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Unmet Medical Home Needs and Educational Services Access in Children with Autism Spectrum Disorder

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UNMET MEDICAL HOME NEEDS AND EDUCATIONAL SERVICES ACCESS IN

CHILDREN WITH AUTISM SPECTRUM DISORDER

by

A Dissertation Submitted in

Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

in Health Sciences

at

The University of Wisconsin-Milwaukee

December 2020

ABSTRACT

UNMET MEDICAL HOME NEEDS AND EDUCATIONAL SERVICES ACCESS IN CHILDREN
WITH AUTISM SPECTRUM DISORDER

by

Sabrin Rizk

The University of Wisconsin-Milwaukee, 2020
Under the Supervision of Kris Barnekow, Ph.D., OTR/L, IMH-E®

One in 54 children is diagnosed with an autism spectrum disorder (ASD) in the U.S. The American Academy of Pediatrics (AAP) is a primary care model defined as accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally-effective care for children with ASD, jointly with educational services. Children with ASD use educational services for cognitive, social, and behavioral needs. Educational services include early intervention (EI) through EI plans or school services under special education plans in public schools. Linking health and educational services reduces fragmented care and collaboratively addresses the needs of children with ASD. Although the AAP has asserted efforts to coordinate health and educational services, whether medical home care contributes to educational services use remains unclear. Using the 2016/2017 National Survey of Children's Health (NSCH), this study measured the association between care that did not meet AAP medical home criteria and educational services use for children aged 1-17 with ASD. Medical home care was operationalized as care that did not meet AAP medical home criteria. Multivariate analyses were performed for two sets of predictive models, with educational services as outcomes: ever had special education or EI plans (n=1,428) and not currently using services under these plans (n=1,248), while controlling for predisposing, enabling, enabling-vulnerability, and need factors in the Andersen behavioral model of health services use with a vulnerability domain. Approximately 68% of children with ASD ever had special education or EI plans, and 10% were not currently using services under these plans, for those without care that met AAP medical home criteria. Medical home care was not significantly associated with ever having special education or EI plans but associated with less likelihood of current service use under these plans (aOR = 0.51, 95% CI [0.29-0.90]). Significant predictors of ever having special education or EI plans were children's ages, three or more children in households, Black or Other races, decreased maternal health status, single parent families, having public insurance, and age at ASD diagnoses. Children's ages (aOR = 1.09, 95% CI [1.00-1.18]), maternal health (aOR = 1.88, 95% CI [1.05-3.36]), and children with special healthcare needs status (aOR = 2.58, 95% CI [1.17-5.68]) were associated with greater odds of not currently receiving services under one of these plans. For children with ASD, care that did not meet AAP medical home criteria was not significantly associated with ever having a special education or EI but was significantly associated with not currently receiving services under one of these plans. This study highlights the gaps in access to medical home care that affects educational services access which are another source of crucial services for children with ASD. Policies and practices improving integrated care systems are needed to increase access to medical home care for children with ASD and to provide a gateway to educational services through coordinated care with medical homes.

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LIST OF ABBREVIATIONS

ASD   Autism spectrum disorder

CSHCN   Children with special health care needs

EI   Early intervention

FAPE   Free Appropriate Public Education

FPL   Federal poverty level

HRSA   Health Resources & Services Administration

IDEA   Individuals with Disabilities Education Act

IDEIA   Individuals with Disabilities Education Improvement Act

IFSP   Individual Family Service Plan

IEP   Individualized Education Program

LRE   Least Restrictive Environment

NSCH   National Survey of Children's Health

MCHB   Maternal and Child Health Bureau

ACKNOWLEDGEMENTS

I have spent a little over 100 pages organizing, synthesizing, and articulating a significant amount of information to leave, what I hope, is the beginning of my own mark on the scholarly world of health services research, children with autism and their families, survey methodology, medical home care, and educational services. I would like to take this opportunity to simply talk, so to speak, through writing these acknowledgements:

First and foremost, I want to thank my advisor, Dr. Kris Barnekow. Fourteen years later, and here we are. Pursuing a PhD. In an MCH area. I am not certain I would have found my way here on my own. Your invitation to participate in MCH Pipeline in 2006 was the invitation of my lifetime. It kickstarted every good thing in my career, and every good and important event and/or lessons has you in it; my Master's Thesis, publications, more MCH training programs, developing networks with MCH professionals, sitting in your Pediatrics class as an undergraduate learning to be better scholarly writer, toning my edge down, and my relentless need to find a career serving children with many different disabilities and their families in an urban setting. It started with that invitation. Thank you for always seeing the best there was in me and shaping, supporting, and promoting my work in this field. It has made all the difference, and you have made all the difference.

Dr. Teal Benevides, I feel incredibly grateful for you. This was *my* privilege to have you on this committee. Thank you for picking up on the nuances of my work that I naively underestimated, for guiding me to understand the seriousness of my methodological decisions, the impact that those decisions have on the people behind these numbers, and the potential to influence policies for children I have spent my clinical career providing services to in educational settings. Thank you for doing it all in a way that made the process less scary, more inviting, and more collaborative as a committee member. You are like a North Star. I watch your work, the way you conduct a career as PhD-trained OT, and I feel braver. When people talk about the health of adults with ASD, funding endeavors, MCH and/or MCH-related national platforms, your name and your work are never too far behind in those conversations. You are leaving a mark and I am very grateful to have your influence as I pursue future research endeavors.

Dr. Emmanuel Ngui, I do not think I would have ever realized my capability of these research questions, and wildly enough, using a national survey, *a complex national survey,* to find my answers if it were not for your MCH course. There would be no way. I am certain of it. I initially appreciated what I thought would be an efficient way to conduct a study since the data are already collected when you described secondary analyses. I learned relatively quickly that it requires much more sophistication, attention to detail, intuitiveness, and a lot of patience to use the data in a way that gets to the heart of my questions. Thank you for the countless hours hashing out how to carry out this study, debating variables, discussing theoretical frameworks, dissecting coding schemes, and your guidance in learning a statistical software I never imagined would now be in my repertoire of research skills. You asked questions that I know made my research better, made me think about the way I performed this study, and what the findings will mean for medical home care and children with ASD.

Dr. Elizabeth Drame, I spent most of my career seated at tables with special educators, families, and other professionals, crafting educational plans we felt would best meet the needs of the students who

filled the many pages that comprise an IEP. I am grateful you were seated at this table to offer your expertise in educational services, the educator perspective, and helping me understand how to make my research accessible to all different professionals who work on behalf of children with ASD in whatever capacity. Thank you.

Dr. Bonnie Klein-Tasman, I will never underestimate the power of an ASD diagnosis, and an early ASD diagnosis, for children and families who bear the greatest disparities in accessing evaluations and receiving a diagnosis in our community. That was important to me in my work with you. You make that possible for families who come through your clinic. You do it in a way that is systematic, accessible, collaborative, and supportive of wherever families are in their personal journeys of bringing their children in for ASD evaluations.

Dr. Victoria Moerchen, MCH Pipeline was my start as a young and hopeful undergraduate. Thank you for continuing to support students from first generation, under-represented backgrounds to pursue health careers that focus on serving children with disabilities and their families. MCH Pipeline made all the difference, and it is people like you who continue to the work of engaging first generation, under-represented students.

To my parents, this PhD is one of the ultimate ways I can honor your sacrifice in coming to a country and starting vastly different lives than the ones you lived in Egypt and the Philippines. I know some of the hopes and dreams you had when you came to this country; making a sustainable living, home ownership, children who would go to college, and pursuing careers that helped others. I honestly do not think a PhD was in your, nor my own, visions for our futures, but *we* are here. Mom, thank you for always nurturing my helper heart at a young age, for always telling me stories of my interest and attention to people with disabilities as a little girl, and my genuine concern for others with differences, even at an age where I could not quite articulate it myself. Dad, thank you for directing my helper heart towards helping children. You were certain a career helping children would be a way to live out *our* dreams of helping others.

To my sisters, we approach our professional lives very differently. Our one common thread, however, is the "first generation" experience we all had together. I admit, it felt like the blind leading the blind, at times, but we all have found individuals along the way who made the experience more tolerable, the path much clearer, and the support we needed. I am certain that it made us much braver, more grateful, and probably a little tougher when it comes to challenges. Thank you for being the best passengers on that ride.

To my sweet nephews, Aiden and Camdon, you were my breaks throughout this journey; sitting in school drop off and pick up lines, being your short-order cook, reading you stories that were honestly for my own mental breaks, and being in your presence to enjoy things through your eyes, even if it was just for a short while. You are literally the pulse of our family, and I am certain we need you more than you need us. I never fully understood what it meant to make things easier for generations who come after me until I met you. You are both so young to comprehend the incredible journey this has been, but the path has been paved. Multiple paths have been paved. Any one of them, even if you create your own, will

be yours to take. I hope your path is filled with incredible adventures, meeting more people than you even knew existed in this world, and that you encounter individuals on your own path who help light the way.

Lastly, to my students with ASD and their families, past, present, and possibly even in the future. You were these research questions, you were the answers, and you were everything in between. Thank you for the privilege of working with you and your children. That was a gift. I am better in many respects because of those experiences, and I hope you live in a world that offers better opportunities for collaborative, coordinated, family-centered, and accessible care in health and education systems.

EPIGRAPH

Success is failure turned inside out—
The silver tint of the clouds of doubt,
And you never can tell just how close you are,
It may be near when it seems so far;
So stick to the fight when you're hardest hit—
It's when things seem worst that you must not quit.

-Unknown

Chapter 1: Introduction

Importance of the Problem

Children with autism spectrum disorder (ASD) require various services and specialized care (e.g., neurology, gastroenterology, and behavioral health) beyond well-child visits (American Academy of Pediatrics [AAP], 2015) and generally needed by other children (McPherson et al., 1998). Health care and educational systems partner with children with ASD and their families through various life stages (e.g., early childhood, adolescence, young adulthood) and in different contexts (e.g., childcare settings, early intervention (EI), school-based services, nutrition services, mental health, social services, and community-based resources) (AAP, 2015). These services vary across systems which have historically operated separately (Shahidullah et al., 2018). Medical homes (AAP, 2002) for children with disabilities, like ASD, provide primary medical care for health-related aspects of their conditions. In contrast, educational services (e.g., EI and school-based services) are provided to children with ASD to increase optimal developmental outcomes (Shahidullah et al., 2018).

Medical homes and educational systems play essential roles in supporting children with ASD and their families in the chronic management of ASD, ASD comorbidities, and to successfully function in daily living. Existing evidence has demonstrated limited integrated and coordinated care between medical and educational sectors (Shahidullah et al., 2018). These systems are crucial aspects in the rising prevalence of children with ASD (Maenner et al., 2020). Families of children with ASD mediate these systems' limited coordination and communication by sharing information between systems (Lipkin et al., 2015; AAP, 2001, AAP, 2007a, AAP, 2007b; AAP, 1999; AAP, 2015; Adams, Tapia, & The Council on Children with Disabilities, 2013; Shahidullah et al., 2018; Shah, Kunnavakkam, and Msall, 2013; Jimenez et al., 2014; Feinberg et al., 2011; Adams, Tapia, & The Council on Children with Disabilities, 2013; Wei et al., 2014; Jimenez et al., 2012; Dunn et al., 2016; Sheppard & Vitalone-Raccaro, 2016). Most cited culprits included limited coordination time, lack of ASD knowledge and resources, separate funding mechanisms, and demographic factors (e.g., poverty, lower educational attainment, cultural and linguistic barriers, and unemployment) which affect medical home care coordination with other systems (Todorow

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et al., 2018). Similar coordination barriers exist for schools but include families' unfamiliarity with the legal rights of students with disabilities and schools' interest in external collaborations (Sheppard & Vitalone-Raccaro, 2016). With increased attention and existing limitations, a requirement arises to examine collective access to medical and educational services through increased research effort. Integrated care is challenging to implement without seismic shifts in how siloed systems work together. Since this can have serious consequences for children and families, it is important to better understand how receipt of one affects the other. In this current study, this is interpreted as not receiving care that meets AAP medical home criteria and *ever* having and *not currently* receiving services under special education or EI plans in children with ASD. Coordinated medical and educational services may reduce inefficiencies, gaps, redundancies, and improve quality of care for these children and their families (Shahidullah et al., 2018). Assembling coordinated care between medical homes and educational settings may also reduce the burden on families to transfer information between these systems (Lipkin et al., 2015; Russell & McCloskey, 2015). Despite AAP efforts to coordinate medical and educational services, whether the medical home plays a role in children with ASD receiving educational services remains unclear. This topic constitutes a new domain with largely unstudied potential. Understanding coordination between medical and educational systems not only has research implications but can give rise to practices and policies governing coordination and equitable access to such services for this population of children.

Theoretical Orientation

The Andersen behavioral model of health services use (Andersen, Davidson, & Baumeister, 2013) was used to examine health care and educational services utilization using a nationally representative sample of children with ASD. The Andersen behavioral model of health services use (Andersen, 1995; Andersen, Davidson, & Baumeister, 2013) is a conceptual framework that explores factors which influence access and use of health services. This model asserts that contextual (i.e., broader systems that affect health care access and use) and individual characteristics (i.e., qualities specific to the people or family units accessing and using health services) provide a backdrop for the way health care services are accessed and used (Andersen, 1968; Andersen, 1995; Andersen, Davidson, & Baumeister,

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2013). Within the contextual and individual characteristics, three groups of factors play a role in the way that individuals get access to and use such services. These are referred to as predisposing, enabling, and need factors (Andersen, 1968; Andersen, 1995; Andersen, Davidson, & Baumeister, 2013). Each set of these factors are situated with contextual and individual determinants. This study included a vulnerability domain embedded within the most recent version of the Andersen behavioral model of health services use (Gelberg, Andersen, & Leake, 2000).

Study Objectives, Research Questions, and Hypotheses

Objectives

This study set out to measure the association between care that did not meet AAP medical home criteria (AAP, 2002) and the receipt of educational services through EI or special education programs in children with ASD using the combined 2016/2017 National Survey of Children's Health. This study was broadly separated into two parts. First, this study examined the association between lack of care per AAP medical home criteria and its association with *ever* and *not currently* receiving services under special education or EI plans. Second, it examined the influence of predisposing, enabling, enabling-vulnerability, and need factors on *ever* and *not currently* receiving services under one of these plans without medical home care per the AAP.

Research Questions

The research questions were:

Research Question 1a. Is care that does not meet AAP medical home criteria associated with decreased likelihood of *ever* having special education or EI plans (i.e., potential access) for children with ASD?

Research Question 1b. Is care that does not meet AAP medical home criteria associated with greater likelihood of *not currently* receiving services under one of these plans (i.e., realized access) for children with ASD?

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Research Question 2a. After controlling for predisposing, enabling, enabling-vulnerability, and need factors, is care that does not meet AAP medical home criteria associated with *ever* having special education or EI plans (i.e., potential access) for children with ASD?

Research Question 2b. After controlling for predisposing, enabling, enabling-vulnerability, and need factors, is care that does not meet AAP medical home criteria associated with *not currently* receiving services under one of these plans (i.e., realized access) for children with ASD?

Hypotheses

The goal of the present study was to test the following hypotheses:

Hypothesis 1a. Care that does not meet AAP medical home criteria will be associated with lesser likelihood of *ever* having special education or EI plans (i.e., potential access).

Hypothesis 1b. Care that does not meet AAP medical home criteria will be associated with greater likelihood of *not currently* receiving special education or EI plans (i.e., realized access).

Hypothesis 2a. Predisposing and enabling factors will be more strongly associated with *ever* having special education or EI plans than enabling-vulnerability and need factors for children without care that met AAP medical home criteria.

Hypothesis 2b. Predisposing and enabling factors will be more strongly associated with *not currently* receiving services under one of these plans than enabling-vulnerability and need factors for children without medical home care per the AAP.

Application to Occupational Therapy

Domain and Process. The Occupational Therapy (OT) Practice Framework: Domain and Process (OTPF-4) (AOTA, 2020) describes the role of OTs as champions for participation in facilitating engagement through adaptation and modification of objects within an environment or the environment itself. Occupational therapy incorporates the use of occupations, or daily life activities, which individuals derive meaning, to promote engagement in a variety of contexts (e.g., home, school, work, and community) (AOTA, 2020). Occupational therapists have specialized training and knowledge in the

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dynamic relationship between an individual, their desired occupations, and the environment and create evidence-based interventions that foster functional performance (AOTA, 2020). The intervention plans developed between practitioners and clients outlines clients' goals, beliefs, and needs, their health and well-being, their skills and patterns, and the cumulative leverage of contextual elements, activity expectations, and client factors (AOTA, 2020).

Population Health. Intervention can target different levels including person, groups, or populations and varies dependent on the context in which the intervention is delivered (AOTA, 2020). Occupational therapy service delivery may be aimed at individuals and those who support an individual's care (e.g., families and other caregivers). Groups may also be a target of OT intervention which may include families, students, or communities. Population-level interventions target groups of individuals who have commonalities based on geographic location, demographics, or collectively share a certain characteristic or attribute. At the group or population level which intervention is implemented, the focus of intervention is geared towards members of a certain group of within a population rather than an individual level (AOTA, 2020).

Policy. Other systems influencing OT practice involve policy, government, and culture. In this current day and age where healthcare reform is front and center in national, state, and local agendas, OT practice must stay involved to preserve the profession's pivotal role in protecting the health of individuals, communities, and populations. Occupational therapy has an opportunity to affect the lives of the individuals they serve through advocacy (AOTA, 2020). The capacity for OT advocacy includes engaging legislators in dialogue concerning the needs and disparities present (e.g., transportation, employment, housing, and education) for people, groups, and populations impacted by these disparities.

Summary

The main objective of this study was to measure the association between care that did not meet AAP medical home criteria and educational services use for children ages 1-17 with a parent-reported condition of ASD. To reach this objective, this study used data from the combined 2016/2017 NSCH to investigate the relationship between health and educational services and factors that influence their use for

this subset of children. The Andersen behavioral model of health services use (Andersen, 1995; Andersen, Davidson, & Baumeister, 2013) with an added vulnerability domain (Gelberg, Andersen, & Leake, 2000) guided this examination.

Pediatricians in the medical home have a significant role in directing coordinated care with EI and school systems for children with ASD and their families. The extent that the medical home is associated with educational services may highlight the joint contributions of these systems of care and the understanding of what factors may affect receiving these services. This may increase the potential for improved quality of care, cost savings, and enhancing experiences with these service systems for children with ASD and their families. These findings may inform integrated care delivery models for children with ASD that scales to different subsets of CSHCN.

Chapter 2: Literature Review

This chapter serves as an introduction to the background of AAP medical home care and educational services for children with ASD. The 6th revision of the Andersen behavioral model of health services use (Andersen, Davidson, & Baumeister, 2013) is the theoretical model used for this study with references to Andersen's seminal work (Andersen, 1968, Andersen, 1995), including the behavioral model for vulnerable populations (Gelberg, Andersen, & Leake, 2000). This study blends the Andersen behavioral model's original intent of predicting health services use while expanding its utility in measuring educational services use for children with ASD.

This chapter begins with a general introduction of the Andersen's behavioral model of health services use (Andersen, 1995; Andersen, Davidson, & Baumeister, 2013) with the added vulnerability domain (Gelberg, Andersen, & Leake, 2000). After an initial overview of the theoretical model, this chapter highlights children with special health care needs with special attention to children with ASD. The chapter discusses the health related needs of children with ASD, their educational needs, and the intersection between health and educational systems for these children. Barriers to these systems' coordination are also highlighted. The chapter concludes with Andersen's predisposing, enabling, enabling-vulnerability, and need parameters in this study in relation to medical home care and educational services use for children with ASD. After a considerable amount of review of previous work in these areas, the classification of these parameters widely varies in previous experimental work (Babitsch, Gohl, & von Lengerke, 2012) (Figure 1).

Theoretical Orientation

Behavioral Model as a Conceptual Framework

Much of the early work by Andersen (1968) on health services use was to understand families' differences in how they used and paid for health services. In the initial work published by Andersen (1968), he described a three-stage model in which predisposing, enabling, and need factors characterized

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Figure 1

Adapted Andersen's Behavioral Model of Health Services Use, 6th edition
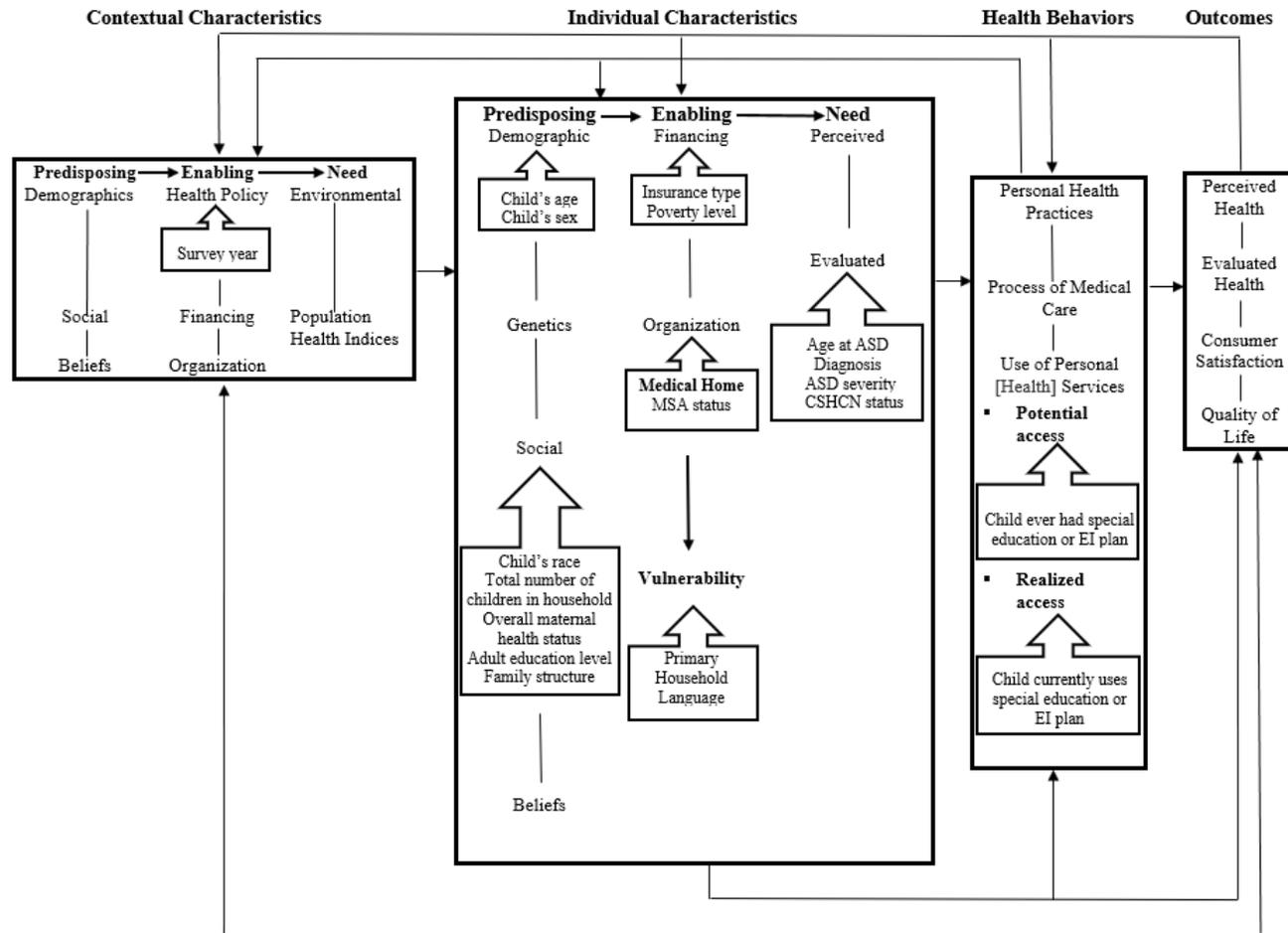
Note. This figure displays the original variables included in the multivariate analyses for predicting *ever* and *not currently* receiving services under special education or EI plans.

patterns between families' resources and health services use. Andersen (1968) defined predisposing factors as those that lend probable likelihood for using health services, enabling characteristics as circumstances that make health care attainable and need characteristics that increase the propensity for its use (Andersen, 1968). Andersen described initial sets of variables within these factors. Predisposing factors included family structure, social systems, and health beliefs. The enabling set of variables included family and community supports. The need aspect contained variables related to health status, such as known illnesses or risks for certain illnesses or diseases (Andersen, 1968). Foundational premises of the behavioral model of families' use of health services asserted that need factors would contribute to the root causes of seeking health services. When families are pressed for resources, their access and use of health services were better explained by need factors (Andersen, 1968). When families have more resources at their disposal, their access and use of such services were better explained by predisposing and enabling factors. Predisposing, enabling, and need factors were suggested to account for the variance in total use; with need factors at the forefront of health services use and predisposing and enabling factors accounting for the remainder of the variance after need factors (Andersen, 1968).

Contextual Characteristics. The 6th revision of the Andersen behavioral model of health services use (Andersen, Davidson, & Baumeister, 2013) differentiated contextual characteristics as the broad-ranging features that promote or impede health services access (Figure 1). These are large-scale influences that are important determinants for allocating resources, structural barriers that enhance or impede access, and understanding the issues that affect populations. Contextual predisposing factors are conditions that make it more likely for people to seek out services. The contextual predisposing domain include population demographics, larger social support networks, and health beliefs. The contextual enabling domain include policies and financing components that influence population health and either hinder or support populations' ability to use services to preserve health. Examples of contextual enabling characteristics include the financial stability of communities, their ability to afford services, and mechanisms to compensate health services providers. The organizational aspect of the contextual enabling characteristics considers the workforce to address population health. This includes ensuring that

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physicians shortages and access to hospitals and health centers are available to populations. Contextual need characteristics are environmental elements (e.g., clean water, safe neighborhoods, decreased pollution) and measures of population health (e.g., condition-specific prevalence or incidences) (Andersen, Davidson, & Baumeister, 2013).

Individual Characteristics. Individual characteristics embody the same three sets of factors (i.e., predisposing, enabling, and need) that influence health services use, but the focus is narrower (Figure 1). Individual predisposing factors include genetic predispositions to certain diseases or conditions, socioeconomic statuses, education level, employment status, and race/ethnicity. Individual need characteristics consider individuals' own health perceptions. The organizational aspect of the individual enabling factor include having a personal doctor or nurse, a usual source of care, and the capacity to use these resources including transportation and flexibility to wait to see providers (Andersen, Davidson, & Baumeister, 2013).

Individual need characteristics include perceived and evaluated need. Perceived need includes individuals' interpretations of the need for care and their responses to internal signals that they may need medical attention. Evaluated need is based on judgements of qualified professionals to determine whether individuals require care to manage their health. Evaluated need can be based on a variety of measures including physiological measures (i.e., blood pressure, weight, body temperature) and influenced criteria and guidelines that support the recommendation to seek health services (Andersen, Davidson, & Baumeister, 2013).

Populations of Interest

Children with Special Healthcare Needs (CSHCN)

Approximately 19% of children in the U.S. have a special health care need (SHCN), and 13% constitute children with ASD (MCHB HRSA, 2020). In 1985, the term, Children with Special Health Care Needs (CSHCN), was instituted to broaden the description of children covered under this definition, and included those with physical disabilities, developmental disabilities, sensory impairments, and chronic conditions (McPherson et al., 1998). These children have, or are at risk for, chronic physical,

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behavioral, developmental, or emotional conditions requiring more health and other services than children without SHCN (McPherson et al., 1998). This definition was incorporated in federal legislation for state program planning and resource allocation for these children (Farel, 2013). Children may qualify as a CSHCN by meeting one or more of the criteria (McPherson et al., 1998): use of prescription medication, elevated service use or needs, functional limitations, use of special therapies, or ongoing emotional, behavioral, or developmental conditions.

Children with developmental disabilities can be classified as CSHCN despite absence of any known medical disease or condition and should have medical homes overseen by qualified health professionals with comprehensive, continuous, and specialized care (AAP, 2006). The medical home should coordinate care and access to services for families in managing their condition (AAP, 2006).

Autism Spectrum Disorder. One in 54 children has an autism spectrum disorder (ASD) according to the Center for Disease Control and Prevention (CDC)'s Autism and Developmental Disabilities Monitoring (ADDM) Network (Maenner et al., 2020). Autism spectrum disorder (ASD) is a developmental disability with impairments in social communication, restrictive and repetitive behaviors, interests, or activities, and sensory processing (APA, 2013). Diagnoses of ASD at age 2 are considered valid and stable (Kleinman et al., 2008), but research shows that children with ASD are not diagnosed until approximately 4 years old (Maenner et al., 2020). Later ASD identification affects access to interventions and supports for children's developmental needs. In one pilot study examining embedding ASD diagnostics in the medical home for increased early ASD identification, a psychologist was incorporated into two primary care settings; the first was an academic general pediatrics clinic which included attending and resident physicians serving approximately 18,000 children in a culturally diverse region (GP clinic), and the second was an academic general pediatric setting staffed by faculty physicians serving approximately 6,000 children, less culturally diverse, and funded by private pay (AP clinic) (Hine et al., 2018). This study found that age at ASD diagnoses in the GP and AP clinics, including a psychologist alternating between the two sites, were lower than the national average at the time of their study (i.e., 32.1 months for the GP and AP clinics; 50 months for children nationally) (Hine et al., 2018).

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This pilot model also had significantly lower waiting times from initial referral to receipt of ASD diagnoses (i.e., 55 days for the GP and AP clinics and 7-12 months for tertiary clinics in the surrounding areas in this study). Children who needed follow-up testing in the pilot study's sample waited 3-4 months for follow-up, while follow-up times in surrounding tertiary clinics were upwards of one year. The results of this study give impetus to ASD diagnostic consultation availability in the medical home and its significant effect on early identification of ASD, especially in more diversely populated areas where accessing ASD diagnostics is severely challenging and delayed in these regions.

Twardzik et al. (2018) studied gaps in service access for children in Oregon diagnosed with developmental delay (DD). In Oregon, children with DD can access special education services between the ages of 3 through 5. If children do not receive a new diagnosis (e.g., ASD), that is not DD, at or before age 5, they lose their eligibility for services under the Individuals with Disabilities Education Improvement Act (IDEIA) (IDEIA, 2004) because they have reached the maximum age limit in Oregon for accessing special education services. It is plausible that occurrence of gaps in developmental and academic outcomes are likely if they are unable to access special education services after age 5 and receiving an eligible qualifying diagnosis for these services.

Children with ASD may qualify as a CSHCN and access medical homes based on the federal definition (Farel, 2013). Lichstein et al. (2018) found that 43.2% of CSHCN were reported to have medical homes using 2016 NSCH data. Children with ASD were 23% less likely to have medical homes using 2016 NSCH data (Kogan et al., 2018). Children with ASD have substantial variability in symptom and severity presentations and providing quality medical homes responsive to their vast needs is challenging (Cheak-Zamora & Farmer, 2015; Hyman & Johnson, 2012; Chiri & Warfield, 2012; Carbone et al., 2010). These challenges can perpetuate pursuing more costly care for non-emergent conditions. Deavenport-Saman et al., 2016 examined emergency department (ED) use by children with ASD. Children with ASD (n=2,426) had 0.26 more ED visits annually and with a higher likelihood of non-emergent needs without in-patient hospitalizations than children without ASD (n=155,476). Three common reasons for ED visits in this sample were acute upper respiratory infections, viral infections, and

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otitis media, which could have all been addressed by having a usual source of primary care (Deavenport-Saman et al., 2016). Families of children with ASD also have reported less family-centered, comprehensive, and coordinated care in medical homes (Brachlow et al., 2007; Kogan et al., 2018). Kogan et al. (2008) reported having a medical home likely reduces challenges to accessing care, unmet needs, employment disruptions, and caregiving demands of children with ASD. Golnik, Ireland, and Borowsky (2009) found primary care physicians reported decreased self-perceived competency providing medical home comprehensive care for children with ASD than children with neurodevelopmental (e.g., hypoxic ischemia, encephalopathy, cerebral palsy, intellectual disability, attention deficit/hyperactivity disorder) and chronic/complex health conditions (e.g., congenital heart disease, chronic asthma, early cystic fibrosis, and diabetes). Barriers to comprehensive care included level of autism education, care coordination, and reimbursement for coordinating care (Golnik, Ireland, & Borowsky, 2009).

Health-Related Needs of Children with ASD: The Medical Home

Children with ASD need healthcare services (e.g., preventative care, diagnostic services, and intervention) as typically developing children, but their need varies by frequency, intensity, and using specialty care (Cummings et al. 2016). Their unique and complex needs exceed capacities of single providers and require interdisciplinary collaboration to adequately address their needs (Carbone et al., 2010). These includes specialized behavior and communication approaches (e.g., applied behavioral analyses (ABA)), picture exchange communication systems (PECS); specialized therapies (e.g., occupational therapy, speech therapy, sensory integration); dietary changes or restrictions (e.g., eliminating different foods, ingredients, incorporating vitamin and mineral supplements), use of prescribed medications, and complementary and alternative treatments (e.g., craniosacral therapy) (CDC, 2019).

Medical Home Access

The medical home is a primary care model for all children, including CSHCN. To intercede on the residuum of rising health care expenditures, longer life expectancies of CSHCN, practice concentrations, and fragmentation of care, the AAP established a solution by creating the medical home

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(Sia et al., 2004). This genesis of the medical home in pediatrics began as a mechanism centralizing medical records of CSHCN (Sia et al., 2004). One of the foundational outcomes of the medical home established by the AAP asserted that "Every child deserves a medical home" (Sia et al., 2004) later updated to "Every child and youth deserves a medical home" (AAP, 2018). The objective was to provide a basis for medical care of infants, children, and adolescents which is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally-effective (AAP, 1992; AAP, 2002).

Within the literature, there is a broad interest in medical home care within the population of CSHCN. The research has focused extensively on quality medical home access for this population (Kogan et al., 2008), but there is also a large body of research surrounding specific components of medical home care: family-centeredness (Montes & Halterman, 2011; Toomey et al., 2010), coordination (Ronis et al., 2015), comprehensiveness (Raphael et al., 2014), continuity (McManus et al., 2013), compassion, and culturally-effective care (Hyman & Johnson, 2012). The medical home has been studied in children without special healthcare needs (SHCN) and positive outcomes resulting from this care (Long et al., 2012). Existing medical home literature is saturated with variants including the family-centered pediatric medical homes. This has been studied by many authors in the literature (Stille et al., 2010), patient-centered medical home (Jackson et al., 2013), and the health home or Medicaid health home (Moses et al., 2014) along with others (Vetter et al., 2013; Ferrari et al., 2013). Medical home research has also examined medical home care by disability type (Fueyo et al., 2015; Waisman Center, 2008; Burke & Liptak, 2011; Wegner et al., 2008; Cooley, 2004), and discipline-specific positions within the medical home (Manion, 2012; Findley et al., 2017) to elucidate challenges within these variations and multiple interpretations of the medical home model (AAP, 1992; AAP, 2002).

Medical homes address children's health issues related to their ASD. The medical home is not a "place" where children and families obtain medical care. It is a primary medical care model overseen by trained physicians for infants, children, adolescents, with and without disabilities. (AAP, 2002). It can be provided in office environments and differs from care in other settings (e.g., emergency departments,

walk-in clinics, and urgent care) (AAP, 1992). Medical homes encompass accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care (AAP, 1992; AAP, 2002). Accessibility includes care in children's communities, accepts all insurance types and changes, accessible by public transportation, direct contact with physicians when needed, and meets American with Disabilities Act (ADA) accessibility requirements (AAP, 2002). Continuous care consists of the same healthcare provider throughout the lifespan (i.e., from infancy to young adulthood), facilitated transitions using health assessments and counseling, and assisting with discharge planning from inpatient hospitalizations or other facilities or providers (AAP, 2002). Comprehensive care is provided by well-trained physicians 24 hours a day, 7 days per week. It includes preventative care (e.g., immunizations, developmental screenings, and assessments), health-related supervision, and patient and family education on health-promoting practices (AAP, 2002). Family-centered care is provided by physicians familiar to children and families. Family-centered care is displayed by mutual trust and responsibility, providing clear and unbiased information, keeping families central in care, sharing decision-making, and acknowledging family expertise in children's care (AAP, 2002). Coordinated care shares plans with children, families, and other professionals on the care team. Coordinating care occurs between physicians (i.e., pediatricians, pediatric medical subspecialists, pediatric surgical specialists, and family practitioners) and other professionals, having a central record containing children's medical information, connecting families to resources, making referrals, and coordinating with educational and community services (AAP, 2002). Compassionate care shows concern for children and families and empathy for their feelings and perspectives (AAP, 2002). Culturally-effective care respects different cultural backgrounds, belief systems, customs, and rituals. Families receive verbal and written information in their primary language, which includes using translators or interpreters (AAP, 2002).

Health Care Infrastructure Supporting Families

Medical homes have a responsibility to bridge these services for children to thrive in wherever context they participate (AAP, 2015). This will ease the burden of coordinating and sharing information between systems of care (Shahidullah et al., 2018). Families are precluded from transferring this

information accurately between services systems based on their socioeconomic, educational, or other demographic backgrounds (Litt & McCormick, 2015). One recommendation to reduce family burden and progress towards integrated care is for medical home providers to obtain written consent for direct communication with other service systems (e.g., EI or school settings) or providers helping to manage comorbidities (Shahidullah et al., 2018). Russell and McCloskey (2016) conducted a qualitative study on parents' care perceptions for children with ASD. One theme emerged, "The Medical Home is Only Medical," representing the issue underscoring this dissertation (Russell & McCloskey, 2016, p. 25). Parents visited their children's providers primarily for yearly physicals and viewed their providers' as solely managing their children's physical health. This was reinforced by their perceptions of providers' limited ASD knowledge, resulting in further unmet comprehensive and family-centered care needs (Russell & McCloskey, 2016).

Educational Needs of Children with ASD: Early Intervention (EI) and School-Based Services

Educational services are provided through two pathways for children with ASD: EI through an IFSP or school-based services through public school systems under an IEP (IDEA, 2004). Educational services, in IDEA Part C for early intervention and IDEA Part B for special education in school settings, support the legal right to early identification, evaluation, eligibility, and access to educationally-based services (IDEA, 2004). Children with ASD benefit from services under IDEA Part C (i.e., early intervention) and Part B (i.e., special education programming). Children diagnosed with ASD between 12-24 months, or younger (APA, 2013), if severe, precipitates educational intervention to increase developmental outcomes. Children with ASD ages 3 through 5 accounted for 10.1% of children served under IDEA Part C, while children ages 6 through 21 accounted for 9.6% (Office of Special Education and Rehabilitative Services, 2018).

Early Intervention

The IDEA Part C (IDEA, 2004) focuses on infants and toddlers, through age 2, and their families. States establish their own eligibility criteria for EI for children with conditions affecting typical development, those diagnosed with a developmental delay, and children at risk. Access to early

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intervention for children younger than 3 years is intended to decrease the risk of developmental delays affecting developmental outcomes later in life (Kerr, Steffen, & Kotch, 2013). Children served under an IFSP receive services targeting their developmental, social, cognitive, and health-related needs. Health-related services under an IFSP can include vision, hearing, nursing, medical services for diagnostic evaluation, or skilled therapies. Families are part of the IFSP team, collaborating with trained service professionals from a variety of disciplines, in IFSP development ensuring the plan's responsiveness to individual children and families' needs.

Special Education

After age 3, children and adolescents with ASD spend a significant portion of their lives in educational settings within public school systems receiving school-based services through individualized education programs (IEP) under IDEA Part B (IDEA, 2004). A student's identification as "a child with a disability" is determined by the IEP team. The student must demonstrate impairments affecting their educational performance requiring specialized instruction and related services to benefit from special education. The IDEA eligibility criteria checklists are used to determine and document whether a student qualifies as a "child with a disability," and children may qualify under one or more of the 11 educational disability categories (e.g., autism, emotional behavioral disability, hearing impairment, speech and language impairment, specific learning disability, etc.) (IDEA, 2004). The IEP document is an education plan, developed by IEP team members composed of students, as appropriate, families/guardians, school staff, and any informed, outside entity with a vested interest in children's school success. One feature of the IEP differing from the IFSP is the opportunity to involve the student in their IEP development, if appropriate, to assure the plan is responsive to the student's goals, priorities, and needs (IDEA, 2004).

For students with an IDEA-qualifying disability, services encompass specialized instruction, related services, and curricular or environmental modifications or accommodations to their educational programming. Each IEP includes information about children's academic progress, progress in special education and related services, annual goals, inclusion with children without disabilities in the general education curriculum, and how progress will be measured in the general education curriculum and annual

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goals. The IEP is updated annually at minimum. As progress towards IEP goals and eligibility for special education is reassessed, services and supports in the IEP can be modified. Students' annual IEP goals commonly focus on near-term outcomes related to the child's development and educational progress aligned with grade level, state-specific standards. With the IDEA requirement that state and local education agencies identify, locate, and evaluate all children needing educational support services (IDEA, 2004), school systems can be an entry point for children and families to connect with more localized disability-related services and resources. Schools deliver disability-related services consisting of educational evaluations and determination of eligibility for an IDEA-qualifying disability, specialized instruction, school-based therapeutic services, health services, when needed, and transition services for a free and appropriate public education (FAPE) in least restrictive environments (LRE) (IDEA, 2004).

The Interface Between the Medical Home and Educational Systems

The Medical Home on Educational Systems

Medical home physicians and their role in EI, preschools, and school settings has been described (Lipkin et al., 2015; AAP, 2001, AAP, 2007a, AAP, 2007b; AAP, 1999; AAP, 2015; Adams, Tapia, & The Council on Children with Disabilities, 2013). Physicians are responsible for coordinating care with multiple providers, in EI or school systems, to meet children's developmental and educational needs within the medical home.

Early Intervention. Early intervention (EI) has positive health, functional, and economical benefits for children with ASD (Noyes-Grosser et al., 2018). Given the strong association between EI and developmental outcomes for children with or at risk for disabilities, evidence supporting early intervention calls upon pediatric medical homes to collaborate with EI programs (Adams, Tapia, & The Council on Children with Disabilities, 2013). Having a medical home provides pathways to developmental surveillance, screening, early identification, and referral to educational services (i.e., EI) (AAP, 2006). When families have developmental concerns, pediatricians are the initial point of contact if they are including developmental surveillance during every well-child preventative care visit (AAP, 2006). Pediatricians also conduct periodic developmental and ASD-specific screening per the AAP-

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recommended schedules, or if developmental concerns arise during surveillance, to increase early identification and access to EI services (AAP, 2006). Validated ASD screening tools, such as the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up™ (M-CHAT-R/F) should be administered during well-child visits for children between 16 to 30 months to determine if further ASD evaluation is needed (Robins et al., 2014). Pediatricians make two key referrals after concerns about a possible ASD are discussed with families or after positive screen scores (Ellerbeck, Smith, & Courtemanche, 2015). These include a referral to pediatric subspecialists (e.g., developmental-behavioral pediatricians, neurologists, psychiatrists, or psychologists) for comprehensive ASD evaluations and to children's educational teams (e.g., EI) for determining eligibility for EI services under an IFSP (Ellerbeck, Smith, & Courtemanche, 2015). Pediatricians initiate the EI referral process for children under age 3 and collaborate with families and EI professionals in IFSP development (AAP, 2001). The IFSP is a legal document that describes services families need to support their children's development (IDEA, 2004).

School-Based Services. All children have the right to a free and appropriate public education (FAPE) despite the bases of disability under IDEA (IDEA, 2004). Access to school-based special education services under IDEA Part B supports their right to FAPE in public school systems. Children with IDEA-qualifying disabilities, between ages 3 to 18 or 21, receive special education services through an IEP. The IEP is a legal document that contains information about their specially designed instruction, supplementary aids and services for learning in least restrictive environments (LRE), and related services to benefit from specially designed instruction (e.g. school-based therapeutic services, transportation, and transition services) (IDEA, 2004).

Educational referrals for children after age 3 with concerns for possible ASD occurs within public school systems (IDEA, 2004). Best-practice or gold standard ASD diagnostic evaluation tools (e.g., Autism Diagnostic Interview-Revised (ADI-R), Autism Diagnostic Observation Schedule-Second Edition (ADOS-2), Childhood Autism Rating Scale-Second Edition (CARS-2)) and cognitive and adaptive measures (e.g., Child Behavior Checklist (CBCL), Vineland Adaptive Behavior Scales-Third Edition) can

be coordinated between medical home providers and other information sources (e.g., parent interviews, classroom staff, other educational personnel) (Shahidullah et al., 2018). For example, pediatricians may use the MCHAT-R/F for ASD screening, while school settings may use the Gilliam Autism Rating Scale or the CARS-2. Behavioral measures differ between medical and educational settings; medical settings may use the CBCL, while schools may use the Behavior Assessment System for Children (BASC) (Shahidullah et al., 2018). The range of ASD evaluation measures suggests pediatricians become familiar with various measures and their purpose in ASD diagnostic evaluations across settings (Shahidullah et al., 2018).

Barriers to Coordination Between Medical and Educational Settings

System Priorities

Barriers to cross-sector collaboration include redefining services, policies, and measuring programs' impact on the health and health outcomes of those they serve (Malin et al., 2018). The challenges are exacerbated by territorial issues and competition for recognition or financial resources. This task complicates engaging organizations who perceive "…upstream approaches as time-consuming, amorphous, and impractical" (Malin et al., 2018, p.227). Differing ASD definitions, frameworks, and professionals (e.g., clinicians, researchers, agencies, service providers, and people with disabilities) challenge consensus among systems that speak different "languages" (Dunn et al., 2016). Medical home pediatricians are governed by AAP- defined practice parameters, reimbursement parties, and organizational guidelines where they practice. Early intervention and special education programs are regulated by IDEA Parts B and C. Funding streams (i.e., public/private insurance, federal/state-level funding) differ from medical providers (e.g., physicians, specialists, nurses, and other health-related professionals outside of education) (National Academies of Science, 2018).

Skilled and Knowledgeable Workforce. Shah, Kunnavakkam, and Msall (2013) surveyed 369 pediatricians on their knowledge, attitudes, and practice patterns, that limit comprehensive care for children with educational needs. Pediatricians' reported their belief that prescriptions were required for IEP development, and children with genetic conditions were automatically eligible for an IEP. Fourteen

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percent of pediatricians reported feeling confident about which children required special education services, and 18% reported they were confident providing parental counseling on the IEP process. Eighty-five percent agreed they should have an active role to facilitate access special education services, but less than 50% reported they should assist with IEP development. Barriers to comprehensive care were attributed to inadequate training on special education and IEP processes, insufficient reimbursement to address special education issues, limited access to resources, and restricted appointment times for special education issues. Consultative services provided by physicians are not reimbursed by public schools per IDEA mandates or by most health insurances (AAP, 2007a).

Measurement Standards. It is difficult to capture ASD-related needs when health outcomes and disparities vary between the entities conducting the measures, what is being measured, and their purposes. This problem is posed in terms of essentially estimating the magnitude of the problem for resource allocation and program development, and it is illustrated by the differences in ASD prevalence estimates. Disability prevalence estimates in the U.S. differ based on disability definitions for national data collection (e.g., National Survey of Children's Health (NSCH)) and federal program characteristics (e.g., Supplemental Security Income (SSI), Social Security Administration (SSA), Maternal and Child Health Bureau (MCHB), and IDEA) (National Academies of Science, 2018). This is evident in prevalence estimates published by CDC's ADDM Network (Maenner et al., 2020) and data from the 2016 National Survey of Children's Health (NSCH) (Kogan et al., 2018). Maenner et al., (2020) reported 1 in 54 U.S. children has an ASD. Data from the 11 CDC's ADDM surveillance states (i.e., Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin) were used to estimate ASD prevalence in 8-year-old children residing in these states using 2016 data (Maenner et al., 2020). Records were reviewed from multiple sources (e.g., medical and educational records) (Maenner et al., 2020). Children met ASD surveillance definitions if: behaviors were consistent with DSM-5 diagnostic criteria (Maenner et al., 2020).

Using population-based data, Kogan et al. (2018) reported 1 in 40 U.S. children ages 3 to 17 had a parent-reported diagnosis of ASD using 2016 NSCH data. During the 2016 NSCH data collection

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period, parents were asked, "Has a doctor or other health care provider ever told you that this child has Autism or Autism Spectrum Disorder (ASD)? Include diagnoses of Asperger's Disorder or Pervasive Developmental Disorder (PDD)." (U.S Census Bureau, 2016). The 2016 NSCH ASD questions were consistent with DSM-5 diagnostic criteria (Kogan et al., 2018). Affirmative responses were followed by asking if the conditions were current. Their analyses included children whose parents were "ever" told their child had ASD and children reported to have "current" ASD. Zablotsky et al. (2015) used the 2014 National Health Interview Survey (NHIS) to examine ASD prevalence in U.S children between ages 2-17. The NHIS is a cross-sectional, in-person survey that measures different health topics (e.g., medical conditions, health insurance, doctor's office visits, physical activity, health behaviors) conducted by the U.S. Census Bureau on behalf of the National Center for Health Statistics (NCHS). Zablotsky et al. (2015) reported 1 in 45 children were reported to have ASD using 2014 NHIS data. Their analyses included children whose parents reported they were "ever" told their child had ASD (i.e., "Has a doctor or health professional ever told you that [fill: S.C. name] had... Autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?") Karpur et al. (2019) conducted on a study using the 2016 NSCH to examine unmet health care needs in children with ASD compared to those without disabilities. They, too, used the "ever" told their child had ASD variable for analyses. Slight differences in ASD prevalence estimates were found between Kogan et al. (2018) using the 2016 NSCH (i.e., 1 in 40) and Zablotsky et al. (2015) using the 2014 NHIS (i.e., 1 in 45). Their ASD survey measures using questions including "ever" and "current" (Kogan et al., 2018) compared to "ever" (Zablotsky et al., 2015) demonstrates the variability in capturing the number of children reported to have ASD. The measurement of ASD in these survey designs are synonymous with the classical problem observed in federal program definitions.

Barriers to Coordination with Early Intervention

Children with ASD and their families face barriers to EI services for many reasons. Lack of communication and miscommunication about developmental concerns (Jimenez et al., 2012), infrastructural barriers (e.g., adequate visit times and reimbursement), families' understanding of

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developmental screening materials, and families' follow through after EI referrals were made (Jimenez et al., 2014) constitute these barriers. Race/ethnicity, culturally diverse backgrounds, and lower socioeconomic statuses (SES) have been linked to gaps in EI participation (Hyman and Johnson, 2012; Feinberg et al., 2011; Adams, Tapia, & The Council on Children with Disabilities, 2013).

Barriers to Coordination with School-Based Settings

Multiple entry points. Comprehensive, diagnostic ASD evaluations is one dimension that may precipitate initiating and determining children's eligibility for educational supports in the school setting. Clinicians in ASD diagnostics use the Diagnostic and Statistical Manual of Mental Disorders. Fifth Edition (DSM-5) to determine whether a child meets criteria for an ASD diagnosis (American Psychiatric Association (APA), 2013). ASD is a neurodevelopmental disorder with onset in early development (i.e., before children begin school) (APA, 2013). Children with ASD demonstrate impairments in learning, executive functioning, global developmental delay, and communication and social functioning (APA, 2013). Four diagnostic criteria (A, B, C, and D) include: impairments in social communication and interaction, restricted and repetitive behavior, interests, or activities, symptoms present early in childhood, and affect daily functioning. Specifiers classify ASD symptom severity (APA, 2013). Common co-morbidities include intellectual disabilities (Matson & Shoemaker, 2009), anxiety (White et al., 2009), attention deficits (Murray, 2010), eating and feeding difficulties (Vissoker, Latzer, & Gal, 2015), and motor skill impairments (Whyatt & Craig, 2012; Lloyd, MacDonald, & Lord, 2013). Kulage, Smaldone, and Cohn (2014) examined how changes to the DSM-5 ASD criteria may potentially affect the number of individuals diagnosed with ASD and service access. Their systematic review reported potential decreases in ASD diagnoses under DSM-5, especially those with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) under DSM-IV-TR. This has significant implications for accessing services and supports through state programs, schools, and large funding sources (i.e., Medicaid) needed by those without ASD diagnoses under DSM-5 (Kulage, Smaldone, & Cohn, 2014; Lobar, 2016).

One pathway to expedite access to diagnostic services and specialized educational and related services is through public school systems (Maenner et al., 2020). This method attempts to bypass some

of the common problems in access to diagnoses within the medical realm. This is not a straightforward solution and only partially solves the problem with early ASD identification. This approach, however, achieves the primary goal of accelerating identification of children with ASD to allow entry to one type of service system. One point of contention relates to medical ASD diagnoses and the educational ASD disability category. Diagnostic criteria for medical ASD is based on the DSM-5 (APA, 2013). The educational ASD disability criteria and determination of eligibility for special education services is defined by IDEA Part B (IDEA, 2004). The conflict occurs in understanding that children may be eligible for the educational ASD disability category under IDEA through public school systems without having a medical diagnosis of ASD under the DSM-5 (Ellerbeck, Smith, & Courtemanche, 2015). Children who receive related services (e.g., occupational therapy, speech therapy, and physical therapy) under an IEP receive these services to benefit from special education. This is a challenge for healthcare professionals and families because the prescription and use of specialized therapies in medical settings differs from educational systems (Dunn, 2016).

The AAP asserted their position in the medical home in the context of educational services with physicians leading the coordination between the medical home and educational settings (Lipkin et al., 2015; AAP, 2000, AAP, 2001, AAP, 2007a, AAP, 2007b; AAP, 1999; AAP, 2015; Adams, Tapia, & The Council on Children with Disabilities, 2013). With evidence strongly supporting the efficacy of EI, pediatric medical homes are called to assertively build collaborative relationships with IDEA Part C programs (Adams & Tapia, 2013), as in EI services. When families have developmental concerns about their children, pediatricians are the initial point of contact for families to express their concerns. Pediatricians incorporating family-centered, compassionate, comprehensive, and coordinated care in medical homes will listen to families' concerns, validate their concerns presented, and conduct periodic developmental and ASD-specific screening per the AAP recommended screening schedules (AAP, 2006). When developmental delays are suspected, or present, pediatricians make EI referrals for children under age 3 to determine eligibility for EI services. The pediatrician must be familiar with services and resources within the community to initiate the EI referral process and collaborate with families and EI

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professionals in IFSP development (Adams, Tapia, & The Council on Children with Disabilities, 2013). Sociodemographic factors (e.g., lower educational attainment, unemployment, race/ethnicity, culturally diverse backgrounds, and socioeconomic statuses (SES) have been cited as challenges in accessing EI services (Feinberg et al., 2011; Adams, Tapia, & The Council on Children with Disabilities, 2013). School-based system barriers include similar challenges: time, reimbursement, diverse family backgrounds, sociodemographic circumstances, parental procedural safeguards, and collaboration (Sheppard & Vitalone-Raccaro, 2016).

Study Variables

Predisposing Factors

    Child's Sex. According to Chaste et al., (2012), while the cause of differences in ASD prevalence by sex is not well understood, ASD affects males at a ratio of 4:1, showing males have an overall higher risk for the condition. While ASD is less common in females, females with ASD who an accompanying intellectual disability do not have may demonstrate increased social behavior, and less demonstration of repetitive behaviors (Frazier et al., 2014; Lai et al., 2012; Head, McGillivray, & Stokes, 2014; Mandy et al., 2012). While the differences in ASD by sex is still unclear in the literature, this study posits that boys in this survey may have a greater likelihood of access to medical homes and higher likelihood of educational services because of increased ASD identification in males.

    Child's Age. Chronological age is a demographic factor used to determine educational service type. Children ages 3 and under qualify for EI, while school-based services are provided to eligible students ages 3-18 or 21 (IDEA, 2004). Transitions between educational services also occurs for young children with disabilities qualifying for EI services. At age 3, these children transition to the school setting where they may qualify for school-based services until the age 18 or 21. During adolescence, this is a salient period of development when they prepare for transition to adulthood (National Academies of Science, 2018). The IDEA (2004) mandates that for students, beginning no later than age 14, an IEP meeting must include a discussion of transition service needs. By age 16, the student is invited to the IEP meeting and participates in the transition discussion, as able. This is intended to give students with

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disabilities an opportunity to communicate goals for their future (e.g., academic, vocational), perceived challenges and barriers, and identifying supports or services easing the transition from school to work or postsecondary education. During young adulthood, transition from pediatric to adult healthcare providers occurs, and this transition involves a similar, thoughtful planning process and eliciting input from young adults about the care they receive (National Academies of Science, 2018).

Child's Race/Ethnicity. Hinojosa et al. (2016) examined racial/ethnic disparities of school-based services through an IEP for children ages 6-17. Hispanic children in this sample were less likely than Black children to have an IEP compared to White children. Having more family and neighborhood resources and increased health and health care needs was associated with higher odds of having an IEP for Black, Hispanic, and multi-racial children.

It has also been recognized that parental attitudes about childhood disability, intervention, cultural and linguistic barriers, and discrimination may be attributed to the differences in prevalence estimates of ASD by race/ethnicity (Kogan et al., 2009; Magaña et al., 2012). Families from different racial and ethnic backgrounds may experience increased burden because of different intervention programs and strategies conflicting with their culture (Algood, Harris, & Hong, 2013). In addition, families of children from different racial and ethnic backgrounds do have behavioral health concerns, but less frequently receive diagnoses compared to most racial and ethnic groups (National Academies of Science, 2018).

Total Number of Children in Household. This variable measured the number of children who reside household that includes the child with ASD. Karp et al. (2018) conducted a study on access to autism services in families residing in low-resourced communities. Eighty-three percent of this study's sample included mothers. Caregivers who reported having at least one sibling in the household were found to have lower odds of accessing autism services. The caregiving demands associated with children with ASD, and managing additional children in the household, demonstrate the difficulty families face when balancing needs of children with ASD and additional children in the household.

Maternal Health Status. Mothers undertake most of the caregiving responsibilities when raising children with disabilities. Extensive information on caregivers of children with chronic conditions and

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disabilities relates to mothers. They are typically the most knowledgeable about their children's needs and are critical to their children's health and inclusion into familial, educational, and community contexts (Bourke-Taylor et al., 2010). This degree of caregiving is uniquely skilled, but inadequately compensated, if ever. Studies on the psychological impact of caring for children with disabilities have reported positive effects associated with caregiving but have also shed light on the consequences of these role demands including employment loss, stress, fatigue, and physical and mental impairments. (Dodgson et al., 2000). While an estimated 60% of mothers of children without disabilities return to the paid workforce, mothers of children with severe disabilities are less likely to return to their work roles outside of the home (Okumura et al., 2009). The significant amount of time spent caring for children with disabilities limits availability of time and resources for other children or family members. Therefore, reliance on extended family members for assisting with caregiving responsibilities for other children in the family is needed (Reichmann, Corman, & Noonan, 2008). The paramount role of informal caregiving makes mothers with poorer overall health vulnerable to effectively coordinating care with multiple services systems for children with ASD. In one study, time spent caregiving and time pressures related to completing activities were higher for mothers of children with ASD and led to decreased maternal mental health (Sawyer et al., 2010). This role has a significant impact on mothers and families increasing stress, anxiety, depression, and decreased participation in other meaningful life roles outside of caregiving (Fordham et al., 2012; Dykens et al., 2014; Fairthorne, de Klerk, & Leonard, 2015; Da Paz & Wallander, 2017; Magaña et al., 2015; Reed et al., 2016). For children with ASD, self-care skill regression (APA, 2013) or severe sensory reactions to daily activities (e.g., eating, bathing, dressing, and toileting) require that mothers expend more time and energy supporting their performance in these daily activities.

Children with ASD present challenging behaviors affecting the mothering experience and increase their levels of distress associated with problem behaviors (Estes et al., 2009). For younger children with ASD, they can be difficult to socially engage (APA, 2013), impacting the quality of the maternal and child relationship for mothers of children with ASD. Restricted and repetitive behaviors and

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insistence on sameness also limit play repertoires, activities, and interactions within social contexts, such as community-based activities, increasing the environmental presses for children with ASD.

Adult Education Level. Parental educational attainment is one indicator of children's well-being, but lower educational attainment has direct and indirect effects on other sociodemographic factors (e.g., income level and insurance status) posing risks for access to medical home care. Crede et al. (2015) measured the moderating relationship between parents' education and adolescents' academic achievement and life satisfaction. Results of this study showed that maternal educational attainment was a significant moderator of this association for mothers who attained the same or higher levels of education as their children (i.e., at least high school completion). For children with disabilities, maternal educational attainment was significantly associated with receiving more hours per week of services, specifically classroom-based intervention, controlling for ASD symptom severity and children's ages at the time of study enrollment. Mothers with some college education or vocational training were 24% less likely to receive increased classroom-based service hours (i.e., less than 15 hours) compared to 25 hours of classroom-based services for mothers with bachelor's degrees (Nguyen et al., 2016). Realized access was more broadly defined in this study to include government-funded regional centers, public school systems, and private practices and dichotomized into individual (i.e., one-to-one services) (e.g., occupational, physical, or speech therapies, nursing, psychologist, sensory integration therapies, respite care/daycare, social skills, training, etc.) versus classroom-based (i.e., group) services.

Family Structure. Children's family structures were another predictor of *ever* having special education or EI plans where single-parent homes, other family types, or no family reported were associated with significantly lower odds of *ever* having a special education or an EI plan if their care did not meet AAP medical home criteria. Lack of father involvement for non-married mothers of children with ASD has been linked to increased employment and caregiving demands leading to increased parenting stress (Johnson & Simpson, 2013). Mothers reportedly relied on school support, namely school attendance, to support their ability to participate in paid work, and schools that can manage their children's behavior minimizes missed work and leisure opportunities (Johnson & Simpson, 2013).

Enabling Factors

Metropolitan Statistical Area Status. Geographical location has been studied as a barrier to timely diagnosis of ASD ultimately affecting service access (Rosenberg et al., 2011). Additionally, regional variation in educational quality has been examined. Logan and Burdick-Will (2017) examined differences in racial composition and educational outcomes in urban, suburban, and rural elementary (i.e., Kindergarten to 5th grade) schools using data from the 2010-2011 National Center for Education Statistics (NCES). This study found that White children had higher percentages of enrollment in rural schools, where higher percentages of children qualify for free/reduced lunch (i.e., poverty indicator), and had the lowest achievement scores compared to other U.S. areas (i.e., educational disparity). White children attending rural schools have similar outcomes as Hispanic and Black children attending urban schools from a poverty and academic achievement standpoint with the finding presenting a case for the role of geographical location on educational quality.

In the Rosenberg et al. (2011) study, qualification for free/reduced lunch programs in suburban schools were the lowest, compared to urban schools, and the highest percentage was seen in rural schools. Eligibility for free/reduced lunch programs served as a proxy measure for poverty in this study and reflects income disparities by geographical location. Higher percentages of White children in this study attended suburban schools (i.e., approximately 60%), with a slightly higher percentage attending rural schools (i.e., approximately 71%). Higher percentages of Hispanic and Black children attended urban schools, but both racial groups comprised smaller percentages in rural settings. Suburban schools scored higher on statewide achievement testing which is calculated by the percentage of students at the proficiency level for literacy and math, while achievement scores were lowest in urban schools, and comparably lower in rural schools.

Children in rural areas travel long distances to receive needed services. This adds to caregiving responsibilities where families must plan for travel time, take time away from work, other family members, and incur transportation expenses than if services were more closely available where they reside. In rural areas, lack of subspecialty providers and surgeons increases the challenges of obtaining

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urgent medical care requiring families to travel considerable distances from home to access care in metropolitan areas (National Academy of Science, 2018). While hospitals in more metropolitan-based areas include access to trauma centers, they may not always be equipped to provide resources to meet specialized behavioral health needs of children with disabilities. The structure of specialized care (e.g., inpatient, outpatient care) is directed by the care needs within a certain region. Children's hospitals in metropolitan areas may allocate resources to condition-specific practice areas, while more rural programs are challenged by financial constraints and workforce capacity in treating specific childhood disabilities (National Academies of Science, 2018). Limited solutions addressing workforce capacity in rural communities and alternate forms of care (e.g., telehealth) for children with disabilities are contributing factors to worsened health outcomes for children in this geographical region (Robinson et al., 2017; Kelleher & Gardner, 2017).

Insurance Type. Insurance coverage is critical to accessing health care services, such as receiving care in a medical home, regardless of insurance type (National Academies of Science, 2018). Public health insurance programs, such as Medicaid and the Children's Health Insurance Program (CHIP), are important third-party payers for services for low-income families with children with disabilities. Children with ASD and their families must have access to needed health care services, with continuous, adequate, and affordable coverage for needed services, accessing providers, and to decrease financial strain on families (National Academies of Science, 2018). Access to health care services is interrelated with having health insurance, either privately or through public programs. Although provision of certain services is mandated for specific subsets of the population of children with disabilities (e.g., early and periodic screening, diagnostic, and treatment services) for children on Medicaid, there is no legal mandate for provision of healthcare services for all children with disabilities or a centralized regulation system monitoring the occurrence of these activities (National Academies of Science, 2018).

Zickafoose, Gebremariam, and Davis (2012) examined medical home disparities for children by insurance type and state of residence, citing differences in medical home care by insurance type (i.e., public versus private) and state. Children with public insurance were 33-63% less likely to receive

medical home care as compared to those with private insurance being 57-76% more likely to have medical home care. Overall, children with public insurance had lower prevalence of medical home care in all states by 5-34 %. This was perpetuated by children either being school-aged or adolescent, in a minority racial/ethnic group, non-English speaker, having a special health care need, gaps in insurance coverage the prior year, or had a parent with lower educational attainment (i.e., less than or equal to high school education). This was also demonstrated in another study where medical home disparities for children with SHCN were driven by differences in race/ethnicity, non- English speakers, and children who were uninsured or publicly insured compared to those with private insurance (Zickafoose & Davis, 2013).

Income Level. This measure in the 2016/2017 NSCH is based on the poverty level guidelines established by the U.S. Department of Health and Human Services (DHHS) (CAHMI, 2018). Children with ASD commonly experience numerous risk factors producing negative health outcomes. Existing research has found bi-directional relationships with families with children with disabilities; families living in poverty have higher rates of disability and disability affects (i.e., decreases) family's income (National Academies of Science, 2018). The relationship between poverty and poorer child health outcomes has also been investigated (Stein et al., 2010). Children living in poverty are also exposed to other risk factors (e.g., environmental toxins, violence, food insecurity, and inadequate nutrition) (Pulcini et al., 2017), contributing to the development of health conditions and chronic disabilities compared to children living in less stressful environments. Effects of poverty on children and youth's health has become exacerbated by, and associated with, decreased school participation (Houtrow et al., 2012).

Survey Year. The 2016 and 2017 individual year survey included differences in the number of children with ASD. In the 2016 NSCH, the unweighted number of children who reportedly "ever" had ASD was 1,254, while in the 2017 NSCH, there were 606 children who reportedly "ever" had ASD. The political climate during the 2016 presidential administration presented its own unique set of challenges with proposed cuts to public school education where IDEA programs, such as special education for

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students with IDEA-qualifying disabilities, are provided. This may present an even greater challenges for students with ASD and their access and use of special education services under an IEP.

Vulnerability Factor

The behavioral model for vulnerable populations is a revision of the Andersen behavioral model of health services use (Andersen, 1995) that is responsive to vulnerable populations and their ability to access services. The vulnerability domain captures increased hardship that further exacerbates individuals' abilities to access and use services over and above what predisposing, enabling, and need factors contribute health services access and use. Within the traditional predisposing, enabling, and need factors, each of these factors includes a vulnerability aspect (Gelberg, Andersen, & Leake, 2000). The predisposing vulnerability domain includes characteristics such as immigration status, children in foster care, homelessness, safe living conditions, and past criminal behavior. Enabling-vulnerability factors include accessing public benefits (e.g., Supplemental Nutrition Assistance Program (SNAP), challenging or competing needs, and the availability of information that supports or hinders access. Need-vulnerability factors include evaluated need such as genetic predisposition to certain conditions (e.g., diabetes), lifestyle (e.g., Human Immunodeficiency Virus (HIV)), or cultural predispositions (e.g., Sickle cell anemia) (Gelberg, Andersen, & Leake, 2000).

Primary Household Language. This study positioned primary household language as an enabling-vulnerability factor that can increase challenges in accessing and using services for families of children with ASD. Language barriers affect the availability and use of information to make decisions about health or health care. There are disparities in ASD services that serve the Spanish speaking population (Zuckerman et al., 2014; Magaña et al., 2012 et al., 2013;). Additional challenges come into play when ASD services sectors cannot accommodate nor adequately service families that speak neither English nor Spanish. St. Amant et al. (2018) examined racial and ethnic disparities in accessing health care for children with ASD through chart reviews to assess the inclusion of social and communication goals in children's IEPs. Parents whose primary language was English were more likely to have goals related to communication and social skills and were provided more time of direct service provision.

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Language barriers also significantly impact access to needed health services with limited ASD services with Spanish-speaking staff, affecting communication with families, which is a critical component in ASD service provision (Zuckerman et al., 2014), and of receipt of care in a medical home (AAP, 2002). Center-based ASD care for families who speak neither English nor Spanish is also currently lacking (National Academies of Science, 2018). St. Amant et al. (2018) examined children with ASD whose families' primary language was English were compared to families whose primary language was other than English. This study found: 1) families who were primary English speakers were more likely to receive more direct service hours (e.g., applied behavior analysis (ABA), discrete trial training (DTT), behavioral therapy, developmental individual-difference relationship-based (DIR)/floortime, social skills training, and other services involving therapists working directly with their child, excluding occupational or physical therapy) from their state disability program (i.e., the California Department of Disabilities Regional Center), and 2) the inclusion of goals in their children's IEPs targeting social and communication skills, compared with families who were non- primary English speakers (i.e., Spanish, Tagalog, Korean, Cantonese, Arabic, Armenian, Bangladeshi, Indonesian, Taiwanese, and Vietnamese).

Need Factors

ASD Severity. Families of children with ASD expend more financial resources caring for children with ASD because of higher costs of care to address their disability-related needs. Costs of care for children with ASD range from $2.4 million for children with intellectual disability and $1.4 million for children without intellectual disability (CDC, 2016). Special education services and loss of parental productivity comprised most of these costs (Buescher et al., 2014). Loss of parental income is evident as caregivers spend less time in paid work roles, either due to unemployment, underemployment, and less career advancement (e.g., parents forgoing challenging work responsibilities or advancing their education). The immediate and long-term effects of caring for children with disabilities, as in ASD, results in increased expenditures for utilization of resources supporting their academic achievement to reduce impairments associated with their condition (National Academies of Sciences, 2018).

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Age at ASD Diagnosis. Diagnoses of ASD at the age of 2 is considered valid and stable (Kleinman et al., 2008). However, research shows a median age at early ASD diagnoses of 51 months (Maenner et al., 2020), delaying access to interventions and supports, given the advantages widely associated with intervening early. Previous studies demonstrated racial/ethnic disparities in ASD diagnoses between White (non-Hispanic) children and Black (non-Hispanic) and Hispanic children. White children were more likely to receive an ASD diagnosis compared with the latter racial groups. Forty-five percent of White children were also evaluated by 36 months compared to Black (non-Hispanic) (40%) and Hispanic children (39%).

CSHCN Status. Children with SHCN have or are at risk for chronic physical, behavioral, developmental, or emotional conditions requiring health and other services beyond the extent of those for children without disabilities (Farel, 2013). Children with ASD meet one or more of the following criteria based on the functional impact of ASD symptoms and the definition in federal legislation (Farel, 2013). Being a CSHCN, such as children with ASD, represents an evaluated need, and should have access to medical home care with this classifier (Farel, 2013). However, children with ASD have exhibited differential access to medical homes as shown in previous work (Cheak-Zamora & Farmer, 2015; Farmer et al., 2014; Hyman & Johnson, 2012; Chiri & Warfield, 2012; Carbone et al., 2010).

Summary

Children with ASD require access to medical and educational services for improved outcomes throughout their lives. Therefore, using the 2016/2017 NSCH, this study will examine children with a parent-reported condition of ASD in a U.S. representative sample. The Andersen behavioral model of health services use (Andersen, Davidson, & Baumeister, 2013) with an added vulnerability domain (Gelberg, Andersen, & Leake, 2000) theoretically guided this examination.

Chapter 3: Methods

This chapter presents information on the research methods used for this study. It includes a description of the National Survey of Children's Health (NSCH), survey participant characteristics, sampling procedures, the research design, the study's measures and covariates, data diagnostics, and the analytic strategy. The chapter draws from past dissertations using national surveys with complex survey design structures (Benevides, 2014; Ngui, 2003).

Data Sources

The NSCH is a web/mail survey that provides data on the health, well-being, health care access, medical home care, family activities, parental health statuses, learning/school activities, and neighborhood supports for children aged 0-17 living in the U.S. and the District of Columbia (CAHMI, .n.d.). The NSCH was conducted by the U.S. Census Bureau, Associate Director for Demographic Programs, on behalf of the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b).

The 2016/2017 NSCH combined dataset was used to measure whether care that did not meet medical home criteria according to the American Academy of Pediatrics (AAP) was associated with a) *ever* having a special education or early intervention (EI) plan (i.e., potential access) or b) children *not currently* receiving services under one of these plans (i.e., realized access). The 2016/2017 NSCH combined dataset used consolidated information from the 2016 and 2017 NSCH individual survey years. Most of the 2016 and 2017 NSCH survey questions are the same (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). Increased sample sizes in the 2016/2017 NSCH combined dataset allows analysts to use variables with small sample sizes or lower prevalence than those available in individual survey year data (Child and Adolescent Health Measurement Initiative (CAHMI), 2018).

During the 2016 and 2017 NSCH individual survey years, two instruments were administered to obtain the sample. These were the individual year household screener and the age-based, detailed, topical questionnaire.

Household Screener

The household screener was used to identify whether children aged 0-17 years resided in household units in the U.S. and the District of Columbia (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). If there were no children in households, these households were excluded from further data collection. If there were children between ages 0-17 in households, respondents who were familiar with their health or health care responded to the remaining screener questions. The first section of the household screener solicited information about the number of children living or staying at the addresses and their primary household languages.

The second section of the household screener solicited children's demographic information including their first names/initials/nickname, races/ethnicities, ages, sexes, English proficiency, and children with special health care needs (CSHCN) statuses for up to four children, beginning with the youngest child in the household. Households with more than four children were asked to provide children's names, ages, and sexes for a total of 10 children on the household screener. One child from the household was randomly selected as the subject for the age-specific, detailed, topical questionnaire (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b).

Determination of CSHCN Status. Parents completed a CSHCN screener embedded in the 2016 and 2017 NSCH household questionnaires. The five questions for determination of CSHCN status underwent empirical testing (Bethell et al., 2002) and reflects the federal MCHB definition of CSHCN as, "…those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p.138). Children qualified as CSHCN by meeting one or more of the following criteria: the need for prescription medication, elevated service need or use, functional limitations, use of special therapies, or emotional, developmental, or behavioral problems. Each CSHCN screener question included two follow-up questions that required affirmative responses for children to qualify as CSHCN, "If yes, is this…because of ANY medical, behavioral, or

other health condition?" and "If yes, is this a condition that has lasted or is expected to last 12 months or longer?" (McPherson et al., 1998 ; U.S. Census Bureau, 2018a ; U.S. Census Bureau, 2018b).

Topical Questionnaire

The topical questionnaire was administered based on the child's age who was randomly selected as the subject for this questionnaire. Parents were administered one of the three age-specific, detailed, topical questionnaires: 0-5 years, 6-11 years, or 12-17 years (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). The topical questionnaire included several sections that obtained information on children's health, children as infants, health care services (which included medical home care questions), experiences with children's health care providers, health insurance coverage, financial provisions for children's health, learning/school activities, family routines and habits, family health, and respondents' demographic and household information. (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). The 2016/2017 NSCH combined topical questionnaire file (CAHMI, 2019c) was used to select the study's variables, address the research questions, and test the associated hypotheses.

Participant Characteristics

Survey Respondents

A parent or guardian knowledgeable about the health and health care of the selected child was the respondent for the topical questionnaire. For the 2016 NSCH topical questionnaire, 63% of the respondents were either biological, step, foster, or adoptive mothers, 30% were biological, step, foster, or adoptive fathers, and 7% were categorized as other relatives or guardians (e.g., aunt or uncle, relatives, or non-relatives (U.S. Census Bureau, 2018a). For the 2017 NSCH topical questionnaire, 63% were mothers (e.g., biological, step, foster, or adoptive), 29% were fathers (e.g., biological, step, foster, or adoptive), and 6% were other relatives or guardians (U.S. Census Bureau, 2018b).

Children with ASD. The NSCH collects data on numerous children's health conditions (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). The subpopulation for this study were children 0-17 years with ASD. These cases were identified by the 2016 and 2017 NSCH surveys' question, "Has a doctor or other health care provider ever told you that this child has Autism or Autism Spectrum Disorder

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(ASD)? *Include diagnoses of Asperger's Disorder or Pervasive Developmental Disorder (PDD).*" (2016 NSCH, *n*=1,254; 2017 NSCH, *n*=606; 2016/2017 NSCH combined, *n*=1,860) (CAHMI, n.d.). There were additional questions in the 2016 and 2017 NSCH that asked, "If yes, does this child CURRENTLY have the condition?" (2016 NSCH, *n*=1,151; 2017 NSCH, *n*=560; 2016/2017 NSCH combined, *n*=1,711) (CAHMI, n.d.). Parents who were ever told their child had ASD (*n*=1860) were selected as the study's intended sample (APA, 2020), hereafter referred to as children with ASD. This was done to increase the available sample and based on the small difference in the sample size between children who reportedly "ever" and 'currently' had ASD. No changes were made to these survey questions or variables between the 2016 and 2017 NSCH survey years (CAHMI, 2019d).

Sampling Procedures

The 2016 and 2017 NSCH used an address-based sampling frame that obtained household addresses from the U.S. and District of Columbia. The goal was to get an approximately *equal number of addresses* per state for the 2016 NSCH (U.S. Census Bureau, 2018a), while the 2017 NSCH sampled across states for an *equal number of responses* (i.e., topical questionnaires) per state (U.S. Census Bureau, 2018b). The sampling procedures and weighting plan summarized in the following sections are more thoroughly described in the 2016 NSCH Methodology Report (U.S. Census Bureau, 2018a) and the 2017 NSCH Methodology Report (U.S. Census Bureau, 2018b). Figure 2 displays a flow diagram of the sampling frame for the 2016 and 2017 NSCH.

2016 NSCH Sampling

The Census Master Address File (MAF) and administrative records-based flags identified households with child-presence flags. Households were categorized into two sampling strata. Stratum 1 contained households that were flagged as more likely to have children residing in the household, Supplemental Security Income (SSI) recipients, high poverty block groups, not SSI recipients, and

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Figure 2

Sampling flow for 2016 and 2017 NSCH and ASD Analytic Samples
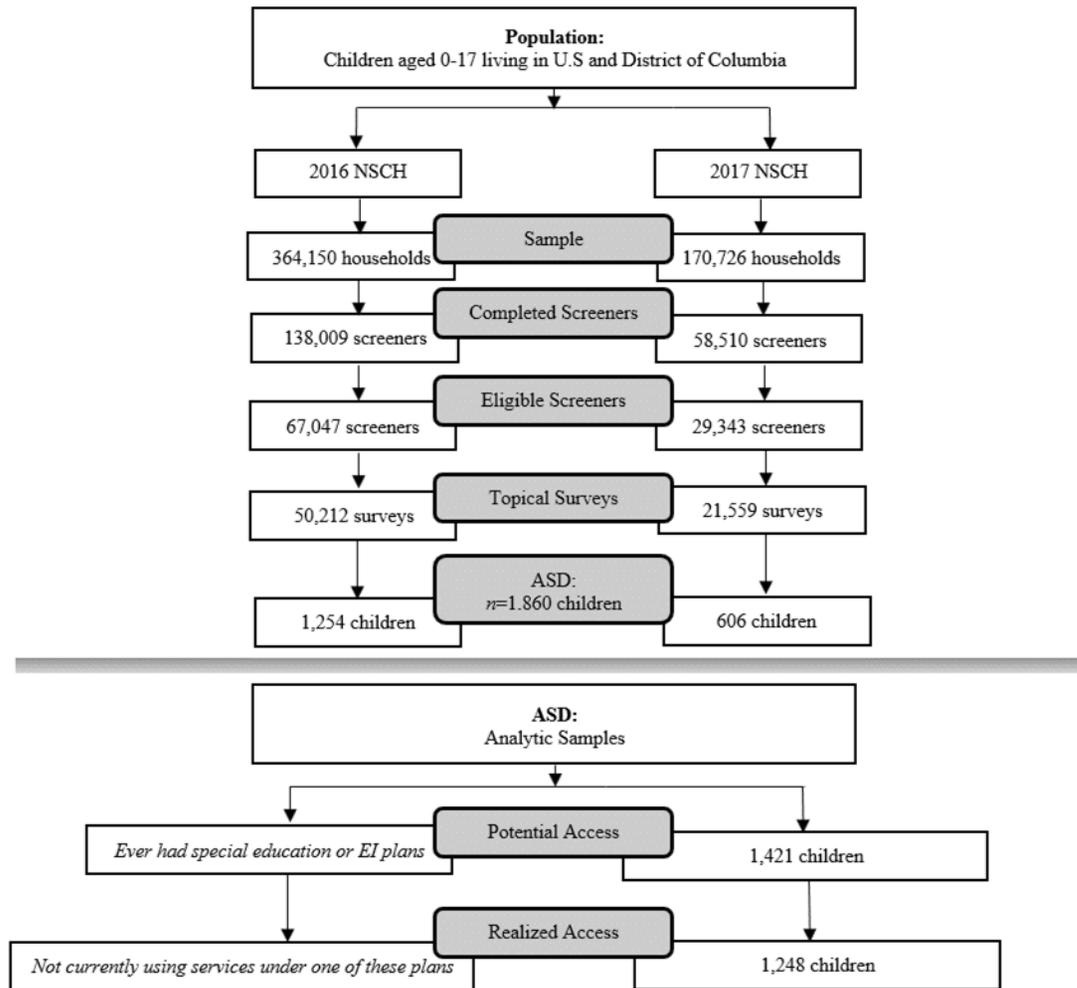
Note. This figure displays the flow of the sampling procedures for the 2016 and 2017 NSCH. The lower portion of this figure displays the analytic samples used for multivariate modeling for potential and realized access (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b; APA, 2020).

remaining households in Stratum 1. Strata 2 included households that were less likely to have children, high poverty block groups, and remaining Stratum 2 households (U.S. Census Bureau, 2018a).

2017 NSCH Sampling

The 2017 NSCH used the Census MAF and 2016 NSCH administrative records-based flags to identify households more likely to include children. Three sampling strata were created for the 2017 NSCH that differed from the two sampling strata created for the 2016 NSCH. Stratum 1 included households that were directly linked to children based on the administrative record-based flags. Strata 2a included households with a higher probability of child-presence flags, while Strata 2b included households with lower probability of child-presence flags (U.S. Census Bureau, 2018b).

2016 and 2017 NSCH Subsampling

To complete one of the three age-based topical questionnaires (i.e., 0-5 years, 6-11 years, and 12-17 years), the sampled household addresses must have been valid, completed the household screener, and reported children residing in the household and the age of at least one child.

Selecting the Sampled Child. Completed household screeners that indicated children resided in the household and the age of at least one child were sampled for one of the three, age-based topical questionnaires. This process began with CSHCN status determination as indicated on the CSHCN screener questions on the household questionnaires. Each household was assigned to one of eight household types (HHTYP) based on the number of children in the household and the CSHCN status (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). Children residing in a sampled household were sorted initially by CSHCN status, their names, and then from youngest to oldest. Each child was assigned a line number on their household's roster. Households with only one child were not subjected to the sorting process and the single child in the household was always selected for the topical questionnaire. Selected line numbers signifying each eligible child on a household's roster were pre-assigned a "% of Probability of Selection" for each HHTYPs. For example, if HHTYP=3, these household contained two children. The number of eligible Non-CSHCN versus CSHCN were 2 (Non-CSHCN) and 0 (CSHCN) or 0 (Non-CSHCN) or 2 (CSHCN). If one of the children were between the ages 0-5, they had a 62%

probability of selection, and the other child had a 38% probability of selection. This was due to the oversampling of children ages 0-5 for the 2016 and 2017 NSCH. If neither child were between the ages of 0-5, they each had a 50% probability of selection (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). If HHTYP=4, these households also contained two children. The number of eligible Non-CSHCN versus CSHCN were 1 (Non-CSHCN) or 1 (CSHCN). The children with CSHCN had a 64% probability of selection compared to the Non-CSHCN with a 36% probability of selection (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). This was due to the oversampling of CSHCN for the 2016 and 2017 NSCH.

Children ages 0-5 were also oversampled due to the underrepresentation of children in this age group in household surveys stemming from their underrepresentation in administrative records (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). The U.S. Census Bureau evaluated the child-presence flags from administrative records used in 2016 sampling processes. The child- presence flags used to create Stratum 1 in 2016 did not perform very well in capturing children ages 0-2. They found that nearly 5 million households with children ages 0-5, out of the approximately 8 million households correctly flagged for children in this age group, were excluded from Stratum 1 in 2016. A secondary reason for oversampling this age group was to reduce age-related biases in response to CSHCN oversampling and older children more reportedly classified as CSHCN (U.S. Census Bureau, 2018a).

For households that used the web-based household screener, the sampled child was selected after the screener responses were electronically submitted. The web-based screener was designed to choose one child and respondents immediately advanced to one of the age-specific topical questionnaires. If households completed the paper-based household screener, the household screener was completed and mailed back to the U.S. Census Bureau. The sampled child was selected in a similar process as the web-based instrument and an age-specific topical questionnaire was mailed back to the household (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b).

Research Design

Retrospective, Cross-Sectional Design

The 2016 NSCH was conducted between June 2016 and February 2017 (U.S. Census Bureau, 2018a), and the 2017 NSCH was conducted between August 2017 and February 2018 (U.S. Census Bureau, 2018b).

Retrospective Design. As of the 2016 NSCH, the NSCH is conducted annually (U.S. Census Bureau, 2017a; U.S. Census Bureau, 2018a). Many of the survey questions about the medical home care components in both the 2016 NSCH and the 2017 NSCH began with, "DURING THE PAST 12 MONTHS…" where respondents were asked to think back over the previous year to consider the child's care.

Cross-sectional Design. Respondents were asked about aspects of their children's health, health care, family health, school, demographic, or neighborhood characteristics at any single point in their own or their children's lives. For example, survey questions such as, "Has this child ever had a special education or an early intervention plan?", "Is this child CURRENTLY receiving services under one of these plans?", "Has a doctor or other health care provider ever told you that this child has Autism or Autism Spectrum Disorder (ASD)?", "Do you have one or more persons you think of as this child's personal doctor or nurse?", or "In general, how is your physical health?" were asked during the individual survey years (CAHMI, n.d.). Figure 3 displays the survey questions and variable names for the dependent and independent variables and covariates taken directly from their corresponding variable lists (U.S. Census Bureau, 2018c; U.S. Census Bureau, 2018d)

Measures and Covariates

Dependent Variable

The primary dependent variable was *potential access* in children with ASD. Potential access increases or decreases the likelihood that individuals will use certain services (Andersen, Davidson, & Baumeister, 2013). In this study, potential access was defined as *ever* having special education or EI plans. Potential access is facilitated by enabling factors under the contextual and individual characteristics of the Andersen Behavioral Model (Andersen, Davidson, & Baumeister, 2013). Respondents were asked,

Figure 3

2016 and 2017 NSCH Variables and Survey Questions
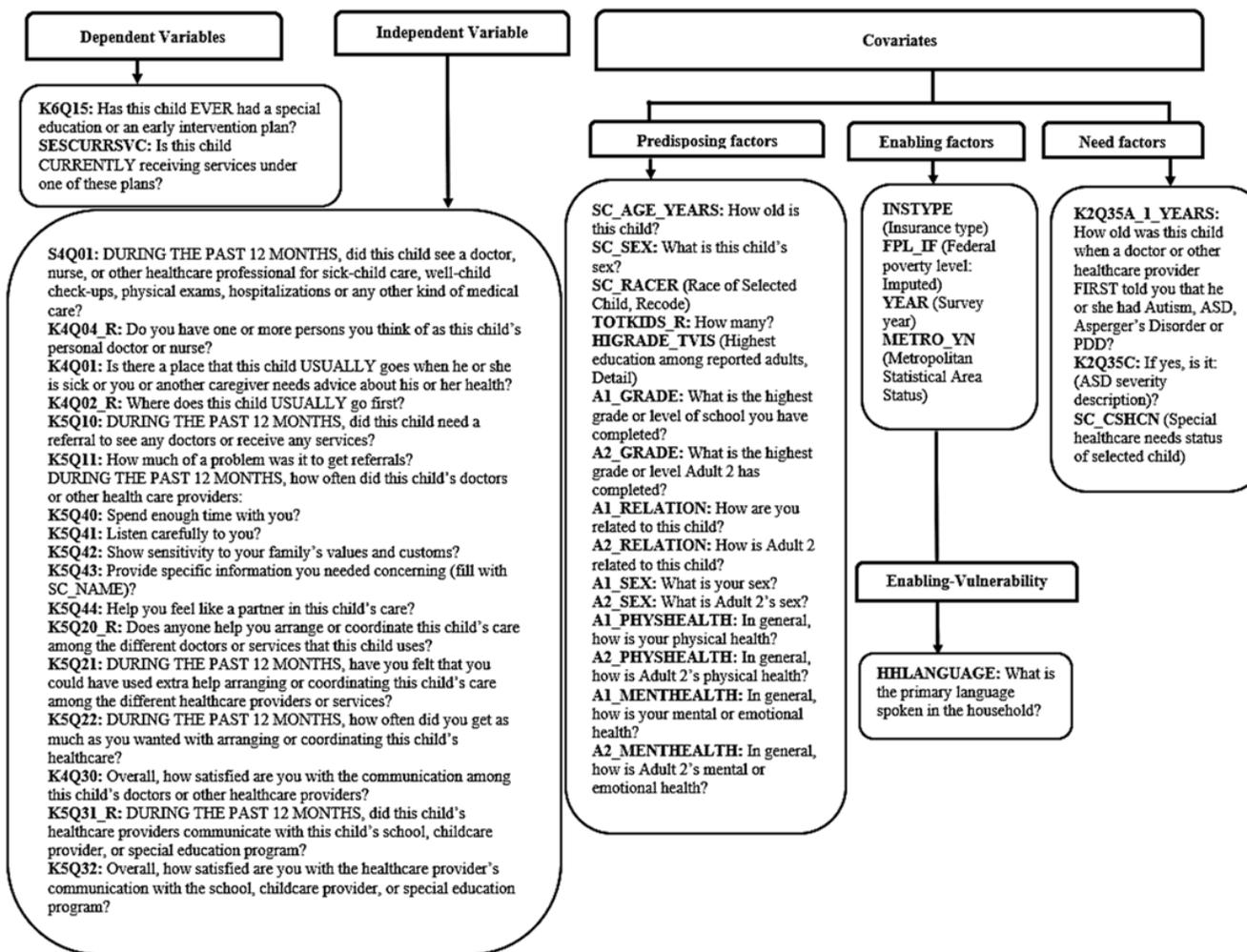
Note. This figure displays the 2016 and 2017 NSCH survey questions corresponding with the study variables (U.S. Census Bureau, 2018c; U.S. Census Bureau, 2018d).

"Has this child ever had a special education or early intervention plan? *Children receiving these services often have an Individualized Family Services Plan (IFSP) or an Individualized Education Plan (IEP)*" (see Figure 3; Variable K6Q15) in the 2016 and 2017 NSCH.

The secondary dependent variable was *realized access* that assessed children who were currently not receiving services under one of these plans. Realized access is the actual use of health services, such as using a physician or hospital-based services (Andersen, Davidson, & Baumeister, 2013). Respondents were asked, "Is this child CURRENTLY receiving services under one of these plans?" (see Figure 3; Variable SESCURRSVC). This variable was dichotomized (i.e., yes/no), and those who responded, "No," were the group of interest.

Independent Variable

The independent variable was the receipt of AAP medical home care (i.e., yes/no). This variable was classified as an enabling factor under the individual characteristics of the Andersen Behavioral Model (Andersen, Davidson, & Baumeister, 2013), and care that did not meet AAP medical home criteria was hypothesized to be associated with decreased access educational services for children with ASD. The survey items that assessed medical home care were asked of all children ages 0-17 years (CAHMI, n.d.). In the combined 2016/2017 NSCH, 16 survey items were used to form a composite measure of medical home care and represented five components: personal doctor or nurse, usual source of sick care, family-centered care, problems getting needed referrals when needed, and effective care coordination when needed (CAHMI, n.d.).

Personal Doctor Or Nurse. The 2016 and 2017 NSCH surveys asked, "Do you have one or more persons you think of as this child's personal doctor or nurse? *A personal doctor or nurse is a health professional who knows this child well and is familiar with this child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant.*" (see Figure 3; Variable K4Q04_R). Respondents indicated, "Yes, have at least one personal doctor or nurse," or "Do not have a personal doctor or nurse," for this medical home component.

Usual Source of Sick Care. The 2016 and 2017 NSCH asked, "Is there a place that this

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child USUALLY goes when he or she is sick or you or another caregiver needs advice about his or her health?" (see Figure 3; Variable K4Q01). If they reported, "Yes," they were asked, "…where does this child USUALLY go first?" The addition of "first" at the end of this question was one of the revisions in the 2017 NSCH. Respondents who indicated they go to any of the following places, 'doctor's office,' 'hospital outpatient department,' 'clinic or health center,' 'retail store clinic or "Minute Clinic,"' 'school (e.g., nurse's office, athletic trainer's office),' 'or some other place' were coded as 'Have usual sources for sick care.' Negative responses to having a place go when children are sick or for advice or going to a 'hospital emergency room' first were coded as, "Do not have usual sources for sick care."

Family-Centered Care. This medical home component was constructed using five intermediate variables that are italicized in the following survey questions: DURING THE PAST 12 MONTHS, how often did doctors or other healthcare providers: spend enough *time* with this child?" (see Figure 3; Variable K5Q40) "…*listen* carefully to you?" (see Figure 3; Variable K5Q41)"…show *sensitivity* to your family's values and customs?" (see Figure 3; Variable K5Q42) "…provide the specific *information* you needed concerning this child?" (see Figure 3; Variable K5Q43) and… "help you feel like a *partner* in this child's care?" (see Figure 3; Variable K5Q44). This medical home component only applied to children in the ASD subpopulation who had at least one healthcare visit during the past 12 months. If respondents indicated, "No," when asked, "DURING THE PAST 12 MONTHS, did this child see a doctor, nurse, or other health care professional for sick-child care, well-child check-ups, physical exams, hospitalizations or any other kind of medical care?" (see Figure 3; Variable S4Q01), these responses were coded as "Did not have a health care visit in the past 12 months" for family-centered care. Respondents rated the frequencies these provider characteristics occurred (i.e., Always, Usually, Sometimes or Never). Combining "Sometimes" and "Never" were based on the low prevalence of these response levels in the ASD subpopulation. "Sometimes" made up 10% or less and "Never" made up less than 2% of the unweighted ASD subpopulation for each of the intermediate family-centered care variables. Parents who responded with "Always," and/or "Usually" to all the intermediate family-centered care variables were coded as "Received family-centered care." Respondents who responded with

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"Sometimes or Never" to all of the intermediate family-centered care variables were coded as "Did not receive family-centered care." Children with reportedly lower frequencies (i.e., "Sometimes or Never") to *at least one* of the intermediate family-centered care variables, and the remaining variables were reportedly higher (i.e., "Always" or "Usually"), were coded as "Did not receive family-centered care." Children with no valid response to *at least one* of the family-centered care intermediate variables, and the remaining intermediate variables had either higher or lower frequencies, were coded as, "Did not receive family-centered care." Children were coded as "Missing" if they had no valid responses to *all* five intermediate family-centered care variables.

Problems Getting Referrals When Needed. This medical home component assessed problems reported by parents when needing referrals. This medical home component only applied to children in the ASD subpopulation who reportedly needed referrals. Parents were asked, "DURING THE PAST 12 MONTHS, did this child need a referral to see any doctor or receive any services?" (see Figure 3; Variable K5Q10). Affirmative responses were followed up with, "How much of a problem was it to get referrals?" Answers to this question were categorized as, "Not a problem," "Small problem," "Big problem," "Logical skip," and "No valid response." For the ASD subpopulation, "Small problem" and "Big problem" were combined into one level, "Had small/big problems getting referrals" based on the distribution of the unweighted subpopulation (i.e., "Small problem" = 9.6%; "Big Problem" = 3.1%). "Logical skip" responses were coded as "Did not need referrals during the past 12 months" when parents indicated, "No," to needing a referral to see any doctor or receive any services in the past 12 months. "No valid response" was coded as "Missing" to needing a referral and problems getting referrals when needed. Other studies used similar coding systems for this medical home component like this current study (Knapp et al., 2012).

Effective Care Coordination When Needed. This medical home component was constructed using three intermediate variables: getting all needed extra help with care coordination when needed, satisfaction with communication among child's doctors and other healthcare providers, and

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satisfaction with communication among child's doctors and school, childcare provider, or special education program.

Getting Needed Extra Help with Care Coordination. This intermediate variable was assessed by asking parents, "Does anyone help you arrange or coordinate this child's care among the different doctors or services that this child uses?" (see Figure 3; Variable K5Q20_R). The responses to this question were coded: "Did not see more than one healthcare provider in the past 12 months," "No," and "Yes." This question was followed up with, "DURING THE PAST 12 MONTHS, have you felt that you could have used extra help arranging or coordinating this child's care among the different healthcare providers?" (see Figure 3; Variable K5Q21) and "If yes, DURING THE PAST 12 MONTHS, how often did you get as much help as you wanted with arranging and coordinating this child's healthcare?" (see Figure 3; Variable K5Q22). Those who did not see more than one healthcare provider in the past 12 months or did not have or need extra help with care coordination were coded as, "Did not see more than one healthcare provider or did not get or need extra help." If parents responded they have someone who helps them arrange and coordinate care, felt they could have used extra help arranging or coordinating care, and they "Usually" got that help, this was coded as, "Got extra help with care coordination and/or extra help when needed." If parents responded they either do or do not have someone who helps them arrange and coordinate care, they could have used extra help arranging or coordinating care, but they "Sometimes or Never" got that help, this was coded as, "Needed extra help/did not get it."

Satisfaction with Communication Between Children's Doctors and Other Health Care Providers. This intermediate variable was assessed by asking, "Overall, how satisfied are you with the communication among this child's doctors and other healthcare providers?" (see Figure 3; Variable K5Q30). If children did not have a healthcare visit or did not see more than one healthcare provider in the past 12 months, they were coded as, "Did not have a healthcare visit or did not see more than one healthcare provider in the past 12 months." Levels of satisfaction were coded as "Very satisfied," and any responses less than "Very Satisfied" were collapsed and coded as "Less than very satisfied." "Less than very satisfied included "Somewhat satisfied," "Somewhat dissatisfied," and "Very

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dissatisfied." This was due to small cell counts. For dissatisfied responses, "Somewhat dissatisfied" and "Very dissatisfied" made up approximately 6% and 2% of the unweighted subpopulation, respectively.

     Satisfaction with Communication Among Children's Doctors and School, Childcare Providers, or Special Education Programs. This intermediate variable was assessed by asking, "DURING THE PAST 12 MONTHS, did this child's healthcare provider communicate with this child's school, childcare provider?" (see Figure 3; Variable K5Q31_R) and "Overall, how satisfied are you with the healthcare provider's communication with the school, childcare provider, or special education program?" (see Figure 3; Variable K5Q32). If parents reported they, "Did not need healthcare provider to communicate with these providers" or "No," to the provider communication question, they were coded as, "No communication needed or did not have healthcare visit in the past 12 months." If parents responded, "Yes," to provider communication with school and childcare professionals, and were "Very Satisfied" with that communication, they were coded as "Very satisfied." If they reported their provider communicated with school and childcare professionals, but were, "Somewhat satisfied," "Somewhat dissatisfied," or "Very dissatisfied," they were coded as, "Less than very satisfied." Collapsing response levels that included all other responses than "Very satisfied" was due to small cell counts in the ASD subpopulation. For dissatisfied responses, "Somewhat dissatisfied" and "Very dissatisfied" made up approximately 1.4% and 0.3% of the unweighted subpopulation, respectively.

  For the final effective care coordination variable, parents who reportedly, "Got help with care coordination and/or extra help when needed" and who were "Very satisfied" with communication among the child's doctor, other healthcare providers, and school and childcare providers, were coded as "Received all needed components of care coordination." Children with no valid response to *at least one* of the effective care coordination intermediate variables, and the remaining intermediate variables had either positive or negative valid responses, were coded as "Did not receive one or more elements of care coordination." Children were coded as "Missing" if they had no valid responses to *all* intermediate effective care coordination variables.

This medical home definition was created to capture the construct of a medical home defined by the AAP, including its seven desirable characteristics and 37 associated features (AAP, 2002). Continuous care is one desirable characteristic that is difficult to capture due to the NSCH's cross-sectional nature, but the remaining attributes are all reflected in the NSCH's medical home measure (Strickland et al., 2011). To qualify for care that meets AAP medical home criteria for this study, all applicable components must be achieved (i.e., having a personal doctor or nurse, having a usual source of sick care, receiving family-centered care, no problems getting referrals when needed, and receiving all elements of effective care coordination, when needed), and were coded as, "Care DOES meet AAP medical home criteria" (AAP, 2002; CAHMI, 2019). Responses including, "Did not have health care visit in the past 12 months," "Did not need referrals during the past 12 months," or "Did not need coordinated care or had less than 2 services during the past 12 months" were also coded as, "Care DOES meet AAP medical home criteria." If there were negative responses to *at least one or more* of the medical home components, and the remaining components were rated positively, these were coded as, "Care DOES NOT meet AAP medical home criteria." Children's care also qualified as, "Care DOES NOT meet AAP medical home criteria" if there were missing responses to one medical home component but had positive or negative valid responses to the remaining components. Lacking one or more criteria, regardless of missingness, still does not meet AAP criteria. This coding decision is consistent with a strict definition of a medical home set forth by the AAP. Children with no valid responses to *all* the medical home components were coded as, "Missing" for this variable.

Covariates

The predisposing, enabling, enabling-vulnerability, and need factors were based on the Andersen Behavioral Model of Health Services Use (Andersen, 1995; Andersen, Davidson, & Baumeister, 2013) and the vulnerability domain (Gelberg, Andersen, & Leake, 2000). The variables and the relationship to the theoretical model are discussed in Chapter 2 and displayed in Figure 1. Figure 4 shows all the study variables used during analyses and the coding structure.

Predisposing Factors

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Figure 4

Coding Scheme for Study Variables

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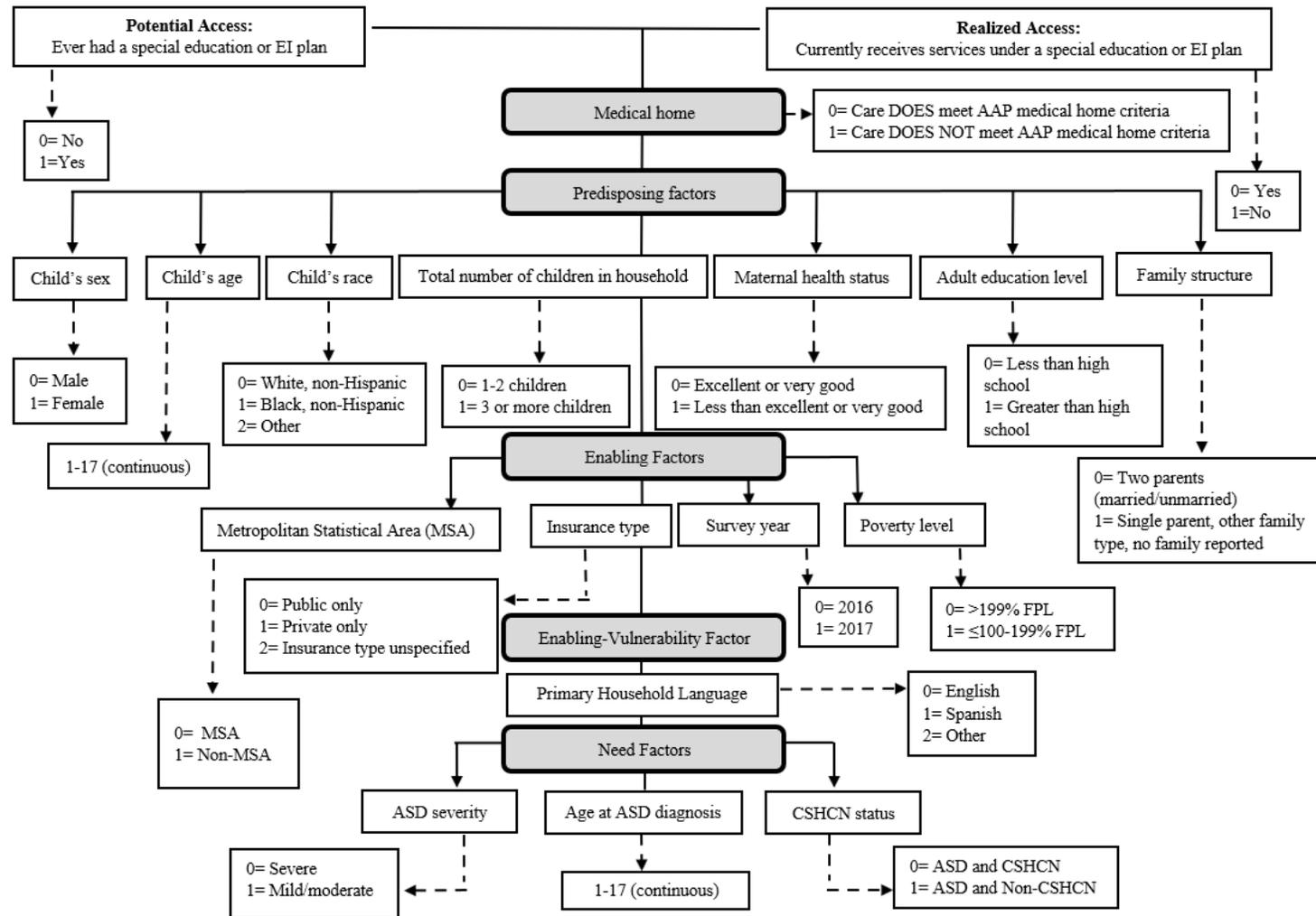
Note. This figure displays the levels of each variable used in multivariate analyses for *ever* having and *not currently* receiving services under special education or EI plans.

Child's Sex. Children's sexes were dichotomized where "Males" were the reference group and compared to "Females."

Child's Age. Children's ages were treated as a continuous variable that represented children's chronological ages in years.

Child's Race/Ethnicity. This variable was cloned from the recoded race/ethnicities variable where 1 "White alone," 2 "Black or African American alone," and 3 "Other." For this study, the coding was changed to 0 "White, Non-Hispanic," 1 "Black, Non-Hispanic," and 2 "Other." In the detailed children's race/ethnicity variable, the "Other" category included children who were American Indian or Alaska Native alone, Asian alone, Native Hawaiian or Other Pacific Islander alone, some other race/ethnicity alone, or two or more races/ethnicities. For the races/ethnicities included in the 'other' category, the unweighted distribution was 16.5% for these races/ethnicities combined.

Total Children in Households. The original variable coded the number of children in households as "1," "2," "3," or "4+." Based on preliminary model testing, families with 3 children were statistically significant in adjusted models predicting *ever* having special education or EI plans. Therefore, levels "3" and "4+" were combined and coded as "3 or more children."

Maternal Health Status. Overall maternal health status began with determining that Adult 1 or Adult 2 were the selected children's biological, foster, or adoptive mother. The maternal physical and mental health status variables were created based on the mothers' responses to their perceptions of their physical and mental health: "Excellent," "Very good," "Good," "Fair," and "Poor." These levels were recoded as "Excellent/very good," "Good," and "Fair/poor." "Fair/poor" were initially combined based on lower prevalence of responses in these categories. Based on preliminary model testing, mothers with "fair/poor" health status were statistically significant in adjusted models predicting *ever* having special education or EI plans. Therefore, this variable was dichotomized as "Excellent/Very Good" and "Less than Excellent/Very Good" that included the levels, "Good," and "Fair/Poor." Any other family members who were not reported as children's biological, foster, or adoptive mothers were excluded from variable coding.

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Adult Education Level. The survey question soliciting information on adults' education level (i.e., Adult 1 and/or Adult 2) changed slightly from the 2016 to the 2017 NSCH. In 2016, respondents were asked, "What is the highest grade or year of school you have completed?" (U.S. Census Bureau, 2018c). In 2017, respondents were asked, "What is the highest grade or level of school you have completed?" (U.S. Census Bureau, 2018d). Highest education level among reported adults was initially categorized as "Less than high school," "High school (i.e., including vocational, trade, or business school)," "Some college or associate degree," and "College degree or higher." Adults with less than high school education and high school education comprised 2.63% and 13.87% of the unweighted ASD subpopulation (*n*=1,860), respectively. Therefore, highest education level among reported adults was coded as "Less than high school," which included those with less than high school and high school education, and "Greater than high school" for those with college or associate degrees and college degrees or higher.

Family Structure. Family structure was dichotomized as "Two parents, married or unmarried" and "Single parent, other family type, or no family reported." Unmarried, two parent households comprised approximately 7% of the unweighted ASD subpopulation. Single parent, other family type, and no family reported were combined in one category based on the low percentages of families within these distinct levels.

Enabling Factors

Metropolitan Statistical Area (MSA). The MSA variable was cloned from the original variable in the dataset and "MSA" served as the reference and compared to "Non-MSA." MSA status is not reported for some states. Small geographic regions with a child population of less than 100,000 were "Suppressed for Confidentiality" to protect respondents' confidentiality (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b). The "Suppressed for Confidentiality" level of the MSA variable was dropped for analyses. The MSA variable was removed prior to multivariate analyses.

Insurance Type. In the 2016 NSCH, insurance type was categorized as: "Public only (e.g., government assistance)," "Private only (e.g., privately purchased, including through ACA marketplace, through employer, or TRICARE)," "Private and Public," "Insurance type unspecified," and "Not insured, or only insured through Indian Health Service or a religious health share." In the 2017 NSCH, the level, "Not insured or only insured through Indian Health Service or a religious health share" was changed to "Not insured." (U.S. Census Bureau, 2018d). Insurance type was recoded and children with private insurance were the reference group. Children with a combination of public and private and public insurance only were combined since children can have lapses or inconsistent private insurance coverage for a variety of reasons (e.g., employment changes, cancellation from overdue premiums, unaffordable coverage, inadequate benefits, inadequate health care provider choices, or application/renewal problems) (U.S. Census Bureau, 2018c; U.S. Census Bureau, 2018d). Therefore, they may rely on public insurance during insurance coverage lapses. Children whose unspecified insurance types made up 0.78% of the unweighted ASD subpopulation and were combined with uninsured children based on the subpopulation's distribution.

Income Level. Household federal poverty level (FPL) was based on survey responses about families' incomes. In the 2016 NSCH, the poverty level variable had 18.56% of missingness and 16.03% in the 2017 NSCH. The 2016/2017 NSCH combined dataset included an imputed value from the 2016 and 2017 data files (FPL_I1) to generate the poverty level variable (CAHMI, 2019). The original poverty level categories were based on the Department of Health and Human Services (DHHS) guidelines: "0-99% FPL," "100-199% FPL," "200-399% FPL," and "400% or greater FPL." Based on preliminary model testing, households in the 100-199% FPL category were statistically significant in adjusted models predicting *ever* having special education or EI plans. Therefore, income level was dichotomized as "≤199% FPL" (i.e., 0-99% FPL and 100-199% FPL) and ">199% FPL" (i.e., 200-399% and 400% or greater FPL).

Survey Year. This variable was cloned from the original survey year variable with "2016" as the reference year compared to "2017."

Enabling-Vulnerability Factor

Primary Household Language. This variable was cloned from the original primary household language variable and coded as "English" as the reference compared to "Spanish" and "Other."

Need Factors

ASD Severity. ASD severity was originally coded as, "Mild," "Moderate," or "Severe." ASD severity level was recoded where "Severe" was the reference group compared to children with 'Mild/Moderate' ASD severity. This was done to isolate the effects of severe ASD on service utilization and the lower prevalence of severe ASD (i.e., 9.25%) in the ASD subpopulation.

Age at ASD Diagnoses. Children's ages at ASD diagnoses were treated as a continuous variable that represented their ages at ASD diagnoses in years. In the 2016 NSCH, the age ranges included 1-16. In the 2017 NSCH, the age ranges included 1-15 or older (U.S. Census Bureau, 2019e).

CSHCN Status. This variable was created to separate children with ASD who met CSHCN criteria on the CSHCN screener compared to children with ASD who did not meet criteria. Children with "ASD and a CSHCN" were coded as 0 and 1 for "ASD but not CSHCN." This was done to examine the contribution of CSHCN status to predicting ever or *not currently* receiving services under special education or EI plans. Many children with ASD meet one or more of the CSHCN criteria. Disaggregating children with ASD who were not CSHCN may provide a case for the benefits of CSHCN classification in accessing services for children with ASD.

Statistical Precision

Confidence Intervals

A confidence interval (CI) is a measure of statistical precision and provides the upper and lower limits where the "true" population value lies when calculating sample estimates. CI width provides information on estimates' precision, with narrower CI bands indicative of better statistical precision. The 95% CI was used to measure the probability that the CI ranges include the true population value for the parameter estimates (CAHMI, 2017). The U.S. Census Bureau recommended presenting statistics

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obtained with sample sizes or unweighted denominators of 30 or higher for better statistical precision (U.S. Census Bureau, 2019a; U.S. Census Bureau, 2019b).

Sample Sizes

A CI is influenced by sample size, with larger sample sizes increasing statistical accuracy and stability of the estimated parameters (U.S. Census Bureau, 2019a; U.S. Census Bureau, 2019b). The U.S. Census Bureau recommended examining CI width exceeding 20 percentage points or 1.2 times the estimate to improve statistical precision (U.S. Census Bureau, 2019a; U.S. Census Bureau, 2019b).

Data Diagnostics

Collinearity

If one predictor variable is highly correlated with other predictor variables in regression models, it provides less information about their unique contribution to predicting dependent variables in regression models (Stata, 2017b). In Stata, the `collin` command was used to check for collinearity between predictor variables. Tolerance values lower than 0.1 and a variance inflation factor (VIF) greater than 10 are indicative of high collinearity between predictor variables. VIF for the predictors in this study was 1.15, and tolerance ranged between 0.6-0.9.

Model Fit

Archer and Lemeshow (2006) recommended investigating model fit for complex surveys using the *F*-adjusted mean residual test, the design-adjusted *F*-statistic, and *p*-value. Traditional Goodness-of-Fit tests (GOF) (e.g., Pearson chi-squared (χ^2) test) operate on the premise that the observations were drawn from simple random samples which violates complex survey design characteristics. The Pearson χ^2 test is sensitive to sample size (Archer & Lemeshow, 2006). Using survey data generally includes larger sample sizes and can inflate Type I error (Archer & Lemeshow, 2006). When using the *F*-adjusted mean residual test, good model fit is attained by non-significant *p*-values (i.e., *p*>0.05) (Archer & Lemeshow, 2006). The `estat gof` command that provides the *F*-statistic in Stata, executed after the `svy: logistic` command, does not work with statistical models that call for a `subpop` during model

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testing (Stata, 2017b). One suggestion to circumvent this issue is to use a conditional command (i.e., `if asd==1`) (Heeringa, West, and Berglund, 2017) instead of subpopulation options recommended by the NSCH survey developers (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b).This is feasible if it does not eliminate the complex survey design structure (e.g., strata, PSU, and/or sample weights) that are critical for correct variance estimation (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b).This solution was attempted using the Stata command, `svy: logistic UseEduc i. MedHome2 if asd==1` and led to missing SEs and CIs. This was indicative of this command's failure to account for the complex survey features. Model fit was also checked using another Stata function for estimating the *F*-adjusted mean residual test using `svylogitgof` (Archer, Lemeshow, & Hosmer, 2006). This command is problematic for studies using a subpopulation. The results of the `svylogitgof` command after `svy: logistic` handled all the valid cases in the total population (n=71,811) for estimating the *F*-adjusted mean residual test instead of the cases identified using the `subpop` command.

These two Stata commands are the recommended ways to assess the adequacy of model fit. Herringa, West, and Berglund (2017) cautioned that selected software systems might not have the capacity to provide GOF estimates, which include the issues that emerged when running `estat gof` and `svylogitgof` to assess model fit. In these cases, Herringa, West, and Berglund (2017) recommended running a standard logistic regression model using a weight specifier (Ryan et al., 2015) (e.g., `logistic everiep i. MedHome2 i.Sex childage i. totalkids i.race i.MomHealth i.famstruct i.Insurtype2 i.adulted i.SES1 i.survyear i.PHL i.asdsevere i.cshcn1 ASDAgeDx [pw=fwc_1617]`). This will yield the same ORs obtained with the design-based model using `svy: logistic` (Archer & Lemeshow, 2006). This allowed for an examination of model fit, despite incorrect variance and covariance estimations corresponding with parameter estimates (Herringa, West, and Berglund, 2017). Herringa, West, and Berglund (2017) recommended that analysts evaluate issues with covariate patterns when using Stata's standard logistic regression approach. This included examining CI width and errors when running models that may predict

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perfect failure resulting from very small cell counts or empty cells. During preliminary analyses, the multivariate model predicting *not currently* using services under one of these plans from medical home care and the predisposing factors produced the following error message in Stata, "`2.family != 0 predicts failure perfectly`" and "`2.family dropped and 5 obs not used.`" This also led to missing SEs and CIs. The family structure variable was dichotomized as, "Single parent, other family type, and no parent reported" and "Two parents, married/unmarried" served as the reference. The error was resolved re-running the model with the newly coded family structure variable to predict *not currently* receiving services under one of these plans from medical home care and the predisposing factors. The new family structure variable was included in the model for *ever* having special education or EI plans for consistency between both dependent variables, though the originally coded family structure variable was not problematic for predicting the 'ever' models.

Model Specification Error

The `linktest` was used to detect errors in the independent variables specified in logistic regression models (UCLA, 2017). The `linktest` uses two variables to examine specification error: the linear predicted value (i.e., `_hat`) and the linear predicted value squared (i.e., `_hatsq`). The `_hat` will yield statistically significant values given that it is predicted from the model, but `_hatsq` should produce insignificant values ($p > .05$) if the model has been specified correctly with the predictors factored into the models (UCLA, 2019). Stata's `linktest` command was executed after `svy: logistic` to assess model specification errors. This command was used to check for specification errors in only the fully adjusted models (i.e., Model 5) for both dependent variables. Determining specification error in Model 5 was performed to detect misspecification of the full model containing all the final predisposing, enabling, enabling-vulnerability, and need factors based on the study's theoretical model (Andersen, 1995; Gelberg, Andersen, & Leake, 2000; Andersen, Davidson, & Baumeister, 2013).

Analytic Strategy

Missing Values

The 2016 and 2017 NSCH included missing values for a variety of reasons previously discussed earlier in this chapter. Some information from the geographical region variables (e.g., MSA) is not reported. Child populations of less than 100,000 in specific regions or certain variables or a combination of variables may compromise a geographical region's identity. These values were coded as "Suppressed for Confidentiality" and excluded from analyses (CAHMI, 2019). "Suppressed for Confidentiality" accounted for approximately 32.9% of the unweighted ASD subpopulation.

Estimation Samples

The predisposing, enabling, enabling-vulnerability, and need survey variables (Andersen, 1995; Andersen, Davidson, & Baumeister, 2013; Gelberg, Andersen, & Leake, 2000) included in the regression analyses had missing values. When variables were sequentially added to multivariate logistic regression models, this led to a reduction in the number of cases available. Stata's `subpop` command in the multivariate models allowed for use of an `if` statement (i.e., `subpop if asd==1`). The `subpop` command tells Stata to use the subpopulation of children with ASD (n=1,860) while retaining the entire population of children in the 2016/2017 NSCH topical questionnaire file (*n*=71,811) for correct variance estimation (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b).

Using subpopulations decreases sample sizes and may widen CI ranges that affect statistical precision, especially with lower prevalence conditions like ASD in the NSCH, despite combined survey years (CAHMI, 2017; CAHMI, 2019d). It is crucial to fit statistical models with the same number of cases for test validity (Heeringa, West, and Berglund, 2017; UCLA, 2019). Therefore, estimation samples for each dependent variable (i.e., *ever* had special education or EI plans or *not currently* receiving services under one of these plans) were produced using new sample variables for each dependent variable. Stata's `e(sample)` function coded cases as "1" if the cases were contained within statistical models (i.e., `if asd==1`), and "0" if excluded (i.e., `if asd==0`) (UCLA, 2019).

To establish the estimation sample when predicting *ever* having special education or EI plans, the full multivariate model containing the independent variable (i.e., medical home) and all the predisposing,

enabling, enabling-vulnerability, and need variables were executed in Stata. After running the fully adjusted model, the Stata command, `gen in_asd= e(sample)`, was used to create the analytic sample variable corresponding with this dependent variable, which differed from the intended sample (*n*=1,860) discussed earlier in this chapter (APA, 2020). This resulted in a final analytic subpopulation of 1,421 children with ASD for predicting *ever* having special education or EI plans. The `in_asd` sample variable was included in all multivariate models (i.e., `subpop (if asd==1 & in_asd==1)`) when predicting *ever* having special education or EI plans.

The same procedure described above was used to establish the estimation sample when predicting *not currently* receiving of services under one of these plans. This Stata command, `gen in_asd1= e(sample)`, was used to create the analytic sample variable for this dependent variable. This resulted in a final analytic subpopulation of 1,248 children, differing from the intended sample (*n*=1,860) described earlier (APA, 2020). The `in_asd1` sample variable was included in all multivariate models (i.e., `subpop (if asd==1 & in_asd1==1)`) when predicting *not currently* receiving services under ones of these plans.

Controlling for Complex Survey Design

The 2016 and 2017 NSCH used a complex survey design structure that included stratified sampling, primary sampling units (PSU), and survey weights. After the initial variable preparation in IBM SPSS Statistics 25 (IBM Corp, 2017), the 2016/2017 NSCH SPSS data set was imported into StataIC 15 (StataCorp, 2017a) (i.e., Stata) for univariate, bivariate, and multivariate analyses. Stata is one statistical software recommended because of its ability to account for the complex survey design structure (U.S Census Bureau, 2017a; U.S. Census Bureau, 2018a). Before preliminary hypotheses testing, declaring the survey design in Stata accounted for the complex survey design features when computing odds ratios (ORs), adjusted odds ratios (aORs), and CIs. This began with specifying the strata, PSU, and survey weight variables that were unique to the 2016/2017 NSCH combined topical questionnaire file. Stata's `svyset` command was used to identify the strata, PSU, and survey weight variables corresponding the

2016/2017 NSCH combined topical questionnaire file (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b).

Strata. The strata for the 2016 and 2017 NSCH are discussed earlier in the chapter in the Sampling Procedures section. Stata allowed for one stratum variable when specifying the strata using the `svyset` command, but two strata identifiers, `FIPSST` (i.e., state of residence) and `STRATUM` (i.e., identifies households with children), were included in the 2016/2017 NSCH topical questionnaire file. A multiplicative command, `egen stratacross = group (FIPSST STRATUM)`, was used to create a single stratum variable, `stratacross`, for the strata identifier in analyses (U.S Census Bureau, 2017a; U.S. Census Bureau, 2018a).

Primary Sampling Unit. The primary sampling unit (PSU) variable in the 2016/2017 NSCH topical questionnaire file was `HHID` (i.e., unique household identifier). This variable represented the selected child residing in a household unit for the 2016 or 2017 NSCH topical questionnaire and whose data were included in the combined topical questionnaire file (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b).

Survey Weights. A child weight was assigned to each sampled child in the detailed topical questionnaire files for the individual survey years. The weighting plan began with assigning a base weight for each sampled household address that adjusted for screener nonresponses. Eligible children for the household screener were adjusted to population controls and topical nonresponses for topical questionnaire cases. Final adjustments to the survey weighting process included adjusting states' weighted survey responses to state-specific demographics (e.g., household size, poverty level, adult education level, race/ethnicity, sex, age, and CSHCN status (CAHMI, 2019).

The final weight for surveyed children variable (FWC) corresponding with the 2016/2017 NSCH topical questionnaire file was `fwc_1617` (U.S Census Bureau, 2018a; U.S. Census Bureau, 2018b). Survey weights used during analyses were critical to producing estimates that represent all non-

institutionalized children ages 0-17 in the U.S. and District of Columbia in household units (U.S Census Bureau, 2018a; U.S. Census Bureau, 2018b).

Univariate Analyses

Univariate analyses using Stata's `svy` features were performed to describe the weighted estimation sample characteristics with the predisposing, enabling, enabling-vulnerability, and need factors for each dependent variable. This was performed using the Stata command, `svy, subpop (if asd==1 & in_asd) tab [everiep] [medical home]` or `[covariate]`. The same procedure was carried out for predicting *not currently* receiving services under one of these plans. This was performed using the Stata command, `svy, subpop (if asd==1 & in_asd1) tab [UseEduc] [medical home]` or `[covariate]`.

Bivariate Analyses

Bivariate analyses were performed using Stata's svy features to test the individual associations of the medical home, predisposing, enabling, enabling-vulnerability, and need factors with both dependent variables. This was performed using the Stata command `svy, subpop (if asd==1 & in_asd) tab [everiep] [medical home]` or `[covariate] row col` for predicting *ever* having special education or EI plans. This was performed using the Stata command `svy, subpop (if asd==1 & in_asd1) tab [UseEduc] [medical home]` or `[covariate] row col` for predicting *not currently* receiving services under one of these plans. The *p*-value set for variable inclusion in multivariate models was *p* < .10 to reduce eliminating variables that may be important in predicting the dependent variables (Bursac, Gauss, Williams, & Hosmer, 2008).

Multivariate Analyses

Figure 4 displays the statistical model structure and the variables included in each model. During the iterative process performed during preliminary multivariate model testing, this variable became increasingly problematic as subsequent variables were added to these models. The inclusion of the MSA variable drastically decreased the subpopulation by approximately 50% for both dependent variables. This

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reduction was evaluated by running the fully adjusted models containing all predisposing, enabling, vulnerability, and need factors, including the MSA variable (i.e., Model 5) for both dependent variables. Generating the estimation sample for predicting *ever* having special education or EI plans included 958 children with ASD. The estimation sample for predicting *not currently* receiving services under of these plans included 835 children with ASD. The 2017 NSCH Methodology Report reported that MSAs have a larger core-based statistical area, with higher population density rates of approximately 50,000 in at least one urbanized area (U.S. Census Bureau, 2018b). The surrounding counties have higher social and economic relationships with the core area measured by commuting and employment ties. This variable does not necessarily connote urbanicity or rurality to make inferences about the contribution of geographical regions in accessing educational services in children with ASD. Therefore, MSA was removed for all multivariate models predicting both dependent variables.

Research Questions and Hypotheses

Research Question 1a. Is care that does not meet AAP medical home criteria associated with decreased likelihood of *ever* having special education or EI plans (i.e., potential access) for children with ASD?

Hypothesis 1a. Care that does not meet AAP medical home criteria will decrease the likelihood of *ever* having special education or EI plans for children with ASD.

Rationale. Barriers to aspects of service provision in EI programs and public school systems exist. Research cited included communication between pediatricians and families about developmental concerns and pursuing EI (Jimenez et al., 2012), organizational processes such as time and reimbursement, families' understanding of developmental screening questions delaying EI referral by pediatricians, and families' pursuit of EI referral (Jimenez et al., 2014). Demographic factors, such as race/ethnicity, families from culturally diverse backgrounds, and lower socioeconomic statuses (SES) have also been cited as other reasons for gaps in EI participation (Feinberg, Silverstein, Donahue, & Bliss, 2011; Adams, Tapia, & The Council on Children with Disabilities, 2013). In the school-based realm of service provision for children with ASD, barriers in school-based settings include limited time,

reimbursement, culture and language in working with families from diverse backgrounds, limited access to resources by families (e.g., poverty, lower educational attainment, and unemployment), parental knowledge of what they could receive from school systems, and schools' lack of interest in collaborating (Sheppard & Vitalone-Raccaro, 2016).

Statistical Procedures. This hypothesis was tested using multivariate logistic regression with the medical home variable as the single predictor. The estimates produced using Stata's `svy` features to calculate a weighted, unadjusted OR, p-value of $\alpha \leq .05$ to reduce Type I error, and the 95% CI for the single parameter in the model predicting *ever* having special education or EI plans. In Stata, the test statistic reported was a Student t-statistic, whereas other statistical software may report an equivalent test statistic (e.g., Wald Chi-Square (χ^2)). The t-test statistic's absolute value is the square root of the Wald χ^2 test. (Heeringa, West, and Berglund, 2017).

A separate logistic regression model predicting *not currently* receiving services under one of these plans from the medical home variable was tested. The weighted, unadjusted OR, a p-value of $\alpha \leq .05$, t-test statistic, and the 95% CI was estimated using the medical home variable as the single parameter in the model (Heeringa, West, and Berglund, 2017).

Research Question 1b: Is care that does not meet AAP medical home criteria associated with greater likelihood of with *not currently* receiving services under one of these plans (i.e., realized access) for children with ASD?

Hypothesis 1b. Care that does not meet AAP medical home criteria will be associated with a greater likelihood of *not currently* receiving services under one of these plans for children with ASD.

Rationale. The medical home is a source of support for families of children with ASD to meet the array of medical, developmental, behavioral, social, and emotional needs early in life and once they enter the school setting. Due to the chronic and pervasive nature of the ASD and its impact on typical development, children with ASD benefit from services specified in IDEA Part C and B. Medical home providers are tasked with coordinating and communicating with educational services, such as EI

programs, public school systems, and the different professionals within each setting. The AAP acknowledged the role physicians play as a link between education and health systems, particularly within the medical home (Lipkin et al., 2015; AAP, 2001; AAP, 2007a, AAP, 2007b; AAP, 1999; AAP, 2015; Adams, Tapia, & The Council on Children with Disabilities, 2013).

Statistical Procedures. This hypothesis was tested ~~using binary logistic regression~~ with the medical home variable as the single predictor. The estimates produced using Stata's `svy` features to calculate a weighted, unadjusted OR, *p*-value of $\alpha \leq .05$ to reduce Type I error, and the 95% CI for the single parameter in the model predicting *ever* having special education or EI plans. In Stata, the test statistic reported was a Student t-statistic, whereas other statistical software may report an equivalent test statistic (e.g., Wald Chi-Square (χ^2)). The t-test statistic's absolute value is the square root of the Wald χ^2 test. (Heeringa, West, and Berglund, 2017). A separate logistic regression model predicting *not currently* receiving services under one of these plans from the medical home variable was tested. The weighted, unadjusted OR, a *p*-value of $\alpha \leq .05$, *t*-test statistic, and the 95% CI was estimated using the medical home variable as the single parameter in the model (Heeringa, West, and Berglund, 2017).

Research Question 2a. After controlling for predisposing, enabling, enabling-vulnerability, and need factors, is care that did not meet AAP medical home criteria associated with *ever* having special education or EI plans (i.e., potential access) for children with ASD?

Hypothesis 2a. Predisposing and enabling factors will be more strongly associated with *ever* having special education or EI plans than enabling-vulnerability and need factors for children without care that met AAP medical home criteria.

Rationale. According to Andersen (1968), when individuals have low discretion in health services access and use, predisposing and enabling factors will account for less of the variance in explaining service utilization. This means that when they are given less power to choose, individuals will be mostly driven by need factors to acquire and use health services. When discretion is higher, the variance in service access and use can be explained by predisposing and enabling factors. This means that when they are given more power to choose, individuals will be mostly driven by predisposing and

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enabling factors in service utilization. For families of children with ASD, medical home care, and educational services support the myriad of issues children with ASD present in educational settings. These are non-discretionary demands for families caring for children with ASD.

Statistical Procedures. Stata's `svy` features were used to calculate weighted, unadjusted and adjusted ORs, *p*-values of $\alpha \leq .05$ to reduce Type I error, and the 95% CIs for model parameters predicting *ever* having special education or EI plans. To test this hypothesis, five statistical models were executed.

Model 1 predicted *ever* having special education or EI plans (i.e., potential access) using the medical home variable as the single parameter as tested in Hypothesis 1a. Model 2 included the medical home variable with the addition of the predisposing variables (i.e., child's sex, child's age, child's race/ethnicity, the total children in household, maternal health status, adult education level, and family structure) to predict *ever* having special education or EI plans. Model 3 included the medical home variable, predisposing, and enabling variables (i.e., insurance type, poverty level, and survey year) to predict *ever* having special education or EI plans. Model 4 contained the medical home, predisposing, enabling, and the enabling-vulnerability variable (i.e., primary household language). Model 5 was the fully adjusted model with the medical home, predisposing, enabling, enabling-vulnerability, and need variables (i.e., ASD severity, age at ASD diagnosis, and CSHCN status). The sequential approach to model building tested the contributions of the sets of predisposing, enabling, enabling-vulnerability, and need factors in the Andersen Model of Health Services Use (Andersen, 1995; Andersen, Davidson, & Baumeister, 2013) with the vulnerability domain (Gelberg, Andersen, & Leake, 2000). Stata's `linktest` was performed for Model 5 to check for model specification errors in the fully adjusted model containing all the final study variables for *ever* having special education or EI plans.

Research Question 2b. After controlling for predisposing, enabling, enabling-vulnerability, and need factors, is care that did not meet AAP medical home criteria associated with *not currently* receiving services under one of these plans (i.e., realized access) for children with ASD?

Hypothesis 2b. Predisposing and enabling factors will be more strongly associated with

not currently receiving services under one of these plans than enabling-vulnerability and need factors for children without medical home care per the AAP.

Rationale. This hypothesis is based on the foundational premises of the Andersen Behavioral Model of Health Services Use (Andersen, 1968). Andersen (1968) proposed that need factors will be the significant driver of service utilization when individuals' discretion is low. Therefore, having quality health care in a medical home and educational supports will be driven by need factors (e.g., ASD severity, CSHCN status, and age at ASD diagnoses). The enabling-vulnerability factor, primary household language, was hypothesized to be more strongly associated with service access and use. Existing literature supports language barriers in timely ASD diagnoses, medical home care, and other supports and services for families of children with ASD (St. Amant et al., 2018).

Statistical Procedures. Stata's `svy` features were used to calculate weighted, unadjusted and adjusted ORs, *p*-values of $\alpha \leq .05$ to reduce Type I error, and the 95% CIs for model parameters predicting *not currently* receiving services under one of these plans (i.e., realized access). To test this hypothesis, five statistical models were executed.

Model 1 predicted *not currently* receiving services under one of these plans using the medical home variable as the single parameter as tested in Hypothesis 1b. Model 2 included the medical home variable with the addition of the predisposing variables (i.e., child's sex, child's age, child's race/ethnicity, the total children in households, maternal health status, adult education level, and family structure) to predict *not currently* receiving services under one of these plans. Model 3 included the medical home variable, predisposing, and enabling variables (i.e., insurance type, poverty level, and survey year). Model 4 contained the medical home, predisposing, enabling, and the enabling-vulnerability variable (i.e., primary household language). Model 5 was the fully adjusted model with the medical home, predisposing, enabling, enabling-vulnerability, and need variables (i.e., ASD severity, age at ASD diagnosis, and CSHCN status). The sequential approach to model building tested the contributions of the sets of predisposing, enabling, enabling-vulnerability, and need factors in the Andersen Model of Health Services Use (Andersen, 1995; Andersen, Davidson, & Baumeister, 2013) with the vulnerability domain

(Gelberg, Andersen, & Leake, 2000). Stata's `linktest` was performed for Model 5 to check for model specification errors in the fully adjusted model containing all the final study variables for *not currently* receiving services under one of these plans.

Protection of Human Subjects

This study met the criteria for Exempt Status by the University of Wisconsin-Milwaukee's Institutional Review Board (Appendix B).

Chapter 4: Results

Sample Characteristics

This study examined the association between care that did not meet AAP medical home criteria and *ever* having and *not currently* receiving services under special education or EI plans in children with ASD. Children whose parents responded affirmatively to *ever* being told their children had ASD in the 2016 NSCH or the 2017 NSCH were classified as this study's sample of children with ASD (n=1,860). Analytic samples were created for each dependent variable, *ever* having special education or EI plans (i.e., potential access) and *not currently* receiving services under one of these plans (i.e., realized access), to fit statistical models with the same number of cases for test validity (Heeringa, West, and Berglund, 2017; UCLA, 2019). The final analytic for *ever* having special education plan or EI plans included 1,421 children with ASD. The final analytic sample for *not currently* receiving services under one of these plans included 1,248 children with ASD. *Ever* having special education or EI plans and *not currently* receiving special education services under one of these plans were examined as a function of care that did not meet AAP medical home criteria and predisposing, enabling, enabling-vulnerability, and need factors.

Statistics and Data Analyses

Univariate Analyses

Table 1 displays the weighted distribution of sample characteristics for children with ASD corresponding with *ever* having special education or EI plans, *not currently* receiving services under one of these plans, and the predisposing, enabling, enabling-vulnerability, and need factors (Andersen, Davidson, & Baumeister, 2013; Gelberg, Andersen, & Leake, 2000). For both dependent variables (i.e., *ever* had or *not currently* receiving services under special education or EI plans), approximately 80% of children with ASD did not have care that met AAP medical home criteria. Most of the children were males, White, living in households with 1-2 children, and in two-parent family structures.

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Table 1

Sample Demographic Characteristics

Variable	Ever Had Special Education or EI Plans (n=1,421)			Not Currently Receiving Services Under Special Education or EI Plans (n=1,248)		
	%	95% CI		%	95% CI	
		LL	UL		LL	UL
Medical home						
Meets AAP criteria	19.18	15.61	23.34	19.57	15.79	24
Does NOT meet AAP criteria	80.82	76.66	84.39	80.43	76	84.21
Predisposing Factors						
Child's Sex						
Male	77.18	70.19	82.93	77.76	70.06	83.94
Female	22.82	17.07	29.81	22.24	16.01	29.94
Child's Age (mean, years)	10.5	9.99	11.03	10.3	9.87	10.90
Total Children in Household						
1-2 children	66.34	59.16	72.84	70.58	64.13	76.29
≥3 children	33.66	27.16	40.84	29.42	23.71	35.87
Child's Race						
White	61.82	53.88	69.17	57.73	49.55	65.5
Black	14.38	10.6	19.21	15.59	11.55	20.73
Other	23.8	16.6	32.89	26.68	18.58	36.71
Overall Maternal Health Status						
Excellent or Very Good	48.25	41.12	55.45	50.22	42.94	57.5
< Excellent or Very Good	51.75	44.55	58.88	49.78	42.5	57.06
Family Structure						
Two parents, married/unmarried	77.22	71.84	81.83	78.3	72.88	82.9
Single parent, other, none reported	22.78	18.17	28.16	21.7	17.1	27.12
Enabling Factors						
Insurance Type						
Private	41.36	35.2	47.8	41.94	35.52	48.65
Public	53.5	46.57	60.29	55.35	48.42	62.06
Unspecified	5.14	2.12	11.93	2.71	1.43	5.06
Adult Education Level						
> High School	67.26	59.14	74.46	70.83	62.81	77.74
≤ High School	32.74	25.54	40.86	29.17	22.26	37.19
Poverty Level						
>199% FPL	46.71	40.01	53.53	49.1	41.91	56.33
≤199% FPL	53.29	46.47	59.99	50.9	43.67	58.09
Survey Year						
2016	45.38	38.78	52.14	46.91	39.93	54.02
2017	54.62	47.86	61.22	53.09	45.98	60.07

Table 1

Sample Demographic Characteristics

Variable	Ever Had Special Education or EI Plans (n=1,421)			Not Currently Receiving Services Under Special Education or EI Plans (n=1,248)		
	%	95% CI		%	95% CI	
		LL	UL		LL	UL
Enabling-Vulnerability Factor Primary Household Language						
English	81.77	72.43	88.46	84.5	75.53	90.59
Spanish	15.29	8.86	25.1	12.16	6.49	21.62
Other	2.93	1.49	5.70	3.34	1.66	6.60
Need Factors ASD Severity						
Severe	8.88	6.54	11.95	9.33	6.79	12.71
Mild/Moderate	91.12	88.05	93.46	90.66	87.29	93.21
CSHCN Status						
ASD, CSHCN	91.27	85.45	94.9	93.98	91.37	95.84
ASD, Non-CSHCN	8.73	5.09	14.55	6.01	4.15	8.63
Age at ASD Diagnosis (mean, years)	4.9	4.39	5.48	4.5	4.13	4.76

Note: The percentages reflect the number of children within each subpopulation, not those answering, "Yes" to *ever* having special education or EI plans or, "No" to *not currently* receiving services under one of these plans.

Data Source: Child and Adolescent Health Measurement Initiative (CAHMI) [2019]. [2016/2017 National Survey of Children's Health], [SPSS] Indicator Data Set. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [01/15/19] from www.childhealthdata.org.

Overall, more children with ASD reportedly had public insurance, adults with greater than high school education, and a slightly higher percentage of children living at or below the 199% FPL. Over 80% of children with ASD in both analytic samples reportedly spoke English as their primary household language. Approximately 90% of children in both analytic samples had reportedly mild/moderate ASD and met CSHCN criteria based on their parents' responses on the CSHCN screeners.

Bivariate Analyses

Table 2 displays the bivariate associations for both dependent variables. More of the selected study variables were significantly associated with *ever* having special education or EI plans than *not currently* receiving services under one of these plans. Many of the variables initially selected for analyses to predict *ever* having and *not currently* receiving services under one of these plans exceeded the 0.10 cutoff recommended by Bursac et al. (2008). Bursac et al. (2008) acknowledged that the decision-making process for retaining variables in statistical models may be specific to the problems under investigation and discipline-specific fields conducting the research. In examining these variables, a thorough review of literature guided the decision to retain these variables based on their clinical relevance (Bursac et al., 2008).

Multivariate Analyses

Selected study variables were sequentially added to subsequent models predicting *ever* having special education or EI plans and *not currently* receiving services under one of these plans. This process began with the base model containing the medical home care parameter and adding the predisposing factors, followed by enabling factors, the enabling-vulnerability factor, and lastly, the need factors. The unadjusted and adjusted odds ratio (*OR*), the 95% CIs (lower limit [LL], upper limit [UL]), and their corresponding *p*-values are displayed in Table 3 for the first dependent variable: *ever* having a special education or EI plans. Table 4 shows the multivariate models and corresponding results for the second dependent variable: *not currently* receiving services under one of these plans.

Research Question 1a. Unadjusted measures of association (i.e., *OR*) were used to predict *ever* having special education or EI plans from care that did not meet AAP medical home criteria. The

Table 2

Bivariate Analyses of Factors Associated with Ever Having Special Education or EI plans and Not Currently Receiving Services Under One of these Plans in Children with ASD

Variable	Ever Had Special Education or EI Plans (n=1,421)				Not Currently Receiving Services Under Special Education or EI Plans (n=1,248)			
	%	95% CI		p	%	95% CI		p
		LL	UL			LL	UL	
Medical home								
Meets AAP criteria	16.64	13.41	20.46	.689	4.65	2.96	7.24	.011*
Does NOT meet AAP criteria	68.45	61.68	74.51		10.01	7.20	13.74	
Predisposing Factors								
Child's Sex								
Male	66.16	58.46	73.13	.655	12.37	9.16	16.49	.190
Female	18.9	13.51	25.8		2.29	1.34	3.89	
Child's Age (mean, years)	10.5	9.99	11.03		10.3	9.87	10.90	
Total Children in Household								
1-2 children	60.05	52.92	66.77	.006**	9.98	7.16	13.75	.670
≥3 children	25.04	20.05	30.79		4.68	3.01	7.19	
Child's Race								
White	49.12	42.13	56.15		9.93	7.42	13.17	
Black	13.25	9.76	17.72	.022*	1.95	0.61	6.07	.422
Other	22.72	15.53	31.97		2.77	1.65	4.60	
Overall Maternal Health Status								
Excellent or Very Good	42.76	35.66	50.17	.293	5.66	3.89	8.15	.070
< Excellent or Very Good	42.32	35.92	49		9.00	6.26	12.78	
Family Structure								
Two parents, married/unmarried	66.58	59.59	72.91	.431	11.73	8.63	15.75	.728
Single parent, other, none reported	18.51	14.54	23.26		2.93	1.75	4.88	
Enabling Factors								
Insurance Type								
Private	35.74	30.21	41.67		6.74	4.74	9.51	
Public	47.05	39.9	54.31	.009**	7.61	5.11	11.21	.785
Unspecified	2.30	1.21	4.31		0.29	0.04	1.79	
Adult Education Level								
> High School	60.31	52.68	67.47	.029*	9.57	7.22	12.57	.427
≤ High School	24.78	18.65	32.12		5.09	2.89	8.82	
Poverty Level								
>199% FPL	41.85	35.7	48.26	.083	8.07	5.86	11.01	.383
≤199% FPL	43.23	35.98	50.79		6.59	4.22	10.16	
Survey Year								
2016	39.98	33.95	46.34	.292	7.55	5.51	10.26	.493
2017	45.1	37.93	52.48		7.11	4.6	10.84	
Enabling-Vulnerability Factor								
Primary Household Language								
English	71.92	63.57	78.98	.064	13.24	9.97	17.36	.349

*p< .05. **p< .01. ***p< .001.

Table 2

Bivariate Analyses for Ever Having Special Education or EI plans and Not Currently Receiving Services Under One of these Plans in Children with ASD

Variable	Ever Had Special Education or EI Plans (n=1,421)				Not Currently Receiving Services Under Special Education or EI Plans (n=1,248)			
	%	95% CI		p	%	95% CI		p
		LL	UL			LL	UL	
Enabling-Vulnerability Factor								
Primary Household Language								
Spanish	10.33	5.46	18.67	.064	1.28	0.49	3.23	.349
Other	2.84	1.41	5.63		0.15	0.03	0.63	
Need Factors								
ASD Severity								
Severe	7.93	5.75	10.83	.474	1.16	0.59	2.28	.623
Mild/Moderate	77.15	70.26	82.84		13.5	10.15	17.73	
CSHCN Status								
ASD, CSHCN	79.96	73.03	85.47	.014*	12.7	9.43	16.87	.002**
ASD, Non-CSHCN	5.12	3.53	7.35		1.97	1.16	3.30	
Age at ASD Diagnosis (mean, years)	4.9	4.39	5.48		4.4	4.13	4.76	

*p< .05. **p< .01. ***p< .001.

unadjusted model indicated that despite having lower odds of *ever* having special education or EI plans if children's care did not meet AAP medical home criteria, this finding was nonsignificant (*OR* = 0.84, 95% CI [0.37, 1.91], *p* = .690) (Table 3).

Research Question 1b. Table 4 shows the unadjusted *OR*s for the association between care that did not meet AAP medical home criteria and *not currently* receiving services under special education or EI plans. The association between *not currently* receiving services under one of these plans and care that did not meet AAP medical home criteria were in the predicted direction, with lack of care meeting AAP medical home criteria significantly associated with increased likelihood of *not currently* receiving services under one of these plans (*OR*=0.45, 95% CI [0.24, 0.84], *p* =.013) (Table 4).

Research Question 2a. In terms of *ever* having special education or EI plans, despite not having care that met AAP medical home criteria, five statistical models were executed to examine the effects of the predisposing, enabling, enabling-vulnerability, and need factors on this association (Table 3).

Adjusted analyses showed that receipt of care that did not meet AAP medical home criteria was not significantly associated with *ever* having special education or EI plans.

Predisposing Factors. After adjusting for predisposing factors, medical home care according to AAP criteria was not significantly associated with *ever* having special education or EI plans (*OR* = 0.71, 95% CI [0.30, 1.67], *p* = .437) (Table 3). Children with ASD in families with three or more children were significantly less likely to *ever* have special education or EI plans if their care did not meet AAP medical home criteria and after adjusting for other predisposing factors (*aOR* = 0.31, 95% CI [0.13, 0.70], *p* = .005). Children in the 'Other' race/ethnicity category were significantly associated with greater odds of *ever* having special education or EI plans if their care did not meet AAP medical home criteria and controlling for additional predisposing factors (*aOR* = 4.46, 95% CI [2.00, 9.98], *p* < .001) (Table 3).

Enabling Factors. After adding enabling factors to the multivariate model that included medical home care and predisposing factors, care that did not meet AAP medical home criteria was not significantly associated with *ever* having special education or EI plans (*aOR* = 0.87, 95% CI [0.34,

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Table 3

Multivariate Analyses of Factors Associated with Ever Having Special Education or EI plans and Medical Home Care for Children with ASD (n = 1,421)

Variable	OR	95% CI for OR LL	95% CI for OR UL	p
Model 1				
Medical home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.84	0.37	1.91	.690
Model 2				
Medical Home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.71	0.30	1.67	.437
Predisposing Factors				
Child's Sex				
Male	Referent			
Female	0.68	0.29	1.58	.376
Child's Age (Continuous)	0.95	0.85	1.06	.405
Total Children in Household				
1-2 children	Referent			
≥3 children	0.31	0.13	0.70	.005**
Child's Race				
White	Referent			
Black	2.99	0.63	14.20	.167
Other	4.46	2.00	9.98	< .001***
Overall Maternal Health Status				
Excellent or Very Good	Referent			
< Excellent or Very Good	0.65	0.27	1.58	.352
Family Structure				
Two parents, married/unmarried	Referent			
Single parent, other, none reported	0.56	0.28	1.12	.102
Model 3				
Medical Home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.87	0.34	2.23	.779
Predisposing Factors				
Child's Sex				
Male	Referent			
Female	0.67	0.29	1.52	.342
Child's Age (Continuous)	1.00	0.91	1.09	.976
Total Children in Household				
1-2 children	Referent			
≥3 children	0.37	0.19	0.71	.003**
Child's Race				
White	Referent			

*p < .05. **p < .01. ***p < .001.

Table 3

Multivariate Analyses of Factors Associated with Ever Having Special Education or EI plans and Medical Home Care for Children with ASD (n = 1,421)

Variable	OR	95% CI for OR		p
		LL	UL	
Black	4.04	1.36	11.98	.012*
Other	4.26	1.88	9.68	.001**
Overall Maternal Health Status				
Excellent or Very Good	Referent			
< Excellent or Very Good	0.50	0.25	0.99	.050
Family Structure				
Two parents, married/unmarried	Referent			
Single parent, other, none reported	0.46	0.20	1.07	.074
Enabling Factors				
Insurance Type				
Private	Referent			
Public	4.28	1.60	11.42	.004**
Unspecified	0.39	0.07	2.11	.281
Adult Education Level				
> High School	Referent			
≤ High School	0.51	0.23	1.13	.101
Poverty Level				
>199% FPL	Referent			
≤199% FPL	0.37	0.17	0.81	.014*
Survey Year				
2016	Referent			
2017	0.64	0.31	1.32	.232
Model 4				
Medical Home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.89	0.33	2.40	.832
Predisposing Factors				
Child's Sex				
Male	Referent			
Female	0.63	0.27	1.45	.282
Child's Age (Continuous)	0.98	0.90	1.08	.818
Total Children in Household				
1-2 children	Referent			
≥3 children	0.39	0.20	0.74	.004**
Child's Race				
White	Referent			
Black	3.40	1.13	10.23	.029*
Other	4.57	1.86	11.17	.001*

*p< .05. **p< .01. ***p< .001.

Table 3

Multivariate Analyses of Factors Associated with Ever Having Special Education or EI plans and Medical Home Care for Children with ASD (n = 1,421)

Variable	OR	95% CI for OR LL	95% CI for OR UL	p
Overall Maternal Health Status				
Excellent or Very Good	Referent			
< Excellent or Very Good	0.48	0.24	0.98	.046*
Family Structure				
Two parents, married/unmarried	Referent			
Single parent, other, none reported	0.36	0.18	0.74	.006**
Enabling Factors				
Insurance Type				
Private	Referent			
Public	4.66	1.69	12.85	.003**
Unspecified	0.52	0.09	3.02	.470
Adult Education Level				
> High School	Referent			
≤ High School	0.64	0.32	1.29	0.21
Poverty Level				
>199% FPL	Referent			
≤199% FPL	0.46	0.21	0.99	.049*
Survey Year				
2016	Referent			
2017	0.67	0.34	1.33	.256
Enabling-Vulnerability Factor				
Primary Household Language				
English	Referent			
Spanish	0.35	0.10	1.22	.100
Other	1.66	0.22	12.09	.615
Model 5				
Medical Home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.98	0.41	2.32	.964
Predisposing Factors				
Child's Sex				
Male	Referent			
Female	0.76	0.33	1.74	.527
Child's Age (Continuous)	1.10	1.00	1.21	.034
Total Children in Household				
1-2 children	Referent			
≥3 children	0.44	0.22	0.88	.021*

*p< .05. **p< .01. ***p< .001.

Table 3

Multivariate Analyses of Factors Associated with Ever Having Special Education or EI plans and Medical Home Care for Children with ASD (n = 1,421)

Variable		OR	95% CI for OR		p
			LL	UL	
Child's Race					
	White	Referent			
	Black	2.97	0.85	10.42	.088
	Other	3.26	1.34	7.95	.009**
Overall Maternal Health Status					
	Excellent or Very Good	Referent			
	< Excellent or Very Good	0.50	0.25	0.98	.045*
Family Structure					
	Two parents, married/unmarried	Referent			
	Single parent, other, none reported	0.38	0.17	0.83	.016*
Enabling Factors					
Insurance Type					
	Private	Referent			
	Public	4.64	1.51	14.25	.007**
	Unspecified	1.16	0.18	7.36	.872
Adult Education Level					
	> High School	Referent			
	≤ High School	0.59	0.28	1.24	.165
Poverty Level					
	>199% FPL	Referent			
	≤199% FPL	0.47	0.20	1.09	.079
Survey Year					
	2016	Referent			
	2017	0.59	0.29	1.18	.137
Enabling-Vulnerability Factor					
Primary Household Language					
	English	Referent			
	Spanish	0.37	0.09	1.50	.166
	Other	1.58	0.17	14.50	.685
Need Factors					
ASD Severity					
	Severe	Referent			
	Mild/Moderate	1.18	0.34	4.13	.789
CSHCN Status					
	ASD, CSHCN	Referent			
	ASD, Non-CSHCN	0.43	0.15	1.19	.105
Age at ASD Diagnosis (Continuous)		0.78	0.71	0.87	<.0001***

$*p< .05. **p< .01. ***p< .001.$

2.23], *p* = .779). Children with three or more children in households was significantly associated with lower odds of *ever* having special education or EI plans after adjusting for predisposing and other enabling factors (*aOR* = 0.37, 95% CI [0.19, 0.71], *p* = .003). Children in the Black and "Other" race/ethnicity categories were more likely to *ever* have special education or EI plans if their care did not meet AAP medical home criteria. Black children with ASD were four times more likely to *ever* have special education or EI plans (*aOR* = 4.04, 95% CI [1.36, 11.98], *p* = .012), while children in the "Other" race/ethnicity category were over four times more likely to have special education or EI plans without care that met AAP medical home criteria (*aOR* = 4.26, 95% CI [1.88, 9.68], *p* = .001) compared to White, Non-Hispanic children. Having public insurance was associated with significantly higher odds of *ever* having special education or EI plans, despite not having care that met AAP medical home criteria (*aOR* = 4.28, 95% CI [1.60, 11.42], *p* = .004). Children with ASD in the 199% federal poverty level (FPL) or less category had significantly lower odds of *ever* having special education or EI plans if their care did not meet AAP medical home criteria and after controlling for predisposing and other enabling factors (*aOR* = 0.37, 95% CI [0.17, 0.81], *p* = .014) (Table 3).

  Enabling-Vulnerability Factor. Primary household languages (i.e., English, Spanish, and Other) were not significantly associated with *ever* having special education or EI plans if care did not meet AAP medical home criteria. This association was nonsignificant after controlling for predisposing and enabling factors. When adding the enabling-vulnerability factors into the multivariate model, children in households with three or more children had lower odds of *ever* having special education or EI plan without care that met AAP medical home criteria (*aOR* = 0.39, 95% CI [0.20, 0.74], *p* = .004). Children in the Black and "Other" race/ethnicity categories continued to have elevated odds of *ever* having special education plans if they did not have care that met AAP medical home criteria in the multivariate model. Black children had three times higher odds of *ever* having special education or EI plans (*aOR* = 3.40, 95% CI [1.13, 10.23], *p* = .029), compared to children in the "Other" race/ethnicity category who had over four times greater likelihood of *ever* having special education or EI plans (*aOR* = 4.57, 95% CI [1.86, 11.17], *p* = .001). Compared to mothers with excellent or very good health, those mothers with less

than excellent or very good health had children with significantly lower odds of *ever* having special education or EI plans without care that met AAP medical home criteria in the multivariate model (*aOR* = 0.48, 95% CI [0.24, 0.98], *p* = .046). Children with ASD from single parent, other family types, or no family reported was significantly associated with lower odds of *ever* having special education or EI plans (*aOR* = 0.36, 95% CI [0.18, 0.74], *p* = .006). Children with public insurance had significantly greater likelihood of *ever* having special education or EI plans if their care did not meet AAP medical home criteria (*aOR* = 4.66, 95% CI [1.69, 12.85], *p* = .003). Poverty level showed that children in the 199% FPL level or less had significantly lower odds of *ever* having special education or EI plans if their care did not AAP medical home criteria (*aOR* = 0.46, 95% CI [0.21, 0.99], *p* = .049) (Table 3).

     Need Factors. The need factors were the final set of variables added to the multivariate models to predict *ever* having special education or EI plans from care that did not meet AAP medical home criteria. The inclusion of need factors constitutes the fully adjusted multivariate model controlling for all selected covariates. Care that did not meet AAP medical home criteria was nonsignificant in predicting *ever* having special education or EI plans (*aOR* = 0.98, 95% CI [0.41, 2.32], *p* = .964). Children with ASD with three or more children in their families showed a statistically lower likelihood of *ever* having special education or EI plans when their care did not meet AAP medical home criteria (*aOR* = 0.44, 95% CI [0.22, 0.88], *p* = .021). Children with ASD in the 'Other' race/ethnicity category continued to have significantly greater odds of *ever* having special education or EI plans if their care did not meet AAP medical home criteria, but their odds decreased in the fully adjusted model (*aOR* = 3.26, 95% CI [1.34, 7.95], *p* = .009). Mothers who reported less than excellent or very good health were less likely to have children who *ever* had special education or EI plans (*aOR* = 0.50, 95% CI [0.25, 0.98], *p* = .045). Single parent, no family reported, and other family types were associated with lower odds of *ever* having special education or EI plans if their care did not meet AAP medical home criteria (*aOR* = 0.38, 95% CI [0.17, 0.83], *p* = .004). Compared to children with private insurance or uninsured, public insurance was significantly associated with greater odds of *ever* having special education or EI plans without care that met AAP medical home criteria (*aOR* = 4.64, 95% CI [1.51, 14.25], *p* = .007). As age at ASD diagnoses

increased in years, children were less likely to *ever* have special education or EI plans without medical home care (*aOR* = 0.78, 95% CI [0.71, 0.87], *p* < .0001) (Table 3).

      Model Fit. The `linktest` was used to examine specification errors in the fully adjusted model predicting *ever* having special education or EI plans from care that did not meet AAP medical home criteria and adjusting for all selected covariates. The `linktest` revealed that _hatsq was nonsignificant (_hatsq = .273) which is indicative of good model fit for the fully adjusted model.

      Research Question 2b. The same process was repeated for testing the association between *not currently* receiving services under special education or EI plans and care that did not meet medical home criteria. Results from the adjusted analyses are presented in Table 4.

      Adjusted analyses showed that receipt of care that did not meet AAP medical home criteria was significantly associated with higher likelihood of *not currently* receiving services under one of these plans.

      Predisposing Factors. The predisposing factors slightly increased the odds of *not currently* receiving services under one of these plans if their care did not meet AAP medical home criteria (*aOR* = 0.49, 95% CI [0.28, 0.88], *p* =.017). As children's chronological ages increased, their odds of *not currently* receiving services under one of these plans increased if their care did not meet AAP medical home criteria and accounting for other predisposing variables in the model (*aOR* = 1.11, 95% CI [1.03, 1.19], *p* = .004). Children whose mothers were in less than excellent or very good health had increased odds of *not currently* receiving services under one of these plans without care that meet AAP medical home criteria with adjustment of additional predisposing factors (*aOR* = 1.93, 95% CI [1.10, 3.46], *p* =.022) (Table 4).

      Enabling Factors. The inclusion of enabling factors continued to show a significant trend towards *not currently* receiving services under one of these plans without care that met AAP medical

Table 4

Multivariate Analyses of Factors Associated with Not Currently Receiving Services Under Special Education or EI plans and Medical Home Care for Children with ASD (n = 1,248)

Variable	OR	95% CI for OR		p
		LL	UL	
Model 1				
Medical home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.45	0.24	0.84	.013*
Model 2				
Medical Home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.49	0.28	0.88	.017*
Predisposing Factors				
Child's Sex				
Male	Referent			
Female	0.65	0.34	1.26	.210
Child's Age (Continuous)	1.11	1.03	1.19	.004**
Total Children in Household				
1-2 children	Referent			
≥3 children	1.22	0.66	2.25	0.515
Child's Race				
White	Referent			
Black	0.83	0.22	3.06	.782
Other	0.84	0.39	1.78	.652
Overall Maternal Health Status				
Excellent or Very Good	Referent			
< Excellent or Very Good	1.93	1.10	3.46	.022*
Family Structure				
Two parents, married/unmarried	Referent			
Single parent, other, none reported	0.78	0.34	1.77	.555
Model 3				
Medical Home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.48	0.27	0.84	.011*
Predisposing Factors				
Child's Sex				
Male	Referent			
Female	0.65	0.32	1.31	.234
Child's Age (Continuous)	1.11	1.04	1.20	.002**
Total Children in Household				
1-2 children	Referent			
≥3 children	1.19	0.62	2.25	.593
Child's Race				
White	Referent			
Black	0.83	0.23	2.92	.775

*$p < .05$. **$p < .01$. ***$p < .001$.

Table 4

Multivariate Analyses of Factors Associated with Not Currently Receiving Services Under Special Education or EI plans and Medical Home Care for Children with ASD (n = 1,248)

Variable	OR	95% CI for OR		p
		LL	UL	
Child's Race				
Other	0.87	0.41	1.86	.732
Overall Maternal Health Status				
Excellent or Very Good	Referent			
< Excellent or Very Good	1.97	1.08	3.56	.025*
Family Structure				
Two parents, married/unmarried	Referent			
Single parent, other, none reported	0.72	0.29	1.79	.488
Enabling Factors				
Insurance Type				
Private	Referent			
Public	0.91	0.52	1.59	.757
Unspecified	0.49	0.04	5.13	.559
Adult Education Level				
> High School	Referent			
≤ High School	1.76	0.83	3.76	.139
Poverty Level				
>199% FPL	Referent			
≤199% FPL	0.91	0.49	1.68	.777
Survey Year				
2016	Referent			
2017	0.91	0.47	1.75	.784
Model 4				
Medical Home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.48	0.27	0.83	.010*
Predisposing Factors				
Child's Sex				
Male	Referent			
Female	0.65	0.32	1.32	.240
Child's Age (Continuous)	1.11	1.03	1.20	.004**
Total Children in Household				
1-2 children	Referent			
≥3 children	1.19	0.63	2.26	.576
Child's Race				
White	Referent			
Black	0.84	0.25	2.82	.784
Other	0.89	0.42	1.90	.782

*p< .05. **p< .01. ***p< .001.

Table 4

Multivariate Analyses of Factors Associated with Not Currently Receiving Services Under Special Education or EI plans and Medical Home Care for Children with ASD (n = 1,248)

Variable	OR	95% CI for OR		p
		LL	UL	
Overall Maternal Health Status				
Excellent or Very Good	Referent			
< Excellent or Very Good	1.92	1.07	3.48	.028*
Family Structure				
Two parents, married/unmarried	Referent			
Single parent, other, none reported	0.72	0.28	1.82	.490
Enabling Factors				
Insurance Type				
Private	Referent			
Public	0.92	0.52	1.61	.781
Unspecified	0.50	0.04	5.17	.565
Adult Education Level				
> High School	Referent			
≤ High School	1.75	0.79	3.87	.167
Poverty Level				
>199% FPL	Referent			
≤199% FPL	0.91	0.48	1.72	.786
Survey Year				
2016	Referent			
2017	0.91	0.47	1.73	.775
Enabling-Vulnerability Factor				
Primary Household Language				
English	Referent			
Spanish	0.97	0.24	3.80	.967
Other	0.52	0.09	2.80	.450
Model 5				
Medical Home				
Meets AAP criteria	Referent			
Does NOT meet AAP criteria	0.51	0.29	0.90	.021*
Predisposing Factors				
Child's Sex				
Male	Referent			
Female	0.66	0.32	1.36	.265
Child's Age (Continuous)	1.09	1.00	1.18	.028*
Total Children in Household				
1-2 children	Referent			
≥3 children	1.25	0.66	2.37	.490

*$p< .05$. **$p< .01$. ***$p< .001$.

Table 4

Multivariate Analyses of Factors Associated with Not Currently Receiving Services Under Special Education or EI plans and Medical Home Care for Children with ASD (n = 1,248)

Variable		OR	95% CI for OR		p
			LL	UL	
Child's Race					
	White	Referent			
	Black	0.87	0.25	3.02	.839
	Other	0.95	0.45	1.97	.895
Overall Maternal Health Status					
	Excellent or Very Good	Referent			
	< Excellent or Very Good	1.88	1.05	3.36	.031*
Family Structure					
	Two parents, married/unmarried	Referent			
	Single parent, other, none reported	0.76	0.30	1.97	.586
Enabling Factors					
Insurance Type					
	Private	Referent			
	Public	1.00	0.55	1.80	.992
	Unspecified	0.55	0.05	5.16	.604
Adult Education Level					
	> High School	Referent			
	≤ High School	1.76	0.78	3.97	.169
Poverty Level					
	>199% FPL	Referent			
	≤199% FPL	0.84	0.43	1.62	.613
Survey Year					
	2016	Referent			
	2017	0.93	0.48	1.81	.842
Enabling-Vulnerability Factor					
Primary Household Language					
	English	Referent			
	Spanish	0.89	0.22	3.60	.872
	Other	0.58	0.10	3.10	.525
Need Factors					
ASD Severity					
	Severe	Referent			
	Mild/Moderate	1.00	0.38	2.63	.994
CSHCN Status					
	ASD, CSHCN	Referent			
	ASD, Non-CSHCN	2.58	1.17	5.68	.018*
Age at ASD Diagnosis (Continuous)		1.04	0.96	1.14	.276

*p< .05. **p< .01. ***p< .001.

home criteria (*aOR* = 0.48, 95% CI [0.27, 0.84], *p* =.002). The addition of these factors also continued to decrease the likelihood of *not currently* receiving services if children were older (*aOR* = 1.11, 95% CI [1.04, 1.20], *p* = .002) and had mothers with less than excellent or very good health (*aOR* = 1.97, 95% CI [1.08, 3.56], *p* =.025) (Table 4).

   Enabling-Vulnerability Factor. Primary household language showed significantly greater odds of *not currently* receiving services under one of these plans without care that met AAP medical home criteria (*aOR* = 0.48, 95% CI [0.27, 0.84], *p* =.011) for children whose primary household language was other than English (i.e., Spanish or Other). Children's chronological ages predicted greater odds of *not currently* receiving services under one of these plans (*aOR* = 1.11, 95% CI [1.03, 1.20], *p* =.004) in addition to the mothers' decreased overall health (*aOR* = 1.92, 95% CI [1.07, 3.48], *p* =.028) (Table 4).

   Need Factors. Need factors increased the odds of not receiving services under one of these plans if children's care did not meet AAP medical home criteria in the fully adjusted multivariate model (*aOR* = 0.51, 95% CI [0.29, 0.90], *p* =.021) (Table 4).

   Older children had lower adjusted odds of *not currently* receiving services without care that met AAP medical home criteria but remained significant (*aOR* = 1.09, 95% CI [1.00, 1.18], *p* = .028). Mothers with less than excellent or very good health had children with increased likelihood of *not currently* receiving these services if their children's care did not meet AAP medical home criteria (*aOR* = 1.88, 95% CI [1.05, 3.36], *p* =.031). Children with ASD who did not qualify as a CSHCN had approximately 2 times greater odds of *not currently* receiving under of these plans if their care did not meet AAP medical home criteria in the fully adjusted model (*aOR* = 2.58, 95% CI [1.17-5.68], *p* = .018) (Table 4).

   Model Fit. Stata's `linktest` command was executed to assess model specification errors for the fully adjusted model and was nonsignificant(_hatsq = .590), indicating good model fit.

Chapter 5: Discussion

This chapter recounts the study's hypotheses, support and nonsupport for each hypothesis, and comparisons with existing research. This study argued that the effect of not having care that met AAP medical home criteria will create barriers to educational services utilization for children with ASD. Educational services utilization was defined as children who reportedly *ever* had special education or EI plans or were *not currently* receiving services under one of these plans. A uniquely constructed medical home definition reflecting the AAP ideals (AAP, 2002) was used to explore the gaps between health and educational services utilization, as a function of predisposing, enabling, enabling-vulnerability, and need factors, within the NSCH survey structure (U.S. Census Bureau, 2018a; U.S. Census Bureau, 2018b; Andersen, Davidson, & Baumeister, 2013; Gelberg, Andersen, & Leake, 2000). Using the combined 2016/2017 NSCH allowed for increased sample sizes of children with ASD given the smaller prevalence of this disability group in the individual year surveys. The Andersen behavioral model of health services use (Andersen, Davidson, & Baumeister, 2013) with the vulnerability domain (Gelberg, Andersen, & Leake, 2000) has not been applied to studies linking health and educational services utilization for a nationally representative sample of children with ASD. The chapter ends with potential biases and threats to internal validity, generalizability, and future research, practice, and policy implications. The revised Behavioral Model of Health Services Use, 6th revision, adapted to reflect this study's variables is shown (Figure 5) (Andersen, Davidson, & Baumeister, 2013; Gelberg, Andersen, & Leake, 2000).

Support of Original Hypotheses

Research Question 1: Unadjusted Associations Between Medical Home Care and Potential and Realized Access

The first research question was divided into two parts. The first part of the question examined whether care that did not meet AAP medical home criteria was associated with less likelihood of *ever* having special education or EI plans (i.e., potential access). The second part examined whether this same care was associated with greater likelihood of *not currently* receiving services under special education or EI plans (i.e., realized access).

Research Question 1a: Unadjusted Association Between Medical Home Care and Potential Access

Children with ASD without care that met AAP medical home criteria were hypothesized to have less likelihood of *ever* having special education or EI plans (i.e., potential access). This hypothesis was not supported. After controlling for medical home care, children with ASD had lower odds of *ever* having special education or EI plans but yielded insignificant results unadjusted and adjusted multivariate models.

Research Question 1b: Unadjusted Association Between Medical Home Care and Realized Access

Children with ASD were hypothesized to have greater likelihood of *not currently* receiving services under one of these plans (i.e., realized access) if their care did not meet AAP medical home criteria. This hypothesis was supported. Lack of care that met AAP medical home criteria was significantly associated with lower odds of *not currently* receiving services under special education or EI plans. This association was consistent in unadjusted and all adjusted multivariate models predicting whether children with ASD were *not currently* receiving services under special education or EI plans.

Research Question 2: Adjusted Associations Between Medical Home Care and Potential and Realized Access

The Andersen behavioral model of health services use with the vulnerability domain guided the analyses of whether care that did not meet AAP medical home criteria predicted *ever* having special education or EI plans (i.e., potential access) and *not currently* receiving services under one of these plans (i.e., realized access) (Andersen, Davidson, & Baumeister, 2013; Gelberg, Andersen, & Leake, 2000). This process began by fitting a base model that predicted *ever* having special education or EI plans from care that did not meet AAP medical home criteria. The next multivariate models added the predisposing factors to the base model, followed by the enabling factors, then the enabling-vulnerability factor, and lastly, the need factors for predicting *ever* having special education or EI plans. This process was repeated for testing hypotheses corresponding with *not currently* receiving services under one of these plans from care that did not meet AAP medical home criteria, predisposing, enabling, enabling-vulnerability, and need factors, respectively.

Research Question 2a: Adjusted Associations Between Medical Home Care and Potential Access

It was hypothesized that predisposing and enabling factors were more strongly associated with *ever* having special education or EI plans than enabling-vulnerability and need factors for children without care that met AAP medical home criteria. This hypothesis was partially supported. Of the factors tested, predisposing factors were the most influential predictors of *ever* having special education or EI plans for children whose care did not meet AAP medical home criteria

Predisposing factors. Children's chronological ages (i.e., older children), total children in households (i.e., three or more children), children's races/ethnicities (i.e., Black or Other), maternal health status (i.e., less than excellent or very good), and family structure (i.e., single parent, other family type, and no family reported) were significantly associated with children reportedly *ever* having special education or EI plans if their care did not meet AAP medical home criteria.

Child's Age. Older children with ASD whose care that did meet AAP medical home criteria were significantly more likely to *ever* have special education or EI plans. This association was significant in the fully adjusted multivariate model containing all the predisposing, enabling, enabling-vulnerability, and need factors.

Child's Race/Ethnicity. The effect of children's races/ethnicities was such that children in the Black and Other race/ethnicity categories had significantly higher odds of *ever* having special education or EI plans. Black children with ASD were significantly more likely to *ever* have special education or EI plans, despite not having care that met AAP medical home criteria. Their odds were higher for the multivariate model controlling for medical home care and other predisposing factors (e.g., children's chronological ages, sexes, total children in households, maternal health statuses, adults' education levels, and family structures). Their odds decreased in the fully adjusted multivariate model with the predisposing, enabling, enabling-vulnerability, and need factors, but remained statistically significant. Children with ASD in the Other race/ethnicity category (i.e., Hispanic, American Indian or Alaska Native, Asian, Native American or other Pacific Islander, some other race/ethnicity, or two or more

races/ethnicities) were approximately three to four times more likely to *ever* have special education plans in the fully adjusted model.

Total Children in Households. Having three or more children in households was significantly associated with lower odds of *ever* having special education or EI plans. This finding remained significant for all adjusted multivariate models.

Maternal Health Status. Mothers with less than excellent or very good health were associated with lower odds of *ever* having special education or EI plans for children whose care did not meet AAP medical home criteria. This finding was significant after the inclusion of enabling factors in the multivariate models and remained significant as the enabling-vulnerability and need factors were added to the subsequent models.

Family Structure. Single-parent, other family types, or no family reported were associated with significantly less likelihood of *ever* having special education or EI plans for those without care that met AAP medical home criteria. This finding was significant after controlling for enabling-vulnerability and need factors only.

Enabling Factors. Insurance type and poverty level were significantly associated with *ever* having special education or EI plans in adjusted models.

Insurance type. Children with public insurance had four times higher odds of *ever* having special education or EI plans, despite their care not meeting AAP medical home criteria. This association was significant after controlling for medical home care, predisposing, and other enabling factors (i.e., poverty level, and survey year). The odds of *ever* having special education or EI plans slightly increased after adding the enabling-vulnerability factor (i.e., primary household language) to the model and in the fully adjusted model with all selected covariates.

Income level. Children in the 199% FPL or less category had significantly lower odds of *ever* having special education or EI plans after controlling for medical home care, predisposing, enabling, and enabling-vulnerability factors. This association diminished in the fully adjusted multivariate model containing all selected covariates.

Enabling-Vulnerability Factor. Primary household language was classified as the vulnerability factor in this study. The vulnerability domain (Gelberg, Andersen, & Leake, 2000) was incorporated to determine whether the effect of primary household language was significant in predicting educational service use for children with ASD.

Primary Household Language. Primary household language (i.e., English, Spanish, and Other) was hypothesized to be more strongly associated with *ever* having special education or EI plans. The analyses indicated that children's primary household language was not significantly associated with *ever* having special education or EI plans after controlling for medical home care, predisposing, and enabling factors.

Need Factors. Among the need factors examined, children's ages at ASD diagnoses were the only statistically significant predictor of *ever* having special education or EI plans in the fully adjusted multivariate model. As children's ages at ASD diagnoses increased in years, their odds of *ever* having special education or EI plans decreased if their care did not meet AAP medical home criteria.

Research Question 2b: Adjusted Associations Between Medical Home Care and Realized Access

It was hypothesized that predisposing and enabling factors were stronger predictors of *not currently* receiving services under special education or EI plans than enabling-vulnerability and need factors. This hypothesis was supported. No enabling factors (i.e., insurance type, poverty level, and survey year) were significantly associated with *not currently* receiving services under special education or EI plans. In addition, the enabling-vulnerability factor, primary household language, was not significantly associated with children *not currently* receiving services under special education or EI plans. Predisposing and need factors were significantly associated with children *not currently* receiving services under one of these plans, if their care did not meet AAP medical home criteria, are described below.

Predisposing factors. Among the predisposing factors examined, children's chronological ages (i.e., older children) and maternal health statuses (i.e., less than excellent or very good) were significantly associated with *not currently* receiving services under special education or EI plans for children without care that met AAP medical home criteria.

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Children's Ages. As children's chronological ages increased in years, their odds of *not currently* receiving services under one of these plans were slightly elevated if their care did not meet AAP medical home criteria.

Maternal Health Status. Mothers with less than excellent or very good health had significantly higher likelihood of their children *not currently* receiving services under one of these plans if their children's care did not meet AAP medical home criteria. These findings were consistent for all adjusted models that included medical home care, predisposing, enabling, enabling-vulnerability, and need factors.

Need factor. CSHCN status (i.e., children with ASD, but not a CSHCN) was the single need factor significantly associated with *not currently* receiving services under special education or EI plans. Children with ASD, not classified as CSHCN, were twice as likely to *not currently* receive services under one of these plans in the fully adjusted model only.

Similarity of Results with Other Studies

Medical Home and Access Types

In the absence of medical home care meeting AAP medical home criteria, the analyses showed different disparities in potential and realized access. Children with ASD were not at risk of gaps in *ever* having special education or EI plans if their care did not meet AAP medical home criteria (i.e., potential access).

However, the multivariate analyses indicated that children without medical home care meeting AAP criteria had increased odds of *not currently* receiving educational services (i.e., realized access). For children with ASD whose care did not meet AAP medical home criteria, the additive factors of being older children, having a mother with less than excellent or very good health, and not classified as a CSHCN increased the likelihood of *not currently* receiving services under ones of those plans.

Potential Access. Children with ASD had greater odds of *ever* having special education or EI plans without medical home care that met AAP criteria. Plausible explanations may include federally-mandated activities for identifying children with disabilities in educational systems, the division between

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health and educational systems' disability identification processes, and the recognized coordination barriers between them.

Children with ASD are being identified in educational systems and receiving services under special education or EI plan at some point in their lives. Child Find activities, as part of IDEA Part C (i.e., EI) and Part B (i.e. special education), are federally mandated activities in every state for identifying children with or at risk for disabilities, and therefore, eligible for EI or special education services. Children from birth and three years old are referred to EI services under IDEA Part C and children between 3 to 21 years old are referred to special education programs in public schools under IDEA Part B. These referrals are the starting points for evaluation and determination of eligibility for either program (IDEA, 2004).

Consistent with this finding, Shahidullah et al. (2018) drew on the conflicts surrounding integrated care involving authentic partnerships between the medical home and educational systems. Health and educational systems have generally operated as separate and distinct systems with colonized roles in the landscape of services for children with ASD. Despite these systems' different emphases, the AAP outlined medical home roles in IFSP and IEP development, the first of which is medical home access (AAP, 1999). Even within existing policy statements published by the AAP promoting the role of pediatricians in EI and special education programming, the actual practice between pediatricians and educational professionals remains complex, which translates to poorly organized coordination of these systems for children with ASD and their families. Pediatricians can serve as coequals within educational sectors to use their clinical skills and implement medical home dimensions for IFSP and IEP development. Comprehensive medical home care aligns with AAP recommendations of screening, surveillance, and diagnoses of children with or at risk for developmental delays or disabilities who may qualify for services under special education or EI plans (AAP, 2002; AAP, 1999; AAP, 2007a, AAP, 2007b; Lipkin et al., 2015; Adams, Tapia, & The Council on Children with Disabilities, 2013). In addition, pediatricians are often the first providers aware of children's delays or disabilities that can benefit from EI or special education services and expedite referrals to these services for evaluation (AAP,

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1999). Making referrals, developing IFSPs with EI programs or IEPs with schools' special education teams, especially when health services are included (i.e., coordinated care), and advising families on their rights and options (i.e., family-centered care) are within the scope of medical home provisions in IFSP and IEP development and implementation (AAP, 2002; AAP, 1999; AAP, 2007a; AAP, 2007b; AAP, 2015).

Early identification, timely referral to EI or special education services, and providing culturally-effective and family-centered care are shared principles among the medical home, EI providers, and special education programs (Lipkin et al., 2015; Adams, Tapia, & The Council on Children with Disabilities; 2013; AAP, 2002). Their collective contributions may eliminate fragmentation, redundancies, and duplication of services through negotiating information and leveraging capacities in reciprocal directions. Achieving these overlapping goals between the medical home and educational systems are met with barriers. Shah, Kunnavakkam, and Msall (2013) surveyed pediatricians and found that pediatricians lacked knowledge on IEP and special education processes, inadequate training in these areas, limited time, reimbursement, access to resources, and specific guidelines to support children and families within special education programs. These practice barriers attenuate the utility of pediatricians' roles in collaboratively addressing health and educational needs for children with ASD. Golnik, Ireland, and Borowsky (2009) found pediatricians have lower self-reported competency, need for more training, and fiscal support for care coordination for patients with ASD. Carbone et al. (2010) cited similar barriers to medical home care for children with ASD, namely with family-centered care and care coordination. These challenges in facilitating access and coordinated care with educational systems, infused with pediatricians decreased self-competence with ASDs, perpetuates poorer quality medical home care for children with ASD.

Realized Access. Medical home care that did not meet AAP criteria was associated with decreased odds of *not currently* receiving services under special education or EI plans for children with ASD. This finding puts a spotlight on the key role medical home providers can have within the context of EI and special education programs. While this study defined realized access as children reportedly not

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receiving services currently under special education or EI plans, high-quality medical homes have been associated with greater likelihood of met needs for other types of service access. These include therapeutic (e.g., occupational, physical, and speech therapy) and supportive services (e.g., special equipment, transportation, home health, and respite) (Benedict, 2008). Benevides, Carretta, and Lane (2016) found that children with ASD had reportedly higher therapeutic needs (e.g., occupational, physical, and speech therapies) and higher unmet therapeutic needs compared to other CSHCN in one study and compared to children with attention deficit hyperactivity disorder (ADHD) in another study (Benevides, Caretta, & Lane, 2017). Chiri and Warfield (2012) had similar findings of higher unmet specialty care or therapeutic services, while Farmer et al. (2014) cited gaps in coordinated and family-centered care for children with ASD. To promote the actual use of therapeutic, supportive, and educational services (i.e., realized access) for children with ASD, quality medical homes must procure access to these essential services for children with ASD.

Medical home components (i.e., personal doctor or nurse, usual source of sick care, family-centered care, getting needed referrals, and effective care coordination when needed) have been examined. Some or all these components may be absent or lacking in medical home care for children with ASD but may be the vital links to facilitate actual use of EI or special education services (i.e., realized access). Emerson, Morrell, and Neece (2016) found that having a consistent source of care (i.e., usual source of sick care) was associated with decreased age at ASD diagnoses.

Long, Cabral, and Garg (2013) found that comprehensive care was associated with decreased outpatient and ED visits for sick care and reportedly increased child health. Comprehensive medical home care incorporates preventative care provision (e.g., growth and development assessments, appropriate screenings, and addressing children's and families' medical, educational, developmental, psychosocial, and other service needs) (AAP, 2002). Jimenez et al. (2014) found that referral mode was associated with completed EI evaluations. Fifty-eight percent of children whose referrals were faxed from their health systems directly to EI programs had completed multidisciplinary evaluations, compared to 33% of children whose parents were given phone numbers and asked to call for an evaluation. More efficient

referral systems within electronic health records and use of patient navigators have also been found to decrease gaps in follow-through with EI referrals and caregiver burden (Conroy et al., 2017). Harstad et al. (2013) examined correlates of IEP receipt for children with ASD between 6 to 17 years old. Parents with increased perceived need for care coordination between children's doctors or health care providers and childcare providers, school or other programs were three times more likely to have an IEP. Carbone et al. (2010) reported physicians not spending enough time with families, recognizing the family as experts in children's care, and engaging in shared decision-making with ASD treatments representing family centered-care medical home attributes (AAP, 2002). Other perceptions included lack of coordinated care, with families reportedly acting as their own "medical home" (Carbone et al., 2010, p. 314), for obtaining needed referrals and effective care coordination. This study's findings reflect cognitive and communicative processes (Pizur-Barnekow, Darragh, & Johnston, 2011) that are particularly pertinent to the operations undertaken by parents of children with ASD and CSHCN with decreased perceptions of medical home care (Carbone et al., 2010). These components are included in the NSCH operationalized medical home definition (CAHMI, 2019) and part of the AAP medical home ideals (AAP, 2002).

Relationship to the Andersen Behavioral Model of Health Services Use and the Vulnerability Domain

Figure 5 displays the variables used in the multivariate analyses and their classification under the predisposing, enabling, enabling-vulnerability and need factors. The difference in this figure was the removal of the Metropolitan Statistical Area (MSA) variable discussed in Chapter 4.

Predisposing Factors. The predisposing factors in the multivariate models were among the strongest predictors of *ever* having and *not currently* receiving services under special education or EI

Figure 5

Adapted Final Andersen Behavioral Model of Health Services Use, 6th edition
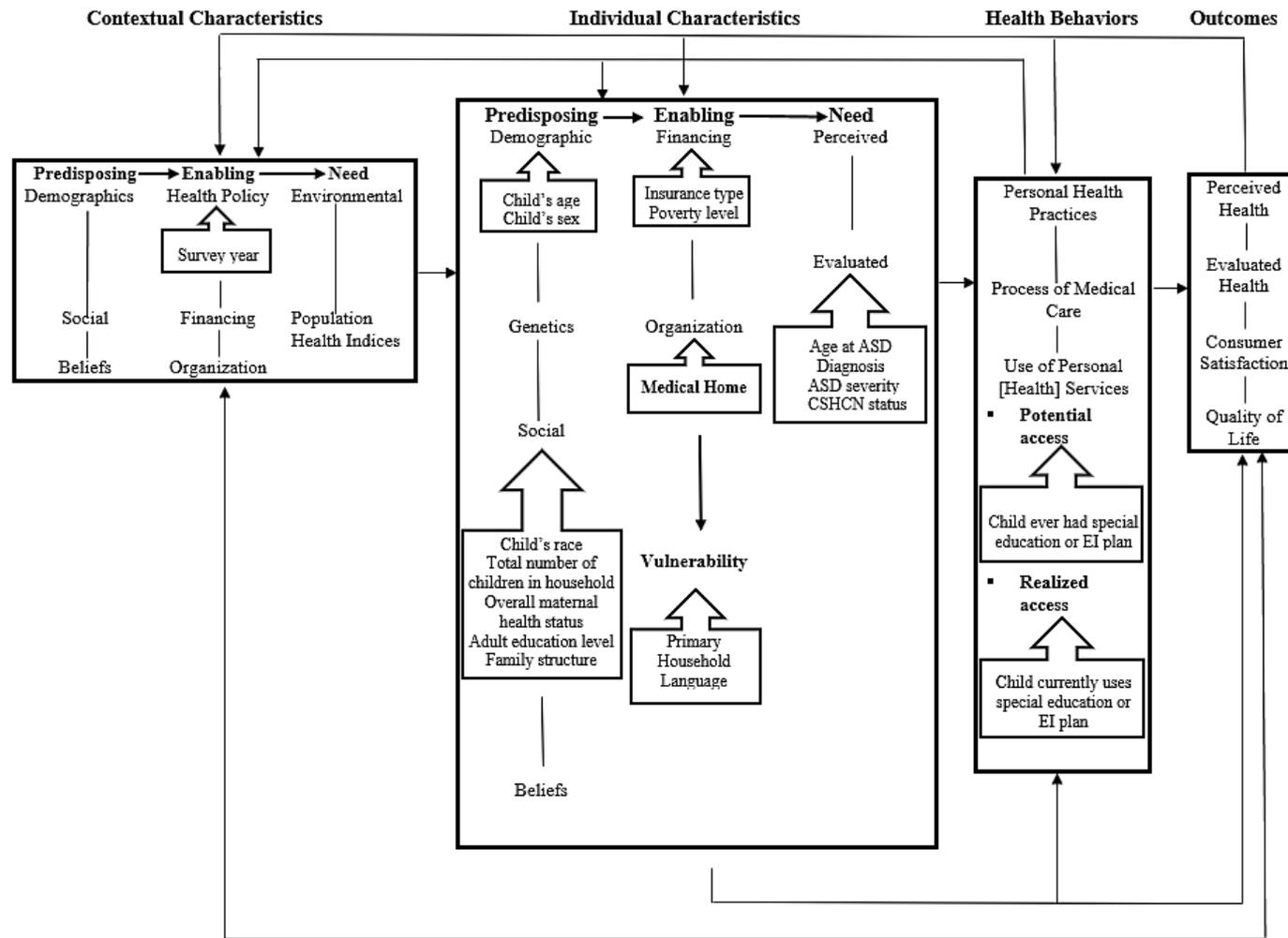
Note. This figure displays the final variables included in the multivariate analyses for predicting *ever* and *not currently* receiving services under special education or EI plans

plans for children without care that met AAP medical home criteria. Children's chronological ages and maternal health statuses were significantly associated *ever* having and *not currently* receiving services under one of these plans.

Child's Age. Children's chronological ages were a significant predictor of *ever* having special education or EI plans in the fully adjusted multivariate model and *not currently* receiving services under one of these plans across all adjusted multivariate models. Children's chronological ages have been significantly associated with service access in previous literature. Knapp et al. (2013) examined children with behavioral health conditions (e.g., ADHD, depression, anxiety, conduct or behavioral problems, ASD, and developmental delays) and found that older children were less likely to have patient-centered medical homes. Older children with ASD (i.e., aged 15-17 years old) had nearly two times higher odds of unmet health care needs compared to CSHCN without ASD, and children without disabilities (Karpur et al., 2019). Unmet health care needs in the Karpur et al. (2019) study focused on medical, dental, vision, and mental health services as the outcome, but is like this current study in terms of age-related disparities for older children with ASD. The added feature of the current study extends the focus of service utilization to educational sectors and the association of lack of health care (i.e., medical home care) and lack of current receipt of educational services.

While the NSCH does not solicit information from respondents on why children were *not currently* receiving services under one of these plans, transitions are a naturally occurring aspect of educational services. Current receipt of services under special education or EI plans (i.e., realized access) may be affected by children naturally aging out of EI programs at age 3, ineligibility for school-based services at EI transitions, and dismissal from special education programs based on ineligibility of IDEA-qualifying disabilities at re-evaluations which are mandated every three years in IDEA Part C (IDEA, 2004).

Parents also reported less support for transitions in their children's lives that represents continuous medical home care (e.g., adult community, guardianship, puberty, and quality of life in adulthood) (Carbone et al., 2010; AAP, 2002). This finding may highlight known gaps, or the waning

supports for children with ASD during transitive periods or as they age in both health care and educational settings. In health care, this transition occurs when children transition from pediatric to adult health care and the transfer of rights from parents to children. Medical transitions from pediatric to adult health care should begin around ages 12 to 14 years old (Hyman et al., 2020).

Within educational settings, transitions occur in high school to post-secondary education or vocational roles. Preparation for transition to post-secondary education or vocational roles begins when a student turns 14 years old (IDEA, 2004). This planning meeting is to determine what services and supports students with ASD will need for college and career readiness after high school (IDEA, 2004). At the age of 16, students with ASD may participate in their IEP meeting which outlines transition services as they prepare to finish high school. Multidisciplinary team approaches may shift (i.e., decrease) as students with ASD age and begin transition planning (Hendricks & Wehman, 2004). The most common educational team members facilitating transition meetings were special education teachers, followed by families, and were less frequently attended by speech-language pathologists, occupational therapists, and assistive technology specialists. These services are considered related services outlined in IDEA Part A that includes general information on IDEA's purpose and provisions (IDEA, 2004). Related services are services delivered to students with qualifying educational disabilities to benefit from special education programming and receive FAPE (IDEA, 2004). Such services include occupational, physical, or speech and language therapy, school nursing and health services, school psychological services, and transportation (IDEA, 2004). Educational teams determine the need for these related services to benefit from their specialized instruction. If students do not need related services delivered directly to students as part of their special education program, they may move to a consultative service model or be dismissed from these services. This may speak to the diminishing supports and services available to students with ASD as they age, both in educational and health care settings.

Child's Race/Ethnicity. Racial/ethnic differences exist based in ASD age at evaluation and age at diagnoses (Maenner et al., 2020). Race/ethnicity was a significant predisposing factor in predicting *ever* having special education or EI plans in multivariate models. Children with ASD in the Black and

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Other racial categories had significantly higher odds of reportedly *ever* having a special education or EI plan if their care did not meet AAP medical home criteria. Although this study found that Black children had more educational services use, a population-based study conducted by Hinojosa et al. (2016) examining racial/ethnic differences in IEP access among White, Black, Hispanic, and Multiracial children ages 6-17. Children from Black, Hispanic, and Multiracial groups had higher odds of IEP use if they had more family and neighborhood resources, comorbid conditions, increased condition severity, and health care needs. A controversial issue has been whether there is an overidentification of children from different racial groups in special education. This association may sound promising in terms of children's access to educational services, but these findings manifest questions about the racial/ethnic-associated differences inherent in personally-mediated racism. Personally-mediated racism originates from the assumptions and stereotypes about others' abilities based on their race/ethnicity (Jones, 2000). Race/ethnicity is often used as a proxy of socioeconomic status (i.e., poverty) or socio-cultural factors (e.g., urbanicity) to explain their contributions to the topic under study (Williams, 1994). Based on these assumptions, overidentification of children from non-White racial groups persists in special education.

National special education data shows under-representation of children from different racial groups including Black children (i.e., 14.8%) and Hispanic (24%) in IDEA Part B special education services under the autism educational category compared to 49.9% of White children ages 6-21 during the 2018-2019 school year (U.S. Department of Education, 2020a). Black children received IDEA Part B special education services under educational categories of specific learning disability category, speech, or language impairment, followed by other health impairment (U.S. Department of Education, 2020b). When compared to all students with disabilities, disparities persisted in the identification of 8.7% of Black children under the autism educational category compared to 10.51% for all other students with disabilities (U.S. Department of Education, 2020b). Appropriate identification in the educational setting translates into educational programming under special education plans that uniquely represent characteristics and presentation of ASD in educational settings.

Total Children in Households. Having three or more children in households was associated with significantly lower odds of *ever* having special education or EI plans for children without care that met AAP medical home criteria. Children with ASD who the only children in households are more likely to receive ASD services (i.e., school-based, and non-school based) that those with sibling(s) (Karp et al., 2018). Karp et al. (2018) dichotomized this variable based on whether children with ASD reportedly had siblings in the home or not, whereas this current study categorized the number of children in households (i.e., 1-2 and 3 or more children) with 3 or more children predicative of lower odds of *ever* having special education or EI plans. Karp et al. (2018) concluded these findings demonstrate the caregiving demands related of children with ASD and balancing additional children in the household.

Maternal Health Status. Mothers who reportedly had less than excellent or very good health were found to have lower odds of *ever* having or currently receiving services under special education or EI plans. Maternal health status has been studied extensively in mothers of children with ASD. (Bourke-Taylor et al., 2013) and higher responsibility, distress, anxiety, and depression (Foody, James, & Leader, 2015). Mothers of children with ID have been linked to poorer maternal well-being and increased maternal stress (Eisenhower, Baker, & Blacher, 2005) and increased physical health problems (Gallagher & Whiteley, 2012). Both studies cited children's behavioral problems as substantial bases for decreased maternal health. This finding is also consistent with other studies examining maternal health and leisure and social participation for mothers of children with ASD (Rizk, Pizur-Barnekow, & Darragh, 2011). Karp et al. (2018) found that parents experienced clinically significant levels of stress caring for children with ASD. Their sample consisted of caregivers of children with ASD, with 83% of their study sample being mothers. Increased parental stress was significantly associated with lower odds of receiving ASD intervention services (i.e., inside school or outside of school) (Karp et al., 2018).

Family Structure. DeRigne and Porterfield (2010) examined employment changes and how the medical home may support employment for married and single mothers of CSHCN. Medical home variables that included having a usual source of care, family-centered care, effective care coordination, and receiving needed referrals were found to decrease the relative risk of employment disruption (i.e.,

reducing hours) by 51%. The relative risk of terminating their employment was reduced by 64%. Single-parent homes must manage competing financial demands caring for children with disabilities. Estimated costs of care for children with ASD who have a comorbid condition (e.g., ID) are approximately $2.4 million in the U.S. and approximately $1.4 million for children with ASD without ID (CDC, 2016). Significant expenses incurred for children with ASD included special education services and loss of parental productivity (Buescher et al., 2014), outpatient services (e.g., therapies, dental, vision, or chiropractic services), hospital services (e.g., ED visits or inpatient admissions), prescription medications, home health, durable medical equipment (DME), and other unknown costs (Thomas, Parish, & Williams, 2014). Loss of parental productivity results from employment disruptions due to the nature of their children's conditions, in which the associated features of their ASDs are likely more challenging. Often these families rely on paid employment to manage out-of-pocket costs associated with ASD, access employee benefits (i.e., insurance), and managing other costs such as food, clothing, housing, or other dependents in their households. Employment disruptions such as schools that call single parents frequently for children's challenging behaviors during work hours compromises single parents' abilities to manage all these demands. Conversely, married mothers with spouses who participated in the study were found to have incongruent expectations in roles (Johnson & Simpson, 2013). Mothers were receiving less help than they expected, had perceived unmet need for how their family operated, and lacked support from their spouses (e.g., inconsistent or different ways of reinforcing children's behavior plans) that were different sources of stress than non-married mothers of children with ASD (Johnson & Simpson, 2013). Being a single mother of a child with ASD has also been associated with unmet routine preventative care and mental health care or counseling for their children (Chiri & Warfield, 2012).

Enabling Factors.

Insurance Type. Insurance type is an essential antecedent for quality medical home access, and children with public or other insurance types, even private insurance, display unmet needs. The accessibility criteria of an AAP medical home describe that the medical home should accept all insurance types (AAP, 2002). Benevides, Caretta, and Lane (2016) found that children with ASD with public

insurance had lower odds of unmet therapy needs compared to those with private insurance, but higher odds of unmet therapy needs compared to public and private insurance. The current study classified children with public and private insurance as having public insurance to capture children who may have lapses in their insurance coverage and rely on public insurance during these lapses. Children with ASD in the current study who had public insurance had approximately four times greater odds of reportedly *ever* having special education or an EI plan if they did not have care that met AAP medical home criteria. This finding is not surprising considering the enabling access barriers, such as insurance type, that are generally not antecedents for educational services accessible through special education or EI plans. In educational settings, insurance type is not a prerequisite for accessing EI services or special education and related services in the public school setting. These are part of the affordances mandated by IDEA Part B and C for children (IDEA, 2004). Although public insurance has shown to be protective, Zickafoose et al. (2011) found disadvantages in receipt of medical home care components between children with public versus private insurance types. Forty-five percent of children with public insurance received three out of the five medical home components while those with private insurance received all five medical home components. Children with public insurance had the lowest prevalence of family-centered care.

Income Level. Children with ASD in the 199% FPL or less category had significantly lower odds of *ever* having a special education or an EI plan if their care did not meet AAP medical home criteria. Poverty is a factor that typically yields poorer service use outcomes for cases that fall into lower SES categories (Corr, Santos, & Fowler, 2015). Kogan et al. 2008 asserted the need for primary medical homes for families of children with ASD may alleviate the family burden associated with access, unmet needs, and increased employment, and time families spending providing care to children with ASD.

Need Factors.

Ages at ASD Diagnoses. Age at ASD diagnoses was significantly associated with *ever* having special education or EI plan for children without care that met AAP medical home criteria. Children who were diagnosed at older ages with ASD had significantly lower odds of *ever* having special education or EI plans if their care did not meet AAP medical home criteria. Children with decreased ASD severity or

average/higher IQ or language skills may not be identified until they enter school when differences between same-aged peers become more pronounced (Hyman et al., 2020). Maenner et al. (2020) found the median age for first ASD evaluations ranged from 29 months to 46 months among the 11 surveillance states. In addition, 38% of children with ASD with higher IQ scores (i.e., >70) were evaluated by 36 months compared to 58% of children with lower IQ scores (i.e., ≤70). Co-occurring symptoms and conditions may also delay ASD diagnoses as children receive other diagnoses that make it difficult to differentiate ASD. These include ID, learning disabilities, ADHD, anxiety disorders, or speech and language disorders (Hyman et al., 2020). In addition, families may be unsure of ASD symptoms or typical child development and not express concerns to pediatricians early enough to warrant evaluation for ASD or other developmental delays. Racial disparities in early ASD evaluation identification has been shown with White (non-Hispanic) children more likely to receive an ASD diagnosis compared with Black (non-Hispanic) children and Hispanic children. Forty-five percent of White (non-Hispanic) children were likely to have comprehensive evaluations by 36 months compared with Black (non-Hispanic) children (40%) and Hispanic children (43%). (Maenner et al., 2020).

The medical home is a crucial component in families' ability to access the array of EI services: early identification, screening, and assessment; care coordination; medical services (e.g., diagnostic and evaluation services only); family education and support; special education; skilled therapies; social work; and assistive technology (e.g., services and equipment) (Ad). Pediatricians working with children with disabilities and their families have a critical role in the medical home to increase referral to EI services. The pediatrician must be familiar with services and resources within the community for children and families and assist in coordination and collaboration with families and professionals in developing the IFSP. With evidence actively supporting the efficacy of EI, pediatric medical homes are called to assertively build collaborative relationships with IDEA Part C programs (Adams, Tapia, & The Council on Children with Disabilities, 2013).

Public school systems are also governed by federal and state mandates where eligibility criteria for entry into special education programming are regulated by IDEA Part B. For children with ASD,

specifically, this becomes challenging surrounding medical ASD diagnoses and the educational ASD disability area. Current diagnostic criteria for the medical diagnosis of ASD is based on criteria from the DSM-5 (APA, 2013). The educational ASD classification is based on whether a student meets criteria outlined in the educational disability area of ASD defined by IDEA Part B (IDEA, 2004). Children who receive services in public school systems, such as related services (e.g., occupational therapy, speech therapy, and physical therapy), receive these services to benefit from their specially designed instruction under their IEP. This is a challenge for health care professionals and families where their definitions of the prescription and use of specialized therapies differ from educational systems.

CSHCN status. Children with ASD, who were not classified as CSHCN, had higher odds of *not currently* receiving services under special education or EI plans. These children were approximately 2.5 times more likely to not receive services currently under special education or EI plans if their medical home care did not meet AAP criteria. One rationale for the decreased likelihood of current receipt of services under special education or EI plans for children with ASD who were not a CSHCN may be the distribution of children based on ASD severity. It is important to note that approximately 6% of children with ASD were without the CSHCN identifier in the estimation sample for *not currently* receiving services under special education or EI plans (n=1,248). Approximately 9% of children were reported to have severe ASD, and it is likely that given the distribution of children with mild or moderate ASD (i.e., 93%), most of these children were CSHCN. CSHCN have been less likely to have a medical home, and they were less likely to receive comprehensive or coordinated care compared to children without SHCN (Long, Cabral, & Garg, 2013). Children with ASD, however, have similar unmet service needs compared to other CSHCN (Benevides , Caretta, & Lane, 2016; Benevides, Caretta, & Lane, 2017), despite the clinical presentations and resulting impairments. CSHCN have disadvantages related to race/ethnicity that produces increased unmet need in dental, mental, and allied health care (Ngui & Flores, 2007).

Limitations

Threats to Internal Validity

Generalizability. This is a national survey based on responses derived from caregivers to the NSCH. Caregivers' report on their children's diagnoses, their health care experience, services received in the school setting, and personal demographic information (e.g., income, family structure, number of children in household, ages of children residing in household, relationship to subject child) may affect the validity of their responses when providing this information. In addition, selection bias may be potential threat. Many of the NSCH survey questions also ask parents to respond about events that occurred, "During the past 12 months…" This may also increase validity of responses based on the length of time respondents are asked to think back to as they respond to a variety of survey questions.

Threats to External Validity

Sampling Validity. This study identifies disparities in health (i.e., medical home care) and educational (i.e., *ever* had and *not currently* receiving services under a special education or an EI plan) services for children with ASD. The NSCH is a robust data source on health and health-related topics for children living in the U.S. and the District of Columbia, but there are constraints. For example, 49% of children with ASD in this study's target population who *ever* had a special education or an EI plan were White. The extent that predisposing, enabling, enabling-vulnerability, and need factors can be generalized may insufficiently inform policies and practices aimed at ameliorating disparities in an increasingly diverse U.S. population.

The study samples included children with ASD who *ever* had or were *not currently* utilizing services under special education or EI plans. Although public schools are required to provides special education services for all students with an IDEA-qualifying disability, even for students who are attending home-schools or private schools, the NSCH does not provide data on school type that may have influenced their access to educational services, either *ever* having special education or EI plans and whether or not they were currently receiving services under one of these plans. The NSCH also does not obtain information for reasons children were *not currently* receiving services under a special education or EI plan. These may include ineligibility for EI or special education services, dismissal from services

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under IDEA, or refusing or declining to give consent for their eligible children to receive special education services.

The small sample of minority children with ASD in the NSCH (i.e., Black and Other) also make it difficult to generalize these findings. Given the challenges for children in these racial/ethnic groups, oversampling children from other races/ethnicities underscore the importance of reducing barriers for minority children and families. These have implications for developing and delivering coordinated care between medical homes and educational services that are responsive to children and families in these groups.

Measurement. This NSCH is based on "parent-reported" data since the 2016 and 2017 NSCH are completed by a parent, guardian, or other adults familiar with children's health and health care (CAHMI, n.d.). Validity and authenticity of parent-reported ASD via virtual platforms has been supported (Daniels et al., 2012).

Time. This study used the first combined NSCH dataset of the newly redesigned NSCH beginning in 2016. Children in this study's samples who were diagnosed with ASD before the release of the DSM-5 may also have impacted their access to *ever* having and *not currently* receiving services under special education or EI plans, although children diagnosed with ASD under DSM-IV would likely receive ASD diagnoses under DSM-5 (Mazurek et al., 2017).

Implications

Future Research. For children to receive EI services, they must be identified with disabilities or delays and evaluated to determine eligibility for services based on state-specific EI criteria. Future research may include controlling for state-specific EI eligibility criteria that may affect children *ever* having or currently receiving services under EI plans. Less stringent state-specific EI criteria may result in greater likelihood of accessing educational services, either *ever* having or their current receipt under EI plans.

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Practice. The crux of this study targeted the link between medical home care and educational services for children with ASD. It is apparent that systems that are governed under different federal and state mandates will be challenged in how they collaborate. EI eligibility criteria that vary by state along with health care infrastructure increases complexity of forging relationships regulated at the federal and state levels. Children with ASD spend a significant amount of their lives in educational settings in which the need for connections between health care and educational settings are important (AAP, 2007b). Golnik, Ireland, & Borowsky (2009) found that 70% of pediatricians' ASD-specific training occurred mostly through continuing medical education, with the least amount of training during medical school (i.e., 37%). The health care workforce is not equipped to meet the demands of children and families with ASD if most of their training occurs by independently pursuing continuing education. Therefore, ASD-specific training for pediatricians embedded in medical school curriculum may reduce the knowledge gaps and increase professional competence to meet the needs of children and families. These systems require coordination, whether medically-related or educationally-based to create balance within the doctor/family/school triad (Sheppard & Vitalone-Raccaro, 2016; AAP, 2007a, AAP, 2007b).

Communication challenges between providers and families exist around sharing developmental concerns, (Jimenez et al., 2012), limited time and reimbursement, families' understanding of developmental screening questions delaying EI referrals by pediatricians, and families' pursuit of EI referrals (Jimenez et al., 2014). The CDC's "Learn the Signs. Act Early." public program is a way to increase families' capacity to track their children's development, monitor their developmental milestones, and knowledgably exchange information or share concerns with their pediatric providers. This may increase families' capability to address concerns about their children's development with their providers that may route them to comprehensive evaluations and EI services sooner, especially for families from under-resourced or minority groups (Graybill et al., 2016).

Policy. The AAP has a recommended schedule for assessments and screenings from infancy to adolescence including ASD-specific screening at the 9-, 18-, and 24- months well-child visits (AAP,

2020). The periodicity schedule also includes recommended maternal depression screenings at the 1-, 2-, 4-, and 6-month well-child visits, but no further maternal mental or physical health screenings beyond the 6-month visit. Medical homes should establish systems to implement maternal health screenings and coordinate services and resources for mothers who have or are at risk for maternal depression caring for children with ASD or other disabilities. This upholds AAP ideals of family-centered care by supporting the child and family along with continuity of care with the recognition of waning supports and services for children into adolescence and adulthood. Aligning with family-centered care, the current study also found that households with more than three children had lower odds of *ever* having or currently receiving services under special education or EI plans. Medical home providers should be cognizant of children's family composition when multiple children reside in households, along with maternal stress, when they make recommendations or referrals.

The medical home variable constructed for this study differs from the NSCH medical home definition and other studies that have constructed their own variable within the NSCH survey structure. This study used a very stringent definition of medical home care. Children with ASD with missing information on at least one variable, and all remaining variables had valid responses, were coded as, "Care that does not meet AAP medical home criteria." In order to be coded as, "Missing," in this study, children with ASD were required have no valid responses on all five medical home components (i.e., personal doctor or nurse, usual source of care, family-centered care, problems getting referrals when needed, and effective care coordination, when needed). The medical home variable created for this study proposes a novel method of capturing a highly complex construct within the parameters of a complex survey design using available data. The definition of medical home care in this study also may reflect a need for policies that push for this type of optimal medical home care.

Conclusion

This study used Andersen's behavioral model of health services use and the vulnerability domain (Andersen, 1995; Andersen, Davidson, & Baumeister, 2013; Gelberg, Andersen, & Leake, 2000). The

foundational premise of the Andersen behavioral model of health services use was that service utilization will vary depending on the degree of families' discretion of resources (Andersen, 1968). When discretion is high, utilization will be driven by predisposing and enabling factors whereas lower discretion will be driven by need factors.

The predisposing factors were the most influential variables for both access types in this study. One consideration may be the degree of discretion (i.e., high, intermediate, or low) associated with educational services utilization and who determines the discretionary levels. Health and educational sectors may define these services' discretionary levels differently and families will exercise their own discretion associated with educational services utilization. In educational sectors, access to special education or EI services is considered low discretion. For children under 3 years old, those who are not identified as children with or at risk for disabilities cannot access EI services that can improve developmental outcomes later in life. For students with ASD in the school setting receiving services under special education plans, they will have no protections under IDEA Part C if they are not identified as students with IDEA-qualifying disabilities. They will be subject to state and school-specific academic standards without proper supplementary aides and services and program modifications and supports within the general or alternative curriculum. Determination of eligibility for special education also opens doors to related services (e.g., occupational, physical, and speech therapies) in the educational environment, to benefit from their specially designed instruction. Therefore, the discretion of educational services utilization, from the educational sector's perspective is low, which makes service use driven by need factors. Families' definition of educational services use may likely align with educational sectors as these services are important supports for success in these settings. With the literature demonstrating the variability of pediatricians' knowledge, perceptions, attitudes, and collaborative barriers with educational programming, the level of discretion may be underestimated (i.e., high) in health care systems, which makes service use driven more by predisposing factors, as shown in this study.

Pediatricians in the medical home have significant roles care coordination with multiple providers servicing children with ASD and their families, as in EI or school systems, to facilitate meeting the needs

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of children and their families. Whether in the context of EI or public school systems, pediatric medical home providers are responsible for assuring the following services are accessible to children with ASD and their families: a medical home, screening, surveillance, and diagnosis, referrals, diagnoses and eligibility, participation in multidisciplinary assessment, advocacy, IFSP or IEP development, coordinating medical services, and supporting families. Building strong, collaborative relationships within EI programs, and, once they attend school, within doctor/family/school triad is integral to collaboratively addressing the health and educational needs of children with ASD and their families.

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APPENDIX A:

The Case for a Life Course Approach

In September 2018, I proposed a study on the association between care in a medical home and receipt of educational services in children with ASD using the theoretical framework, Timeline, Timing, Environment, & Equity (T2E2) (Fine & Kotelchuck, 2010; Lu & Halfon, 2003). The pervasive and chronic nature of ASD requires a longitudinal approach to care (Lubetsky, Handen, Lutetsky, & McGonigle, 2014; Shahidullah, Azad, Mezher, McClain, & McIntyre, 2018).

When I proposed in September, I did not comprehend what applying this model would realistically entail. I was motivated by the Bethell et al. (2014) paper. Life course research is limited to examining cross-sectional influences of health and disease early and throughout the life course currently, given the scarcity of longitudinal and population-based data (Russ, Larson, Tullis, & Halfon, 2014). One prevailing practice in life course research is gleaning from cross-sectional, population-based data, such as the NSCH, (Russ, Larson, Tullis, &, Halfon, 2014), while recognizing cross-sectional nature of the Cross-sectional studies yield prevalence and associational findings useful for developing future hypotheses and launching new inquiries when longitudinal data become available (Buka, Rosenthal, & Lacy, 2018; Bethell et al., 2014). In "Optimizing Health and Health Care Systems for Children with Special Health Care Needs Using the Life Course Perspective," Bethell et al. (2014) presented findings from published, cross-sectional, population-based studies using the 2009/2010 National Survey-Children with Special Health Care Needs (NS-CSHCN) and the 2011/2012 NSCH framed within T2E2 (Fine & Kotelchuck, 2010). Examples included, "Prevalence of CSHCN across age groups: by complexity and presence of EBD (p. 471)", "Prevalence of young children at high risk for DBS [developmental, behavioral, or social] delays who also have an early intervention plan: by whether standardized developmental and behavioral screening (SDBS) occurred in the past 12 months (p. 471)", "Prevalence of youth CSHCN whose parents report having to cut back or stop working due to child's health needs, by receipt of transition services (p. 472)", and "Prevalence of children with two or more ACEs, by CSHCN status and age" (p. 472)).

The issues surrounding the theoretical framework and the fit of the data became clearer when I began preparing variables from the 2016 NSCH, and later the 2016/2017 NSCH. The ability to interact with the data directly and begin to code my variables proposed for this study required a level of attention to detail and the intermediate variables that make up the final variables used in the analyses for this study. I looked at every possible combination of responses and traced codes back and forth until I arrived at the final codes for each variable. The coding of each variable, examining their intermediate variables, the levels for both intermediate and final variables, and all while holding them up to the T2E2 model was where it became profoundly clear on why using this theory was not going to work.

The proposal acknowledged critical periods for young children, school-age children, and adolescents (i.e., ages 1-17) benefiting from EI services and school-based services. The concept underpinning "timing" in T2E2 with access to EI and school-based supports theoretically make sense. Survey questions about children's use of IFSPs and IEPs in the dataset and my coding scheme could not be explained by "timing" in the way that it is represented in T2E2. I briefly considered how the "…ever had a special education or EI plan" could work within T2E2 because it does not encompass, "During the past 12 months," as many of the 2016/2017 NSCH questions begin asking parents. Wrapping the "timing" concept around the potential findings would not be accurate of this aspect of the model and to make inferences about children with ASD and their educational service use as this theory asserts.

I understand that a variable like a child's chronological age, their age at ASD diagnosis, and their CSHCN identification would influence their later health (i.e., having a medical home and having educational services). The cross-sectional time point, the survey questions specifically designed to solicit this information from respondents, and the construction of these variables (i.e., age at ASD diagnosis and CSHCN) do not correctly depict what is meant by how today's experiences and exposures influence tomorrow's health from a measurement standpoint.

At the proposal meeting, timeline was proposed to assess the overall health status of mothers of children with current ASD through 2016/2017 NSCH survey items. A variable like Overall Health Status of the Mother, cannot work under Timeline (i.e. "Health trajectories are particularly affected during

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critical or sensitive periods of development."). The type of questions that respondents answer, and the levels of their responses, do not accurately or measurably depict the way Timeline is conceptualized, aside from the fact that it is cross-sectional. The coding of this variable included very general questions about maternal mental health, maternal physical health, and relationship to the SC.

Another challenge is that there is not a roadmap (i.e., existing literature on how to test this model with this type of data). All the literature is conceptual, which made it even harder than I anticipated going into analyses. This was an experience, and I think that it was crucial in helping me put this idea to rest. I needed to see that, or I would feel like I was leaving something on the table by not getting the time and space to try, and owning this dissertation, which I have now.

APPENDIX B:

Protection of Human Subjects

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Modification/Amendment Notice of IRB Exempt Status

Date: December 6, 2018

To: Kris Barnekow, PhD
Dept: Occupational Science & Technology

CC: Sabrin Rizk

IRB#: 19.094
Title: Effects of Medical Home Access on Receipt of Educational Services in Children with Autism Spectrum Disorder (ASD)

After review of your proposed changes to the research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol still meets the criteria for Exempt Status under Category 4 as governed by 45 CFR 46.101 subpart b, and your protocol has received modification/amendment approval for:

- Changes to dataset that will be used in analysis

This protocol has been approved as exempt for three years and IRB approval will expire on October 16, 2021. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, please respond to the IRB's status request that will be sent by email approximately two weeks before the expiration date. If the study is closed or completed before the IRB expiration date, you may notify the IRB by sending an email to irbinfo@uwm.edu with the study number and the status, so we can keep our study records accurate.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. The principal investigator is responsible for adhering to the policies and guidelines set forth by the UWM IRB, maintaining proper documentation of study records and promptly reporting to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Respectfully,

Melody Harries

Melody Harries
IRB Administrator

Sabrin Rizk

Place of Birth: Milwaukee, WI

Education:

      B.S. University of Wisconsin-Milwaukee, May 2007
      Major: Occupational Therapy

      M.S. University of Wisconsin-Milwaukee, August 2008

Dissertation Title: Unmet Medical Home Needs and Educational Services Access in Children with Autism Spectrum Disorder