated or judged unfairly due to race and/or ethnicity. The ACE variable was then a count of the number of ACEs the child experienced. The results were collapsed into three categories: no ACEs, one ACE, and two or more ACEs. Age at diagnosis was reported by mothers based on three categories: diagnosed before 3 years old, diagnosed between 3 and 5 years old, and diagnosed after 5 years old. Mothers reported their child's ASD severity as either mild, moderate, or severe. The moderate and severe categories were combined into one category in the NSCH dataset. The final ASD severity variable is dichotomous with mild severity as one response category and moderate or severe as the other response category. ASD severity has been used as a covariate in studies of parental psychological well-being (Hastings et al., 2005) and maternal mental health (Hodge et al., 2013).

Procedure

The current sample is a combined dataset of the NSCH for 2017 and 2018. Data was collected from August 2017 to February 2018 and from June 2018 to January 2019. For the combined dataset, 52,129 surveys were completed by parents and caregivers across the United States. Parents could choose to complete the NSCH either online or on paper. Invitations to complete the survey were mailed to households asking parents to complete a screener indicating how many children ages 0-17 years lived in the house. If parents completed the screener online, they were immediately redirected to the full questionnaire. Parents were asked to complete the survey for one child per household

who was randomly selected through the online system. Parents could also request paper copies of the screener and survey to complete and mail in. Informed consent was obtained, and more detailed procedures can be found at the Data Resource Center for Child & Adolescent Health website (https://www.childhealthdata.org/learn-about-the-nsch/methods).

Statistical Analysis

Descriptive analysis of the sample demographics was completed in R (R Core Team, 2018). Statistical analysis of the mediation models was completed using Mplus, Version 7.2 (Muthén & Muthén, 1998–2012). A theoretically driven multiple mediation model (See Figure 1.2) was tested to assess the effects of having a medical home on maternal mental health, both directly and indirectly, through coping, social support, and child health insurance. A similar model was tested to assess the effects of having a medical home on parental aggravation (See Figure 1.3). Covariates (child age, sex, and household poverty level) were included in the analysis. Weighted least square mean and variance adjusted (WLSMV) estimation was used to test the mediation models. This estimation method was used because there are nominal and ordinal variables in both models (Brown, 2006). WLSMV estimation is also appropriate when sample sizes are greater than 200 (Bandalos, 2014; Flora & Curran, 2004; Muthén et al., 1997; Rhemtulla et al., 2012). Missing data is handled using pairwise deletion under WLSMV estimation (Asparauhov & Muthén, 2010). There is no evidence that missing data is not at least missing at random, so the way WLSMV estimation handles missing data is appropriate for this sample (Asparauhov & Muthén, 2010). The results were standardized with

respect to both the predictor and outcome variables in both models. Total, direct, total indirect, and specific indirect effects for both models were examined.

CHAPTER THREE

Results

Participant Characteristics

The demographic information of the children with ASD of the mothers in the current study can be seen in Table 3.1. The age of children in the ASD subsample was higher than the total sample of children from the NSCH (n = 52,129, M = 10.45, SD = 5.24). Children are most often diagnosed with ASD around age 4 (Baio et al., 2018). In this sample, 38.16% of children were diagnosed between 3 and 5 years old. Eighteen percent of children were diagnosed before age 3 and 36.44% were diagnosed after age 5. The greater proportion of male children in the sample (78.14%) is expected because boys are approximately four times more likely to be diagnosed with ASD than girls (Baio et al., 2018). The distribution of race in the subsample of children with ASD differed from the total sample of children from the NSCH [$\chi^2(7) = 23.665$, $p = .001$], though the effect size is quite small ($\widehat{w} = .15$). The large proportion of white, non-Hispanic children is expected based on previous estimates of the prevalence of ASD among these children in national samples (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators, 2012; Baio et al., 2018; Jarquin et al., 2011). See Table 3.2 for the observed frequencies of race/ethnicity in the subsample of children with ASD and the expected frequencies based on the proportions of the total sample of children from the NSCH. Thirty six percent of children had experienced none of these ACEs, 26.21% had experienced one of these nine ACEs, and 37.35% had

Table 3.1. *Child characteristics*

Demographic	*M* (*SD*)
Age	12.31 (4.19)
Age at ASD Diagnosis	*n* (%)
Younger than 3 years of age	179 (18.12)
3-5 years of age	377 (38.16)
Older than 5 years of age	360 (36.44)
Missing	72 (7.29)
Sex	
Male	772 (78.14)
Female	216 (21.86)
Race/Ethnicity	
White, non-Hispanic	672 (68.02)
Hispanic	128 (12.96)
Multi-Race, non-Hispanic	79 (8.00)
Black, non-Hispanic	73 (7.39)
Asian, non-Hispanic	23 (2.33)
American Indian or Alaska Native, non-Hispanic	8 (0.81)
Native Hawaiian and Other Pacific Islander, non-Hispanic	1 (0.10)
Missing	4 (0.40)
Number of Adverse Childhood Experiences (ACEs)	
No ACEs	358 (36.23)
1 ACE	259 (26.21)
At least 2 ACEs	369 (37.35)
Missing	2 (.20)
ASD Severity	
Mild	458 (46.36)
Moderate or severe	439 (44.43)
Missing	91 (9.21)

experienced at least two ACEs. Of the mothers who reported on their child's ASD severity, approximately half of the mothers reported their child's ASD was mild, and half of the mothers reported their child's ASD was moderate or severe.

Table 3.2. *Observed frequencies of race/ethnicity in the subsample of children with ASD and expected frequencies based on the proportions of the total sample of children from the NSCH*

Race/Ethnicity	Observed frequencies	Expected frequencies
White, non-Hispanic	672	681.87
Hispanic	128	115.59
Multi-Race, non-Hispanic	79	63.23
Black, non-Hispanic	73	63.19
Asian, non-Hispanic	23	48.27
American Indian or Alaska Native, non-Hispanic	8	5.72
Native Hawaiian and Other Pacific Islander, non-Hispanic	1	2.22
Missing	4	7.90

Household characteristics are shown in Table 3.3. The distribution of household poverty in the subsample of children with ASD differed from the total sample of children from the NSCH [$\chi^2(3) = 113.900$, $p < .001$]. There was a medium effect ($\widehat{w} = .34$). The expected frequencies suggested that, compared to the total NSCH sample, there were fewer children with ASD at 0-99% of the FPL and 100-199% of the FPL and more children with ASD at 200-299% of the FPL and 400% of the FPL or greater (see Figure 3.1). The majority of children (50.81%) in the current sample of children with ASD lived with two biological or adoptive parents who were currently married. Approximately 28% of children lived with a single mother.

Table 3.3. *Household characteristics*

Demographic	*n* (%)
Household Poverty	
0-99% FPL	172 (17.41)
100-199% FPL	243 (24.60)
200-399% FPL	298 (30.16)
400% FPL or greater	275 (27.83)
Family Structure	
Two biological/adoptive parents, currently married	502 (50.81)
Single mother	276 (27.94)
Two parents (at least one not biological/adoptive), currently married	71 (7.19)
Two biological/adoptive parents, not currently married	54 (5.47)
Grandparent household	47 (4.76)
Two parents (at least one not biological/adoptive), not currently married	17 (1.72)
Single father	7 (0.71)
Other	14 (1.41)

Note. FPL = Federal Poverty Line

Characteristics of the mothers in the sample are shown in Table 3.4. Mothers were 30 years old, on average. The majority of mothers (88.56%) were the child's biological or adoptive parent. Most mothers' highest level of education was either a bachelor's degree (24.80%) or a master's, doctorate, or professional degree (20.40%).

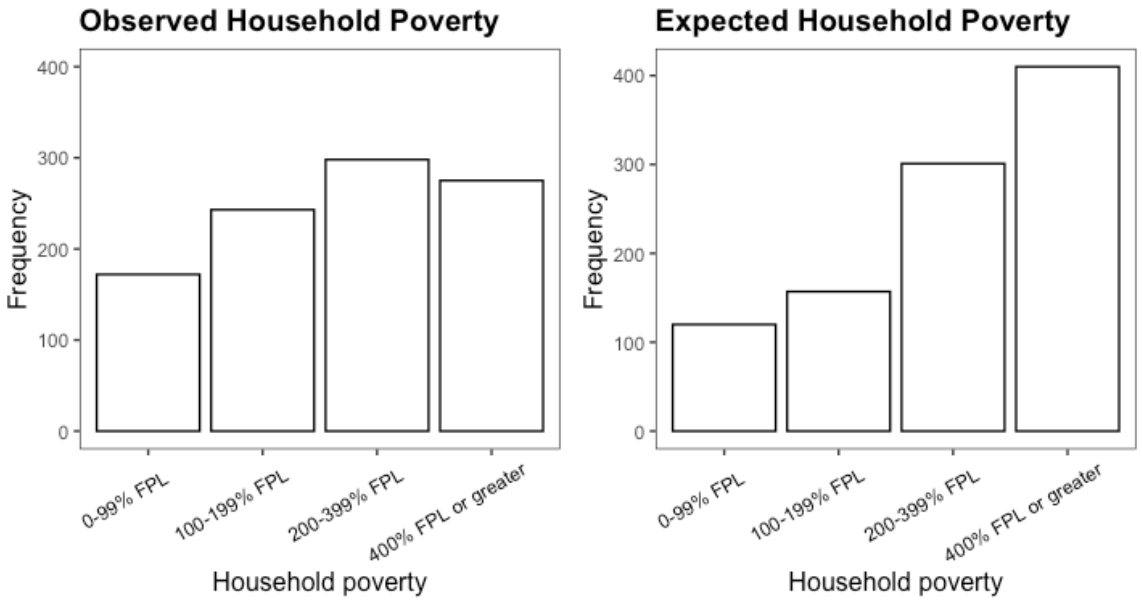

Figure 3.1. Observed and expected frequencies of the children's household poverty in terms of the Federal Poverty Line (FPL). Expected frequencies are based on the proportion of children in each category in the total NSCH sample.

Descriptive Statistics

Descriptive statistics of the variables in the mediation models are presented in Table 3.5. On average, the mothers reported that their aggravation was 7.29 points out of 12 possible points. Most mothers described their mental health as excellent (20.34%), very good (39.17%), or good (27.63%). More than half of the mothers (59.11%) reported that their child did not meet the criteria for having a medical home. Almost all of the mothers reported that they were handling the day-to-day demands of raising children either very well (45.75%) or somewhat well (50.10%). The majority of mothers (78.04%) reported that the child was living with a parent who had someone they could turn to for day-to-day emotional support with parenting or raising children. Most children had either private (47.37%) or public (37.96%) health insurance. Sixty four percent of mothers reported that their child had adequate health insurance.

Table 3.4. *Mother characteristics*

Demographic	*M* (*SD*)
Age	29.54 (6.33)
Relation	*n* (%)
Biological or adoptive parent	875 (88.56)
Grandparent	75 (7.59)
Step-parent	19 (1.92)
Other relative	8 (0.81)
Foster parent	6 (0.61)
Other non-relative	1 (0.10)
Missing	4 (0.40)
Highest Level of Education	
Master's, doctorate, or professional degree	198 (20.04)
Bachelor's degree	245 (24.80)
Associate degree	133 (13.46)
Some college, no degree	177 (17.91)
Completed vocational, trade, or business school program	71 (7.19)
High school graduate or GED completed	117 (11.84)
No high school degree	47 (4.76)

Table 3.5. *Descriptive statistics of medical home, mediating variables, and outcomes*

Variable	*M* (*SD*)
Maternal Aggravation	7.29 (2.32)
Maternal Mental Health	*n* (%)
Excellent	201 (20.34)
Very Good	387 (39.17)
Good	273 (27.63)
Fair	107 (10.83)
Poor	14 (1.42)
Medical Home	
Yes	404 (40.89)
No	584 (59.11)
Coping	
Very well	452 (45.75)
Somewhat well	495 (50.10)
Not very well	26 (2.63)
Not very well at all	12 (1.21)
Social Support	
Yes	771 (78.04)
No	210 (21.26)
Health Insurance Type	
Public	374 (37.96)
Private	486 (47.37)
Both	137 (13.87)
Health Insurance Adequacy	
Yes	633 (64.07)
No	355 (35.93)

The relationships among the mediating and outcome variables are shown through tetrachoric correlations (see Table 3.6). The variables were allowed to correlate to one another in the mediation analysis. The variables were all statistically significantly related to one another, except for some relationships with insurance type and adequacy. When children with both types of health insurance were compared to children with either public or private health insurance, the variable was only statistically significantly related to maternal aggravation ($r = .149$, $p = .001$). When children with private health insurance were compared to children with public health insurance, the variable was only statistically significantly related to maternal mental health ($r = .115$, $p = .002$). Insurance adequacy was related to all variables except social support and insurance type when children with both types of health insurance were compared to children with either public or private health insurance. Maternal mental health was negatively related to maternal aggravation. This was expected because mothers who report more desirable levels of mental health would theoretically also report lower levels of aggravation. All other significant relationships were also in the expected direction.

Table 3.6. *Tetrachoric correlations among mediating and outcome variables*

	1	2	3	4	5	6	7
1. Mental Health	—						
2. Aggravation	-.277*	—					
3. Coping	-.425*	.405*	—				
4. Social support	-.186*	.151*	.036*	—			
5. Insurance type (Both vs. average)	-.045	.149*	.009	.023	—		
6. Insurance type (Public vs. private)	.115*	-.052	.019	-.058	.004	—	
7. Insurance adequacy	-.112*	.194*	.050*	.023	.005	.100*	—

Note: $*p < .05$

Maternal Mental Health Mediation Model

The results of the multiple mediation model of the association between having a medical home and maternal mental health can be seen in Table 3.7. All of these effects were standardized with respect to both the predictor and the outcomes. Child's age, sex, and household poverty were included as covariates in the model. In the absence of mediators, there was a statistically significant positive effect (B = .165) of having a medical home on maternal mental health. This effect was further parsed into a nonsignificant residual direct effect and a significant total indirect effect of via the collective set of mediators. The absence of a significant residual direct effect indicated that the total effect was fully mediated, per the Baron and Kenny (1986) definition of mediation. The total indirect effect through the mediating variables was 0.138, which was 83.6% of the total effect. This total indirect effect was further distributed across the individual mediating variables, shown in Table 3.7 as specific indirect effects. There were significant indirect effects for coping, social support, and health insurance adequacy. Thus, having a medical home was related to improved maternal mental health indirectly through coping, social support, and health insurance adequacy. Comparing children who had both public and private insurance to children who had either private or public insurance yielded a nonsignificant specific indirect effect of 0.003. Comparing children who had private health insurance to those who had public health insurance showed a nonsignificant specific indirect effect of -0.002. As neither of these effects were significant, health insurance type did not serve a mediating role in the relationship between having a medical home and maternal mental health. The model explained 27.6% of the variance in maternal mental health based on the R^2.

Table 3.7. *Effect coefficients and test-statistics for multiple mediation model predicting maternal mental health*

Effects	*B*	SE	Ratio	Proportion of total effect
Total Effect	0.165*	0.033	5.000	
Direct Effect	0.027	0.036	0.742	.164
Total Indirect Effects	0.138*	0.024	5.652	.836
Specific indirect effects				
Medical home influencing mental health through coping	0.080*	0.017	4.818	.485
Medical home influencing mental health through social support	0.033*	0.012	2.746	.200
Medical home influencing mental health through health insurance type – Both vs. average of private and public	0.003	0.004	0.712	.018
Medical home influencing mental health through health insurance type – Private vs. public	-0.002	0.003	-0.703	.012
Medical home influencing mental health through health insurance adequacy	0.024*	0.010	2.434	.145

Note: $n = 988$; $*p < .05$; Model $R^2 = .276$

Maternal Aggravation Mediation Model

The results of the second theoretical multiple mediation model of the association between having a medical home and maternal aggravation can be seen in Table 3.8. Again, all of these effects were standardized with respect to both the predictor and the outcomes, and child's age, sex, and household poverty are included as covariates in the model. In the absence of mediators, there was a statistically significant total effect of -0.119. This negative effect indicated that having a medical home was associated with

Table 3.8. *Effect coefficients and test-statistics for multiple mediation model predicting maternal aggravation*

Effects	*B*	SE	Ratio	Proportion of total effect
Total Effect	-0.119*	0.031	-3.792	
Direct Effect	0.040	0.035	1.139	.336
Total Indirect Effects	-0.159*	0.026	-6.127	1.336
Specific indirect effects				
Medical home influencing aggravation through coping	-0.075*	0.016	-4.719	.630
Medical home influencing aggravation through social support	-0.032*	0.012	-2.594	.269
Medical home influencing aggravation through health insurance type – Both vs. average of private and public	-0.010	0.008	-1.266	.084
Medical home influencing aggravation through health insurance type – Private vs. public	-0.009	0.006	-1.481	.076
Medical home influencing aggravation through health insurance adequacy	-0.033*	0.011	-3.057	.277

Note: $n = 988$; $*p < .05$; Model $R^2 = .252$

decreased maternal aggravation. This total effect was split into a nonsignificant residual direct effect and a significant total indirect effect via the collective set of mediators, again suggesting a fully mediated model (Baron & Kenny, 1986). The total indirect effect through the mediating variables was -0.159, which was distributed across the individual mediating variables, shown in Table 3.8 as specific indirect effects. The same pattern of significance as in the previous model was shown in this model with maternal aggravation as the outcome. There were again significant indirect effects for coping, social support,

and health insurance adequacy. Having a medical home was related to decreased maternal aggravation indirectly through coping, social support, and health insurance adequacy. Neither of the specific indirect effects for health insurance type were statistically significant, so health insurance type was not a significant mediating variable in the relationship between having a medical home and maternal aggravation. The model explained 25.2% of the variance in maternal aggravation based on the R^2.

Alternative Models

This was the first study to examine the mechanisms of the relationships between having a medical home and maternal adaptations. There was no way of guaranteeing that the models specified here were correct, even though they were based on theory and empirical evidence. There are many alternative models that may have fit the true relationships more accurately. Four sets of analyses were conducted with alternative models to explore the relationships among these variables. First, simple mediation models were conducted to independently test for unconditional indirect effects through each of the proposed resistance factors (see Figure 3.2).

Second, because bivariate correlation analyses evidenced a significant association between maternal mental health and maternal aggravation within the present sample (r = -.277, $p < .001$), a multiple mediation model explicitly incorporating a direct association between maternal factors, as well as indirect paths to both outcomes, through the full set of resistance factors, was tested (see Figure 3.3). Theoretically, differences in maternal mental health may lead to differences in maternal aggravation. Abidin (1990) described a

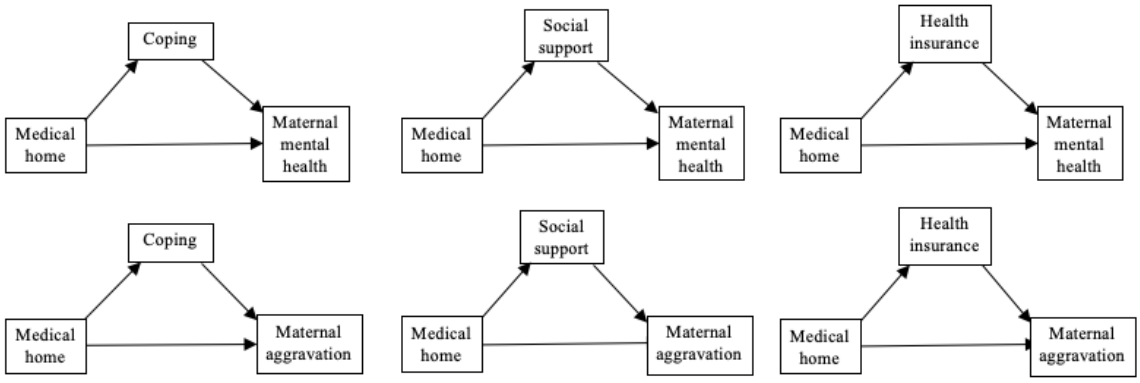

Figure 3.2. Conceptual simple mediation models predicting maternal outcomes from having a medical home.

model of parenting stress in which depression and other parent personality and psychopathology characteristics lead to parenting stress. This has been expanded to include parenting aggravation in the same category as parenting stress (Bronte-Tinkew et al., 2010). Parenting aggravation is a subdomain of parenting stress (Blumberg et al., 2005), so this is expected. The direction of this relationship has been tested in cross-sectional studies. In a path analytic model, Pfefferle and Spitznagel (2009) found that poor maternal mental health was significantly related to more maternal aggravation. Lyons-Ruth et al. (2002) found that mothers with depression were more aggravated by their children.

In contrast to mediation mechanisms, which assume a causal effect of a predictor variable(s) on one or more intermediary variables, that in turn influences the outcome variable(s), moderation analyses test whether associations between predictors and outcomes vary across levels of the moderating variables (Hayes, 2018). In the third set of alternative models, both simple and conditional moderation models were tested. In the simple moderation analyses, interactions were assessed via standardized estimates for the

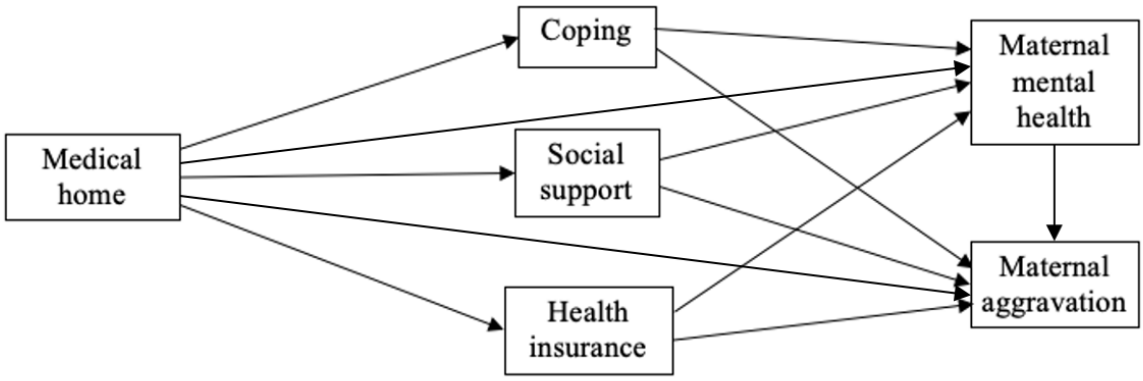

Figure 3.3. Conceptual multiple mediation model predicting maternal outcomes from having a medical home.

product term of the predictor and a single moderating variable (e.g., medical home * coping; see Figure 3.4). In the conditional moderation analyses, an interaction term was created for each of the moderating variables with the medical home variable (see Figure 3.5). Each interaction between the medical home variable and moderating variable was examined while controlling for the other interaction terms. This allowed for simultaneously looking at these three moderators of the association between having a medical home and the maternal outcomes. It was only of interest to examine the interactions of each moderating variable with the medical home variable rather than examining the interactions among the resistance variables, although that would be an interesting area of future research.

Finally, the original multiple mediation models for maternal mental health and maternal aggravation were reanalyzed after including the following covariates: child's race, number of ACEs, age at diagnosis, and ASD severity. Each of these four covariates were separately added to the original multiple mediation models (see Figures 1.2 and 1.3). This allowed for examination of the additional explained variance in the outcome

measures for each covariate to see whether or not they may be added as covariates in future studies of these mechanistic relationships.

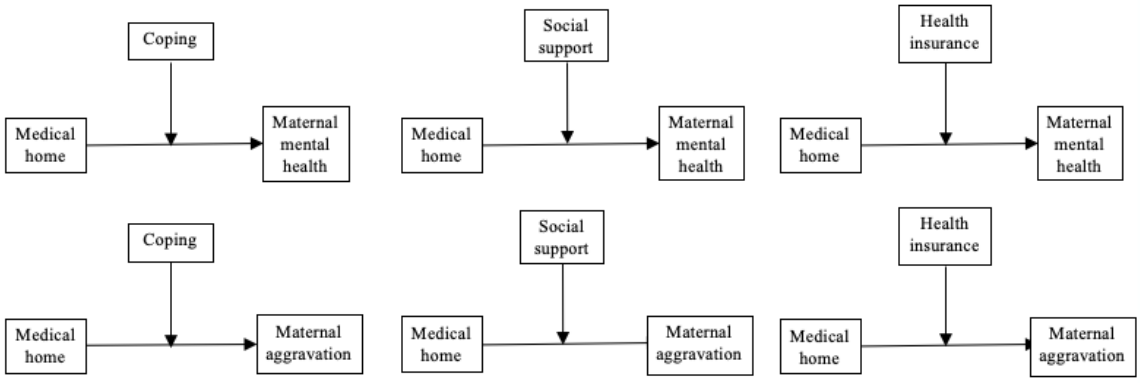

Figure 3.4. Conceptual simple moderation models predicting maternal mental health and maternal aggravation.

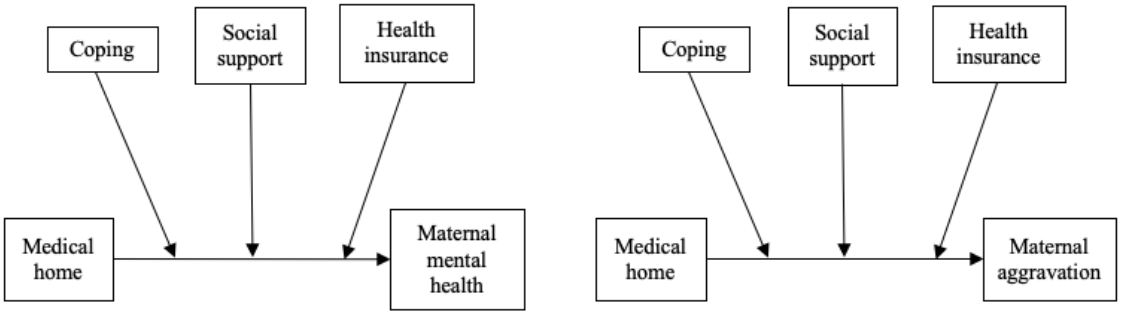

Figure 3.5. Conceptual conditional moderation models predicting maternal mental health and maternal aggravation.

Simple Mediation Models

The first set of alternative models that were tested were simple mediation models. These allow for examining the relationships through the resistance factors to tease apart their effect on the relationship between having a medical home and maternal adaptation. The conceptual simple mediation models are shown in Figure 3.2. These models were tested using WLSMV estimation. The results of the estimation of the six simple

mediation models can be seen in Table 3.9. All effects were standardized with respect to the predictor and outcome variables. Each model included the children's age, sex, and household poverty as covariates.

The total effect for each of the models with maternal mental health as the outcome (B = 0.165) was statistically significant and the same as the multiple mediation model above, as expected. In all three models, the total direct effects and the total indirect effects were statistically significant when separated out from the total effect. This indicated that the relationship between having a medical home and maternal mental health was partially mediated by the mediating variable in each of the models (Baron & Kenny, 1986). The magnitude of the mediated effects, as represented by the proportion of the total effect operating indirectly through the mediating variables, was greatest in the model with coping as the mediating variable (48.5%) compared to the model with social support as the mediating variable (20.0%) or the model with health insurance as the mediating variable (15.2%). In the model with coping as the mediating variable, 23.9% of the variance in maternal mental health was accounted for by variability in medical home status and maternal coping. In the model with social support as the meditating variable, 9.2% of the variance was explained by the other variables in the model, and in the model with health insurance as the mediating variable, 8.8% of the variance in maternal mental health was explained by the other variables.

The total effect for each of the models with maternal aggravation as the outcome (B = -0.119) was statistically significant and the same as the multiple mediation model above, as expected. In the models with social support and health insurance as the mediating variables, the total direct effects and the total indirect effects were statistically

Table 3.9. *Effect coefficients and test-statistics for six simple mediation models predicting maternal mental health and aggravation*

Model	Model R^2	Total direct effect			Total indirect effect			Total effect			Mediated proportion of total effect
		B	SE	Ratio	*B*	SE	Ratio	*B*	SE	Ratio	
Maternal mental health								.165*	.033	5.001	
1. Medical home influencing mental health through coping	.239	.085*	.032	2.621	.080*	.017	4.817				.485
2. Medical home influencing mental health through social support	.092	.132*	.035	3.806	.033*	.012	2.746				.200
3. Medical home influencing mental health through health insurance type and adequacy	.088	.140*	.034	4.082	.025*	.011	2.265				.152
Maternal aggravation								-.119*	.031	-3.794	
4. Medical home influencing aggravation through coping[a]	.170	-.044	.031	-1.401	-.075*	.016	-4.719				.630
5. Medical home influencing aggravation through social support[b]	.041	-.087*	.033	-2.630	-.032*	.012	-2.594				.269
6. Medical home influencing aggravation through health insurance type and adequacy	.085	-.067*	.033	-2.051	-.052*	.014	-3.655				.437

Note. $n = 988$; $^*p < .05$; [a]$n = 985$; [b]$n = 984$

significant when separated out from the total effect. This indicated that the relationship between having a medical home and maternal mental health was partially mediated by the mediating variable in each of the models (Baron & Kenny, 1986). In the model with coping as the mediating variable, the total effect was split into a nonsignificant residual direct effect and a significant indirect effect of the mediator, indicating a fully mediated relationship (Baron & Kenny, 1986). The magnitude of the mediated effects was greatest in the model with coping as the mediating variable (63.0%) compared to the model with social support as the mediating variable (26.9%) or the model with health insurance as the mediating variable (43.7%). Additionally, in the model with coping as the mediating variable, 17.0% of the variance in maternal mental health was accounted for by having a medical home and coping. The analytic samples for the models with social support and health insurance as the mediating variables were reduced by three participants and four participants, respectively, due to missing data on all variables except the predictor. In the model with social support as the meditating variable, 4.1% of the variance was explained by the other variables in the model, and in the model with health insurance as the mediating variable, 8.5% of the variance in maternal mental health was explained by the other variables.

Mediation Model with Both Outcomes

Maternal mental health and maternal aggravation were also empirically related to one another (r = -.277, p < .001), so it was of interest to do a test of a single model that includes both outcomes. The relationship between maternal mental health and maternal aggravation is represented in the path in Figure 3.3. The model was estimated with

WLSMV estimation, included child's age, sex, and household poverty as covariates, and all effects were standardized. The results of the model are shown in Table 3.10. The total effect of having a medical home on maternal aggravation was -0.119, statistically significant, and equal to the total effect in the original conceptual multiple mediation model above, as expected. The total effect was split into a nonsignificant direct effect and a significant indirect effect, indicating a fully mediated model (Baron & Kenny, 1986). The specific indirect effect through maternal mental health was nonsignificant. The paths through the original mediating variables followed the same pattern of significance as in the model that did not include maternal mental health. The indirect path through coping and mental health was statistically significant (B = -0.008, p = .022), and the indirect path through social support and mental health was statistically significant (B = -0.003, p = .039). All the paths with a health insurance variable and mental health were nonsignificant. Including maternal mental health in the model only explained 0.7% more variance in maternal aggravation than the model that did not include mental health (Table 3.8).

Moderation Models

The third set of alternative model analyses included both simple and conditional moderation models. Both simple moderation models (see Figure 3.4) and conditional moderation models (see Figure 3.5) were examined.

All moderation models with mental health as the outcome were analyzed using the WLSMV estimator, and included child's age, sex, and household poverty as covariates. All resulting coefficients reflect standardized estimates with respect to the

Table 3.10. *Effect coefficients and test-statistics for multiple mediation model predicting maternal aggravation from mediating variables and mental health*

	B	SE	Ratio	Proportion of total effect
Total Effect	-0.119*	0.031	-3.796	
Direct Effect	0.043	0.034	1.248	.361
Total Indirect Effects	-0.161*	0.025	-6.441	1.353
Specific indirect effects				
Medical home influencing aggravation through mental health	-0.003	0.004	-0.674	.025
Medical home influencing aggravation through coping	-0.067*	0.015	-4.447	.563
Medical home influencing aggravation through social support	-0.028*	0.012	-2.346	.235
Medical home influencing aggravation through health insurance type (both vs. average of private and public)	-0.010	0.008	-1.263	.084
Medical home influencing aggravation through health insurance type (private vs. public)	-0.009	0.006	-1.496	.076
Medical home influencing aggravation through health insurance adequacy	-0.030*	0.010	-2.890	.252
Medical home influencing aggravation through coping and mental health	-0.008*	0.004	-2.288	.067
Medical home influencing aggravation through social support and mental health	-0.003*	0.002	-2.062	.025
Medical home influencing aggravation through health insurance type (both vs. average of private and public) and mental health	0.000	0.000	-0.739	.000
Medical home influencing aggravation through health insurance type (private vs. public) and mental health	0.000	0.000	0.679	.000
Medical home influencing aggravation through health insurance adequacy and mental health	-0.002	0.001	-1.873	.017

Note: $n = 988$; $*p < .05$; Model $R^2 = .259$

predictors and outcome (see Table B.1). In the simple model with only coping as a moderating variable, medical home and coping significantly predicted mental health, but the interaction term was not significant. The predictors explained 18.5% of the variance in maternal mental health in this model. In the model with social support as the moderating variable, only 8.3% of the variance was explained by the predictors. The medical home variable did not significantly predict mental health, but the coefficient associated with social support was significant. The interaction term was not statistically significant. In the moderation model with the health insurance variables, the medical home variable was the only statistically significant predictor of mental health. The predictors explained 8.3% of the variance in maternal mental health. In the conditional moderation model, the predictors explained 19.9% of the variance in maternal mental health, as shown by the R^2. Medical home and coping were the only statistically significant predictors of maternal mental health. None of the interaction coefficients were statistically significant.

As maternal aggravation was assessed on a continuum, all corresponding moderation models were analyzed in Mplus using a robust maximum likelihood estimation procedure (Muthén & Muthén, 1998–2012), and included child's age, sex, and household poverty as covariates. Again, the resulting coefficients reflect standardized estimates with respect to the predictors and outcome (see Table B.2). In the simple model with only coping as a moderating variable, neither of the predictors or interaction term were statistically significant. The predictors explained 12.4% of the variance in maternal aggravation in this model. In the model with social support as the moderating variable, only 3.1% of the variance was explained by the predictors. The medical home variable

did not significantly predict aggravation, but the coefficient associated with social support was significant. The interaction term was not statistically significant. In the moderation model with the health insurance variables, health insurance type when private health insurance was compared to public health insurance and health insurance adequacy were statistically significant predictors of maternal mental health. The interaction between having a medical home and health insurance type (both vs. average of private and public) was the only significant interaction in any of the eight models tested (B = 0.089, p = .041). For children with either private or public health insurance, having a medical home was associated with maternal aggravation in a different way than for children with both public and private health insurance. The predictors explained 6.6% of the variance in maternal aggravation. In the conditional moderation model, the predictors explained 16.2% of the variance in maternal aggravation, as shown by the R^2. Coping, health insurance type when private health insurance was compared to public health insurance, and health insurance adequacy were the only statistically significant predictors of maternal mental health. None of the interaction coefficients in the conditional moderation model were statistically significant.

Additional Covariates

Four additional covariates were also examined in the models. The original covariates, child's sex, age, and household poverty were chosen based on a previous study (Limbers et al., 2020). The literature and disability-stress-coping model also identify other possible factors in the relationships examined in the multiple mediation models. The disability-stress-coping model includes demographics and family environment as resistance factors for adaptation (Wallander et al., 1989). It also includes

diagnosis and disorder severity as risk factors (Wallander et al., 1989). In this current study, these variables are not resistance or risk variables of interest, but they may be impactful covariates along with age, sex, and household poverty.

Table 3.11 *Variance explained by adding additional covariates to multiple mediation models predicting maternal mental health and aggravation.*

	Mental Health Model R^2	Aggravation Model R^2
Mediation model with sex, age, and household poverty as covariates[a]	.276*	.252*
Race/ethnicity added[b]	.278*	.256*
ACEs added[c]	.300*	.247*
ASD severity added[d]	.267*	.250*
Age at ASD diagnosis added[e]	.285*	.251*

Note: $*p < .05$, [a]$n = 988$, [b]$n = 984$, [c]$n = 986$, [d]$n = 984$, [e]$n = 850$

The demographic and family environment covariates here were race/ethnicity and ACEs. The diagnosis variables used as covariates were ASD severity and age at diagnosis. Each of these four covariates were separately added to the original multiple mediation models (see Figures 1.2 and 1.3). Child's sex, age, and household poverty were retained as covariates in each of the models. The models were estimated in the same way as the original models – the only difference was adding each of the new covariates in separate models. The explained variance for each of the models as well as the original models can be seen in Table 3.11. When the ACEs covariate was added to the model predicting maternal mental health, 2.4% more variance in maternal mental health was explained. There were also increases in the explained variance when race/ethnicity and age at diagnosis were added to the original model. For all of the maternal mental health models with the new covariates, the patterns of significant direct and specific indirect

effects were the same as in the original model – there was a nonsignificant direct effect and a significant total indirect effect. Coping, social support, and health insurance adequacy all had statistically significant indirect effects on maternal mental health. Health insurance type did not have a significant indirect effect on maternal mental health.

In the models where the additional covariates were added to the model predicting maternal aggravation, the explained variance in maternal aggravation was similar to the original model. The largest discrepancy was a 0.5% decrease in explained variance in the model with ACEs as a covariate. For the maternal aggravation models with the new covariates of race/ethnicity, ACEs, and ASD severity, the patterns of significant direct and specific indirect effects were the same as in the original model – there was a nonsignificant direct effect and a significant total indirect effect. Coping, social support, and health insurance adequacy all had statistically significant indirect effects on maternal mental health. Health insurance type did not have a significant indirect effect on maternal mental health. However, when age at ASD diagnosis was added as a covariate, social support was no longer associated with a statistically significant indirect effect (B = -0.016, SE = 0.012, Ratio = -1.403, p = .160).

CHAPTER FOUR

Discussion

In the present study, multiple mediation models were analyzed to examine coping, social support, and health insurance as potential mechanisms underlying the association between having a medical home and maternal outcomes in mothers of children with ASD. The outcomes of interest were maternal mental health and maternal aggravation.

Maternal Mental Health

The first hypothesis of the current study was supported. There was a significant positive total effect of having a medical home on maternal mental health. This is consistent with previous studies of the relationship between having a medical home and maternal mental health (Limbers et al., 2020). This is also consistent with previous research in parents of children with diabetes (Cohen & Limbers, 2019) and children with chronic health conditions in general (Farmer et al., 2011). This study adds to the evidence that having a medical home is associated with improved outcomes for the entire family, such as better health status, timeliness of care, family centeredness, and improved family functioning (Homer et al., 2008).

The third hypothesis, related to maternal mental health, was also supported. The relationship between having a medical home and maternal mental health was fully mediated by including coping, social support, and health insurance as resistance factors in the mediation model. Further, the specific indirect effects indicated that coping, social support, and health insurance adequacy were significant mediating variables. Health

insurance type was not associated with a significant indirect effect. This was the first study to examine the mechanisms underlying the relationship between having a medical home and maternal mental health. The results are consistent with the theoretical disability-stress-coping model (Wallander, et al., 1989), which postulates that these three constructs are resistance factors in the relationship between risk factors, such as having a medical home, and maternal adaptation. When all three of these factors were included in the mediation model, the direct effect of having a medical home on maternal mental health was no longer significant. The effect of having a medical home on maternal mental health operated fully through the indirect effects of the mediating variables. This indicates that the medical home is associated with improved maternal mental health, but only through coping, social support, and health insurance adequacy. There is a strong empirical link between coping and mental health (Benson, 2010; Dunn et al., 2001; Major, 2003; Zablotsky et al., 2013). There is also evidence that social support is strongly related to maternal mental health (Cohen & Wills, 1985; Dunn et al., 2001; Dunst et al., 1986; Horton & Wallander, 2001; Sawyer et al., 2010). The association between health insurance and maternal mental health in mothers of children ASD is not as prevalent in the literature, but there are ties between finances and/or health insurance to maternal mental health in general (Brown et al., 2008; Lesesne et al., 2003; Shalowitz et al., 2006). The abundance of evidence of the relationships between these resistance factors and maternal mental health is consistent with the complete mediation in the current model. The only resistance factor that did not have a statistically significant indirect effect is health insurance type. There is more evidence in the literature that children having health insurance, as opposed to not having insurance, has an effect on maternal mental health

(Edmunds & Joel Coye, 1998; Watson et al., 2020). It may be that there would have been an effect of having health insurance at all on maternal mental health, but the type of health insurance a child has is not related to maternal mental health.

Maternal Aggravation

The second hypothesis of the current study was supported. There was a significant negative total effect of having a medical home on maternal aggravation. This is consistent with previous studies that found that increased parental aggravation was associated with lack of medical home (Arauz Boudreau et al., 2012; Schieve et al., 2007; Schieve et al., 2011).

The third hypothesis, in the context of maternal aggravation, was also supported. The relationship between having a medical home and maternal aggravation was fully mediated by including coping, social support, and health insurance as resistance factors in the mediation model. The specific indirect effects also indicated that coping, social support, and health insurance adequacy were significant mediating variables, but health insurance type was not associated with a significant indirect effect. This was the first study to test these constructs as resistance factors, but the results are in alignment with the theoretical disability-stress-coping model (Wallander et al., 1989). The effect of having a medical home on maternal aggravation was again fully mediated through the indirect effects of the mediating variables. This indicates that the medical home is associated with decreased maternal aggravation, but only through the resistance factors. The literature provides strong evidence for the association between coping and aggravation (Hastings & Johnson, 2001; Miranda et al., 2019) and the association between social support and aggravation (Benson & Karlof, 2008; Gray, 2003; Moore &

Ehrle, 1999; Schieve et al., 2011). There is evidence that having health insurance in general may impact maternal aggravation (Schieve et al., 2011; Schmit & Matthews, 2017), but there is less known about the relationship between health insurance type and aggravation. In the current study, health insurance adequacy, but not type, had a significant indirect effect on maternal aggravation. Future research may include having health insurance at all as a potential explanatory variable rather than health insurance type.

Alternative Models

Four sets of analyses of alternative models were conducted to further examine the mechanisms potentially underlying the relationships between having a medical home and maternal adaptations. Simple mediation models were tested to see if the effects were different than when the resistance factors were all included in a single model. In all three of the models predicting maternal mental health, the total effect was partitioned into significant direct and indirect effects, indicating partial mediation. The medical home is related to maternal mental health, both directly and indirectly, through each of the resistance factors in these separate models. Including all three resistance factors in the multiple mediation models above leads to a fully mediated relationship between having a medical home and maternal mental health. The mechanism in the relationship between having a medical home and maternal mental health is more fully explained by including all three resistance factors simultaneously than examining each factor separately, indicating that there is a complex relationship between having a medical home and maternal mental health. In the simple models predicting maternal aggravation, the models with social support and health insurance indicate that the relationship between having a

medical home and maternal aggravation is partially mediated by these variables. However, the relationship between having a medical home and maternal aggravation is fully mediated by coping. The R^2 of the models indicate that much more of the variance in both maternal mental health and aggravation is explained by coping. Coping may be the driving factor in the relationship between the medical home and maternal outcomes, but the multiple mediation models indicate that the relationship is complex, and it is valuable to include all three resistance factors in the models.

In the multiple mediation model where both maternal adaptations are included as outcomes and maternal mental health is specified as directly related to maternal aggravation, including mental health as a mediating variable did not explain much more of the variance in maternal aggravation compared to the first multiple mediation model predicting maternal aggravation. A total of 13.4% of the total effect of having a medical home on maternal aggravation is due to the indirect effects that include maternal mental health. The specific indirect effect through maternal mental health is nonsignificant. Including mental health in the model may lead to a less parsimonious model than keeping the two maternal adaptation outcomes separate. They are significantly related to one another (r = -.277, $p < .001$) and there is a theoretical basis for maternal mental health leading to maternal aggravation (Abidin, 1990; Bronte-Tinkew et al., 2010; Lyons-Ruth et al., 2002; Pfefferle & Spitznagel, 2009), but the results of this analysis do not support this relationship when examined through this multiple mediation framework.

Both simple and conditional moderation analyses were conducted to examine whether the resistance factors should be treated as explanatory variables, as in mediation analysis, or as variables that influence the strength of the association between the medical

home and maternal outcomes, as in moderation analysis. Across all of the moderation models, the R^2 values were less than the R^2 values from the multiple mediation models. The multiple mediation model predicting maternal mental health had an R^2 of .276 while the conditional moderation model had an R^2 of .199. The multiple mediation model predicting maternal aggravation had an R^2 of .252 while the conditional moderation model had an R^2 of .162. Additionally, in all of the models none of the interaction effects were statistically significant, except for the interaction between one of the health insurance type variables and the medical home in the model predicting maternal aggravation from the medical home and health insurance. Health insurance type was not a significant mediating variable in the original mediation models, so it may be more accurate to the data in future studies to include health insurance type as a moderating variable rather than a mediating variable. The results of these analyses indicate that the relationship between having a medical home and maternal outcomes is explained by the resistance factors of coping, social support, and health insurance adequacy rather than the different levels of these resistance factors influencing the strength of the association between the medical home and maternal outcomes. Mediation is a more appropriate analytic method for this relationship.

In the last set of alternative model analysis, additional covariates were tested in the original multiple mediation models. The four covariates, race/ethnicity, ACEs, ASD severity, and age at ASD diagnosis, were all added to the original set of covariates, child sex, age, and household poverty, in four separate models. For all of the models with the new covariates, except one, the patterns of significant direct and specific indirect effects were the same as in the original multiple mediation models – there was a nonsignificant

direct effect and a significant total indirect effect. Coping, social support, and health insurance adequacy all had statistically significant indirect effects on maternal mental health. Health insurance type did not have a significant indirect effect on maternal mental health. However, when age at ASD diagnosis was added as a covariate in the model predicting maternal aggravation, social support was no longer associated with a statistically significant indirect effect. The model R^2 increased when race/ethnicity, ACEs, and age at ASD diagnosis were added to the model predicting maternal mental health but decreased when ASD severity was added. The model R^2 increased when race/ethnicity was added to the model predicting maternal aggravation but decreased when the other three covariates were added. Race/ethnicity may be a valuable covariate to include in future analyses. This is in alignment with previous studies that have included race/ethnicity as a covariate in research of families of children with ASD (Hock & Ahmedani, 2012; Montes & Halterman, 2007).

Altogether, the alternative models indicated that the original, theoretically driven multiple mediation models adequately modeled the relationship between having a medical home and maternal outcomes. Since this study is the first to examine the mechanism of the relationship between having a medical home and maternal outcomes, these alternative models are a useful way to explore other possible explanations for the relationship. Even though the multiple mediation models proposed were theoretically driven from the disability-stress-coping model and the literature, other models may have fit the relationship in the data better. In this case, the alternative models revealed that the multiple mediation models explained the relationship well and provided evidence that future research could include race/ethnicity as an additional covariate to child's sex, age,

and household poverty. Additionally, health insurance type may be more appropriately included as a moderating variable rather than a mediating variable in future studies. Examining these alternative models provided more insight to the relationships among these variables than only examining one possible mechanism based on the theoretical disability-stress-coping model. Future studies could use the results here to more accurately model the relationship between having a medical home and maternal outcomes through coping, social support, and health insurance adequacy as mediating variables and health insurance type as a moderating variable.

Clinical Implications

Understanding the complex mechanism of the relationships between having a medical home and maternal adaptations could inform clinical interventions to improve maternal mental health and aggravation. If the goal is to help improve mental health and reduce aggravation in these mothers, understanding these complex relationships can provide additional tools for clinicians to try in treatment (Watson, et al., 2020). The results indicate that coping, social support, and health insurance adequacy are all significant explanatory variables in the relationship between having a medical home and maternal outcomes. Clinicians may want to use interventions that focus on these three constructs in their work with mothers of children with ASD to improve their mental health and decrease their aggravation, particularly because all three of these variables fully explained the relationship between having a medical home and maternal outcomes. For example, Benson (2010) suggested that interventions that encourage mothers to use positive behavioral and cognitive coping strategies, while discouraging avoidant coping strategies, may improve maternal mental health. Social support was also a significant

explanatory variable in the relationship between having a medical home and maternal outcomes, so group-based interventions may improve maternal outcomes. There is qualitative evidence that group-based interventions may improve maternal mental health (Kane et al., 2007). There was also a meta-analysis that illustrated that parental psychosocial outcomes were improved short-term after group-based interventions (Barlow et al., 2014). It could be beneficial for mothers to participate in interventions that address both coping and social support to improve their psychosocial outcomes.

One of the key components of the medical home is care coordination for the entire family (AAP, 2002). In a medical home, the child's physician may not themselves address maternal interventions, but they may provide referrals for specialty services and coordinate the care mothers require as they navigate their child's ASD diagnosis and treatment. Care coordination is often complex for children with ASD because their treatment may involve many different providers, such as speech therapists and occupational therapists (Brown et al., 2012; Gurney et al., 2006). With the complexity of the health care needs of children with ASD, mothers may be overwhelmed if they are the care coordinators for their children (Carbone et al., 2010). Thus, they may not feel it is feasible to organize their own mental health care. The medical home is intended to ease the burden of care coordination from parents. This may allow them to seek out clinical therapies aimed at improving their mental health and aggravation, potentially through the coping and social support interventions mentioned above.

These results have the potential to inform policies related to health insurance. As of August 2019, all 50 states have laws that require coverage for ASD treatments, but in some states there are still limits on the age of the child who has guaranteed coverage

and/or limits on the medical costs that insurance companies are required to cover (Autism Speaks, 2019a; Callaghan & Sylvester, 2019). Health insurance adequacy is a significant explanatory variable in the relationship between having a medical home and maternal outcomes, so policies that improve the coverage of ASD treatments may increase mothers' perception of health insurance adequacy. Autism Speaks is an organization that has advocated for therapies, such as Applied Behavior Analysis (ABA) to be covered by health insurance (Autism Speaks, 2019b). Organizations such as this may use research such as this as evidence for the ways improved health insurance coverage for ASD treatments may benefit the entire family as they continue to advocate for better health insurance for children with ASD.

These results could also have an impact on policies related to implementing medical home practice since having a medical home improves maternal mental health and decreases aggravation. The AAP has been advocating for implementation of the medical home since the 1990s, and this study provides evidence for the positive effect the medical home has on the entire family. With the complexity and many different health needs of children with ASD, a pediatrician may not be able to fully address all of the needs of these children without the resources to fully implement a medical home (Carbone et al., 2010). Rather, an interdisciplinary team, such as in the Leadership Education for Neurodevelopmental and Related Disabilities (LEND) program (Association of University Centers on Disabilities [AUCD], 2009), may be used to provide medical homes for these families. Policies that fund and promote the use of these kinds of programs may provide additional implementation of medical homes for families of children with ASD.

One of the common critiques of the medical home is that implementation of this model of health care is not always feasible (Carbone et al., 2010). Restructuring a medical practice into a medical home often requires funding for care coordination or patient registries (Homer et al., 2008). Rather than fully reorganizing a healthcare practice to the model of a medical home, specific components related to fostering coping, social support, and health insurance adequacy could be incorporated into healthcare visits. For example, one point under the comprehensive component of the medical home is that "the child's or youth's and family's medical, educational, developmental, psychosocial, and other service needs are identified and addressed" (AAP, 2002). Physicians who are attending to the service needs of the family may specifically refer mothers to programs that will help them cope with their child's ASD and the day-to-day experience of caring for them. Another point under the comprehensive component of the medical home is that "information is made available about private insurance and public resources, including Supplemental Security Income, Medicaid, the State Children's Health Insurance Program, waivers, early intervention programs, and Title V State Programs for Children With Special Health Care Needs" (AAP, 2002). Healthcare professionals who provide this information may inform the mothers' decisions about their children's health insurance which could influence their perception of the adequacy of their children's coverage. Taking the steps to implement these specific subcomponents of the medical home into healthcare professionals' practice could improve maternal outcomes in the absence of the resources needed to implement every aspect of the medical home.

This study also provides evidence that more children with ASD have a medical home than in prior years. In this sample from 2017 and 2018, 40.89% of children had a medical home. In a sample of children with ASD from 2011 and 2012, 32.2% of children had a medical home (Limbers et al., 2020), and in a sample of children with ASD from 2009 and 2010, 18.9% of children had a medical home (Farmer et al., 2014). Both the current sample and the sample from Limbers et al. (2020) came from iterations of the NSCH. The sample from Farmer et al. (2014) was smaller (n = 365) and included children without health insurance. This increase in the use of the medical home model in children with ASD mirrors the general increase in implementation of the patient-centered medical home in the United States (Nielsen et al., 2013). The medical home is a growing health care model that may have many benefits for children with ASD and their parents (Kogan et al., 2008). As the use of medical homes increases, parents and children may have more access to the specialty services that could alleviate unmet needs of the children (Farmer et al., 2014; Kuhlthau et al., 2017; Rogers & Vismara, 2008) and improve outcomes for parents (Homer et al., 2008).

Limitations

There are several limitations to this study. Single item measures may not fully capture the constructs of mental health, coping, and social support. Mothers of children with ASD have limited time to devote to filling out a battery of psychological assessments over multiple time points when they have to spend time in their role as mothers to children, coordinate their child's ASD various treatments, and spend time in additional support their child with ASD may need in daily activities. Mothers of children with ASD report feeling as though they do not have time to complete their daily life

activities and cited this as a reason to not participate in scientific studies (Sawyer et al., 2010). Therefore, it would be beneficial to design empirical tests of these models with quick, but still psychometrically sound, measurements of the constructs of interest. This would increase the likelihood of more mothers participating in these studies. Single-item measures of self-rated mental health have been widely used in health research. In a review of these single-item measures, they were associated with multi-item measures of mental health, overall health, and health service satisfaction (Ahmad et al., 2014). However, drawing conclusions from single item measures should be done with caution.

Another limitation of the study is that the directionality of many of the relationships in the models have not been assessed, so the directions have been assumed based on theory. For example, all of the studies examining the relationship between having a medical home and maternal coping are cross-sectional. There is also evidence of a bidirectional relationship between having a medical home and health insurance (Ghandour et al., 2011; Strickland et al., 2009; Watson et al., 2020). A mediation model, by nature, includes causal relationships among variables. The directions of these causal relationships are theoretically established either through the theory and literature about these constructs or through longitudinal research designs. Conducting a study with this longitudinal research design would provide evidence for the causality posited by a mediation model, but often in psychological research it is not possible for researchers to collect data at multiple time points from a sensitive population, such as mothers of children with ASD (Institute of Medicine and National Research Council, 2011). In this case, the literature presented in the current study is evidence for the directions of the causal relationships in the mediation model, but this argument for directionality is not as

strong as from a longitudinal study (Jose, 2016). Longitudinal studies would have to be done to examine the true direction of these relationships, but the empirical evidence we currently have points to the directions specified in the models.

A third limitation of the current study is that this is the first study to examine the mechanisms of the relationships between having a medical home and maternal adaptation. There is no way of guaranteeing that the models specified in this study are correct, even though they are based on theory and empirical evidence. There are many alternative models that may fit the true relationships more accurately. This was addressed through alternative models, but the results would need to be replicated in both cross-sectional and longitudinal studies before researchers place undue confidence in the mediation models presented here. George Box said, "all models are wrong, but some are useful" (Box & Draper, 1987). This quote seems particularly relevant in a study such as this one where it is the first to explore these relationships. This study is the first step in understanding the mechanisms underlying the relationship between having a medical home and maternal adaptations, and there is potential for many future directions examining these mechanisms through the disability-stress-coping theoretical framework.

Future Directions

These mediation models provide a conceptual basis for the relationship between having a medical home and maternal outcome directly and indirectly through three resistance factors: coping, social support, and health insurance. These are all specifically related to families of children with ASD. Future research should focus on empirically testing these models both cross-sectionally and longitudinally. The focus in this study was on mothers in the United States, but empirical tests of the models could expand to

other countries with different policies of health care and the medical home (Kuo et al., 2006; Schoen et al., 2007). Compared to other high-income countries with universal healthcare, the United States ranks low on financial access to health care and availability of health care on nights and weekends (Davis & Ballreich, 2014). People in countries with universal health care may not feel that the accessible and comprehensive care components of the medical home are as salient as people from the United States where there is more difficulty in accessing care. There are also cultural differences in the belief that all health care is the responsibility of a single primary care physician, which would affect the implementation of a medical home (Kuo et al., 2006). ASD is a spectrum disorder that encompasses a wide range of functionality, so these models could also be tested in mothers of children at various places along the continuum of ASD. Children with more severe clinical manifestations of ASD may require more intensive treatments and more care coordination than children with less severe ASD symptoms (Parker & Killian, 2020). The increase in health care needs may impact the effect of having a medical home on maternal outcomes (Schieve et al., 2007). These models were also limited to maternal outcomes, but future research could also examine the applicability of these conceptual models to paternal outcomes (Davis & Carter, 2008; Hartley & Schultz, 2014; Tehee et al., 2009).

Future research could also examine more resistance factors from the disability-stress-coping framework as they relate to having a medical home and maternal outcomes. For example, the disability-stress-coping model includes a category of resistance factors of intrapersonal factors, such as perceived mastery and commitment to self (Wallander et al., 1989). These are less salient in the literature of mothers of children with ASD than

the stress processing and social-ecological resistance factors but may be an area of future research.

It would be beneficial for health care systems, including patient-centered medical homes, to assist mothers of children with ASD with available health insurance options so they feel less unsure about the impact their changes in employment may have on their child's health insurance (Watson et al., 2020). Future research could include development of a reliable and validated measure of health insurance adequacy that could be used to assess the health insurance resistance factor in the models. The financial toxicity literature has primarily focused on children with cancer but could be a useful starting point for developing a measure of health insurance adequacy in families of children with ASD (Santacroce & Kneipp, 2018). The field defines financial toxicity as both the financial costs to the patients and the subjective view of the financial distress patients and their families experience (Santacroce & Kneipp, 2018; Santacroce et al., 2019). Much of the out-of-pocket costs for families of children with ASD are related to health insurance deductibles and co-pays (Candon et al., 2019). The subjective view of a child's health insurance adequacy and the distress associated with the costs of health insurance and health care as described in the financial toxicity literature (Zafar & Abernethy, 2013) would provide a basis for developing a measure that would reflect the health insurance adequacy in these proposed mediation models.

Another area for future research on this conceptual framework is testing bidirectional relationships between the child having a medical home, resistance factors, and maternal outcomes. The disability-stress-coping model and the proposed mediation models only hypothesize unidirectional relationships from risk factors to resistance

factors to adaptations (See Figure 1.1; Wallander et al., 1989) Although this study has focused on a unidirectional mediation framework from a child having a medical home to the resistance factors to maternal outcomes, these relationships are likely to be reciprocal and dynamic in nature. For example, there is evidence that the relationship between having a medical home and having adequate health insurance is bidirectional – that children with adequate health insurance are more likely to have a medical home (Strickland et al., 2009) and that having a medical home may lead to more stable health insurance (Ghandour et al., 2011; Watson et al., 2020). This relationship would need to be assessed longitudinally to discern the direction of the relationship. It may be beneficial to expand the proposed models here to allow for examination of these potential bidirectional relationships.

Structural equation modeling (SEM) could be used in future studies to incorporate both mediation and moderation modeling when examining the mechanism underlying the relationships between having a medical home and maternal outcomes. Coping, social support, and health insurance adequacy were all significant mediating variables in this study and health insurance type was a significant moderating variable. These variables could be incorporated in these ways through an SEM framework in future studies to reflect the kinds of relationships among the variables illustrated in this study.

Conclusions

Understanding the relationship between having a medical home and outcomes in mothers of a child with ASD is a recent topic of study (Limbers et al., 2020) that has implications for policies and procedures regarding the implementation of medical homes

for these families (Rast et al., 2018; Todorow et al., 2018). By continuing to empirically examine the direct and indirect relationship between having a medical home and maternal outcomes presented in these proposed mediation models, researchers will understand more about the mechanisms through which these constructs are related. This could inform clinical interventions aimed at improving maternal mental health and aggravation. Services and interventions that are needed to effectively meet the needs of mothers of children with ASD include services that alleviate financial burden and employment changes and interventions focused on maternal coping and social support (Watson, et al., 2020). These services, policies, and interventions are becoming more essential as the prevalence rates of ASD diagnoses continue to rise (Christensen et al., 2016; McDonald & Paul, 2010; Maenner et al., 2020). A better understanding of the complex mechanisms through which medical homes impact maternal outcomes will lead to more effective interventions for this vulnerable population of mothers of children with ASD.

APPENDICES

APPENDIX A

Characteristics of a Medical Home

Component	Description
Accessible	Care is provided in the child's or youth's community. All insurance, including Medicaid, is accepted. Changes in insurance are accommodated. Practice is accessible by public transportation, where available. Families or youth are able to speak directly to the physician when needed. The practice is physically accessible and meets Americans With Disabilities Act requirements.
Family centered	The medical home physician is known to the child or youth and family. Mutual responsibility and trust exist between the patient and family and the medical home physician. The family is recognized as the principal caregiver and center of strength and support for child. Clear, unbiased, and complete information and options are shared on an ongoing basis with the family. Families and youth are supported to play a central role in care coordination. Families, youth, and physicians share responsibility in decision making. The family is recognized as the expert in their child's care, and youth are recognized as the experts in their own care.
Continuous	The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood. Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family. The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.
Comprehensive	Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.

(continued)

Component	Description
	Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year. Preventive care is provided that includes immunizations, growth and development assessments, appropriate screenings, health care supervision, and patient and parent counseling about health, safety, nutrition, parenting, and psychosocial issues. Preventive, primary, and tertiary care needs are addressed. The physician advocates for the child, youth, and family in obtaining comprehensive care and shares responsibility for the care that is provided. The child's or youth's and family's medical, educational, developmental, psychosocial, and other service needs are identified and addressed. Information is made available about private insurance and public resources, including Supplemental Security Income, Medicaid, the State Children's Health Insurance Program, waivers, early intervention programs, and Title V State Programs for Children With Special Health Care Needs. Extra time for an office visit is scheduled for children with special health care needs, when indicated.
Coordinated	A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient. Care among multiple providers is coordinated through the medical home. A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved. The medical home physician shares information among the child or youth, family, and consultant and provides specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals. Families are linked to family support groups, parent-to-parent groups, and other family resources. When a child or youth is referred for a consultation or additional care, the medical home physician assists the child, youth, and family in communicating clinical issues. The medical home physician evaluates and interprets the consultant's recommendations for the child or youth and family and, in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.

(continued)

Component	Description
	The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.
Compassionate	Concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions. Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth.
Culturally effective	The child's or youth's and family's cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan. All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of (para)professional translators or interpreters, as needed. Written materials are provided in the family's primary language.

Note. Reproduced from AAP (2002)

APPENDIX B

Simple and Conditional Moderation Model Results

Table B.1 *Simple and conditional moderation models with maternal mental health as the outcome*

Model	Predictor	*B*	SE	Ratio	Model R^2
Simple moderation with coping[a]					.185
	Medical home	0.199*	0.081	2.444	
	Coping	-0.316*	0.031	-10.304	
	Medical home × coping	-0.097	0.080	-1.213	
Simple moderation with social support[b]					.083
	Medical home	0.132	0.225	0.586	
	Social support	-0.307*	0.097	-3.153	
	Medical home × social support	0.157	0.179	0.882	
Moderation with health insurance[c]					.083
	Medical home	0.454*	.231	1.967	
	Health insurance type (both vs. average of private and public)	-0.038	0.039	-0.976	
	Medical home × health insurance type (both vs. average of private and public)	0.038	0.076	0.497	
	Health insurance type (private vs. public)	0.000	0.060	0.001	

(continued)

Model	Predictor	*B*	SE	Ratio	Model R^2
	Medical home × health insurance type (private vs. public)	-0.025	0.081	-0.303	
	Health insurance adequacy	-0.162	0.098	-1.642	
	Medical home × health insurance adequacy	-0.084	0.159	-0.527	
Conditional moderation[d]					.199
	Medical home	0.312*	0.152	2.049	
	Coping	-0.293*	0.031	-9.325	
	Medical home × coping	-0.139	0.081	-1.709	
	Social support	-0.057	0.036	-1.562	
	Medical home × social support	0.049	0.104	0.472	
	Health insurance type (both vs. average of private and public)	-0.040	0.037	-1.099	
	Medical home × health insurance type (both vs. average of private and public)	0.045	0.048	0.949	
	Health insurance type (private vs. public)	-0.028	0.049	-0.579	
	Medical home × health insurance type (private vs. public)	-0.005	0.043	-0.104	
	Health insurance adequacy	-0.038	0.042	-0.891	
	Medical home × health insurance adequacy	-0.119	0.103	-1.156	

Note: *$p < .05$, [a]$n = 979$, [b]$n = 975$, [c]$n = 984$, [d]$n = 967$

Table B.2 *Simple and conditional moderation models with maternal aggravation as the outcome*

Model	Predictor	*B*	SE	Ratio	Model R^2
Simple moderation with coping[a]					.124
	Medical home	-0.061	0.086	-0.710	
	Coping	0.325	0.037	8.911	
	Medical home × coping	-0.005	0.085	-0.062	
Simple moderation with social support[b]					.031
	Medical home	-0.100	0.103	-0.967	
	Social support	0.097*	0.038	2.568	
	Medical home × social support	-0.006	0.102	-0.058	
Moderation with health insurance[c]					.066
	Medical home	0.003	0.100	0.032	
	Health insurance type (both vs. average of private and public)	0.030	0.039	0.767	
	Medical home × health insurance type (both vs. average of private and public)	0.089*	0.044	2.048	
	Health insurance type (private vs. public)	-0.177*	0.049	-3.648	
	Medical home × health insurance type (private vs. public)	0.014	0.043	0.324	
	Health insurance adequacy	0.174*	0.042	4.175	
	Medical home × health insurance adequacy	-0.052	0.098	-0.536	
Conditional moderation[d]					.162
	Medical home	-0.069	0.143	-0.479	

(continued)

Model	Predictor	*B*	SE	Ratio	Model R^2
	Coping	0.310*	0.037	8.355	
	Medical home × coping	0.013	0.085	0.148	
	Social support	0.022	0.037	0.591	
	Medical home × social support	0.068	0.097	0.698	
	Health insurance type (both vs. average of private and public)	0.021	0.037	0.566	
	Medical home × health insurance type (both vs. average of private and public)	0.080	0.042	1.917	
	Health insurance type (private vs. public)	-0.158*	0.046	-3.414	
	Medical home × health insurance type (private vs. public)	0.017	0.041	0.423	
	Health insurance adequacy	0.136*	0.040	3.408	
	Medical home × health insurance adequacy	-0.011	0.093	-0.123	

Note: *$p < .05$, [a]$n = 978$, [b]$n = 975$, [c]$n = 970$, [d]$n = 967$

REFERENCES

Abidin, R. R. (1990). *Parenting Stress Index (PSI).* Charlottesville, VA: Pediatric Psychology Press

Abidin R. R. (1997). Parenting Stress Index: A measure of the parent-child system. In C. P. Zalaquett & R. J. Wood (Eds.), *Evaluating stress: A book of resources* (pp. 277–91). Scarecrow Press, Inc.

Adams, D., Rose, J., Jackson, N., Karakatsani, E., & Oliver, C. (2018). Coping strategies in mothers of children with intellectual disabilities showing multiple forms of challenging behaviour: Associations with maternal mental health. *Behavioural and Cognitive Psychotherapy, 46*(3), 257–275. https://doi.org/10.1017/S1352465817000704

Ahmad, F., Jhajj, A., Stewart, D., Burghardt, M., & Bierman, A. (2014). Single item measures of self-rated mental health: A scoping review. *BMC Health Services Research, 14*(1), 398–408. https://doi.org/10.1186/1472-6963-14-398

Allen, K., Blascovich, J., & Mendes, W. B. (2002). Cardiovascular reactivity and the presence of pets, friends, and spouses: The truth about cats and dogs. *Psychosomatic Medicine, 64*(5)*,* 727–739. https://doi.org/10.1097/01.PSY.0000024236.11538.41

American Academy of Pediatrics, Ad Hoc Task Force on Definition of the Medical Home. (1992). The medical home. *Pediatrics*, *90*(5), 774.

American Academy of Pediatrics, Medical Home Initiatives for Children with Special Health Care Needs Project Advisory Committee. (2002). Policy statement: The medical home. *Pediatrics, 110*(1), 184-186. https://doi.org/10.1542/peds.110.1.184

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). http://doi.org/10.1176/appi.books.9780890425596

Anderson Moore, K., & Vandivere, S. (2000). Stressful family lives: Child and parent well-being. *Child Trends, B*(17), 3-8.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving; The unexpected career*. Academic Press, Inc.

Arauz Boudreau, A., Van Cleave, J., Gnanasekaran, S., Kurowski, D., & Kuhlthau, K. (2012). The medical home: Relationships with family functioning for children with and without special health care needs. *Academic Pediatrics, 12*(5), 391–398. https://doi.org/10.1016/j.acap.2012.06.001

Asparouhov, T., & Muthén, B. (2010). *Weighted least squares estimation with missing data.* Unpublished manuscript.

Association of University Centers on Disabilities (AUCD). (2009). *Leadership education in neurodevelopmental and related disabilities (LEND).* http://www.aucd.org/template/page.cfm?id=6

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators (2012). *Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008.* Morbidity and Mortality Weekly Report Surveillance Summaries, *61*(SS03), 1–19.

Autism Speaks. (2019a). Autism Speaks commends Tennessee as it becomes 50th state requiring that insurance plans cover autism. *Autism Speaks*. https://www.autismspeaks.org/press-release/autism-speaks-commends-tennessee-it-becom es-50th-state-requiring-insurance-plans

Autism Speaks. (2019b). Health insurance coverage for autism. *Autism Speaks*. https://www.autismspeaks.org/health-insurance-coverage-autism

Baio, J., Wiggins, L., Christensen, D., Maenner, M., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahorodny, W., Rosenberg, C. R., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L., -C., Harrington, R., Lopez, M., Fitzgerald, R. T., Hewitt, A., … Dowling, N. (2018). Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, D.C.: 2002)*, *67*(6), 1–23. https://doi.org/10.15585/mmwr.ss6706a1

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5)*,* 271-230. https://doi.org/10.1046/j.1365-2788.2003.00484.x

Bandalos, D. (2014). relative performance of categorical diagonally weighted least squares and robust maximum likelihood estimation. *Structural Equation Modeling, 21*(1), 102–116. https://doi.org/10.1080/10705511.2014.859510

Barlow, J., Smailagic, N., Huband, N., Roloff, V., Bennett, C., & Barlow, J. (2014). Group-based parent training programmes for improving parental psychosocial health. *Cochrane Library, 2014*(5), CD002020–CD002020. https://doi.org/10.1002/14651858.CD002020.pub4

Baron, R., & Kenny, D. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(6), 1173–1182. https://doi.org/10.1037/0022-3514.51.6.1173

Baron-Lee, J., Bonner, B., Knapp, C., Bright, M., & Hinojosa, M. (2015). Factors associated with having a medical home for children at-risk of experiencing negative events: Results from a national study. *Maternal and Child Health Journal, 19*, 2233–2242. https://doi.org/10.1007/s10995-015-1742-x

Barrera, M., D'Agostino, N., Gibson, J., Gilbert, T., Weksberg, R., & Malkin, D. (2004). Predictors and mediators of psychological adjustment in mothers of children newly diagnosed with cancer. *Psycho-Oncology (Chichester, England), 13*(9), 630–641. https://doi.org/10.1002/pon.765

Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD. *Journal of Autism and Developmental Disorders, 36*(5), 685-695. https://doi.org/10.1007/s10803-006-0112-3

Benson, P. (2010). Coping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders, 4*(2), 217–228. https://doi.org/10.1016/j.rasd.2009.09.008

Benson, P. R. & Karlof, K. L. (2008). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders, 39*, 350–362. https://doi.org/10.1007/s10803-008-0632-0

Bethell, C., Newacheck, P., Hawes, E., & Halfon, N. (2014). Adverse childhood experiences: Assessing the impact on health and school engagement and the mitigating role of resilience. *Health Affairs (Project Hope), 33*(12), 2106–2115. https://doi.org/10.1377/hlthaff.2014.0914

Blumberg, S. J., Foster, E. B., Frasier, A. M., Satorius, J., Skalland, B. J., Nysse-Carris, K. L., Morrison, H. M., Chowdhury, S. R., & O'Connor, K. S. (2009). Design and operation of the National Survey of Children's Health, 2007. *National Center for Health Statistics. Vital and health statistics. Ser. 1, Programs and collection procedures, 55,* 1–149.

Blumberg, S. J., Olson, L., Frankel, M. R., Osborn, L., Srinath, K. P., & Giambo, P. (2005). Design and operation of the National Survey of Children's Health, 2003. *National Center for Health Statistics. Vital and health statistics. Ser. 1, Programs and collection procedures*, *43*, 1-131.

Bonds, D. D., Gondoli, D. M., Sturge-Apple, M. L., & Salem, L. N. (2002). Parenting stress as a mediator of the relation between parenting support and optimal parenting. *Parenting, Science and Practice, 2*(4), 409–435. https://doi.org/10.1207/S15327922PAR0204_04

Box, G., & Draper, N. (1987). *Empirical model-building and response surfaces*. Wiley.

Boyd, B. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*(4), 208–215. https://doi.org/10.1177/10883576020170040301

Boyer, B. B. (2008). Theoretical models of health psychology and the model for integrating medicine and psychology. In B. B. Boyer & M. I. Paharia (Eds.), *Comprehensive handbook of clinical health psychology* (pp. 1–30). John Wiley & Sons, Inc. https://doi.org/10.1002/9781118269657.ch1

Bromley, J., Hare, D., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*(4), 409–423. https://doi.org/10.1177/1362361304047224

Bronte-Tinkew, J., Horowitz, A., & Carrano, J. (2010). Aggravation and stress in parenting: Associations with coparenting and father engagement among resident fathers. *Journal of Family Issues, 31*(4), 525–555. https://doi-org.ezproxy.baylor.edu/10.1177/0192513X09340147

Brown, R. T., Lambert, R., Devine, D., Baldwin, K., Casey, R., Doepke, R., Ievers, C. E., Hsu, L., Buchanan, I., & Eckman, J. (2000). Risk-resistance adaptation model for caregivers and their children with sickle cell syndromes. *The Society of Behavioral Medicine, 22*(2), 158–169. https://doi.org/10.1007/BF02895780

Brown, H., Ouellette-Kuntz, H., Hunter, D., Kelley, E., & Cobigo, V. (2012). Unmet needs of families of school-aged children with an autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 25*(6), 497–508. https://doi.org/10.1111/j.1468-3148.2012.00692.x

Brown, R. T., Wiener, L., Kupst, M. J., Brennan, T., Behrman, R., Compas, B. E., Elkin, T. D., Fairclough, D. L., Friebert, S., Katz, E., Kazak, A. E., Madan-Swain, A., Mansfield, N., Mullins, L. L., Noll, R., Patenaude, A. F., Phipps, S., Sahler, O. J., Sourkes, B., & Zeltzer, L. (2008). Single parents of children with chronic illness: An understudied phenomenon, *Journal of Pediatric Psychology, 33*(4)*,* 408–421, https://doi.org/10.1093/jpepsy/jsm079

Cairney, J., Boyle, M., Offord, D. R., & Racine, Y. (2003). Stress, social support and depression in single and married mothers. *Social Psychiatry and Psychiatric Epidemiology, 38*(8), 442–449. https://doi.org/10.1007/s00127-003-0661-0

Callaghan, T., & Sylvester, S. (2019). Autism spectrum disorder, politics, and the generosity of insurance mandates in the United States. *PloS One, 14*(5), e0217064–e0217064. https://doi.org/10.1371/journal.pone.0217064

Candon, M., Barry, C., Marcus, S., Epstein, A., Kennedy-Hendricks, A., Xie, M., & Mandell, D. (2019). Insurance mandates and out-of-pocket spending for children with autism spectrum disorder. *Pediatrics (Evanston), 143*(1), e20180654–. https://doi.org/10.1542/peds.2018-0654

Carbone, P. S., Behl, D. D., Azor, V., & Murphy, N. A. (2010). The medical home for children with autism spectrum disorders: Parent and pediatrician perspectives. *Journal of Autism and Developmental Disorders, 40*(3), 317–324. https://doi.org/10.1007/s10803-009-0874-5

Caruso, D. (2010). Autism in the U.S.: Social movement and legal change. *American Journal of Law & Medicine, 36*(4), 483–539. https://doi.org/10.1177/009885881003600401

Centers for Disease Control and Prevention. (2019, September 23). *Treatment and intervention services for autism spectrum disorder.* https://www.cdc.gov/ncbddd/autism/treatment.html

Chartier, M. J., Walker, J. R., & Naimark, B. (2010). Separate and cumulative effects of adverse childhood experiences in predicting adult health and health care utilization. *Child Abuse & Neglect, 34*(6), 54–64.

Cheak-Zamora, N., & Farmer, J. (2015). The impact of the medical home on access to care for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 45*(3), 636–644. https://doi.org/10.1007/s10803-014-2218-3

Child and Adolescent Health Measurement Initiative. (2009). *Measuring medical home for children and youth: Methods and findings from the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health.* U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, and National Center for Health Statistics. https://www.childhealthdata.org/docs/medical-home/mhmanual_withappendices-updated-12-7-10-pdf

Child and Adolescent Health Measurement Initiative. (2019). *2017-2018 National Survey of Children's Health (2 Years Combined Data Set): Child and family health measures, national performance and outcome measures, and subgroups, SPSS Codebook, Version 1.0, Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services*, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). https://www.childhealthdata.org/learn-about-the-nsch/nsch-codebooks

Chiri, G., & Warfield, M. (2011). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal, 16*(5), 1081–1091. https://doi.org/10.1007/s10995-011-0833-6

Christensen, D. L., Baio, J., Braun, K. V. N., Bilder, D., Charles, J., Constantino, J., N., Daniels, J., Durkin, M. S., Fitzgerald, R. T., Kurzius-Spencer, M., Lee, L. -C., Pettygrove, S., Robinson, C., Schulz, E., Wells, C., Wingate, M. S., Zahorodny, W., & Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveillance Summaries, 65*(3), 1–23. https://doi.org/10.15585/mmwr.ss6503a1

Clark, N. M., Gong, M., Schork, M. A., Evans, D., Roloff, D., Hurwitz, M., Maiman, L., & Mellins, R. B. (1998). Impact of education for physicians on patient outcomes. *Pediatrics (Evanston), 101*(5), 831–836. https://doi.org/10.1542/peds.101.5.831

Cohen L. A., & Limbers C. (2019) Mental health and parenting stress in mothers of children with diabetes treated in a patient-centered medical home. *Family Practice, 36*(4), 486–492. https://doi.org/10.1093/fampra/cmy110

Cohen, S. (2006). *Targeting autism: What we know, don't know, and can do to help young children with autism spectrum disorders* (3rd ed.). University of California Press. https://doi.org/10.1525/j.ctt1pp6dm

Cohen, S. & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310–357. https://doi.org/10.1037/0033-2909.98.2.310

Cole, L., Kharwa, Y., Khumalo, N., Reinke, J., & Karrim, S. (2017). Caregivers of school-aged children with autism: Social media as a source of support. *Journal of Child and Family Studies, 26(*12), 3464–3475. https://doi.org/10.1007/s10826-017-0855-9

Conger, R. D., Conger, K. J., Elder, G. H., Lorenz, F. O., Simons, R. L., & Whitbeck, L. B. (1992). A family process model of economic hardship and adjustment of early adolescent boys. *Child Development, 63*(3)*,* 526–541. https://doi.org/10.1111/j.1467-8624.1992.tb01644.x

Cox, B. Buman, M. P., Woods, E. R., Famakinwa, O., & Harris, S. K. (2012). Evaluation of raising adolescent families together program: a medical home for adolescent mothers and their children. *American Journal of Public Health, 102*(10), 1879–1885. https://doi.org/10.2105/AJPH.2012.300766

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*(3), 266–280. https://doi.org/10.1111/j.1365-2788.2010.01258.x

Davis, K., & Ballreich, J. (2014). Equitable access to care — How the United States ranks internationally. *The New England Journal of Medicine, 371*(17), 1567–1570. https://doi.org/10.1056/NEJMp1406707

Davis, N. O., & Carter, A. S. (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. https://doi.org/10.1007/s10803-007-0512-z

Dieleman, L. M., De Pauw, S. S. W., Soenens, B., Mabbe, E., Campbell, R., & Prinzie, P. (2018). Relations between problem behaviors, perceived symptom severity and parenting in adolescents and emerging adults with ASD: The mediating role of parental psychological need frustration. *Research in Developmental Disabilities, 73*, 21–30. https://doi.org/10.1016/j.ridd.2017.12.012

Dolgin, M., Phipps, S., Fairclough, D., Sahler, O., Askins, M., Noll, R., Butler, R. W, Varni, J. W., & Katz, E. (2007). Trajectories of adjustment in mothers of children with newly diagnosed cancer: A natural history investigation. *Journal of Pediatric Psychology, 32*(7), 771–782. https://doi.org/10.1093/jpepsy/jsm013

Drummond, A., Looman, W., & Phillips, A. (2012). Coping among parents of children with special health care needs with and without a health care home. *Journal of Pediatric Health Care, 26*, 266–275. https://doi.org/10.1016/j.pedhc.2010.12.005

Duarte, C., Bordin, I., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism: The International Journal of Research and Practice, 9*(4), 416–427. https://doi.org/10.1177/1362361305056081

Dunn, M., Burbine, T., Bowers, C., & Tantleff-Dunn, S. (2001). Mediators of stress in parents of children with autism. *Community Mental Health Journal, 37*(4), 39–52. https://doi.org/10.1023/A:1026592305436

Dunst, C. J., Trivette, C. M., & Cross, A. H. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American Journal of Mental Deficiency, 90*(4), 403–417.

Dworzynski, K., Ronald, A., Bolton, P., & Happé, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry, 51*(8), 788–797. https://doi.org/10.1016/j.jaac.2012.05.018

Dykens, E., Fisher, M., Taylor, J., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: A randomized trial. *Pediatrics (Evanston), 134*(2), e454–e463. https://doi.org/10.1542/peds.2013-3164

Easterbrooks, M. A., & Goldberg, W. A. (1984). Toddler development in the family: Impact of father involvement and parenting characteristics. *Child Development, 55*(3), 740–752.

Edmunds, M., & Joel Coye, M. (1998). *America's children: Health insurance and access to care.* National Academy Press.

Ehrle, J., & Moore, K. A. (1997). *NSAF benchmarking measures of child and family well-being, Report No 6.* NSAF Methodology Reports. https://www.urban.org/sites/default/files/publication/69906/410137---NSAF-Benchmarking-Measures-of-Child-and-Family-Well-Being.PDF

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism: The International Journal of Research and Practice, 13*(4), 375–387. https://doi.org/10.1177/1362361309105658

Farmer J., Clark M., Drewel E., Swenson T., & Ge B. (2011). Consultative care coordination through the medical home for CSHCN: A randomized controlled trial. *Maternal and Child Health Journal, 15*(7), 1110–1118. https://doi.org/10.1007/s10995-010-0658-8

Farmer, J., Clark, M., Mayfield, W., Cheak-Zamora, N., Marvin, A., Law, J., & Law, P. (2014). The relationship between the medical home and unmet needs for children with autism spectrum disorders. *Maternal and Child Health Journal, 18*(3), 672–680. https://doi.org/10.1007/s10995-013-1292-z

Farmer, J. E., Clark, M. J., Sherman, A., Marien, W. E., & Selva, T. J. (2005). comprehensive primary care for children with special health care needs in rural areas. *Pediatrics, 116*(3), 649–656. https://doi.org/10.1542/peds.2004-0647

Farmer, J. E., & Deidrick, K. K. (2006). Introduction to childhood disability. In J. E. Farmer, J. Donders, & S. Warschausky (Eds.), *Treating neurodevelopmental disabilities: Clinical research and practice* (pp. 3-20). Guilford Press.

Feeney, B. C., & Collins, N. L. (2014). A theoretical perspective on the importance of social connections for thriving. In M. Mikulincer & P. Shaver (Eds.), *Mechanisms of social connections: From brain to group* (pp. 291–314). American Psychological Association.

Flora, D., & Curran, P. (2004). An empirical evaluation of alternative methods of estimation for confirmatory factor analysis with ordinal data. *Psychological Methods, 9*(4), 466–491. https://doi.org/10.1037/1082-989X.9.4.466

Florence, C., Brown, D.S., Fang, X., & Thompson, H.F. (2013). Health care costs associated with child maltreatment: Impact on Medicaid. *Pediatrics*, *132*(2), 312–8.

Fombonne, E. (2018). Editorial: The rising prevalence of autism. *Journal of Child Psychology and Psychiatry, 59*(7), 717–720. https://doi.org/10.1111/jcpp.12941

Frosch, D. L., & Kaplan, R. M. (1999). Shared decision making in clinical medicine: Past research and future directions. *American Journal of Preventive Medicine, 17*(4), 285–294. https://doi.org/10.1016/s0749-3797(99)00097-5

Ghandour, R. M., Perry, D. F., Kogan, M. D., & Strickland, B. B. (2011). The medical home as a mediator of the relation between mental health symptoms and family burden among children with special health care needs. *Academic Pediatrics, 11*(2), 161–169. https://doi.org/10.1016/j.acap.2010.12.015

Golnik, A., Scal, P., Wey, A., & Gaillard, P. (2011). Autism-specific primary care medical home intervention. *Journal of Autism and Developmental Disorders, 42*(6), 1087–1093. https://doi.org/10.1007/s10803-011-1351-5

Gotham, K., Pickles, A., & Lord, C. (2008). Standardizing ADOS scores for a measure of severity in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(5), 693–705. https://doi.org/10.1007/s10803-008-0674-3

Gray, D. (2002). Ten years on: a longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability, 27*(3), 215–222. https://doi.org/10.1080/1366825021000008639

Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine, 56*(3), 631–642. https://doi.org/10.1016/s0277-9536(02)00059-x

Green, B. L., Furrer, C., & McAllister, C. (2007). How do relationships support parenting? Effects of attachment style and social support on parenting behavior in an at-risk population. *American Journal of Community Psychology, 40*(1-2), 96–108. https://doi.org/10.1007/s10464-007-9127-y

Gurney, J. G., McPheeters, M. L., & Davis, M. M. (2006). Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. *Archives of Pediatrics and Adolescent Medicine, 160*(8), 825–830. https://doi.org/10.1001/archpedi.160.8.825

Hartley, S., Mihaila, I., Otalora-Fadner, H., & Bussanich, P. (2014). Division of labor in families of children and adolescents with autism spectrum disorder. *Family Relations, 63*(5), 627–638. https://doi.org/10.1111/fare.12093

Hartley, S., & Schultz, H. (2014). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(6), 1636–1648. https://doi.org/10.1007/s10803-014-2318-0

Hastings, R.P. (2008). Stress in parents of children with autism. In E. McGregor, M. Nunez, K. Williams, & J. Gomez (Eds.), *Autism: An integrated view* (pp. 303–324). Blackwell.

Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal on Mental Retardation, 111*(1), 48-61. https://doi.org/10.1352/0895-8017(2006)111[48:MDAEEC]2.0.CO;2

Hastings R. P., & Johnson E. (2001). Stress in UK families conducting intensive home-based behavioural intervention for their young child with autism. *Journal of Autism and Developmental Disorders, 31*(3), 327–336. https://doi.org/10.1023/A:1010799320795

Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35,* 635–644.

Hayes, A. (2018). *Introduction to mediation, moderation, and conditional process analysis: A regression-based approach* (2nd ed.). The Guilford Press.

Hess, K., Morrier, M., Heflin, L., & Ivey, M. (2007). Autism Treatment Survey: Services received by children with autism spectrum disorders in public school classrooms. *Journal of Autism and Developmental Disorders, 38*(5), 961–971. https://doi.org/10.1007/s10803-007-0470-5

Hock, R., & Ahmedani, B. (2012). Parent perceptions of autism severity: Exploring the social ecological context. *Disability and Health Journal, 5*(4), 298–304. https://doi.org/10.1016/j.dhjo.2012.06.002

Hock, E., & Schirtzinger, M. (1992). Maternal separation anxiety: Its developmental course and relation to maternal mental health. *Child Development, 63*(1), 93–102. https://doi.org/10.1111/j.1467-8624.1992.tb03598.x

Hodge, D., Hoffman, C. D., Sweeney, D. P., & Riggs, M. L. (2013). Relationship between children's sleep and mental health in mothers of children with and without autism. *Journal of Autism and Developmental Disorders, 43*(4), 956–963. https://doi-org.ezproxy.baylor.edu/10.1007/s10803-012-1639-0.

Hodgetts, S., Zwaigenbaum, L., & Nicholas, D. (2014). Profile and predictors of service needs for families of children with autism spectrum disorders. *Autism: The International Journal of Research and Practice, 19*(6), 673–683. https://doi.org/10.1177/1362361314543531

Homer, C., Klatka, K., Romm, D., Kuhlthau, K., Bloom, S., Newacheck, P., Van Cleave, J., & Perrin, J. (2008). A review of the evidence for the medical home for children with special health care needs. *Pediatrics, 122*(4), e922–37. https://doi.org/10.1542/peds.2007-3762

Horton, T. V., & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology, 46*(4), 382-399. https://doi.org/10.1037/0090-5550.46.4.382

House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science, 241*(4865), 540–545. https://doi.org/10.1126/science.3399889

Ingersoll, B., & Hambrick, D. Z. (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. https://doi.org/10.1016/j.rasd.2010.04.017

Institute of Medicine and National Research Council. (2011). Current data collection methods and sources. In *Child and adolescent health and health care quality: Measuring what matters* (pp. 67-90). National Academies Press. https://doi.org/10.17226/13084

Institute of Medicine Committee on the Consequences of Uninsurance. (2002). Family well-being and health insurance coverage. In *Health insurance is a family matter* (pp. 91-106). National Academies Press. https://www-ncbi-nlm-nih-gov.ezproxy.baylor.edu/books/NBK221008/

Jarquin, V.G., Wiggins, L.D., Schieve, L.A., & Van Naarden-Braun, K. (2011). Racial disparities in community identification of autism spectrum disorders over time; Metropolitan Atlanta, Georgia, 2000–2006. *Journal of Developmental and Behavioral Pediatrics, 32*, 179–87. https://doi.org/10.1097/DBP.0b013e31820b4260

Jose, P. E. (2016). The merits of using longitudinal mediation. *Educational Psychologist, 51*(3-4), 331-341, https://doi.org/10.1080/00461520.2016.1207175

Kane, G., Wood, V., & Barlow, J. (2007). Parenting programmes: A systematic review and synthesis of qualitative research. *Child: Care, Health & Development, 33*(6), 784–793. https://doi.org/10.1111/j.1365-2214.2007.00750.x

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2,* 217–250

Karimzadeh, M., Rostami, M., Teymouri, R., Moazzen, Z., Tahmasebi, S., & Karimzadeh, M. (2017). The association between parental mental health and behavioral disorders in pre-school children. *Electronic Physician, 9*(6), 4497–4502. https://doi.org/10.19082/4497

Karpur, A., Lello, A., Frazier, T., Dixon, P., & Shih, A. (2018). Health disparities among children with autism spectrum disorders: Analysis of the National Survey of Children's Health 2016. *Journal of Autism and Developmental Disorders, 49*(4), 1652–1664. https://doi.org/10.1007/s10803-018-3862-9

Katz, E. R., & Varni, T. W. (1988). *The impact of social skills training on cognitions and adjustment in newly diagnosed children with cancer*. (Grant funded by the American Cancer Society). Long Beach Memorial Hospital.

Khanna, R., Madhavan, S., Smith, M., Patrick, J., Tworek, C., & Becker-Cottrill, B. (2010). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 41*(9), 1214–1227. https://doi.org/10.1007/s10803-010-1140-6

Klebanov, P., Brooks-Gunn, J., & Duncan, G. (1994). Does neighborhood and family poverty affect mothers' parenting, mental health, and social support? *Journal of Marriage and Family, 56*(2), 441–455. https://doi.org/10.2307/353111

Kogan, M., Strickland, B., Blumberg, S., Singh, G., Perrin, J., & van Dyck, P. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States. *Pediatrics, 122*(6), e1149–e1158. https://doi.org/10.1542/peds.2008-1057

Kuhlthau, K., McDonnell, E., Coury, D., Payakachat, N., & Macklin, E. (2017). Associations of quality of life with health-related characteristics among children with autism. *Autism: The International Journal of Research and Practice, 22*(7), 804–813. https://doi.org/10.1177/1362361317704420

Kuo, A. A., Inkelas, M., Lotstein, D. S., Samson, K. M., Schor, E. L., & Halfon, N. (2006). Rethinking well-child care in the United States: An international comparison. *Pediatrics (Evanston), 118*(4), 1692–1702. https://doi.org/10.1542/peds.2006-0620

Kuster, P., & Badr, L. (2009). Mental health of mothers caring for ventilator-assisted children at home. *Issues in Mental Health Nursing, 27*(8), 817–835. https://doi.org/10.1080/01612840600840588

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publication Company.

Lesesne, C., Visser, S., & White, C. (2003). Attention-deficit/hyperactivity disorder in school-aged children: Association with maternal mental health and use of health care resources. *Pediatrics (Evanston), 111*(5 Pt 2), 1232.

Levy-Shiff, R., Dimitrovsky, L., Shulman, S., & Har-Even, D. (1998). Cognitive appraisals, coping strategies, and support resources as correlates of parenting and infant development. *Developmental Psychology, 34*(6), 1417–1427. https://doi.org/10.1037/0012-1649.34.6.1417

Limbers, C. A., Gutierrez, A., & Cohen, L. A. (2020). The patient-centered medical home: Mental health and parenting stress in mothers of children with autism spectrum disorder. *Journal of Primary Care and Community Health, 11,* 1-11. https://doi.org/10.1177/2150132720936067

Linares, D., Azuine, R., & Singh, G. (2020). Social determinants of health associated with mental health among U.S. mothers with children aged 0-5 years. *Journal of Women's Health (Larchmont, N.Y. 2002), 29*(8), 1039-1051. https://doi.org/10.1089/jwh.2019.8111

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, 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. https://doi.org/10.1097/DBP.0b013e318165c7a0

Lyons-Ruth, K., Lyubchik, A., Wolfe, R., & Bronfman, E. (2002). Parental depression and child attachment: Hostile and helpless profiles of parent and child behavior among families at risk. In S. H. Goodman & I. H. Gotlib (Eds.), *Children of depressed parents: Mechanisms of risk and implications for treatment* (pp. 89–120). American Psychological Association. https://doi-org.ezproxy.baylor.edu/10.1037/10449-004

MacCallum, R. C., Wegener, D. T., Uchino, B. N., & Fabrigar, L. R. (1993). The problem of equivalent models in applications of covariance structure analysis. *Psychological Bulletin, 114*(1), 185–199. https://doi.org/10.1037/0033-2909.114.1.185

Macomber, J. E., Moore, K. A. (1999). *1997 NSAF benchmarking measures of child and family well-being. Report No. 6, NSAF Methodology Reports*. Urban Institute. https://www.urban.org/sites/default/files/publication/69906/410137---NSAF-Benchmarking-Measures-of-Child-and-Family-Well-Being.PDF

Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Rosenberg, C. R., Lee, L. -C., Harrington, R. A., Huston, M., …Dietz, P. M. (2020). Prevalence of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2016. *MMWR Surveillance Summaries, 69*(4), 1–12. http://dx.doi.org/10.15585/mmwr.ss6904a1

Major, D. A., (2003) Utilizing role theory to help employed parents cope with children's chronic illness. *Health Education Research, 18*(1), 45–57. https://doi.org/10.1093/her/18.1.45

Mancil, G., Boyd, B., & Bedesem, P. (2009). Parental stress and autism: Are there useful coping strategies? *Education and Training in Developmental Disabilities, 44*(4), 523–537.

Mandell, D., & Salzer, M. (2007). Who joins support groups among parents of children with autism? *Autism, 11*(2), 111–122. https://doi.org/10.1177/1362361307077506

Manuel, J. (2001). Risk and resistance factors in the adaptation in mothers of children with juvenile rheumatoid arthritis. *Journal of Pediatric Psychology, 26*(4), 237–246. https://doi.org/10.1093/jpepsy/26.4.237

McCall, B. P., & Starr, E. M. (2018). Effects of autism spectrum disorder on parental employment in the United States: Evidence from the National Health Interview Survey. *Community, Work & Family, 21*(4), 367–392. https://doi.org/10.1080/13668803.2016.1241217

McCoach, D. B., Black, A. C., & O'Connell, A. A. (2007). Errors of inference in structural equation modeling. *Psychology in the Schools, 44*(5), 461-470. https://doi.org/10.1002/pits.20238

McDonald, M. E., & Paul, J. F. (2010). Timing of increased autistic disorder cumulative incidence. *Environmental Science & Technology, 44*(6), 2112–2118. https://doi.org/10.1021/es902057k

McGovern, C., & Sigman, M. (2005). Continuity and change from early childhood to adolescence in autism. *Journal of Child Psychology and Psychiatry, 46*(4), 401–408. https://doi.org/10.1111/j.1469-7610.2004.00361.x

McPheeters, M., Warren, Z., Sathe, N., Bruzek, J., Krishnaswami, S., Jerome, R., & Veenstra-VanderWeele, J. (2011). A systematic review of medical treatments for children with autism spectrum disorders. *Pediatrics (Evanston), 127*(5), e1312–e1321. https://doi.org/10.1542/peds.2011-0427

Meadows, S. (2011). The association between perceptions of social support and maternal mental health: A cumulative perspective. *Journal of Family Issues, 32*(2), 181–208. https://doi.org/10.1177/0192513X10375064

Medway, M., Tong, A., Craig, J., Kim, S., Mackie, F., McTaggart, S., Walker, A., & Wong, G. (2015). Parental perspectives on the financial impact of caring for a child with CKD. *American Journal of Kidney Diseases, 65*(3), 384–393. https://doi.org/10.1053/j.ajkd.2014.07.019

Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Frontiers in Psychology, 10*, 1-12. https://doi.org/10.3389/fpsyg.2019.00464

Moh, T., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders, 6*(1), 293–303. https://doi.org/10.1016/j.rasd.2011.05.011

Montes, G., & Halterman, J. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics, 119*(5), e1040–e1046. https://doi.org/10.1542/peds.2006-2819

Moodie-Dyer, A., Joyce, H. D., Anderson-Butcher, D. & Hoffman, J. (2014) Parent–caregiver experiences with the autism spectrum disorder service delivery system, *Journal of Family Social Work, 17*(4), 344-362, https://doi.org/10.1080/10522158.2014.903581

Moore, K., & Ehrle, J. (1999). *Adults' environment and behavior: Parental aggravation.* Urban Institute. http://webarchive.urban.org/UploadedPDF/900872_1997Snapshots.pdf

Murphey, D., Bandy, T., Anderson Moore, K., & Cooper, P. M. (2014). Do parents feel more aggravated these days? *Child Trends, 2014*(14), 1-5. https://www.childtrends.org/wp-content/uploads/2014/04/2014-14ParentalAggravation.pdf

Murphy, N., Christian, B., Caplin, D., & Young, P. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health & Development, 33*(2), 180–187. https://doi.org/10.1111/j.1365-2214.2006.00644.x

Muthén, B.O, du Toit, S., & Spisic, D. (1997). *Robust inference using weighted least squares and quadratic estimating equations in latent variable modeling with categorical and continuous outcomes.* Unpublished manuscript.

Muthén, L. K., & Muthén, B. O. (1998–2012). *Mplus Users's Guide* (7th ed.). Muthén & Muthén.

Myers, S., Johnson, C., & Council on Children With Disabilities (2007). Management of children with autism spectrum disorders. *Pediatrics, 120*(5), 1162–1182. https://doi.org/10.1542/peds.2007-2362

National Autism Center. (2015). *Findings and conclusions: National Standards Project, phase 2.* National Autism Center.

National Research Council. (2001). *Educating Children with Autism.* The National Academies Press. https://doi.org/10.17226/10017

Nevison, C. D. (2014). A comparison of temporal trends in United States autism prevalence to trends in suspected environmental factors. *Environmental Health, 13*(1), 73. https://doi.org/10.1186/1476-069X-13-73.

Nielsen, M., Langner, B., Zema, C., Hacker, T., & Grundy, P. (2013). *Benefits of implementing the primary care patient-centered medical home: A review of cost & quality results, 2012.* Patient-Centered Primary Care Collaborative.

Noojin, A., & Wallander, J. (1997). Perceived problem-solving ability, stress, and coping in mothers of children with physical disabilities: Potential cognitive influences on adjustment. *International Journal of Behavioral Medicine, 4*(4), 415–432. https://doi.org/10.1207/s15327558ijbm0404_10

Oster, H., Morales, L., Andersen, R., Wold, C., Simon, P., & Gelberg, L. (2002) *The Aggravation in Parenting Scale: Language application issues among Spanish-speaking Latino families living in Los Angeles County* [Paper presentation]. Academy for Health Services Research and Health Policy Annual Research Meeting. Washington, DC, United States.

Parish, S., Thomas, K., Williams, C., & Crossman, M. (2015). Autism and families' financial burden: The association with health insurance coverage. *American Journal on Intellectual and Developmental Disabilities, 120*(2), 166–175. https://doi.org/10.1352/1944-7558-120.2.166

Parker, M. L., & Killian, M. (2020). Autism spectrum disorder and complex healthcare needs: The role of healthcare experiences. *Research in Autism Spectrum Disorders, 73*, 1-10. https://doi.org/10.1016/j.rasd.2020.101535

Peele, P. B., Lave, J. R., & Kelleher, K. J. (2002). Exclusions and limitations in children's behavioral health care coverage. *Psychiatric Services, 53*(5), 591–594. https://doi.org/10.1176/appi.ps.53.5.591

Perry, A. (2004). A model of stress in families of children with developmental disabilities: Clinical and research applications. *Journal on Developmental Disabilities, 11*(1), 1-16.

Pfefferle, S., & Spitznagel, E. (2009). Children's mental health service use and maternal mental health: A path analytic model. *Children and Youth Services Review, 31*(3), 378–382. https://doi.org/10.1016/j.childyouth.2008.09.003

R Core Team. (2018). *R: A language and environment for statistical computing.* R Foundation for Statistical Computing, Vienna. https://www.R-project.org

Radey, M., & McWey, L. (2021). Safety nets, maternal mental health, and child mental health outcomes among mothers living in poverty. *Journal of Child and Family Studies, 30*(3), 687–698. https://doi.org/10.1007/s10826-021-01909-3

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., & Wood, E. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics, 4(1)*, 1–13. https://doi.org/10.1186/1471-2431-4-1

Rast, J., Shattuck, P., Roux, A., Anderson, K., & Kuo, A. (2018). The medical home and health care transition for youth with autism. *Pediatrics (Evanston), 141*(Supplement 4), S328–S334. https://doi.org/10.1542/peds.2016-4300j

Reszka, S., Boyd, B., McBee, M., Hume, K., & Odom, S. (2013). Brief report: Concurrent validity of autism symptom severity measures. *Journal of Autism and Developmental Disorders, 44*(2), 466–470. https://doi.org/10.1007/s10803-013-1879-7

Rhemtulla, M., Brosseau-Liard, P. É., & Savalei, V. (2012). When can categorical variables be treated as continuous? A comparison of robust continuous and categorical SEM estimation methods under suboptimal conditions. *Psychological methods, 17*(3), 354–373. https://doi.org/10.1037/a0029315

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child and Adolescent Psychology, 37*(1), 8–38. https://doi.org/10.1080/15374410701817808

Roter, D. L., & Hall, J. A. (1992). *Doctors talking with patients/patients talking with doctors: Improving communication in medical visits.* Auburn House/Greenwood Publishing Group.

Santacroce, S. J. & Kneipp, S. M. (2018). A conceptual model of financial toxicity in pediatric oncology. *Journal of Pediatric Oncology Nursing, 36*(1), 6–16. https://doi.org/10.1177/1043454218810137

Santacroce, S. J., Tan, K. R., & Killela, M. K. (2019). A systematic scoping review of the recent literature (~2011–2017) about the costs of illness to parents of children diagnosed with cancer. *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society, 35*, 22–32. https://doi.org/10.1016/j.ejon.2018.04.004

Sawyer, M. G., Bittman, M., La Greca, A. M., Crettenden, A. D., Harchak, T. F., & Martin, J. (2010). Time demands of caring for children with autism: What are the implications for maternal mental health? *Journal of Autism and Developmental Disorders, 40*(5), 620–628. https://doi.org/10.1007/s10803-009-0912-3

Schall, C. (2000). Family perspectives on raising a child with autism. *Journal of Child and Family Studies, 9*(4), 409–423. https://doi.org/10.1023/A:1009456825063

Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PloS One, 14*(7), 1–18. https://doi.org/10.1371/journal.pone.0219888

Schieve, L., Blumberg, S., Rice, C., Visser, S., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics (Evanston), 119*(Supplement 1), S114–S121. https://doi.org/10.1542/peds.2006-2089q

Schieve, L., Boulet, S., Kogan, M., Yeargin-Allsopp, M., Boyle, C., Visser, S., Blumberg, S., & Rice, C. (2011). Parenting aggravation and autism spectrum disorders: 2007 National Survey of Children's Health. *Disability and Health Journal, 4*(3), 143–152. https://doi.org/10.1016/j.dhjo.2010.09.002

Schmit, S. & Matthews, H. (2017). Children need health insurance – so do their parents. *Clasp.* https://www.clasp.org/sites/default/files/publications/2017/04/Children-Need-Health-Insurance-1.pdf

Schoen, C., Osborn, R., Doty, M. M., Bishop, M., Peugh, J., & Murukutla, N. (2007). Toward higher-performance health systems: Adults' health care experiences in seven countries, 2007. *Health Affairs, 26*(Suppl2), w717–w734. https://doi.org/10.1377/hlthaff.26.6.w717

Shalowitz, M., Mijanovich, T., Berry, C., Clark-Kauffman, E., Quinn, K., Perez, E., & Shalowitz, M. (2006). Context matters: A community-based study of maternal mental health, life stressors, social support, and children's asthma. *Pediatrics, 117*(5), e940–e948. https://doi.org/10.1542/peds.2005-2446

Shattuck, P., Seltzer, M., Greenberg, J., Orsmond, G., Bolt, D., Kring, S., Lounds, J., & Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*(9), 1735–1747. https://doi.org/10.1007/s10803-006-0307-7

Sheldrick, R. C., & Carter, A. S. (2018). State-level trends in the prevalence of autism spectrum disorder (ASD) from 2000 to 2012: A reanalysis of findings from the Autism and Developmental Disabilities Network. *Journal of Autism and Developmental Disorders, 48*(9), 3086–3092. https://doi.org/10.1007/s10803-018-3568-z

Siefert, K., Bowman, P. J., Heflin, C. M., Danziger, S., & Williams, D. R. (2000). Social and environmental predictors of maternal depression in current and recent welfare recipients. *American Journal of Orthopsychiatry, 70*(4), 510–522. https://doi.org/10.1037/h0087688

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 921–929. https://doi.org/10.1097/CHI.0b013e318179964f

Simpson, J., Schneider, M., & Zlomke, K. (2021). Beyond autism severity: The role of medical providers in parenting/caregiver aggravation. *Advances in Neurodevelopmental Disorders, 5,* 183–192. https://doi.org/10.1007/s41252-021-00194-x

Singer, G. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal of Mental Retardation, 111*(3), 155–169. https://doi.org/10.1352/0895-8017(2006)111[155:MOCSOD]2.0.CO;2

Smith, J. P., & Smith, G. C. (2010). Long-term economic costs of psychological problems during childhood. *Social Science & Medicine, 71*(1), 110–5.

Sobotka, S., Francis, A., & Vander Ploeg Booth, K. (2016). Associations of family characteristics with perceptions of care among parents of children with autism. *Child: Care, Health and Development, 42*(1), 135–140. https://doi.org/10.1111/cch.12290

Strickland, B., Singh, G., Kogan, M., Mann, M., van Dyck, P., & Newacheck, P. (2009). Access to the medical home: New findings from the 2005-2006 National Survey of Children with Special Health Care Needs. *Pediatrics, 123*(6), e996–1004. https://doi.org/10.1542/peds.2008-2504

Szatmari, P., Georgiades, S., Duku, E., Bennett, T. A., Bryson, S., Fombonne, E., Mirenda, P., Roberts, W., Smith, I. M., Vaillancourt, T., Volden, J., Waddell, C., Zwaigenbaum, L., Elsabbagh, M., & Thompson, A. (2015). Developmental trajectories of symptom severity and adaptive functioning in an inception cohort of preschool children with autism spectrum disorder. *JAMA Psychiatry, 72*(3), 276–283. https://doi.org/10.1001/jamapsychiatry.2014.2463

Taylor, J. L., & Warren, Z. E. (2012). Maternal depressive symptoms following autism spectrum diagnosis. *Journal of Autism and Developmental Disorders, 42*(7), 1411–1418. https://doi.org/10.1007/s10803-011-1375-x

Taylor, S. E. (2011). Social support: A review. In *The Oxford Handbook of Health Psychology* (Vol. 1). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780195342819.013.0009

Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 34–42. https://doi.org/10.1111/j.1468-3148.2008.00437.x

Thomas, K., Williams, C., deJong, N., & Morrissey, J. (2016). Examination of parent insurance ratings, child expenditures, and financial burden among children with autism: A mismatch suggests new hypotheses to test. *Pediatrics (Evanston), 137*(Supplement), S186–S195. https://doi.org/10.1542/peds.2015-2851q

Tippy, K., Meyer, K., Aronson, R., & Wall, T. (2005). Characteristics of coordinated ongoing comprehensive care within a medical home in Maine. *Maternal and Child Health Journal, 9*(S2), S13–S21. https://doi.org/10.1007/s10995-005-4747-z

Todorow, C., Connell, J., & Turchi, R. (2018). The medical home for children with autism spectrum disorder. *Current Opinion in Pediatrics, 30*(2), 311-317. https://doi.org/10.1097/MOP.0000000000000605

Tomeny, T. (2017). Parenting stress as an indirect pathway to mental health concerns among mothers of children with autism spectrum disorder. *Autism, 21*(7), 907–911. https://doi.org/10.1177/1362361316655322

Totsika, V., Hastings, R., Emerson, E., Lancaster, G., & Berridge, D. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology and Psychiatry, 52*(1), 91–99. https://doi.org/10.1111/j.1469-7610.2010.02295.x

Vandenberg, R. J., & Grelle, D. M. (2009). Alternative model specifications in structural equation modeling: Facts, fictions, and truth. In C. E. Lance & R. J. Vandenberg (Eds.), *Statistical and methodological myths and urban legends* (pp. 185–212). Routledge. https://doi.org/10.4324/9780203867266-15

Wallander, J. L. (1991). *Mentally retarded adolescents' stress and coping.* (Grant funded by the National Institute of Child Health and Human Development). University of Alabama at Birmingham.

Wallander, J., & Noojin, A. (1995). Mothers' report of stressful experiences related to having a child with a physical disability. *Children's Health Care, 24*(4), 245–256. https://doi.org/10.1207/s15326888chc2404_4

Wallander, J. L., Pitt, L. C., & Mellins, C. A. (1990). Child functional independence and maternal psychosocial stress as risk factors threatening adaptation in mothers of physically or sensorially handicapped children. *Journal of Consulting and Clinical Psychology, 58*(6), 818-824.

Wallander, J. L., & Varni, J. W. (1992). Adjustment in children with chronic physical disorders: Programmatic research on a disability-stress-coping model. In A. M. La Greca, L. J. Siegel, J. L. Wallander, & C. E. Walker (Eds.), *Stress and coping in child health* (pp. 279-298). The Guilford Press.

Wallander, J. L., Varni, J. W., Babani, L. V., Banis H. T., & Wilcox, K. T. (1989). Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *Journal of Pediatric Psychology, 14*, 157-173.

Wang, L., Ma, J., Dholakia, R., Howells, C., Lu, Y., Chen, C., Li, R., Murray, M., & Leslie, D. (2019). Changes in healthcare expenditures after the autism insurance mandate. *Research in Autism Spectrum Disorders, 57*, 97–104. https://doi.org/10.1016/j.rasd.2018.10.004

Wang, L., Mandell, D., Lawer, L., Cidav, Z., & Leslie, D. (2012). Healthcare service use and costs for autism spectrum disorder: A comparison between Medicaid and private insurance. *Journal of Autism and Developmental Disorders, 43*(5), 1057–1064. https://doi.org/10.1007/s10803-012-1649-y

Watson, S. L., Stine, F., Tumin, D., & Stiles, K. M. (2020). Employment and well-being among caregivers of children with autism spectrum disorder, *Children's Health Care*, 1–12. https://doi.org/10.1080/02739615.2020.1810576

Weiss, J., Robinson, S., Fung, S., Tint, A., Chalmers, P., & Lunsky, Y. (2013). Family hardiness, social support, and self-efficacy in mothers of individuals with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7*(11), 1310–1317. https://doi.org/10.1016/j.rasd.2013.07.016

Weiss, S., & Chen, J. (2002). Factors influencing maternal mental health and family functioning during the low birthweight infant's first year of life. *Journal of Pediatric Nursing, 17*(2), 114–125. https://doi.org/10.1053/jpdn.2002.124129

Whitehead A. (2017). Neighborhoods, family functioning, and mother's mental health for families with a child with an autism spectrum disorder. *Applied Research in Quality of Life, 12*(3), 633-651. https://doi.org/10.1007/s11482-016-9480-9

Wiles, B., Cooper, A. N., & McWey, L. M (2019). Using child services: The importance of the mother-child relationship and maternal social support. *Journal of Social Service Research, 45*(3), 418–428. https://doi.org/10.1080/01488376.2018.1480567

Wills, T. A. (1991). Social support and interpersonal relationships. In M. S. Clark (Ed.), *Prosocial behavior* (pp. 265–289). Sage.

Wu, A. D., & Zumbo, B. D. (2008). Understanding and using mediators and moderators. *Social Indicators Research, 87*(3), 367–392. https://doi.org/10.1007/s11205-007-9143-1

Xu, G., Strathearn, L., Liu, B., O'Brien, M., Kopelman, T. G., Zhu, J., Snetselaar, L. G., & Bao, W. (2019). Prevalence and treatment patterns of autism spectrum disorder in the United States, 2016. *JAMA Pediatrics, 173*(2)*,* 153–159. https://doi.org/10.1001/jamapediatrics.2018.4208

Yirmiya, N., & Shaked, M. (2005). Psychiatric disorders in parents of children with autism: A meta-analysis*. Journal of Child Psychology and Psychiatry, 46*(1), 69–83. https://doi.org/10.1111/j.1469-7610.2004.00334.x

Young, A., Ruble, L., & McGrew, J. (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. https://doi.org/10.1016/j.rasd.2009.06.006

Younger, J. B., Kendell, M. J., & Pickler, R. H. (1997). Mastery of stress in mothers of preterm infants. *Journal of the Society of Pediatric Nurses, 2*(1), 29-35.

Yu, S., & Singh, G. (2012). High parenting aggravation among U.S. immigrant families. *American Journal of Public Health (1971), 102*(11), 2102–2108. https://doi.org/10.2105/AJPH.2012.300698

Zablotsky, B., Bradshaw, C., & Stuart, E. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(6), 1380–1393. https://doi.org/10.1007/s10803-012-1693-7

Zafar, S., & Abernethy, A. (2013). Financial toxicity, Part I: a new name for a growing problem. *Oncology (Williston Park, N.Y.), 27*(2), 80–149.

Zaidman-Zait, A., Mirenda, P., Szatmari, P., Duku, E., Smith, I., Vaillancourt, T., Volden, J., Waddell, C., Bennett, T., Zwaigenbaum, L., Elsabaggh, M., & Georgiades, S. (2018). Profiles of social and coping resources in families of children with autism spectrum disorder: Relations to parent and child outcomes. *Journal of Autism and Developmental Disorders, 48*(6), 2064–2076. https://doi.org/10.1007/s10803-018-3467-3

Zhang, W., & Baranek, G. (2016). The impact of insurance coverage types on access to and utilization of health services for U.S. children with autism. *Psychiatric Services, 67*(8), 908–911. https://doi.org/10.1176/appi.ps.201500206