The Impact of Medical Home on Outcomes for Children with Special Health Care Needs

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Copyright Statement

Abstract

The dominant pediatric model of patient-centered care is the medical home (MH). According to the American Academy of Pediatrics (2017), the MH is an *approach* to healthcare, which places patient needs and preferences at the center of care decisions; provides accessible, comprehensive, and continuous care; and ensures patients receive necessary referrals and care coordination. This dissertation examines the MH model's relationship to pediatric outcomes, with a particular focus on the social, emotional, behavioral, health, and educational needs of children with special health care needs.

- **Study One:** The first study is a systematic review of the MH literature with special attention to the types of outcomes measured in individual studies. Eighty-two studies were reviewed, 65 of which were not captured in past reviews. Only 57.2% of outcomes were statistically significantly associated with the MH model; however, the MH model's relationship with these outcomes appeared to be in the desired direction for 86% of the significant outcomes captured in this review.
- **Study Two:** The second study investigated the role of MH in a discrete, objective, educational outcome. Using the 2011/2012 National Survey of Children's Health, this study examined the MH's role in public early intervention (EI) receipt among a nationally representative sample of children birth to five, finding significantly reduced odds of public EI receipt for children with a MH.
- **Study Three:** Using the 2009/2010 National Survey of Children with Special Health Care Needs, the third study investigated how the MH impacts the role of condition type on six child health outcomes (preventive services receipt; unmet need for health care; ease of use of community-based services; special education receipt; unmet need for family support services; and shared decision-making). This study determined that MH-consistent care was most beneficial for children with developmental disabilities and multiple conditions, while also showing positive effects for children with physical and mental health conditions.

While the MH model's effect on pediatric outcomes was generally positive, counterintuitive and non-significant effects were also noted. More research is needed to determine the model's effectiveness in everyday medical care settings and to determine best practices for dissemination and implementation of the model.

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Dedication

This dissertation is dedicated to Dr. Leona Kanter. Without your persistent advice, support, and encouragement, I would never have pursued this academic path. Thank you for the many ways you have mentored me and made an impact in my life.

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List of Abbreviations

- ACE, Adverse Childhood Experiences
- ADHD, Attention Deficit Hyperactivity Disorder
- aOR, adjusted odds ratio
- aPR, adjusted prevalence ratio
- ASD, Autism Spectrum Disorder
- B, Beta
- CAHPS, Consumer Assessment of Healthcare Providers and Systems
- CHIPRA, Children's Health Insurance Program Reauthorization Act of 2009
- CI, Confidence Interval
- CMC, children with medical complexity
- CP, Cerebral palsy
- CSHCN, Children with Special Healthcare Needs
- CYSHCN, Children & Youth with Special Health Care Needs
- DD, Developmental Disability
- DS, Down Syndrome
- ED, Emergency Department
- FFS, Fee For Service
- FNS, Family Needs Survey
- FPL, Federal poverty level
- FS II R, Functional Status II-Revised
- HCT, Health Care Transition
- HPV, Human Papilloma Virus
- HRSA, Health Resources & Services Administration
- HS, High School
- ID, Intellectual Disability
- IFS, Impact on Family Scale
- IL, Illinois
- LBW, Low Birth Weight
- MEPS, Medical Expenditure Panel Survey
- MH, Medical Home
- MHC, Mental Health Condition
- MHI, Medical Home Index
- MO, months
- NC, North Carolina
- NCQA, National Council on Quality Assurance
- NDE, Natural direct effect
- NIE, Natural indirect effect
- NSCH, National Survey of Children's Health
- NS-CSHCN, National Survey of Children with Special Health Care Needs
- NYC, New York City
- P3C, Parent's Perception of Primary Care
- PCCM, Primary Care Case Management
- PCP, primary care practice
- PHC, Physical Health Condition
- RCT, Randomized Control Trial
- RX, prescription medication
- SC, South Carolina
- SDM, Shared decision-making
- SE, Standard Error
- SF-12, Short Form Health Survey
- SHCN, Special Health Care Needs
- US, United States
- Y, years
- YSHCN, Youth with Special Health Care Needs

CHAPTER 1. LITERATURE REVIEW AND STATEMENT OF PURPOSE

Patient-Centered Care

A shift is occurring in the American healthcare system. Expert-centered models of care have long-dominated the landscape; however, the U.S. healthcare system is slowly shifting towards more patient-centered models of care (Berwick, 2009; Wagner et al. 2012). Patient-centered care (PCC) is a model of healthcare delivery that places the patient's needs, preferences, values, and culture at the center of care decisions and delivery. True PCC occurs when providers communicate with patients in culturally appropriate ways and acknowledge the unique expertise that each patient has concerning his or her own health (Patient-Centered Primary Care Collaborative [PCPCC], 2015). In the context of PCC, the provider-patient relationship changes from one in which physicians are viewed as the sole experts to a true partnership between patient and provider, where both partners possess a specific knowledge and make care decisions together.

Patient-centered research abounds in both the pediatric and adult healthcare literature covering topics such as patient satisfaction, patient perceptions of quality, physician-patient communication, care coordination, the patient-centered medical home (PCMH), and shared-decision making (Rathert, Wyrich, & Boren, 2013; Joosten et al. 2008; Alexander & Bae, 2012; Kuo et al., 2012). The Institute of Medicine (IOM), the Institute for Healthcare Improvement, and the Affordable Care Act have all endorsed PCC as a way to improve healthcare access, quality, and costs (IOM, 2014; Johnson et al. 2008; Cassidy, 2010). The establishment of the Patient-Centered Outcomes Research Institute (PCORI) in 2010 further emphasizes this shift in the U.S. healthcare system away from expert-centered models of care towards patient-centered models of care.

Medical Home Model of Care

The dominant model of PCC in pediatrics is the medical home (MH), which originated in pediatrics in the 1960s as an approach to ensure that children and youth with special healthcare needs (CYSHCN) had a centralized location for their healthcare records (National Center for Medical Home Implementation, 2017). Currently the MH model expands beyond healthcare record-keeping; rather the MH model now includes healthcare delivery focused on providing quality care to patients in a clinic or physician practice for both pediatric and adult populations. In pediatrics specifically, the concept of a MH has evolved from its original focus on CYSHCN to an approach for all children. The American Academy of Pediatrics [AAP] defines a MH as a healthcare approach that is:

- Accessible: Care is easy for the child and family to obtain, including geographic access and insurance accommodation.
- Family-centered: The family is recognized and acknowledged as the primary caregiver and support for the child, ensuring that all medical decisions are made in true partnership with the family.
- Continuous: The same primary care clinician cares for the child from infancy through young adulthood, providing assistance and support to transition to adult care.
- Comprehensive: Preventive, primary, and specialty care are provided to the child and family.
- Coordinated: A care plan is created in partnership with the family and communicated with all health care clinicians and necessary community agencies and organizations.
- Compassionate: Genuine concern for the well-being of a child and family are emphasized and addressed.

- Culturally Effective: The family and child's culture, language, beliefs, and traditions are recognized, valued, and respected (AAP, 2017).

According to the AAP (2017), a MH is not a physical place but is instead an *approach* to healthcare that places the patient's needs and preferences at the center of care decisions; provides accessible, comprehensive, and continuous care as needed; and ensures patients receive necessary referrals and care coordination. While a number of healthcare organizations (e.g., Health Resources & Services Administration [HRSA], n.d.) offer official PCMH accreditation, many practices and clinics utilize the MH model of care to provide high quality healthcare to their patients without seeking formal accreditation. Because this approach is utilized in both pediatric and adult healthcare, both *with* and *without* accreditation in a wide variety of settings, it is important to differentiate between the MH model of care and those clinical sites or physician practices achieving varying levels of PCMH accreditation. In this dissertation, the term "medical home" refers to the MH model of care and those physicians, clinics, and practices employing the model regardless of accreditation.

A true MH is characterized by care that is family and patient-centered, comprehensive, coordinated, and accessible when the patient needs it (PCPCC, 2015). Alternatively, when children lack a usual source of culturally-competent care, experience lapses in healthcare, or have issues obtaining needed referrals and services, they are at risk of unnecessary health complications, inappropriate utilization of healthcare services (e.g., emergency department), poorer health outcomes, and missed linkages to community-based services (Homer et al., 2008). Provision of care meeting MH criteria is a best practice in pediatrics and is particularly important for children with special healthcare needs (CSHCN) (AAP, 2002).

The Importance of Medical Home for Children with Special Healthcare Needs

The Maternal and Child Health Bureau defines 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). An estimated 20% of children in the United States have some sort of special healthcare need (National Survey of Children's Health [NSCH], 2011/2012). Because CSHCN often require care from multiple providers including specialists and therapists, the presence or absence of a MH is especially important to ensure children receive quality care that is receptive to their and their family's needs and preferences, thus helping them to reach their optimal development (Homer et al. 2008; Cassidy, 2010). Unfortunately, only 58.8% of children nationwide receive care that meets MH criteria, with certain vulnerable groups experiencing lower rates of medical home access (NSCH, 2011/2012).

Disparities in Access to Medical Home

Disparities for CSHCN. Most of the pediatric literature focuses on access to MH, recognizing the model as a standard for high quality healthcare for *all* children. Disparities in access to MH are widely documented at the child, family, and community levels both for typically developing children and for CSHCN. Past research indicates that CSHCN have *reduced* access to a MH compared to non-CSHCN (Zickafoose & Davis, 2013; Strickland et al. 2009). In a study investigating why certain vulnerable groups lack care that meets the standard of a quality MH, Zickafoose and Davis (2013) found that when compared to non-CSHCN, **caregivers of CSHCN** were less likely to receive care coordination when needed and more likely to report problems obtaining necessary referrals. Disparities in access to MH for other groups, however, were driven by disparities in family-centered care (FCC), with White, English-speaking, privately insured respondents reporting greater access to MH and receipt of FCC.

Child level disparities. In addition to disparities experienced by CSHCN, past research demonstrates that **uninsured** (Stevens, Seid, Pickering, & Tsai, 2010; Kogan et al., 2010; DeCamp, Choi, & Davis, 2011; Zickafoose & Davis 2013; Strickland et al., 2009) and **under-insured** (Kogan et al., 2010; DeCamp et al., 2011) children are less likely to receive healthcare meeting MH criteria. **Publicly insured** children experience reduced access to a MH when compared to privately insured children, which is particularly concerning as many CSHCN and children with disabilities are insured through public sources (Zickafoose & Davis, 2013; Davidoff, 2004). Additionally, **racial and ethnic disparities** in MH access abound with non-white children consistently having reduced MH access (Stevens et al., 2010; Aysola, Orav, & Ayanian, 2011; Zickafoose & Davis, 2013; Strickland et al. 2009). Finally, **age** is significantly associated with MH access with caregivers of children birth to five more likely to report access than caregivers of older children (6-11 and 12-17) (Zickafoose, Gebremariam, & Davis, 2012; Strickland et al., 2009; Singh et al., 2009).

Family level disparities. Disparities also exist at the family level. Children whose parents **report lower levels of education** (Stevens et al., 2010), children in **non-English speaking households** (Stevens et al., 2010; Aysola et al., 2011; DeCamp et al., 2011; Zickafoose & Davis, 2013; Strickland et al., 2009), and children residing in households with **lower incomes** (Stevens et al., 2010; DeCamp et al., 2011; Strickland et al., 2009) are all less likely to receive care from a MH compared to children in otherwise comparable households. **Family structure** is also significantly associated with MH access; children living in two-parent households are more likely to have MH access than children living in single-mother or other households (Zickafoose et al., 2012).

Community level disparities. In addition to the existing child and family level disparities in MH access, place-based factors impact MH access. Past research indicates that negative parental perceptions of **neighborhood characteristics** (Aysola et al., 2011) and **residential mobility** (i.e. moving multiple times a year) were negatively associated with MH access (Busacker & Kasehagen 2012). There is also substantial **state by state variation** in MH access (Zickafoose et al., 2012; Singh, Strickland, Ghandour, & van Dyck, 2009) with state level **poverty** rates, rates of **foreign-born population**, rates of **non-English population**, Medicaid **eligibility policy**, and state **workforce capacity** all impacting access to MH (Singh et al., 2009). Regional variation also exists with children in the Midwest, South, and West less likely to receive care meeting all MH criteria when compared to children in the Northeast (Stevens et al., 2010).

Intersectional disparities. CSHCN hold **multiple identities** at the individual, family, and community levels. As a result of these intersecting identities, CSHCN and their families often find themselves facing increased barriers to accessing appropriate care and services that meet their needs (Chen & Cisler, 2011). Reduced access to MH is particularly problematic for CSHCN as they often have increased social, emotional, behavioral, and healthcare needs compared to their typically developing peers (Blackman, Gurka, Gurka, & Oliver, 2011). These needs, combined with their intersectional identities, place these children at greater risk for poor outcomes later in life (Stein, Siegel, & Bauman, 2010).

The Medical Home's Relationship to Child Outcomes

Studies documenting disparities in MH access are troubling because this model of care is promoted as a way to improve health and quality of life outcomes for children and their families. Indeed, several studies demonstrate benefits of the MH model of care for pediatric patients. Among the general pediatric population, the MH is positively associated with appropriate health services utilization and positive child health outcomes including HPV vaccination (Sara Test, Caskey, & Ranking, 2013; Kramer & Dunlop, 2012;); developmental screening (Richmond, Tran, & Berry, 2014); reduced emergency department (ED) use (Roberts & Mitchell, 1990; Gadomski, Jenkins, & Nichols, 1998); and improved health-related quality of life (Stevens, Vane, & Cousineau, 2011). The MH model shows promise for CSHCN also. Among CSHCN, the MH has been linked to fewer unmet health care needs (Knapp et al., 2012; Strickland et al., 2009; Miller et al., 2013), fewer unmet needs for family support services (Strickland et al., 2009; Miller, Nugent, Gaboda, & Russell, 2013), reduced emergency department use (Lin, Margolis, Yu, & Adirim, 2014; Diedhiou, Probst, Hardin, Martin, & Xirasagar, 2010; Martin et al., 2007; Raphael et al., 2013), less delayed or forgone care (Strickland et al., 2009), reduced hospitalizations (Raphael et al., 2013), and fewer missed school days (Knapp et al., 2012).

While the MH model of care demonstrates promise for improving pediatric outcomes, not all studies reveal positive impacts. Other studies show no association or negative associations between MH and child outcomes. While one study found a positive link between MH and early childhood vaccines (Santoli, Rodewald, Maes, Battaglia, & Coronado, 1999), three other studies found no association (Allred, Wooten, & Kong, 2007; Ortega, Stewart, Dowshen, & Katz, 2000; Roberts & Mitchell, 1990). In a study linking the MH to fewer unmet health needs and fewer missed school days among kids with ADHD, children with a MH were significantly *less* likely to receive necessary mental healthcare (Knapp et al., 2012).

Several studies also examine the MH's ability to mediate or moderate negative impacts of certain predisposing, enabling, and need-based factors. In a study of low birth weight (LBW) children, MH care did not moderate the effect of LBW status on functional status (Salas, Xaverius, & Chang, 2012). Similarly, MH status made no difference in receipt of preventive services among immigrant children (Belue, Degboe, Miranda, & Francis, 2012), and in a study of CSHCN, MH status did not mediate the impact of race on unmet physical and mental healthcare needs (Bennett, Rankin, & Rosenberg, 2012). Richmond, Tran, and Berry (2012) also found that racial disparities in transition services persisted despite MH access. The wide variety of studies investigating the impact of MH on child outcomes and their mixed results brings into question the MH's utility for meeting the diverse needs of CSHCN and their families, particularly those who experience other forms of social disadvantage.

Limitations of Existing Literature

Reviewing the MH literature, particularly for pediatric populations, reveals some important gaps. While a great deal of research exists on access to the MH and on the care model's relationship to varying child health services and outcomes, few sources synthesize the data in a meaningful way (Homer et al., 2008; Hadland & Long, 2014). Furthermore, no systematic reviews have investigated the model's relationship to outcomes for both CSHCN and non-CSHCN.

Several general systematic reviews on MH explore inconsistencies for adults and note the following limitations: 1) over-reliance on cross-sectional data; 2) inconsistent operationalization and measurement of the medical home concept (practice self-report, patient self-report, medical record audits); and 3) poor understanding of the specific contexts and mechanisms in a MH that lead to improved outcomes (Alexander & Bae, 2012; Jackson et al. 2013; Hoff, Weller, & DePuccio, 2012). Additionally, little attention has been paid to ways MHs affect social, emotional, behavioral, and educational outcomes for children in need. There is an increasing recognition that collaboration between physical health services and these supports can improve the developmental trajectories of at-risk children (Institution of Medicine and National Research Council, 2015).

Statement of Purpose

With these gaps in the literature in mind, this dissertation investigated the MH's role in meeting the social, emotional, behavioral, health, and educational needs of children with disabilities.

Study one. The first study is a systematic review of the MH literature with special attention to the types of outcomes measured in individual studies. The MH appears to demonstrate great promise in improving traditional clinical outcomes such as emergency department use and physician behaviors like developmental screening. The evidence is less clear for social, emotional, behavioral, and educational impacts and outcomes that are of interest for children with developmental disabilities or delays. As such, this review categorically classifies outcomes (traditional and non-traditional [social, emotional, behavioral, educational]) and determines the MH's usefulness in helping children achieve positive outcomes. This review also classifies studies as using either subjective or objective outcome variables. Many studies investigate discrete, measurable, objective outcomes (ED use, hospitalization, vaccination, etc.) (Hadland & Long, 2014; Hoff et al., 2012); however, many studies also investigate more subjective outcomes such as patient or family satisfaction, quality of care, and patient/family experiences (Alexander & Bae, 2012; Hoff et al., 2012; Jackson et al., 2013). This review explores the direction of effects for all outcomes and discusses implications for future research.

Study two. The second study investigates the role of MH in predicting a discrete, objective, educational outcome. Using the 2011/2012 National Survey of Children's Health, this study examines the MH's role in public early intervention receipt among children birth to five years old. Few studies to date have examined the role of the MH specifically for early childhood populations. Those studying the MH's role for young children display mixed results: one study found no difference in functional status between LBW children with and without a medical home (Salas et al., 2012); another found a positive association between developmental screening and MH (Richmond et al., 2014). Few studies report data on the role health services play in linking children to early intervention; two studies examined the role of a usual source of care, but findings were conflicting (Marshall, Kirby, & Gorski, 2016; McManus, Magnusson, & Rosenberg, 2014). No study to date has reported on how receiving care that meets MH criteria may impact a child's odds of public early intervention receipt. Study two fills that gap.

Study three. The third study investigates how the MH impacts the role of condition type on six specific child health outcomes. These outcomes fall into the broad areas of health services (receipt of recommended preventive services; unmet need for care), community-based services (ease of use of community-based services); educational services (IEP or IFSP receipt); and family support (unmet need for family support services; shared decision-making). Several studies have used the National Survey of Children with Special Health Care Needs to document access, quality, and outcome disparities for CSHCN based on the type of special health care need (SHCN) they have (Cheak-Zamora & Thullen, 2017; Vohra, Madhavan, & St. Peter, 2014; DuPaul, Carson, & Fu, 2013; Nageswaran, Parish, Rose, & Grady, 2011; Nageswaran, Silver, &

Stein, 2008). These studies commonly group conditions together as physical health conditions (PHC), mental health conditions (MHC), developmental disabilities (DD), and various combinations of these health conditions. Disparities driven by condition-type also exist with children with MHCs, DDs, and multiple conditions experiencing reduced access to MH (Cheak-Zamora & Thullen, 2017; DuPaul et al., 2013; Knapp et al., 2013). While these studies have documented disparities in MH access for children with different types of conditions, no studies have investigated how the MH may operate differentially for children with different types of SHCNs. Study three fills that gap by investigating how the medical home operates for children with PHCs, MHCs, DDs, and Multiple conditions.

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CHAPTER 2. SYSTEMATIC REVIEW OF THE MEDICAL HOME'S RELATIONSHIP TO TRADITIONAL AND NON-TRADITIONAL OUTCOMES FOR CSHCN

The medical home (MH) is a primary care delivery model hallmarked by care that is accessible, coordinated, patient and family-centered, and as continuous and comprehensive as possible. The MH is promoted as a way to improve health outcomes, promote quality care, and reduce costs in the American healthcare system.[1,2] The American Academy of Pediatrics (AAP), the Maternal & Child Health Bureau, and Healthy People 2020 endorse the MH model of care as one way to meet the needs of children with special healthcare needs (CSHCN) and their families.[3–5] In its simplest form, many professionals treat the MH concept as synonymous with high quality primary care[6]; however, the AAP defines the MH model as care that is "accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective."[3] Operationalized, the MH model is characterized by excellent physician/family relations (family-centered, compassionate, culturally effective), a care coordination or referral mechanism for necessary outside services (continuous, comprehensive, coordinated), and care that is available when the patient or family needs it (accessible).

The MH demonstrates great promise in improving traditional clinical outcomes such as inappropriate emergency department use[7,8]; unnecessary hospitalizations[9,10]; and physician behaviors like developmental monitoring, developmental screening, and anticipatory guidance.[11,12] Additionally, this model of care is associated with fewer caregiver-reported unmet needs for health and family support services[13–15] and less delayed or forgone care.[15] The evidence, however, is less clear for MH's impact on childhood social, emotional, behavioral, and educational outcomes, which may be considered non-traditional outcomes that are not historically associated with health services research[13,16] Additionally, while the MH shows positive effects for children in general, the evidence is less positive for children from underrepresented and vulnerable groups[16–18]

Compared to typically developing children, CSHCN and their families are at an increased risk of financial burden, issues related to family functioning, barriers to community services and specialty care, and higher burdens of unmet need.[19–21] Since the Joint Principles of the Patient-Centered Medical Home were released in 2007, several systematic reviews have been conducted focusing on the MH model's traditional clinical impacts including outcomes such as access to care, hospitalizations, treatment adherence, inappropriate emergency department use, and costs[22–24] Within the pediatric literature, Homer et al.[25] investigated the impact of the MH for CSHCN, while more recently, Hadland et al.[27] investigated its impacts for non-CSHCN. However, the majority of studies captured in both reviews investigated traditional clinical outcomes and patient/family satisfaction with few studies investigating non-traditional outcomes. Furthermore, the most recent systematic review on the MH for CSHCN is nearly ten years old.[25] More research is needed to determine how this model of care impacts social, emotional, behavioral, and educational outcomes for CSHCN and their families.

This systematic review seeks to extend our understanding of the pediatric MH model by examining studies of both CSHCN and non-CSHCN. An updated review is particularly timely as the 2010 passage of the Affordable Care Act ushered in a new era of healthcare innovation and a new emphasis on patient-centered care in the United States. The literature surrounding the MH for children is heterogeneous. This review examines this literature through a new lens and considers potential patterns related to MHs connecting children and families to social, emotional, behavioral, and educational services. Specifically, this review examines the MH's relationship to these less traditional outcomes and impacts while also reviewing how MH receipt predicts more traditional clinical and medical outcomes. Comparisons are made in the model's predictions for each type of outcome. The model's impacts on outcomes for underrepresented and vulnerable groups is also considered. This review also examines how the MH is associated with subjective versus objective outcomes. The goal of this review is to improve our understanding of how the medical home operates for different types of pediatric outcomes and to describe the role that the MH plays in helping meet the needs of the whole child and family beyond traditional clinical outcomes.

Method

Inclusion and exclusion criteria

I performed a systematic review of the medical literature for studies investigating the impact of the MH model of care on pediatric outcomes. Studies examining the relationship between MH and social, emotional, behavioral, educational, or health outcomes for children ages 0-21 in the United States were considered for inclusion in this systematic review. While other systematic reviews to date use definitions of the MH that align with definitions from the Agency for Healthcare Research and Quality[24] or the Patient-Centered Primary Care Collaborative[23], this review was explicitly concerned with the MH's impact on pediatric outcomes. As a result, the American Academy of Pediatrics' (AAP) definition of MH, which describes care that is "accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective"[3] was used for this review. Realizing that the ideal of a MH is hard to achieve, however, this review cast a broad net and included studies describing MHs with one or more components of the model. Studies only investigating single concepts such as family-centered care or care coordination that do not tie these phenomena to the larger MH concept were excluded.

Outcomes were defined broadly to include traditional clinical outcomes, other service receipt, child-level outcomes, and family-level outcomes. Because this review is specifically interested in how the MH operates for a spectrum of outcomes of interest to CSHCN and their families, outcomes were classified as traditional or non-traditional. Traditional outcomes include medical and health-related outcomes historically investigated in the pediatric and health services literature (hospitalizations, emergency department use, utilization, satisfaction, etc.) Non-traditional outcomes include outcomes not traditionally investigated in the health services literature (family burden, community-based services, educational outcomes, etc.).

Additionally, outcomes were classified as either subjective, objective, or validated measures. To my knowledge, no systematic review or study has investigated the MH's impact on health and related outcomes through this lens. As a result, classifying outcomes as subjective or objective is exploratory. Objective outcomes are defined as discrete, observable occurrences; examples include hospitalizations, emergency department use, and receipt of early intervention. Classification of outcomes as subjective or objective should not be confused with the concept of self-reported outcomes. While many studies of MH rely on patient or caregiver self-report, the classification of an objective outcome refers to an occurrence that *could* be recorded objectively (e.g. via insurance claims or other patient records) and occurred at discrete points in time even if the outcome was actually self-reported. Alternatively, subjective outcomes included perceptions and opinions; examples include satisfaction and perceived quality of care. To qualify as subjective, an outcome must have been explicitly measured as a perception or opinion, or the measure must have been constructed using a Likert scale. For example, "my child's physician never, sometimes, usually, always spends enough time with my child."[26] Validated measure is a new classification that emerged during the extraction and coding process. These measures were multi-question scales or measures that often examined opinions, perceptions, and verifiable truths alongside one another using a variety of questions including Likert scales. Examining each individual measure was unfeasible; as a result, a separate category was created for these outcomes.

The AAP delivered its first official statement on the importance of the MH for child health in 1992[27]; as a result, only studies published in or after 1992 were included in this review. Both qualitative and quantitative studies were considered for inclusion in this review; however, theoretical and conceptual articles, policy statements, opinion or editorial articles, and systematic reviews and meta-analyses were excluded. Finally, for quantitative studies, MH had to be an independent variable under investigation; studies solely examining access to MH as an outcome were excluded.

Search strategy

Databases included Proquest Central, Global Newsstream, and selected health databases in Ebscohost (Academic Search Complete, Alt HealthWatch, Child Development & Adolescent Studies, CINAHL Plus with Full Text, Consumer Health Complete, Education Source, ERIC, Health Source, MEDLINE, PycARTICLES, Psychology and Behavioral Sciences Collection, PsycINFO, and Social Work Abstracts). Search terms included ("medical home"[Title/Abstract]) AND (child*[Title/Abstract] OR infan*[Title/Abstract] OR young*[Title/Abstract] OR toddler*[Title/Abstract] OR adoles*[Title/Abstract]). In addition to searching Proquest and Ebscohost databases, I performed ancestral reviews of key MH systematic reviews.[23–25,28]

Study selection

Figure 2.1 outlines the article selection process. I screened 1,391 titles/abstracts for inclusion in the systematic review and excluded non-empirical articles, solely adult-focused articles, duplicate articles, and articles that did not focus on MH as an independent variable. I assessed 149 full-text article for eligibility. Articles with ambiguous titles/abstracts were reviewed by myself and a research assistant (n=48). During the full-text stage of eligibility screening, articles were most commonly excluded due to their definition of MH (n=27). Studies were also excluded because: 1) the article was solely descriptive; 2) MH was not a predictor and was either the setting of the study or an outcome in the study; 3) the unit of measurement was not individual patients or families; 4) the article was not empirical (i.e., review articles, policy statements, conference proceedings); 5) the study was solely adult-focused or failed to disaggregate child & adult data; or 6) the study was conducted outside the United States.

Seventy-eight articles met inclusion criteria from the original systematic review search of Proquest & Ebsco databases. An additional four articles gleaned from a review of existing MH systematic reviews also met inclusion criteria. My initial search of both Proquest and Ebsco yielded 15 articles identified in previous systematic reviews[23–25,28]; 13 of those studies were included in this review. Two studies[29,30] previously identified in other reviews were excluded because authors used the term “medical home” as a synonym for primary care, demonstrating the evolution of the medical home concept and subsequent research in the past 20 years. The current updated review yielded 65 articles published on the MH model not previously captured in other reviews.

Data Extraction & Coding

The following data points were extracted from each included article: 1) study type; 2) MH setting; 3) definition and measurement of MH; 4) sample population; 5) sample age; 6) number of participants or observations in the sample; 7) study design; 8) main predictors; 9) outcomes; 10) outcome source; 11) objective/subjective outcome classifications; 12) traditional/non-traditional outcome classifications; 13) key findings; and 14) length of follow-up.

Study types were either survey-based, in which caregivers and participants were surveyed about their health care experiences, or practice-based studies, which were MH models implemented in health care settings. *MH settings* included actual health care settings and survey-based reports of health care settings. In survey-based studies, caregivers respond to questions about their child's care setting; however, researchers are unable to determine the exact care setting that a caregiver is describing or if a caregiver is thinking of a single provider or multiple providers in their answers. As a result, I could not determine the exact care setting that respondents were describing in survey-based studies. Based on these constraints, final categories for the MH setting data point included national survey data; local, state, regional survey data; primary care practice(s) or clinic(s); and specialty clinics for high-risk children, children with special health care needs, and/or children with medical complexity.

Definition and measurement of MH was either through a parent-reported measure, practice self-report (study authors report the setting is a medical home), or objective measurement through a state or national recognition program. Additional details for each study's definition and measurement were also noted (i.e. measure used; individual components of the model utilized). *Study population* was recorded per author report then grouped into mutually exclusive classification groups: CSHCN, non-institutionalized children, "at-risk" children, and Medicaid-specific populations. CSHCN included any study investigating high-risk patients, children with medical complexity, or children with specific conditions. Non-institutionalized children included any study investigating a general sample of children. "At-risk" was a term used by individual studies to describe children with low birth weight or who were at-risk due to socio-economic status. *Age* and *number of participants/observations* were recorded based on author-report; no classification system was created for these variables.

Study design categories were created based on author-reported designs and included cross-sectional, quasi-experimental, pre-post, cohort, randomized controlled trial, and retrospective. *Main predictors* were recorded based on author-report. The main predictor in all studies included a variation of the MH model; for studies in which MH was a covariate, or if the study explicitly investigated a specific demographic in addition to MH, these predictors were also recorded. Main predictors were recorded in detail; as a result, no classification system was created for this data point.

All *outcomes* were also recorded based on author report. After recording, they were first classified by the *source* of the outcome: parent self-report, chart review, or in some rare cases, both. Second, outcomes were classified as *objective, subjective, or validated-measure* as previously described. Third, outcomes were classified as *traditional, non-traditional, or mixed* based on earlier described definitions. *Key findings* were recorded for each outcome and included effect sizes, proportions, and significance levels. Length of *follow-up* was also recorded per author report. This data point was recorded verbatim, and meaning differed based on study design and execution. For some practice-based studies using self-report data or chart review, length of follow-up typically described the length of the MH intervention and time between pre and post measures. For other practice-based studies using claims data, length of follow-up referred to the observational period (i.e., 7 years of claims data).

As data extraction and coding progressed, two challenges emerged related to classifying outcomes. First, classifying outcomes as subjective or objective proved to be difficult as the majority of outcomes were parent/caregiver reported (n=409; 81.31%). While Likert-scale measured outcomes or opinion-based satisfaction measures were clearly subjective, other self-reported outcomes such as “unmet need in the past 12 months” or recalling discussions with physicians were less clear. While some may consider these outcomes as opinion or classify them as subjective due to potential recall bias, I chose to classify them as objective as they could have clearly taken place at a specific point in time. This is one unavoidable limitation of this study since the majority of included studies relied on caregiver reported outcomes data (81.31%). All chart review outcomes were classified as objective.

Second, outcomes differed widely across studies, contexts, and populations. To standardize reporting of key findings, all outcomes were classified as increased, decreased, non-significant, or significance not assessed. Desired effects were frequently context and study specific. While one can reasonably argue that reductions in family stress levels or increased levels of family centered care are always a positive effect, classifying utilization outcomes was less clear. For example, if children with asthma in a MH intervention had increased use of their rescue inhalers, some may view this as a negative effect as their asthma was not being well-controlled in other ways. However, if increased use of the rescue inhaler meant a reduction in unplanned visits to the emergency department, then the outcome of increased rescue inhaler usage could be viewed positively.[31] Furthermore, health economists and health services researchers often emphasize the goal of reducing utilization and costs of health care services; however, for certain populations and in certain contexts, increased utilization is viewed positively when it means children in need are accessing necessary care.

I reviewed and tabled the above data points for 82 articles. Twenty studies were reviewed by myself and a research assistant, and thirteen items from each study were compared for a total of 260 items (20 x 13). An 88% reliability rate was reached due to coding discrepancies for 32/260 items (percentage of agreement for individual coding items is located in Appendix 2.1).

These discrepancies were discussed and resolved between the two reviewers. I analyzed the results for themes and synthesized results.

Results

Definition and Measurement of MH

I identified 82 articles for inclusion in this systematic review (Figure 2.1). Table 2.1 includes descriptive counts and frequencies of selected study characteristics. The definition source and measurement of medical home in the majority of studies was parent self-report (n=57, 69.5%); followed by practice self-report (n=20, 24.4%); and objective measurement (n=5, 6.1%). Table 2.2 details the ways that included studies defined and/or implemented the MH model. Studies measuring medical home using parent self-report used a variety of survey measures including the National Survey of Children's Health (NSCH)/National Survey Children with Special Health Care Needs (NS-CSHCN) criteria (n=46); items from the Medical Expenditure Panel Survey (MEPS) (n=6); items from the Consumer Assessment of Health Plans Study (CAHPS) (n=2); and the Parent's Perception of Primary Care (P3C) (n=3).

Practice-reported categorization as a medical home was typically part of an ongoing quality improvement initiative. Common features of the MH in these studies included 1) multi-disciplinary teams; 2) care coordination; and 3) presence of a family or consumer advocate in the clinic. A few studies with practice-reported MH definition used a practice-report measure such as the Medical Home Index (MHI) (n=3) or the National Council on Quality Assurance (NCQA) self-assessment (n=1) to measure practice uptake of the medical home model and compare that measure to patient outcomes.[9,32,33] A small group of studies (n=5) were considered MHs based on an objective standard. Four of these studies were part of a state-certified MH initiative [31,34–36] while one study reported on 10 practices that had achieved Patient-Centered Medical Home recognition from the National Council on Quality Assurance.[37]

Study Settings

Studies were classified as either "practice-based" or "survey-based" studies. Practice-based studies reported results from an actual medical home intervention implemented in or in collaboration with a medical care setting (n=24; 29.3%; Table 2.1). The vast majority of studies included in this review, however, were survey-based (n=58; 70.7%). These studies either involved the use of National Survey Data like the MEPS, NSCH, or NS-CSHCN, or researchers surveyed a local, state, or regional sample of caregivers about their child's care. Forty-nine (59.8%) studies included in this review investigated the MH model of care utilizing national survey data. In addition to these large-scale, survey-based investigations, nine (11.0%) studies employed local, state, or regional surveys to question caregivers about their child's health, care, and access to resources and then examined various outcomes in relationship to the presence of MH or in relationship to reported levels of "medical homeness."

Practice-based studies (n=24, 29.3%) included traditional quality improvement initiatives designed to enhance patient care by utilizing MH principles (Table 2.1). These interventions took place in Primary Care Practices/Clinic (n=19, 23.1%) or in Specialty Clinics designed to meet the needs of "high-risk" patients, CSHCN, or children with medical complexity (CMC) (n=5, 6.1%). Among these practice-based studies, five explicitly investigated the medical home model by studying varying levels of care coordination. These care coordination models included external consultative models in which the care coordinator was housed outside the actual physician's office[38,39] office-based care coordination[40]; and telehealth care coordination models.[34,36] Also among practice-based MH models, three studies reported on the use of an “enriched” or “enhanced” medical home intervention in which a community health worker (CHW) visited patients and provided support, resources, and care coordination.[7,41,42]

Study Designs

The majority of studies utilized cross-sectional methods (72.0%). The remaining studies used quasi-experimental (8.5%); cohort (6.1%); pre-post (6.1%); and retrospective (2.4%) methodologies. Only four studies employed a randomized controlled trial design (4.9%). Three-quarters of practice-based studies (n=18) utilized a unique comparison or control group. Participants served as their own controls in the remaining six practice-based studies, all of which used pre-post or cohort methods. All survey-based studies used cross-sectional methodologies.

Outcomes

The 82 articles included in this review reported results for over 403 outcomes. Some studies reported on one or two outcomes for a specific population while other studies reported on several unique process, impact, and outcome measures for their samples (Table 2.3). Table 2.3 details specific studies that reported outcomes for more than one group of children indicated in parentheses. Roughly a quarter of included studies analyzed the MH’s relationship to pediatric outcomes for multiple groups of children (i.e., reporting outcomes for CSHCN, CSHCN with limitations, and CSHCN without limitations; CSHCN with autism and CSHCN w/o autism).

All outcomes were classified as either chart review (18.0%), parent-self report (81.2%), or both (.2%). One study collected outcomes data using both methods.[43] Chart review outcomes were extracted from children’s medical records, Medicaid claims data, or other billing data and were most common in practice-based studies. However, some local, state, or regional survey-based studies also used chart review to gather outcomes and then compare outcomes to parent self-reported MH status. Outcomes were parent self-report in most survey-based studies and in some practice-based studies.

Eighteen studies reported eight or more outcomes (Table 2.3). These studies often investigated several utilization and cost measures.[10,31,44–46] Some of these studies also investigated utilization and cost outcomes along with process and impact measures, which frequently included caregiver ratings of the physician, office staff, provider communication, ability to get needed care in a timely manner, and connection to outside resources.[36,38–40,47–50]

The MH model's relationship with pediatric outcomes appeared to be in the desired direction for 86% of the statistically significant outcomes captured in this review. The MH model was associated with potentially undesirable outcomes only 39 times. These outcomes frequently included increased service utilization,[31,48,51] and increased expenditures,[10,31,45,46,52] both of which could be viewed as positive or negative depending on vantage point. Three practice-based studies also reported lower post-scores for three caregiver-reported outcomes: caregiver satisfaction,[39] quality of caregiver's physical health,[47] and caregiver ever viewing the child's medical record.[49] National survey-based studies also produced some counterintuitive associations between the medical home and various outcomes such as reduced odds of mental health care receipt,[11,13] increased odds of uncontrolled asthma,[53] increased odds of no preventive dental visit,[54] and increased odds of missed school days.[55]

Traditional v. Non-Traditional

The breakdown of traditional and non-traditional outcomes was fairly equal with 246 outcomes categorized as traditional (50.83%), 222 outcomes categorized as non-traditional (45.87%), and 16 outcomes categorized as mixed (3.31%). Traditional outcomes included well-child visits, hospitalizations, costs, ED visits, prescription medication usage, child health status, vaccinations, satisfaction measures, and anticipatory guidance. Non-traditional outcomes were comprised of family outcomes such as family and caregiver functioning, missed work days, missed school days, mental health treatment, assistive technology, therapies, and community-based resources and services. Several studies examined unmet need for either "health care" or "family support services," which are two measures from the National Survey of Children's Health/National Survey of Children with Special Health Care Needs. Because the surveys operationalize these measures for a variety of services including both traditional and non-traditional outcomes these outcomes were categorized as mixed.

Subjective v. Objective

The majority of reported outcomes were objective point in time occurrences (n=351, 72.5%). These included events like hospitalizations, well-child visits, unmet needs, cost measures, missed days of work and/or school, and family outcomes such as financial needs and employment changes due to the child's condition. The remaining outcomes were classified as subjective (n=105, 21.7%). Subjective outcomes were based on caregiver opinion and were frequently measured using a Likert scale. Common subjective outcomes included family stress, satisfaction, healthcare transition, family-centered care, and shared decision-making. Twenty-eight outcomes (5.8%) were classified as validated measures, a new classification that emerged during the extraction process. These included the Beck Depression Inventory-II (BDI-II),[38] Family Support Scale (FSS),[38,47] Impact on Family Scale (IFS),[39,38,47] Short Form Health Survey (SF-12),[47,48] Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0),[56] and the Functional Status II-R (FS II-R).[38,39,47]

Outcomes for underrepresented and vulnerable groups.

Table 2.2 presents detailed descriptions of each included study's sample population. These specific groups were further classified into four groups presented in Table 2.1. Only 19 studies examined the impact of the MH for children generally. The remaining studies (76.8%) focused on CSHCN (generally or with specific conditions); children enrolled in Medicaid; or "at-risk" children. The majority of these studies reported outcomes for their sample only (i.e. children with asthma, autism, etc.), and results were generally in the desired direction or non-significant (Table 2.1).

Because so many studies investigated vulnerable populations, finding a way to qualitatively assess the MH's impact for underrepresented and vulnerable groups was challenging. However, a small number of studies (all using data from the NSCH or NS-CSHCN) explicitly analyzed the medical home's relationship to outcomes by comparing specific groups of children or by assessing MH as a mediator, moderator, or effect modifier for other demographic traits. These studies are presented in Table 2.4. In all but one of these studies, MH was not associated with the effect of the main predictor on the outcome. One study[57] investigated the relationship between MH and adverse childhood experiences and found that MH was able to moderate the relationship between total adverse childhood experiences (ACEs) and child well-being for children ages 6-11. MH was not able to attenuate differences in outcomes in the other studies investigating race/ethnicity[18,58]; immigrant status[59]; and condition type[16,60,61]

Meaningful Themes

Tables 2.5 and 2.6 outline the MH model's relationship to selected Health Care and Family Outcomes respectively.[11,13,32,35,41,44–46,54,59,62–64] Other investigated outcomes included preventive medical visits,[11,13,32,35,41,44–46,54,59,62–64]; dental care[11,35,45,46,54]; health care costs and expenditures[10,37,45,46,52,65]; caregiver satisfaction[36,38–40,47–50,66]; hospitalizations[7,9,10,31,33,35,37,39,43,45,46,49,50,63,65,67–69]; access[15,39,40,70]; missed days of work for caregivers and school for children[11,13,15,38,39,44,49,50,55,56,71]; care coordination measures[34,36,38,40,47]; outpatient utilization[31,38,39,44–46,48,50,65,68]; and receipt of specific needed services.[11,13,72,73] Several studies also investigated need[39] or unmet need for specific services.[11,13–15,18,48,54,61,66,74,75,75–78] Fewer studies investigated non-traditional social, emotional, behavioral, or educational outcomes (missed school days, unmet need for specific non-traditional services, and receipt of specific non-traditional services as noted above). As a result, I chose not to generalize results from these few studies to the medical home's relationship to these non-traditional outcomes. Family outcomes and health care outcomes were examined in several studies, so these results are highlighted in this review.

Although the weight of the evidence captured in this review indicated largely positive to neutral findings for the MH model's impact on outcomes generally, no apparent differences emerged in the effect of the MH model on subjective versus objective outcomes or on traditional versus non-traditional outcomes. For example, the MH's relationship to emergency department (ED) use (an objective, traditional health care outcome) was not significant in 13 studies; indicated reduced ED use in 13 instances; and was associated with increased ED use two times. For non-traditional outcomes (both objective and subjective), the MH's impact on selected family outcomes was similarly split. In one practice-based study and in four survey-based studies, the MH model was positively predictive of increased shared decision-making (Table 2.6). Alternatively, practice-based studies investigating the impact of the MH on parental reports of family centered care[34,36]; family stress scores[66]; perception of the care team and certain validated measures of family and caregiver functioning, all yielded non-significant findings.[47]

In other practice-based studies, the pattern of positive and non-significant findings continued. Farmer et al.[38] and Farmer et al.[37] investigated the model's impact on family needs. In the 2011 randomized controlled trial, the MH intervention predicted reduced overall needs, needs for information, support, need for help explaining the child's condition to others, need for community services, and financial needs. The 2005 study (a pre-post design) revealed non-significant associations between the MH intervention and family need for information, need for help explaining the child's condition to others, and need for community services but also revealed significant reduced need for help with family functioning. These differences demonstrate the potential for mixed findings due to study design, intensity, and quality. For example, the four RCTs[10,34,36,38] yielded significant associations between the MH model and 39 out of 56 outcomes (69.6%) while the literature generally indicated significant associations for only 57.2% of outcomes included in this review. Longitudinal practice-based studies that utilized claims data[31,51] also yielded a higher percentage of statistically significant outcomes (86.2%).

One striking theme emerged. Often in studies using national survey data, the MH model had an overwhelmingly positive effect on certain outcomes under investigation; however, when those same outcomes were investigated in a true medical care setting using the MH model, results were mixed. For example, studies utilizing national survey data to study family outcomes found consistently reduced odds of families providing and/or arranging a child's care,[79–81] work loss or other employment problems due to the child's care,[82–85] and financial problems due to the child's care.[79,85] Only three out of the 24 practice-based studies demonstrated positive impacts on family outcomes like reduced needs,[38,39] reduced impact on family,[38,39] and increased shared decision-making.[66]

This same pattern was also true for certain traditional health care outcomes like child health status (Table 2.5). Survey-based studies largely indicated increased levels of health and well-being and reduced odds of illness and disability. Alternatively, in three practice-based studies investigating four child health status outcomes[38,39,47] only one study yielded significant findings indicating that the MH was associated with caregiver-reported child health ratings.[38]

Another emergent theme was the impact of the MH model on physician behaviors (Table 2.5). Of measured "behaviors," the MH was non-significant for only three out of 29 outcomes. The majority of these outcomes were derived from survey-based studies. Four practice-based studies reported significant outcomes. Devries et al.[36] reported reduced inappropriate antibiotic use and increased appropriate antibiotic use. Three other studies found increased parental reports of having a written care plan post-intervention.[38,47,49]

Discussion

Since the AAP released its policy statement on the importance of the MH for children in 1992, research in this area has evolved tremendously. The earliest "medical home" studies treated medical home as synonymous with primary care.[29,30] The release of the Joint Principles of the Medical Home (2007) and the Affordable Care Act's passage in 2010 spurred renewed interest in the MH model, and research has accelerated since. The current review captured 65 articles (out of 82 included articles) not previously included in other systematic reviews of the MH literature and appears to be the first pediatric-focused review to include studies of CSHCN *and* non-CSHCN. Since the ACA, the acceleration of MH research has resulted in a majority of studies using cross-sectional methods (72.0%) and often utilizing local, state, regional, or national survey data (70.7%). Only 24 out of 82 studies (29.3%) included in this review actually took place in a medical practice setting.

Although study methods and design may be easily categorized, synthesizing the MH model's impact on pediatric outcomes as a whole is more challenging due to the large number and diversity of outcomes investigated. While earlier systematic reviews (including the current study) have generally examined the model for a broad range of outcomes, my review captured 82 studies examining over 400 outcomes, indicating a need for more focused reviews of the literature. For example, 23 studies investigated the MH's relationship to ED use; 19 studies investigated MH's impact on hospitalizations; 14 studies reported on family outcomes; and 10 studies investigated the model's role in reducing missed work days for caregivers and/or missed school days for pediatric patients. While the evidence for the MH model's impact on most outcomes was positive to neutral, meta-analyses may be needed to determine the strength of evidence for the MH on specific pediatric outcomes, particularly those that have been examined by multiple investigators.

In addition to the breadth of outcomes studied, there were almost as many statistically non-significant findings (n=207, 42.8%) as there were significant associations between the MH model and pediatric outcomes (n=275, 56.8%). While the MH model has enjoyed widespread support and produced a positive to neutral benefit for most significant outcomes in this review (86%), researchers can assume that the model is beneficial with only moderate certainty due to limitations of the literature.[86]

Over half of the studies included in this review (n=49, 59.8%) utilized national survey data. These surveys include extremely large sample sizes to reflect the national profile of children in the United States, and they have significant statistical power to detect differences in the MH's impact on a wide variety of outcomes. A number of practice-based studies utilized data from large health care systems or from insurance systems; these studies also had fairly large sample sizes, and many of them produced noticeable difference in outcomes between the MH and non-MH groups. Actual MH interventions conducted in smaller pediatric practices, however, did not have the benefit of large sample sizes. Furthermore, intervention intensity, quality, and length also differed across studies, which may explain non-significant findings in practice-based studies. Outcomes in these studies were frequently mixed; as a result, my ability to draw conclusions about the model's effectiveness in actual health care settings is limited.

The heterogeneity of results across outcomes is a reminder that while the MH concept has taken off in popularity, it is still a widely used term with minimal standardization across settings. National surveys like the NSCH, NS-CSHCN, and MEPS offer uniform definitions and reporting of the model's relationships to outcomes; however, these studies lack the ability to simulate the ways that care is delivered in the real world and the barriers families may face in accessing needed services. Furthermore, while practice-based studies employed many of the same common features like multidisciplinary teams, care coordination, a written care plan, and family-centered practices, levels and intensity of those interventions were neither uniform nor uniformly reported across studies making true comparisons challenging. For example, intervention length varied across studies, ranging from six months[38,39] to two years or more.[34,36,41,49,63,87] Implementation of the MH model also varied with some models providing families with home-based visits from a community health worker,[7,41,42]while others provided families with varying levels of care coordination (onsite, consultative, or telephone models).[34,36,38–40] A thorough exploration of the differences between individual studies and their implementation of the MH model is beyond the scope of this review; however, future reviews should examine how practice-based study characteristics may be tied to differences in outcomes.

To fully realize the possibilities of the MH model, more standardized practice-based research is needed. Large, representative, national survey-based studies indicated the benefits of the MH model conceptually; however, these findings can only inform health care practice and do not confirm the model's effectiveness in the health care setting. Practice-based studies yielded findings that were neutral to positive. RCTs yielded the most positive findings, suggesting that in ideal circumstances, the model can be quite effective. Longitudinal, claims-based studies also indicated significant results for the model's impact on health utilization and costs. The challenge for successful MH uptake and implementation is putting the conceptual definitions into practice in a sustainable way that works for all children and their families.

One notable result from this review is the way that the MH model is associated with physician behaviors. These relationships were overwhelmingly positive and significant, particularly when compared to the model's relationship to family outcomes, caregiver perceptions, caregiver behaviors, utilization measures, and child health status. Results appear to indicate that once physicians learn, implement, and incorporate a behavior into their practice workflow, the behavior is practiced at very high levels. The AAP has 63 health initiatives and counting, the majority of which have accompanying clinical guidelines and policy statements promoting their importance.[88] The 17th Edition of *Pediatric Clinical Practice Guidelines & Policies* includes over 1600 pages outlining these policies and best practices.[89] While this guidance is important, expecting pediatricians and health care providers to be "all things to all people" is unrealistic.[90]

The hope for the future of the medical home model for children, particularly those with special or complex health care needs is in physicians' willingness and ability to practice and implement interdisciplinary, family-centered models that help caregivers and patients learn and adopt pro-health behaviors and connect to necessary services. To help children and families achieve successful outcomes, it seems health care providers must collaborate with community health workers, public health educators, care coordinators, and families themselves. Furthermore, at a systems level, incentivizing and investing in these collaborations is critical to ensure families are informed and connected to necessary services so that children can achieve optimal outcomes.

Health care services should have the goal of improving, enhancing, and ensuring health for patients. If the MH model's relationship to these outcomes is non-significant roughly half of the time, this indicates a gap in existing research. The model's inconsistent relationship to actual health outcomes, service receipt, and family outcomes is troubling. As many studies in this review focused on CSHCN, "at-risk" children, or children with Medicaid, the mix of positive and non-significant results (and particularly results that indicate the MH cannot "make up" for disparities related to child demographics) is a reminder that the MH model and other similar health care innovations cannot reverse the effects of the social determinants of health. Despite this reality, the MH model holds promise and is worthy of further investigation.

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Figure 2.1 Article Selection

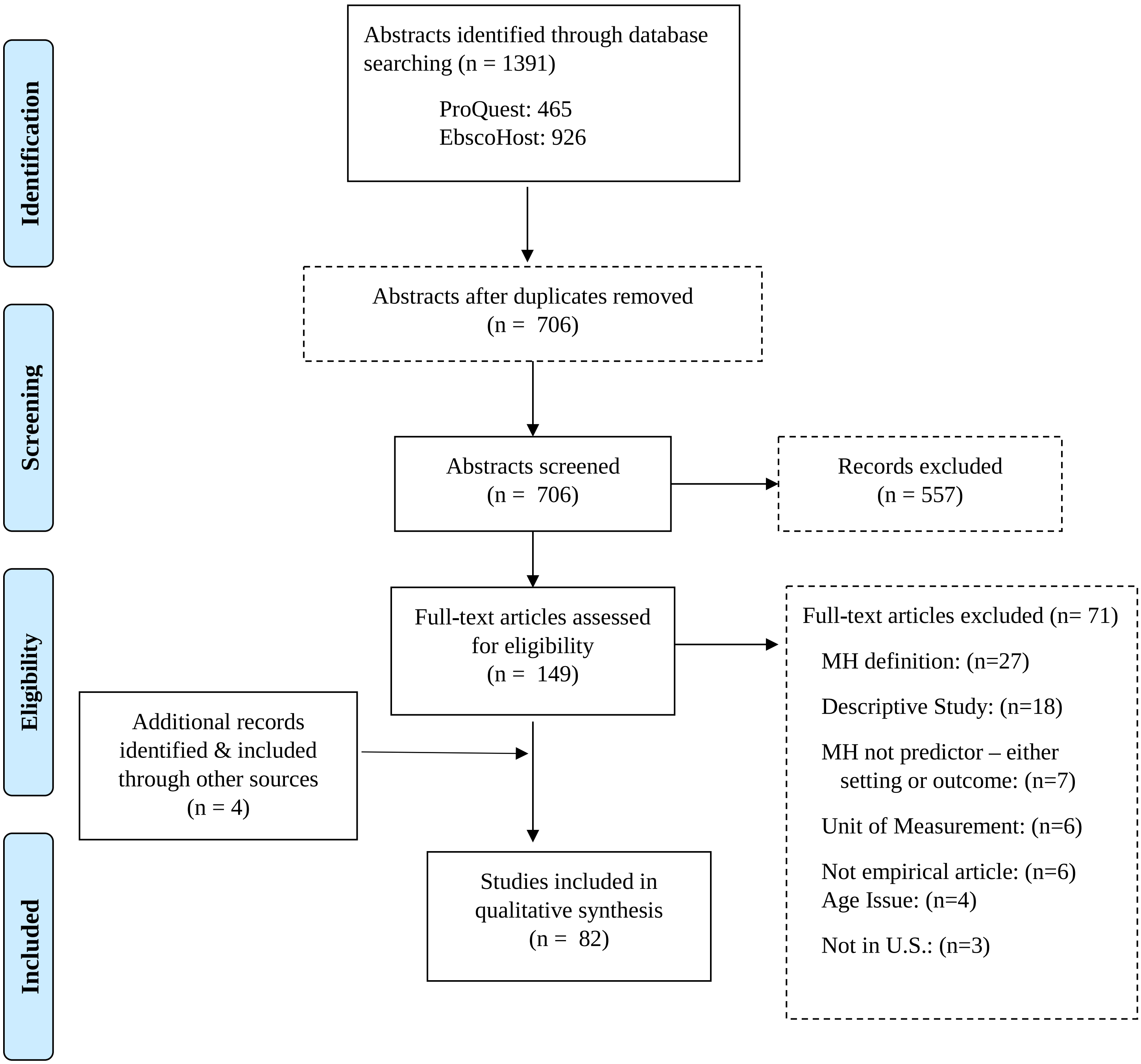

Table 2.1 Selected Descriptive Characteristics of Included Studies

	N	**%**
Study Type		
Survey-based	58	70.7%
Practice-based	24	29.3%
Medical Home Settings		
National Survey Data	49	59.8%
Primary Care Practice(s) or clinic(s)	19	23.2%
Local, State, Regional Survey data	9	11.0%
High-Risk/CSHCN/CMC clinic(s)	5	6.1%
Definition & Measurement of Medical Home		
Parent self-report	57	69.5%
Practice self-report	20	24.4%
Objective	5	6.1%
Sample Population		
CSHCN	53	64.6%
Non-institutionalized children	19	23.2%
"At-risk" children	5	6.1%
Medicaid-specific populations	5	6.1%
Study Design		
Cross-sectional	59	72.0%
Quasi-experimental	7	8.5%
Pre-post	5	6.1%
Cohort	5	6.1%
Randomized Controlled Trial (RCT)	4	4.9%
Retrospective	2	2.4%
Outcome Source		
Parent self-report	396	81.8%
Chart Review	87	18.0%
Both	1	0.2%
Objective or Subjective Outcome		
Objective	351	72.5%
Subjective	105	21.9%
Validated Measure	28	5.8%
Traditional Health Care Outcome		
Traditional	246	50.8%
Non-Traditional	222	45.9%
Mixed	16	3.3%
Key Findings		
Significant Effect	275	57.2%
Increased	140	28.9%
Reduced	135	27.9%
Not Significant ($p<.05$)*	207	42.8%
NA (significance not assessed)	2	.4%

CSHCN, Children with special health care needs; CMC, Children with medical complexity

Note: Descriptive statistics for sample population age is located in Appendix 2.2. Not all extracted data points are included in this table. *Martin et al., (2007) set significance at $p<.10$ due to small sample size.

Table 2.2 Detailed Characteristics of Included Studies

Author, Year	MH Setting	MH Definition	Study Design	Sample Population	Sample Age
Anugu et al., 2017	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Cohort	Pediatric patients - at risk for poor outcomes	0 to 17 y
Auger et al., 2012	Survey-based, Local, State, Regional Survey	P3C, Parent-self report	Cohort	Children w/asthma, hospitalized for asthma exacerbations	1 to 16 y
Aysola et al., 2013	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Non-institutionalized Children	0 to 17 y
Balistreri et al., 2015	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Non-institutionalized Children	6 to 17 y
Baruffi et al., 2005	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN – Hawaii	0 to 17 y
BeLue et al., 2012	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Non-institutionalized Children	0 to 17 y
Benedict et al., 2007	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN - who needed therapeutic or supportive services	0 to 17 y
Benedict et al., 2009	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN - with reported need for assistive technology	0 to 17 y
Bennett et al., 2012	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	CSHCN - Non-Hispanic White and Black	0 to 17 y
Bethell et al., 2014	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Non-institutionalized Children	0 to 17 y
Bottino et al., 2014	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Pre-post	Pediatric patients in Boston	24 mo
Boudreau et al., 2014	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Brown et al., 2015	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Quasi-experimental	Pediatric patients – infants in one low income neighborhood	<5 mo
Butler et al., 2014	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Children with 1) Physical Health Conditions (PHC); 2) Mental Health Conditions	2 to 17 y

				(MHC); 3) comorbid conditions (MHC and PHC)	
Cady et al., 2014	Practice-based, High Risk, CSHCN, CMC clinic(s)	State Certified, Objective	RCT	Children w/medical complexity	2 to 15 y
Cheak-Zamora et al., 2014	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Children w/ASD	0 to 17 y
Christensen et al., 2014	Practice-based, PCP or Clinic	MHI, NCQA self-assessment, practice self-report	Cross-sectional	Children continuously enrolled for 12 mo In FFS or PCCM Medicaid in 64 primary care practices in 3 states participating in CHIPRA Quality Demonstration Grant Program.	0 to 18 y
Coller et al., 2015	Survey-based, Local, State, Regional Survey	NS-CSHCN, Parent self-report	Cohort	Pediatric patients during an acute hospitalization last >24 hours	0 to 18 y
Cooley et al., 2009	Survey-based, Local, State, Regional Survey	MHI, practice self-report	Cross-sectional	Pediatric patients identified from 43 primary care practices, covered by a mix of 7 health plans in 5 states	1 to 19 y
Damiano et al., 2006	Survey-based, Local, State, Regional Survey	CAHPS, Parent self-report	Cross-sectional	Pediatric enrollees - Iowa Medicaid managed care	6 mo to 12 y
DeRigne et al., 2017	Survey-based, National Survey	MEPS, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
DeRigne et al., 2009	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN - married couple families	0 to 17 y
DeVries et al., 2012	Practice-based, PCP or Clinic	NCQA, Objective	Retrospective	Pediatric enrollees in Empire Blue Cross and Blue Shield who lived in NYC and its suburbs	0 to 17 y
Diedhiou et al., 2010	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Children w/asthma	0 to 17 y

Domino et al., 2009	Practice-based, PCP or Clinic	State, Certified Objective	Quasi-experimental	Children w/asthma	0 to 21 y
Downig et al., 2017	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Adolescents w/heart problems	12 to 17 y
Farmer et al., 2005	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Pre-post	Children with a complex chronic health condition in the rural Midwest	0 to 17 y
Farmer et al., 2011	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	RCT	Children w/chronic health conditions, enrolled in a Medicaid managed care plan, in a 16 county area	0 to 17 y
Golnik et al., 2012	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Quasi-experimental	Children w/ASD	0 to 18 y
Guerrero et al., 2011	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Non-institutionalized Children	0 to 5 y
Han et al., 2017	Survey-based, National Survey	MEPS, Parent self-report	Cross-sectional	Non-institutionalized Children	0 to 17 y
Hill et al., 2007	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN - Massachusetts, US	0 to 17 y
Hubner et al., 2016	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN w/ASD, CP, or DS	2 to 17 y
Jaudes et al., 2012	Practice-based, PCP or Clinic	State Certified, Objective	Cross-sectional	Foster children in Illinois w/Medicaid.	0 to 17 y
Kieckhefer et al., 2005	Survey-based, National Survey	MEPS, Parent self-report	Cross-sectional	Children w/asthma	0 to 17 y
Klitzner et al., 2010	Practice-based, High Risk, CSHCN, CMC clinic(s)	Practice-based MH initiative, Practice self-report	Pre-post	Children with complex disease	1 to 13 y
Knapp et al., 2012	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Children w/ADHD, ADHD & comorbidities	0 to 17 y
Kogan et al., 2008	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Children w/ASD	3 to 17 y
Kramer et al., 2012	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Adolescent girls	12 to 17 y
Kuo et al., 2013	Practice-based,	Practice-based MH initiative, Practice self-report	Cohort	Children w/medical complexity	Not Reported

	High Risk, CSHCN, CMC clinic(s)				
Lawson et al., 2011	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Cross-sectional	CSHCN – Massachusetts	1 to 20 y, at follow up
Lin et al., 2017	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Children w/asthma	0 to 17 y
Litt et al., 2014	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Long et al., 2011	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Children without SHCN	0 to 17 y
Looman et al., 2015	Practice-based, High Risk, CSHCN, CMC clinic(s)	Practice-based MH initiative, Practice self-report	RCT	Children with medical complexity	2 to 15 y
Lotstein et al., 2008	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	YSHCN	12 to 17 y
Lutiffya et al., 2010	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Children w/asthma	5 to 17 y
Martin et al., 2007	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Quasi-experimental	CSHCN	2 to 18 y
McGrath et al., 2009	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Children w/ASD, DS, or ID	0 to 17 y
McManus et al., 2013	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	YSHCN	12 to 17 y
McManus et al., 2016	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Medicaid-enrolled CSHCN	3 to 17 y
Miller et al., 2013	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Miller et al., 2015a	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Miller et al., 2015b	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Mosquera et al., 2014	Practice-based, High Risk, CSHCN, CMC clinic(s)	Practice-based MH initiative, Practice self-report	RCT	Pediatric Patients w/chronic illness & high health care use during past year	0 to 18 y
Okumura et al., 2009	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y

Palfrey et al., 2004	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Pre-post	CSHCN – Boston	0 to 18 y
Paradis et al., 2013	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Quasi-experimental	Children of low income mothers who gave birth to first child younger than 21 w/no previous involvement w/child welfare system	1 to 26 mo, at enrollment
Pati et al., 2015	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Quasi-experimental	Children at risk for poor health outcomes	<=2 y
Rankin et al., 2009	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Pre-post	CYSHCN in Illinois	0 to 20 y
Raphael et al., 2003	Survey-based, Local, State, Regional Survey	NSCH, Parent self-report	Cross-sectional	Children w/Sickle Cell Disease	1 to 17 y
Raphael et al., 2015	Survey-based, Local, State, Regional Survey	MHI, Practice self-report	Cross-sectional	Low income, publicly insured children w/chronic conditions	1 to 17 y
Raphael et al., 2016	Survey-based, Local, State, Regional Survey	CAHPS, Parent self-report	Cross-sectional	Low income, publicly insured children w/recent ED or urgent care visit	0 to 19 y
Romaire et al.., 2010	Survey-based, National Survey	MEPS, Parent self-report	Cross-sectional	Children w/at least 1 office-based visit for health care in past year	0 to 17 y
Romaire et al., 2012a	Survey-based, National Survey	MEPS, Parent self-report	Cross-sectional	Non-institutionalized Children	0 to 17 y
Romaire et al., 2012b	Survey-based, National Survey	MEPS, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Ronis et al., 2015	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	Children w/ADHD	4 to 17 y
Salas et al., 2012	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Low birth weight (LBW) children	0 to 5 y
Samuels et al., 2007	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Pre-post	CSHCN in 6 Boston practices.	Not Reported
Sara Test et al., 2017	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Adolescent girls	12 to 17 y

Schieve et al., 2011	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Non-institutionalized Children	4 to 17 y
Singhal et al., 2015	Survey-based, Local, State, Regional Survey	NSCH, Parent self-report	Cross-sectional	Non-institutionalized Children in Iowa	0 to 17 y
Smalley et al., 2014	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Stevens et al., 2010	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Children w/asthma	6 to 17 y
Stevens et al., 2011	Survey-based, Local, State, Regional Survey	P3C, Parent-self report	Cross-sectional	Low income, mostly Latino children affiliated with California safety-net Healthy Kids insurance program	2 to 18 y
Strickland et al., 2009	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Strickland et al., 2010	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Non-institutionalized Children	0 to 17 y
Toomey et al., 2007	Survey-based, National Survey	NSCH, Parent self-report	Cross-sectional	Children w/ADHD	6 to 17 y
Vasan et al., 2015	Practice-based, PCP or Clinic	P3C, Parent-self report	Retrospective	Pediatric patients - mostly African American & Medicaid insured children	0 to 21 y
Wang et al., 2007	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN	0 to 17 y
Willits et al., 2013	Survey-based, National Survey	NS-CSHCN, Parent self-report	Cross-sectional	CSHCN who attended traditional school	0 to 17 y
Wood et al., 2008	Practice-based, PCP or Clinic	Practice-based MH initiative, Practice self-report	Cohort	CYSHCN enrolled in Title V	0 to 12+ y

ADHD, Attention Deficit Hyperactivity Disorder; ASD, Autism Spectrum Disorder; CAHPS, Consumer Assessment of Healthcare Providers and Systems; CHIPRA, Children's Health Insurance Program Reauthorization Act of 2009; CMC, children with medical complexity; CMC, children with medical complexity; CP, Cerebral palsy; CSHCN, Children with Special Health Care Needs; CYSHCN, Children & Youth with Special Health Care Needs; DS, Down Syndrome; ED, Emergency Department; FFS, Fee For Service; ID, Intellectual Disability; LBW, Low Birth Weight; MEPS, Medical Expenditure Panel Survey; MH, medical home; MHI, Medical Home Index; MO, months; NCQA, National Council on Quality Assurance; NSCH, National Survey of Children's Health; NS-CSHCN, National Survey of Children with Special Healthcare Needs; NYC, New York City; P3C, Parent's Perception of Primary Care; PCCM, Primary Care Case Management; PCP, primary care practice; PHC, Physical health condition; RCT, Randomized Control Trial; SHCN, Special Health Care Needs; US, United States; Y, years; YSHCN, Youth with Special Health Care Needs

Note: Full APA style citations for all 82 included studies can be found in Appendix 4.3

Table 2.3 Number of Outcomes Reported for Included Articles

Author, Year	# of Outcomes Reported (details)
Practice-based	
Farmer et al, 2011	31+ reported (both between & within group outcomes; reports 3 between group outcomes - the rest were not significant)
Farmer et al, 2005	30
Domino et al, 2009	19 (reports 19 outcomes for 2 groups v. reference)
Palfrey et al, 2004	19
Mosquera et al, 2014	17
Kuo et al, 2013	14
Lawson et al, 2011	12
Rankin et al, 2009	12+ (22 items on satisfaction not reported)
Looman et al, 2015	8 (reports 8 outcomes for 2 groups v. reference - 16)
Wood et al, 2008	8
DeVries et al, 2012	6
Klitzner et al, 2010	6
Jaudes et al, 2012	5 (reports 5 outcomes for 2 groups - 10)
Golnik et al, 2012	4
Paradis et al, 2013	4
Brown et al, 2015	3
Cady et al, 2014	3 (reports 3 outcomes for 2 groups v. reference, MH as covariate)
Martin et al, 2007	3
Anugu et al, 2017	2
Christensen et al, 2014	2 (reports 2 outcomes in 2 locations)
Bottino et al, 2014	1
Pati et al, 2015	1 (reports 1 outcome for 2 age groups)
Samuels et al, 2007	1
Vasan et al, 2015	1 (MH covariate)
Survey Based	
Miller et al, 2013	18
Romaire et al, 2010	14
Romaire et al, 2012a	13
Romaire et al, 2012b	13 (reports 13 outcomes for 3 groups)
Aysola et al, 2013	10
Long et al, 2011	10
Stevens et al, 2011	9
Han et al, 2017	8 (reports 8 outcomes for 2 groups)
Stevens et al, 2010	6
Kogan et al, 2008	5 (reports 5 outcomes for 2 groups)
Salas et al, 2012	5 (MH as covariate, also investigated as effect modifier)
Downig et al, 2017	4
Knapp et al, 2012	4
Raphael et al, 2016	4

Strickland et al, 2009	4
Strickland et al, 2010	4
Cooley et al, 2009	3
Kieckhefer et al, 2005	3
Miller et al, 2015a	3
Miller et al, 2015b	3 (reports 3 outcomes, 1 measured 3 ways)
Benedict et al, 2007	2
Benedict et al, 2009	2
Bethell et al, 2014	2 (MH as covariate)
Coller et al, 2015	2
DeRigne et al, 2009	2 (reports 2 outcomes for 2 groups of children)
DeRigne et al, 2017	2 (reports 2 outcomes for mothers and fathers of 2 groups of children)
Kramer et al, 2012	2
Ronis et al, 2015	2
Raphael et al, 2003	2
Raphael et al, 2015	2
Auger et al, 2012	1
Balistreri et al, 2015	1 (reports 1 outcome for 2 age groups, 3 models for each age group)
Baruffi et al, 2005	1
BeLue et al, 2012	1
Bennett et al, 2012	1
Boudreau et al, 2014	1
Butler et al, 2014	1 (MH as covariate)
Cheak-Zamora et al, 2014	1
Damiano et al, 2006	1 (reports 1 outcome for 3 groups of children)
Diedhiou et al, 2010	1
Hill et al, 2007	1 (reports 1 outcome for 3 groups, MH as covariate)
Hubner et al, 2016	1 (reports 1 outcome measured 2 ways, MH as covariate)
Lin et al, 2017	1 (MH also investigated as effect modifier)
Litt et al, 2014	1 (MH as covariate)
Lotstein et al, 2008	1
Lutiffya et al, 2010	1
McGrath et al, 2009	1
McManus et al, 2013	1
McManus et al, 2016	1 (MH as covariate)
Okumura et al, 2009	1
Sara Test et al, 2017	1 (1 outcome reported for 6 groups)
Schieve et al, 2011	1 (1 outcome reported for 5 groups, MH as covariate)
Singhal et al, 2015	1
Smalley et al, 2014	1
Toomey et al, 2007	1 (1 outcome reported for 2 groups)
Wang et al, 2007	1
Willits et al, 2013	1

Guerrero et al, 2011	1
Total Outcomes	**403+ outcomes**

MH, Medical Home

Table 2.4 Characteristics of Studies Investigating the Medical Home's (MH) Impact for Underrepresented Groups

Author, Year	MH Setting	MH Definition	Main Predictors	Study Design	Sample Population	Outcomes	Key findings
Balistreri et al., 2015	Survey-based, National Survey	NSCH, Parent self-report	Adverse Childhood Experiences (ACE), MH as covariate	Cross-sectional	6 to 11 y, Non-institutionalized Children	Child Well-Being Index	MH was positively predictive of higher child well-being scores in all three models (B=.496, B=.510, B=.433, p<.001) and had a positive multiplicative interaction with ACES (B=.077, p<.05) for kids 6-11.
					11 to 17 y, Non-institutionalized Children		MH was similarly positively predictive of well-being for kids 12-17 (B=.583, B=.620, B=.621, p<.001), but no interaction effect was present.
BeLue et al., 2012	Survey-based, National Survey	NSCH, Parent self-report	Immigrant Status, MH as potential moderator	Cross-sectional	0 to 17 y Non-institutionalized Children	Preventive Services Receipt	Even w/MH, immigrant children (aOR: 1.00) were less likely to receive preventive services compared to non-immigrant children w/MH (aOR: 1.613, p<.05) . MH was unable to moderate the relationship between immigrant status and receipt of preventive care. Table 4 and p.6.
Bennett et al., 2012	Survey-based, National Survey	NSCH, Parent self-report	Race, MH as potential mediator	Cross-sectional	0 to 17 y, CSHCN - Non-Hispanic White and Black	Unmet need for medical, mental health, or other health care services	Higher odds of unmet need for black CSHCN due to reduced access to MH (OR, NIE: 1.2, CI: 1.1, 1.3); but even if black CSHCN had

							same level of access to MH, they would still have higher unmet needs than whites (OR, NDE: 1.6, CI: 1.1,2.4). MH cannot completely eliminate racial disparities in unmet need.
Butler et al., 2014	Survey-based, National Survey	NS-CSHCN, Parent self-report	Type of health condition, MH as covariate	Cross-sectional	2 to 17 y, Children with 1) PHC; 2) MHC; 3) comorbid conditions (MHC & PHC)	Shared decision-making	Families w/o MH were statistically significantly less likely to report SDM (B=-2.04, SE:.04, p= .000).
					2 to 17 y, Children with comorbid conditions (MHC & PHC)		Table 3 - w/MH in model, statistically significant difference in SDM persisted between Children w/comorbid conditions (B=-.35, SE: .05, p=.000) v. PHC only (ref)
					2 to 17 y, Children with MHC		Table 3 - w/MH in model, no statistically significant differences in SDM between MHC (B=-.09, SE: .06, p=.088) and PHC only (ref).
Lin et al., 2017	Survey-based, National Survey	NS-CSHCN, Parent self-report	Race, MH as potential effect modifier	Cross-sectional	0 to 17 y, Children w/asthma	One or more ED visits	Children with MH had reduced prevalence of ED services (aPR: .90, CI: .84, .96) - table 1, page 28.
					0 to 17 y, Children w/asthma Black v. White		MH was unable to modify the effect of race on ED use - Black v. White w/MH - aPR: 1.51, CI: 1.36, 1.67 - table 3, page 28.

					0 to 17 y, Children w/asthma Hispanic v. White		MH was not able to modify the effect of race on ED use - Hispanic v. White w/MH - aPR: 1.23, CI: 1.03, 1.46 - table 3, page 28.
Salas et al., 2012	Survey-based, National Survey	NSCH, Parent self-report	Low birth weight (LBW), MH as potential moderator	Cross-sectional	0 to 5 y, Low birth weight (LBW) children	Child Functional Status (all 5 items below)	Having a MH independent of birthweight, decreased odds of all outcomes by 40-80%. Table 4 & pS146. MH was not an effect modifier between LBW and any outcomes.
					0 to 5 y	Current physical conditions	(B = -0.27, SE = 0.31, p = .39) - pS146
					2 to 5 y	Developmental condition	(B = 0.12, SE = 0.41, p = .78) - pS146
					2 to 5 y	Mental/behavioral health conditions	(B = 0.60, SE = 0.69, p = .39) - pS146
					0 to 5 y	Condition severe (likert)	(B = 0.64, SE = 0.43, p = .14) - pS146
					0 to 5 y	Poorer overall health status (likert)	(B = -0.08, SE = 0.55, p = .89) - pS146
Toomey et al., 2007	Survey-based, National Survey	NSCH, Parent self-report	MH, Condition (asthma v. ADHD)	Cross-sectional	6 to 17 y Children w/asthma	Unmet need	Children w/asthma and MH had reduced odds of any unmet need (aOR: .43, CI: .26, .73; p=.002). Table 4
					6 to 17 y Children w/ADHD		No significant association for kids w/ADHD and MH.

ACE, Adverse Childhood Experiences; ADHD, Attention Deficit Hyperactivity Disorder; aOR, adjusted odds ratio; aPR, adjusted prevalence ratio; B, Beta; CI, Confidence Interval; CSHCN, Children with Special Healthcare Needs; ED, Emergency Department; LBW, Low Birth Weight; MH, Medical Home; MHC, Mental Health Condition; NDE, Natural direct effect; NIE, Natural indirect effect; NSCH = National Survey of Children's Health; NS-CSHCN, National Survey of Children with Special Health Care Needs; PHC, Physical Health Condition; SDM, Shared decision-making; SE, Standard Error; Y, years

Table 2.5 Medical Home's Association with Selected Health Care Outcomes

Author, Year	Outcome	Effect	O/S	T/NT
Emergency Department Utilization				
Jaudes et al., 2012 [#]	Odds of ED visits – Foster children	▲	O	T
Domino et al., 2009 [#]	ED use – asthma on claim	▲	O	T
Palfrey et al., 2004 [#]	Any ED visit rate	NS	O	T
Paradis et al., 2013 [#]	Absence of ED visits for injury rate	NS	O	T
	# of ED visits for any reason rate	NS	O	T
Rankin et al., 2009 [#]	3 or more ED visits rate	NS	O	T
Raphael et al., 2003 [%]	ED visit rates	NS	O	T
Raphael et al., 2015 [%]	ED visit rates	NS	O	T
Kieckhefer et al., 2005 [%]	Odds of Asthma-related ED visits	NS	O	T
Romaire et al., 2012b [%]	ED visits – all CSHCN, CSHCN w/ & w/o limitation	NS	O	T
Singhal et al., 2015 [%]	ED visit in past year	NS	O	T
Christensen et al., 2014 [#]	Odds of Non-urgent ED visits – NC & SC	NS	O	T
Han et al., 2017 [%]	# of ED visits	NS	O	T
Coller et al., 2015 [%]	Odds of ED visit within 7 days of previous hospitalization	NS	O	T
Cooley et al., 2009 [%]	ED visit rate	NS	O	T
Anugu et al., 2017 [#]	# of Preventable ED visits	▼	O	T
Christensen et al., 2014 [#]	Non-urgent ED visits - IL	▼	O	T
DeVries et al., 2012 [#]	ED use rate	▼	O	T
Diedhiou et al., 2010 [%]	# of ED visits	▼	O	T
Domino et al., 2009 [#]	ED use – emergent	▼	O	T
Jaudes et al., 2012 [#]	ED visits – Foster children w/chronic conditions	▼	O	T
Klitzner et al., 2010 [#]	Average # of ED visits per patient	▼	O	T
Lin et al., 2017 [%]	Prevalence of one or more ED visits in past year	▼	O	T
Long et al., 2011 [%]	Odds of ED sick visits	▼	O	T
Martin et al., 2007 [#]	ED visit rate	▼	O	T
Mosquera et al., 2014 [#]	ED visit rate	▼	O	T
Romaire et al., 2012a [%]	ED visit rates	▼	O	T
Child Health Status Outcomes				
Balistreri et al., 2015 [%]	Child well-being index	▲	M	M
Lutiffya et al., 2010 [%]	Uncontrolled asthma	▲	S	T
Han et al., 2017 [%]	Health Care Quality	▲	S	T
Long et al., 2011 [%]	Child health status rating	▲	S	T
Stevens et al., 2011 [%]	Pediatric Quality of Life Inventory 4.0 – total health	▲	VM	
	Pediatric Quality of Life Inventory 4.0 – physical	▲	VM	
	Pediatric Quality of Life Inventory 4.0 – social	▲	VM	
	Pediatric Quality of Life Inventory 4.0 – emotional	▲	VM	
	Pediatric Quality of Life Inventory 4.0 – school/daycare	▲	VM	
Farmer et al., 2011 [#]	Child overall health ratings	▲	S	T
Farmer et al., 2005 [#]	Functional Status II-R	NS	VM	T
Farmer et al., 2011 [#]	Functional Status II-R	NS	VM	T
Kuo et al., 2013 [#]	Functional Status II-R	NS	VM	T
Mosquera et al., 2014 [#]	# of children w/a serious illness	▼	O	T
	Total # of serious illnesses	▼	O	T
Litt et al., 2014 [%]	Child's functional disability	▼	S	NT
Salas et al., 2012 [%]	Odds of current physical condition	▼	O	T

	Odds of developmental condition	▼	O	T
	Odds of mental/behavioral condition	▼	O	T
	Odds condition is severe	▼	O	T
	Poorer overall health status	▼	S	T
Patient/caregiver behaviors				
Brown et al., 2015 [#]	% of children at 2 mo well-child visit on time	▲	O	T
	% of children at 4 mo well-child visit on time	▲	O	T
Domino et al., 2009 [#]	Use of maintenance meds for children w/asthma	▲	O	T
	Use of rescue meds for children w/asthma	▲	O	T
Pati et al., 2015 [#]	Age specific up to date immunizations – newborn, infant/toddler	▲	O	T
Sara Test et al., 2017 [%]	HPV vaccine receipt – Low income adolescent girls w/ parents <HS education	▲	O	T
	HPV vaccine receipt – 5 other groups	NS	O	T
Kramer et al., 2012 [%]	HPV vaccine initiation, completion	NS	O	T
Aysola et al., 2013 [%]	Tetanus vaccination	NS	O	T
	Meningitis vaccination	NS	O	T
Bottino et al., 2014 [#]	General immunization rates	NS	O	T
Farmer et al., 2011 [#]	Up to date immunizations	NS	O	T
Paradis et al., 2013 [#]	Up to date immunizations by 24 months	NS	O	T
Samuels et al., 2007 [#]	Up to date immunization rates	NS	O	T
Kieckhefer et al., 2005 [%]	RX fill/refill of rescue med – children w/asthma	NS	O	T
Brown et al., 2015 [#]	Age at newborn visit	▼	O	T
Physican behaviors				
Aysola et al., 2013 [%]	Developmental Screening	▲	O	T
	Developmental Monitoring	▲	O	T
Guerrero et al., 2011 [%]	Elicitation of parent’s developmental concerns	▲	O	T
DeVries et al., 2012 [#]	Strep test w/pharyngitis and antibiotic RX	▲	O	T
Farmer et al., 2011 [#]	Presence of written care plan	▲	O	NT
Kuo et al., 2013 [#]	Presence of written care plan	▲	O	NT
Palfrey et al., 2004 [#]	Presence of written care plan	▲	O	NT
Aysola et al., 2013 [%]	Physician recommended HPV vaccination	▲	O	T
Romaire et al., 2010 [%]	Anticipatory guidance on child’s diet	▲	O	T
	Anticipatory guidance on child exercising	▲	O	T
	Anticipatory guidance on secondhand smoke	▲	O	T
	Anticipatory guidance on dental checkup	▲	O	T
	Anticipatory guidance on bike helmet use	▲	O	T
	Anticipatory guidance on safety seat use	▲	O	T
	Anticipatory guidance on booster seat use	▲	O	T
	Anticipatory guidance on seat belt use	▲	O	T
	Anticipatory guidance – Any topic	▲	O	T
	Odds of height measurement	▲	O	T
	Odds of weight measurement	▲	O	T
	Odds of blood pressure measurement	▲	O	T
	Odds of any health screening	▲	O	T
Downig et al., 2017 [%]	Healthcare Transition (HCT) – Discuss Adult needs	▲	S	NT
	HCT – Discuss adult insurance	▲	S	NT
	HCT Discuss shift to adult provider	NS	S	NT
	HCT – Encouraged to take responsibility for health	NS	S	NT
Romaire et al., 2010 [%]	Odds of vision check	NS	O	NT
DeVries et al., 2012 [#]	Antibiotic RX for upper respiratory infection	▼	O	T

Lotstein et al., 2008 %	Odds of NOT receiving HCT	▼	S	NT
McManus et al., 2013 %	Odds of NOT receiving HCT	▼	S	NT

Legend: ▲: Increased; NS: Not significant; ▼: Reduced; O: Objective; S: Subjective; VM: Validated Measure; T: Traditional; NT: Non-Traditional; % = Survey Based Study; # = Practice-based

Note: Table is grouped by direction of effect then by study author.

CSHCN, Children with Special Healthcare Needs; ED, Emergency Department; HCT, Health Care Transition; HPV, Human Papilloma Virus; HS, High School; IL, Illinois; MH, Medical home; MO, months; NC, North Carolina; RX, prescription medication; SC, South Carolina

Table 2.6 Medical Home's Association with Selected Family Outcomes

Author, Year	Outcome	Effect	O/S	T/NT
Shared Decision-making, Communication, & Family-Centered Care				
Hubner et al., 2016 [%]	Levels of Shared Decision Making	▲	S	NT
Butler et al., 2014 [%]	Levels of Shared Decision-Making	▲	S	NT
Smalley et al., 2014 [%]	Odds of Shared Decision-Making	▲	S	NT
Hubner et al., 2016 [%]	Odds of Shared Decision Making	▲	S	NT
Golnik et al., 2012 [#]	Odds of Shared Decision Making	▲	S	NT
Kuo et al., 2013 [#]	Care team helps parent understand child's emotional needs	NS	S	NT
	Care team shows concern for impact of child's health on family	NS	S	NT
	Received information about family support	NS	O	NT
	Received information about current research	NS	O	NT
Cady et al., 2014 [#]	Family Centered Care scores	NS	S	NT
Looman et al., 2015 [#]	Family Centered Care	NS	S	NT
Family Employment Problems				
Ronis et al., 2015 [%]	Risk of Family Employment Problem	▼	O	NT
Okumura et al., 2009 [%]	Odds of work loss (quit and/or reduce hours)	▼	O	NT
	Risk of family member quitting job	▼	O	NT
	Risk of family member cutting hours at work	▼	O	NT
DeRigne et al., 2017 [%]	Odds of mother quit work – all children, CSHCN	▼	O	NT
	Odds of father quit work – all children, CSHCN	NS	O	NT
	Odds of mother reduce hours – all children, CSHCN	NS	O	NT
	Odds of father reduce hours – all, CSHCN	NS	O	NT
Family Time Burden				
Kogan et al., 2008 [%]	Family spent >10 hrs/week providing/coordinating child's care	▼	O	NT
Miller et al., 2015a [%]	Odds of combined time burden providing & arranging care being time burden	▼	O	NT
	Odds of family arranging/coordinating care	▼	O	NT
	Odds of family providing care at home	▼	O	NT
Miller et al., 2015b [%]	Odds of combined time burden providing & arranging care being time burden	▼	O	NT
	Odds of family arranging/coordinating care	▼	O	NT
	Odds of providing 11+ hours of care at home	▼	O	NT
	Odds of providing 6+ hours of care at home	▼	O	NT
	Odds of providing 1+ hours of care at home	NS	O	NT
Family Financial Burden				
Ronis et al., 2015 [%]	Risk of Family Financial Problem	▼	O	NT
Kogan et al., 2008 [%]	Family Financial Problems cause by child's care	▼	O	NT
	Family needed extra income to cover child's care	▼	O	NT
	Family member stopped or reduced employment	▼	O	NT
	Family paid $1000 or more for child's care in past year	▼	O	NT
Family Needs				
Farmer et al., 2005 [#]	Family Needs Survey (FNS), Total # of Needs	▼	O	NT
	FNS, Need for support	▼	O	NT
	FNS, Financial Needs	▼	O	NT
	FNS, Need help w/family functioning	▼	O	NT

Farmer et al., 2011 #	Family Needs Survey (FNS), Total # of Needs	▼	O	NT
	FNS, Need for community services	▼	O	NT
	FNS, Need for information	▼	O	NT
	FNS, Need for support	▼	O	NT
	FNS, Need for help explaining child's condition to others	▼	O	NT
	FNS, Financial Needs	▼	O	NT
Farmer et al., 2011 #	FNS, Need help w/family functioning	NS	O	NT
Farmer et al., 2005 #	FNS, Need for community services	NS	O	NT
	FNS, Need for help explaining child's condition to others	NS	O	NT
	FNS, Need for information	NS	O	NT
General Family Impacts				
Farmer et al., 2005 #	IFS, Familial/Social impact	▼	VM	NT
	Impact on Family Scale (IFS)	▼	VM	NT
Farmer et al., 2011 #	Impact on Family Scale (IFS)	▼	VM	NT
	IFS, Familial/Social impact	▼	VM	NT
	IFS, Personal strain	▼	VM	NT
Kuo et al., 2013 #	Impact on Family Scale, Social	NS	VM	NT
	Impact on Family Scale, Personal	NS	VM	NT
	Family Support Scale	NS	VM	NT
Farmer et al., 2011 #	Family Support Scale	NS	VM	NT
Farmer et al., 2005 #	IFS, Personal strain	NS	VM	NT
Golnik et al., 2012 #	Family stress score	NS	S	NT
Caregiver Health				
Kuo et al., 2013 #	Short Form Health Survey (SF-12), Parent Physical Health Score	▼	VM	NT
	SF-12, Parent Mental Health Score	NS	VM	NT
Farmer et al., 2011 #	Caregiver depressive symptoms – Beck Depression Inventory II	NS	VM	NT
Lawson et al., 2011 #	SF-12, Parent Physical Health Score	NS	VM	NT
	SF-12, Parent Mental Health Score	NS	VM	NT

Legend: ▲: Increased; NS: Not significant; ▼: Reduced; O: Objective; S: Subjective; VM: Validated Measure; T: Traditional; NT: Non-Traditional

% = Survey Based Study; # = Practice-based

Note: Table is grouped by direction of effect then by study author.

FNS, Family Needs Survey; IFS, Impact on Family Scale; SF-12, Short Form Health Survey

CHAPTER 3. MEDICAL HOME'S ASSOCIATION WITH EARLY INTERVENTION RECEIPT

Recent population estimates indicate that between 13 and 15% of children birth through age 17 have a developmental disability or delay.[1-2] When developmental disabilities and delays are identified early, clinicians can refer families for support, resources, and interventions to improve developmental outcomes for young children.[3-4] In the United States, young children with developmental delays are eligible to receive public Early Intervention (EI) services as part of the Individuals with Disabilities Education Act (IDEA).[5] Children birth to three years of age are eligible for home-based EI services (Part C of IDEA), while children ages three through five are eligible for special education EI through the local school system or other community programs (Part B of IDEA).

Intervening early is crucial to improve outcomes for these children; consequently, it is critical that disabilities and delays are identified early, children are referred to services, and they receive those services in a timely manner.[6-8] The American Academy of Pediatrics (AAP) has recommended developmental surveillance (also called “developmental monitoring”) and screening as a best practice since 2001[9]; research on improving early identification processes has prevailed in the pediatric literature since then.[4,10-11] Like developmental surveillance and screening, the AAP also recommends that all children receive care from a medical home (MH).[12]

The MH is the dominant model of patient-centered care in pediatrics. Originally conceived in the 1960s as a central primary care location to house the records of children with special healthcare needs (CSHCN), the MH concept has evolved and is now a widely recognized approach to healthcare for both children and adults.[13] In pediatrics, a single primary care provider serves as a child’s “medical home” and coordinates all care and referrals needed by families. The MH model is characterized by care that is family and patient-centered, comprehensive, coordinated, culturally effective, and accessible. Linkages to necessary services and a recognition of the family's central role in children's lives are also key to providing care meeting MH criteria.[13]

In 2007, the AAP issued a policy statement affirming the role of the MH in ensuring children receive EI services.[14] Likewise, recently the AAP cited the benefits of MH participation for children and identified the ways that MHs and EI programs share many goals related to the care and development of young children.[15] That recent report called on EI systems and MHs to collaborate for the optimal development of young children; however, few studies investigate how health system factors impact EI receipt.[3-4,16] Those studies examining healthcare predictors of EI demonstrate positive associations between EI and developmental monitoring[16] and parent-completed developmental screening.[3]

The potential for collaboration between pediatricians, medical homes, and public EI systems is clear and is supported by case studies and anecdotally[17]; however, no empirical studies have specifically examined associations between MH and EI receipt. The only aspect of the MH model of care investigated in relation to EI receipt is the impact of having a usual source of care. These findings are conflicting with one study[18] finding that a usual source of care was positively associated with public EI while another study[16] found no significant differences in public EI receipt between children with and without a usual source of care. Thus, the evidence is limited. Our study fills a gap by investigating the relationship between MH and EI receipt in a nationally representative sample of children ages birth through five.

Theoretical Framework:

In this study, I examined associations between public EI and MH access among U.S. children aged birth through five years using Andersen's Behavioral Model of Health Services Utilization, which is commonly used to study the relationship between MH and patient outcomes (Figure 3.1).[19-21] This model posits that true access to care occurs when healthcare resources are available to individuals whenever, wherever, and however they need them. It recognizes that healthcare availability results from environmental characteristics, including the health care system and a person's community; personal characteristics such as predisposing factors, enabling factors, and need; and health behavior, which includes personal health behaviors and one's use of health services.[19] Access to EI fits well within this framework as multiple health system, predisposing, need-based, enabling, and behavioral factors must converge for at-risk children to receive EI. The present study utilized data from the National Survey of Children's Health (NSCH) 2011/2012 to determine if children receiving primary care that meets MH criteria were more likely to receive EI than children whose care did not meet MH criteria.

Method

Data Source and Sampling Procedures.

I used data from the 2011/2012 NSCH which is a cross-sectional survey administered by the National Center for Health Statistics. Between February 2011 and June 2012[22-23], parents/caregivers of noninstitutionalized children ages 0-17 were interviewed by phone about factors related to their child's health and well-being. Respondents were reached by landlines and cell phones. Responses are weighted to be representative at both the state and national levels, and estimates are adjusted for non-response bias.[22] The survey is nationally representative; however, certain variables and questions in the survey are only asked of specific subpopulations of the sample like questions related to early childhood development and early intervention. While the full survey sample includes 95,677 observations, the present study is concerned with early childhood outcomes and thus only utilized data from 29,887 survey respondents. This study was deemed exempt by the [*institution name blinded for review*] institutional review board.

Outcome Variable

In this analysis, I examined parent-reported receipt of public EI, and treated EI plan receipt as a proxy for EI. Caregivers of children ages birth through five years old were asked if the child has "any developmental problems for which [he/she] has a written intervention plan called an Individualized Family Services Plan/IFSP or an Individualized Education Program/IEP." This variable measures whether children with an identified delay participate in a state EI program, special education, or a similar state-funded program.

Predictor Variables

Guided by Andersen's Behavioral Model of Health Services Utilization (Figure 3.1),[19] our study sought to examine how health system factors (MH, developmental monitoring); predisposing factors (age, gender, race/ethnicity, children with special healthcare need [CSHCN] status); need (child health status; caregiver-reported developmental concern); and enabling factors (household language, poverty status, maternal education, insurance, Health Resources & Services Administration [HRSA] region) are related to public EI receipt among young children with specific focus on the role of MH.

The main predictor of interest in this study, receipt of care from a MH, is a dichotomous composite measure derived from 19 NSCH items. The measure includes 5 domains that are required for care to meet MH criteria: 1) Usual source of care; 2) Personal doctor or nurse; 3) Receipt of family centered care; 4) No problems getting necessary referrals; and 5) Effective care coordination when needed. Details outlining the specific domains of the MH variable are displayed in Table 3.1.[22]

Additional health system, predisposing, need-based, and enabling, variables were investigated based on past associations with MH[24] and/or EI receipt[16,18,25-26]. In addition to MH, I included one additional *health system factor* in our conceptual model. Developmental monitoring was measured by one question: “During the past 12 months did [the child’s] doctor ask if you have concerns about his/her learning, development, or behavior?” *Predisposing factors* include age (in years), sex (male/female), race/ethnicity (White, Black, Hispanic, Multi-Racial/Other), and CSHCN status (yes/no). In the NSCH, children are identified as having a special healthcare need if their caregiver responds affirmatively to one or more of the following screening criteria: 1) prescription medication use; 2) elevated service use or need; 3) functional limitations; 4) use of special therapies; or 5) ongoing emotional, developmental, or behavioral condition[23]. *Need-based factors* include child health status (excellent/very good, good, fair/poor) and caregiver-reported developmental concern (one or more concerns, no concerns). *Enabling factors* include insurance type (Public, Private, or Uninsured), household language (English or not), maternal education (less than high school [HS], HS graduate, more than HS), poverty level (<100%, 100-199%, 200-399%, or 400% or more FPL), and HRSA region. HRSA region was included as a place-based measure to account for regional variations in physician practices and in early-intervention policy.

Statistical Analysis

I used SAS 9.3 software for all statistical analyses. To account for the complex nature of the NSCH, I used SAS survey procedures to weight and stratify the data. As mentioned previously, our study only utilized data for children birth through five; however, all sub-setting occurred after weighting and stratification. I conducted bivariate chi-square analyses to test crude associations between EI receipt and all covariates (Table 3.2). Covariates were included in the final model if they approached significance at .20 or less. All variables identified in our theoretical model met inclusion criteria except poverty level (p value=.3454). After assessing for multi-collinearity among the independent variables and finding none, I conducted multivariable logistic regression analysis to determine associations between EI receipt and MH while controlling for additional health system (developmental monitoring); predisposing (age, gender, race/ethnicity, CSHCN status); need-based (child health status; caregiver-reported developmental concern); and enabling (household language, maternal education, insurance, HRSA region) factors. Observations with missing values were excluded from the final multivariable logistic models.

Results

Table 3.2 shows the characteristics of children birth through five whose caregivers participated in the 2011/2012 National Survey of Children's Health. While 9.1% ($n_{unweighted}$=2427; $n_{weighted}$=2,214,320) of caregivers reported having one or more concerns about their child's development, only 4.6% ($n_{weighted=}$1391; $n_{weighted}$=1,117,409) reported their child had an IFSP/IEP for EI. Among caregivers of CSHCN, only 24.5% reported EI receipt. Among children birth through five, 54.4% ($n_{unweighted}$ =56,257; $n_{weighted}$ =38,826,906) received care that met MH criteria. Final models utilized data from 24,296 survey respondents, for whom all predictors and outcome variables were present (Table 3.3).

Health system factors. Health system factors were significant predictors of EI receipt. Contrary to our hypothesis, children whose care met MH criteria were at a *reduced odds* of EI receipt (aOR: .60; CI: .46, .80). Odds of EI were higher for children whose physician had asked about the caregiver's developmental concerns in the past year (aOR: 1.96; CI: 1.46, 2.61). Because of the unexpected relationship between MH and EI receipt, I performed several *post hoc* analyses investigating 1) the impact of age classification (age in 2 categories: 0-2, 3-5; age in years with models subset to children ages 0-2, 3-5, 1-5); 2) the role of state EI eligibility criteria (narrow, medium, broad); 3) the effect of including developmental monitoring; and 4) potential collinearity between MH and CSHCN status. These analyses yielded similar findings showing children whose care met MH criteria at significantly reduced odds of EI receipt.

Predisposing factors. Statistically significant predisposing factors included age and CSHCN status. Children ages 3, 4, and 5 were significantly more likely to receive EI than children less than 1 year old (Table 3.3). As expected, CSHCN were more than five times as likely to report EI as non-CSHCN (aOR: 5.80; CI: 4.35, 7.74).

Need-based factors. Odds of EI were higher for children identified as having one or more developmental concerns (aOR: 5.12; CI: 3.82, 6.85) and for children with fair/poor health (aOR: 1.78; CI: 1.08, 2.93).

Enabling factors. Publicly insured children were 1.5 times as likely to receive EI when compared to those with private insurance (CI: 1.15, 2.02) while there were no significant differences in EI receipt between publicly insured children and uninsured children. Odds of EI receipt were significantly lower for children whose mothers had attained lower levels of education - less than HS (aOR: .46; CI: .26, .82) or a HS diploma (aOR: .68; CI: .47, .97) - when compared to children of mothers with more than a HS diploma (Table 3.3). Household language approached significance (p = .08) with children living in non-English-speaking households being at reduced odds of receiving EI (aOR: .57; CI: .31, 1.06). Children living in HRSA region IV (Kentucky, Tennessee, North Carolina, South Carolina, Georgia, Florida, Alabama, and Mississippi) were also significantly less likely to receive EI (aOR: .55, CI: .33, .91) compared to children living in HRSA region I (Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, and Connecticut). No other significant regional differences emerged.

Discussion

This is the first analysis to our knowledge examining the relationship between reported MH and public EI receipt. Although EI receipt is a rare outcome (roughly only 5% of the population), children whose caregivers reported care from a MH had reduced odds (.60) of EI receipt compared to children who did not receive care from a MH. While the negative association between MH and EI receipt is surprising, Marshall et al.[16] found that children with a usual source of care (one aspect of the MH construct) were similarly at reduced odds of EI receipt (aOR: .56; CI: .25, 1.26) although their findings were not statistically significant. Our findings run contrary to McManus et al.[18] who found that a usual source of care was positively associated with EI receipt ($p < .001$).

In addition to these unexpected findings, our analyses yielded some expected results related to healthcare system, predisposing, need-based, and enabling, predictors of EI. Our findings were consistent with past studies linking age, insurance status[16], maternal education[26], developmental monitoring[3], and need-based factors[16,18] to EI receipt. Interestingly, HRSA Region IV was the only region where children were at statistically significant reduced odds of EI receipt. This region yielded 19.3% of the NSCH respondents age 0 to 5 and covers eight states. One hypothesis for this disparity in EI receipt may be that the large percentage of young children living in the region combined with constrained state budgets and fiscally conservative political environments may result in fewer children served.[18]

While many of the healthcare system, predisposing, need-based, and enabling, factors and their relationships to EI receipt fit within the existing literature, the negative association between MH and EI is counterintuitive. It is possible that families who lack care meeting MH criteria may be more likely to utilize public services like EI. Past studies indicate that children with public insurance [24,27] and CSHCN[24] are less likely to receive care meeting MH criteria. In the absence of comprehensive, coordinated, family-centered care, these families may be more likely to access EI through established public-sector channels due to federal mandates requiring healthcare providers to screen publicly insured children regularly and refer positively screened children to EI.

Past research on physician perspectives indicates that physicians believe EI is effective[28]; however, provider referrals largely depend on family perceptions of the child's need for EI, family preferences for EI, and effective referral mechanisms.[4,29] In a multi-site quality improvement project designed to improve developmental screening and referrals, physician practices reported difficulties placing and tracking referrals both to specialists and to local early intervention providers.[4] Parental perspectives echo these findings indicating that the pursuit and receipt of EI partially depends on whether families agree with physicians' developmental concerns, families' readiness to pursue services (versus taking a wait and see approach), and families' ability to follow through with referrals despite practical barriers[30]. Additionally, some families report issues with family-provider communication indicating that physicians need to help families understand children's need for EI, the EI referral process, and specifics about what EI entails.[30]

While reduced utilization of public EI services for children with MHs (especially after controlling for CSHCN status, developmental concern, and developmental monitoring) seems troubling, it is possible that families may find other ways to meet their child's developmental needs through private therapies or other non-EI services. In a world of multiple services and therapies (presumably coordinated by one's MH), adding one more service or program to a family's weekly schedule may be overly burdensome. This possibility is particularly salient as constrained state EI program budgets may result in increased wait time for evaluations and services, a shortage of available providers and programs, or minimal intervention hours per week.[31] With state Part C systems averaging only 6 hours of intervention provided per child per month, it is understandable why some families might judge these services as not sufficiently helpful, particularly if other therapies and services are already being successfully coordinated by their MH. Existing data on satisfaction of Part C EI recipients yield no insights in determining exactly which factors may deter prospective families from seeking and accepting EI services.[32] Furthermore, although the AAP has encouraged pediatricians to play an active role in linking children to EI and special education services[33], little is known about the relationships between MHs and Part B EI services, which are coordinated through local school systems.

This evidence from the literature reminds us of the importance of communication, care coordination, and family-centered care, all of which are integral parts of the MH model of care. Our findings in the context of this literature support the need for future research to understand reasons that families whose care meets MH criteria may not be receiving EI services. Furthermore, it is important to understand what pathways may be supporting children without MHs in receiving EI and how MHs can learn from these mechanisms to better support their birth to five populations.

Limitations and Future Directions

These findings should be interpreted considering our study's limitations. As with all variables in the NSCH, MH and EI receipt are caregiver-reported variables, which are largely dependent on caregiver understanding and interpretation of survey questions. Additionally, cross-sectional data (like the NSCH) limits our ability to infer a causal relationship. Finally, idiosyncratic local and state-level variables could have influenced our results. These include potentially unmeasured policies and programs aimed for either EI or MH, workforce capacity and provider shortages within state EI systems, and individual differences within school districts for children eligible for Part B services.

During the peer review process, reviewers were critical of the decision to investigate EI receipt for children birth to five in aggregate because the public EI system for children birth to two differs significantly from the system for children ages three to five. As a result, analyses are underway to correctly subset these analyses to children birth to two who would be eligible for EI in the Part C system (n=14,087). Reviewers also critiqued this study and suggested “selection bias” or “confounding by indication” may have caused the counterintuitive associations between MH and EI receipt because analyses were conducted on all children and not just subset to children with a potential need for EI.

One reviewer suggested subsetting analyses only to children with a parent-identified developmental concern due to this variable’s large effect on EI receipt (aOR: 5.12 CI: 3.82, 6.85); however, among children identified as receiving EI in our original analyses, 718 observations had no parent-reported concern, and 672 observations had one or more parent-reported concern. Subsetting to this group would result in a loss of those 718 observations with EI but no parent-reported concern. Additional subgroup analyses to target children most at need for EI are underway and only include children birth to two. Potential subsetting strategies include subsetting to children with parent-reported developmental concern (n=849); subsetting to CSHCN who qualify as CSHCN because of elevated services use, functional limitations, use of special therapies, or due to an ongoing emotional, developmental, or behavioral condition (n=586); or subsetting based on reported EI eligible conditions (n=410). Initial analyses of the full, adjusted models (ages 0-2) for these subgroups reveal significantly smaller sample sizes as indicated in the previous sentence.

Conclusion

With these significant limitations and future directions in mind, the data reported here indicate that among the full sample of children birth to five in the 2011/2012 NSCH, those with MH have reduced odds of public EI receipt. These counterintuitive findings raise questions about the central role of the MH for identifying and referring children to state EI programs and existing mechanisms facilitating families' receipt of EI and the NSCH's ability to help us understand those mechanism better. In the absence of a robust literature base on pathways to EI,[8,34] studies are needed to understand the appropriate mechanisms allowing physicians to help families better understand and make informed decisions concerning public EI services in the context of the MH model of care. Furthermore, as indicated in the limitations section, options to study public EI receipt in the NSCH are limited based on variables available to subset and correctly identify at-risk children who might need EI services.

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Figure 3.1 Andersen's Behavioral Model of Health Services Utilization[19]

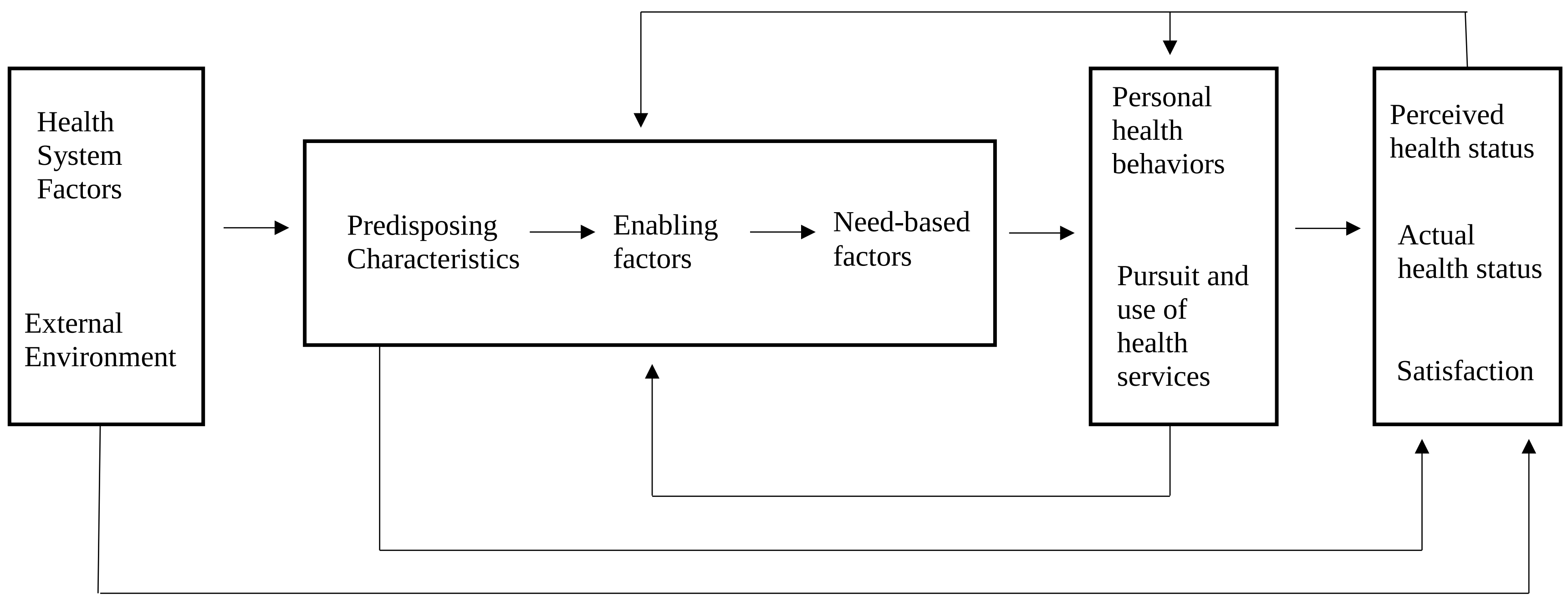

Table 3.1 Medical Home Measure Domains

Domains	Criteria to meet Medical Home status [a]
Usual source for sick care	Yes, besides emergency department
Personal doctor or nurse	Yes, has at least one personal doctor or nurse
Family-centered care	Provider usually/always:
	• Spends enough time
	• Listens carefully
	• Is sensitive to family values and customs
	• Provides needed information
No problems getting referrals (when needed)	No problems getting referral, when needed
Effective care coordination (when needed)	Caregiver usually/always:
	• gets help coordinating care when needed
	• satisfied with communication among child's providers
	• satisfied with communication between child's providers, school, and other programs

[a] Children must meet all five domains for their care to meet medical home criteria.

Table 3.2 Study Population Characteristics and Unadjusted Differences in EI by Key Variables

	Population Characteristics Weighted % (SE)	EI Receipt Weighted % (SE)	No EI Weighted % (SE)	Rao Scott χ^2
Early intervention				
No	95.4 (.25)			
Yes	4.6 (.25)			
Health system				
Medical home status				<.001 [a]
No	45.6 (.37)	60.7 (2.65)	40.8 (.67)	
Yes	54.4 (.37)	39.3 (2.65)	59.2 (.67)	
Developmental monitoring				<.001 [a]
No	48.2 (.66)	27.2 (2.54)	49.4 (.68)	
Yes	51.8 (.66)	72.8 (2.54)	50.7 (.68)	
Predisposing				
Age, y				<.001 [a]
<1	17.6 (.50)	5.8 (1.41)	18.2 (.52)	
1	16.2 (.47)	9.9 (1.68)	16.5 (.49)	
2	14.3 (.45)	10.8 (1.57)	14.5 (.47)	
3	16.9 (.48)	15.0 (1.90)	17.0 (.50)	
4	17.5 (.48)	21.1 (2.05)	17.3 (.49)	
5	17.5 (.49)	37.6 (2.81)	16.5 (.49)	
Sex				<.001 [a]
Female	51.2 (.37)	38.8 (2.71)	49.5 (.66)	
Male	48.8 (.37)	61.2 (2.71)	50.5 (.66)	
Race/Ethnicity				.04 [b]
White	52.5 (.36)	54.0 (2.86)	49.9 (.64)	
Black	13.5 (.25)	15.7 (2.06)	12.0 (.42)	
Hispanic	23.7 (.37)	20.8 (2.67)	26.7 (.67)	
Multi-racial/Other	10.3 (.22)	9.6 (1.61)	11.4 (.41)	
CSHCN status				<.001 [a]
No	80.2 (.28)	41.3 (2.74)	91.0 (.36)	
Yes	19.8 (.28)	58.7 (2.74)	9.0 (.36)	
Need				
Child health status				<.001 [a]
Excellent/very good	84.2 (.30)	66.4 (2.74)	87.0 (.49)	
Good	12.7 (.27)	23.3 (2.53)	10.8 (.46)	
Fair/poor	3.2 (.14)	10.3 (1.75)	2.2 (.22)	
Developmental concern				<.001 [a]
No concerns	90.8 (.38)	52.7 (2.80)	92.8 (.36)	
1 or more concerns	9.19 (.38)	47.3 (2.80)	7.2 (.36)	
Enabling				
Insurance status				.007 [b]

Private	57.4 (.37)	43.6 (2.75)	52.2 (.66)	
Public	37.1 (.37)	52.8 (2.77)	43.1 (.67)	
Uninsured	5.6 (.20)	3.6 (1.20)	4.7 (.35)	
Household language				.003 [b]
English	84.5 (.32)	88.7 (2.06)	80.9 (.61)	
Non-English	15.5 (.32)	11.3 (2.06)	19.1 (.61)	
Maternal education				.01 [b]
More than HS	63.8 (.39)	69.0 (2.69)	63.0 (.69)	
HS graduate	21.9 (.33)	21.8 (2.48)	22.0 (.60)	
Less than HS	14.3 (.32)	9.2 (1.50)	15.0 (.58)	
Household income				.35
<100% FPL	22.4 (.33)	29.1 (2.49)	25.9 (.61)	
100-199% FPL	21.5 (.32)	23.5 (2.52)	22.0 (.55)	
200-399% FPL	28.2 (.32)	25.4 (2.43)	26.9 (.59)	
400% or more FPL	27.8 (.30)	22.0 (2.18)	25.5 (.53)	
HRSA region				.07
Region 1	4.2 (.05)	5.1 (.77)	3.8 (.09)	
Region 2	8.6 (.13)	11.5 (1.64)	8.3 (.23)	
Region 3	9.0 (.13)	9.5 (1.45)	8.9 (.24)	
Region 4	19.3 (.17)	16.7 (2.01)	19.4 (.32)	
Region 5	16.6 (.16)	19.6 (2.09)	16.1 (.28)	
Region 6	13.9 (.23)	13.4 (2.54)	14.4 (.43)	
Region 7	4.5 (.05)	4.1 (.57)	4.6 (.10)	
Region 8	3.8 (.05)	4.2 (.60)	3.9 (.09)	
Region 9	16.1 (.28)	12.4 (2.12)	16.4 (.52)	
Region 10	4.1 (.06)	3.5 (.70)	4.2 (.11)	

Abbreviations: CSHCN, Children with Special Healthcare Needs; FPL, Federal Poverty Level; HRSA, Health Resources & Services Administration; HS, High school.

[a] $P < .001$; [b] $P < .05$

Table 3.3 Adjusted Association Between Medical Home and EI Receipt

	EI Receipt OR (95% CI)	*P*
Health system		
Medical home status		
No	1.00	
Yes	.60 (.46, .80)	<.001[a]
Developmental monitoring		
No	1.00	
Yes	1.96 (1.47, 2.61)	<.001[a]
Predisposing		
Age, y		
<1	1.00	
1	1.09 (.58, 2.05)	.79
2	1.57 (.88, 2.81)	.12
3	1.85 (1.05, 3.24)	.03[b]
4	2.24 (1.27, 3.93)	.005[b]
5	3.87 (2.31, 6.50)	<.001[a]
Sex		
Female	1.00	
Male	1.04 (.80, 1.36)	.78
Race/Ethnicity		
White	1.00	
Black	.99 (.65, 1.52)	.96
Hispanic	.78 (.50, 1.21)	.26
Multi-racial/Other	.69 (.42, 1.15)	.15
CSHCN status		
No	1.00	
Yes	5.80 (4.35, 7.74)	<.001[a]
Need		
Child health status		
Excellent/very good	1.00	
Good	1.39 (.93, 2.06)	.11
Fair/poor	1.78 (1.08, 2.93)	.02[b]
Developmental concern		
No concerns	1.00	
1 or more concerns	5.12 (3.82, 6.85)	<.001[a]
Enabling		
Insurance status		
Private	1.00	
Public	1.53 (1.15, 2.02)	.003[b]
Uninsured	.88 (.33, 2.35)	.80
Household language		
English	1.00	
Non-English	.57 (.31, 1.06)	.08

Maternal education		
More than HS	1.00	
HS graduate	.68 (.47, .97)	.03[b]
Less than HS	.46 (.26, .82)	.008[b]
HRSA region		
Region 1	1.00	
Region 2	1.39 (.78, 2.45)	.26
Region 3	.77 (.46, 1.32)	.34
Region 4	.55 (.33, .91)	.02[b]
Region 5	.82 (.50, 1.37)	.45
Region 6	.60 (.33, 1.07)	.08
Region 7	.76 (.46, 1.28)	.30
Region 8	.99 (.56, 1.73)	.96
Region 9	.71 (.38, 1.32)	.28
Region 10	.80 (.42, 1.54)	.50

Abbreviations: OR, odds ratio; CSHCN, Children with Special; Healthcare Needs; HRSA, Health Resources & Services Administration, HS, High school.

[a] $P < .001$; [b] $P < .05$

CHAPTER 4. THE IMPACT OF MEDICAL HOME ON PEDIATRIC OUTCOMES FOR CHILDREN WITH DIFFERENT SPECIAL HEALTH CARE NEEDS

Provision of care meeting MH criteria is a best practice in pediatrics and is particularly important for children with special healthcare needs (CSHCN) (American Academy of Pediatrics Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002). The United States Maternal & Child Health Bureau defines 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). The National Survey of Children’s Health (2011/2012) estimates that 20% of children in the United States have some sort of special healthcare need (2011/12 NSCH, Child and Adolescent Health Measurement Initiative [CAHMI], 2013). Because CSHCN often require care from multiple providers including specialists and therapists, the presence or absence of a MH is especially important to ensure children receive quality care that is receptive to theirs and their family’s individual needs and preferences, thus allowing them to reach their optimal development (Cassidy, 2010; Homer et al., 2008). Unfortunately, only 58.8% of children nationwide receive care that meets MH criteria, with certain vulnerable groups experiencing more pronounced disparities in access (2011/12 NSCH, Child and Adolescent Health Measurement Initiative [CAHMI], 2013).

Disparities in MH-consistent care are widely documented with several studies demonstrating reduced access for uninsured, under-insured, (DeCamp, Choi, & Davis, 2011; Kogan et al., 2010) and publicly insured children (Zickafoose & Davis, 2013); racial/ethnic minorities; and children living in Non-English speaking households (Aysola, Orav, & Ayanian, 2011; Stevens, Seid, Pickering, & Tsai, 2010; Strickland et al., 2009; Zickafoose & Davis, 2013). CSHCN are also less likely to have care MH-consistent care compared to non-CSHCN (Aysola et al., 2011; Strickland et al., 2009; Zickafoose & Davis, 2013); however, disparities to MH even exist when comparing children with different types of special health care needs (SHCNs) (Brachlow, Ness, McPheeters, & Gurney, 2007; DuPaul, Carson, & Fu, 2013; Knapp, Hinojosa, Baron-lee, et al., 2012; Toomey, Homer, & Finkelstein, 2010).

In addition to disparities in MH receipt, children with different types of health conditions also experience differential rates of other child health outcomes including access to services, quality of care (Vohra, Madhavan, Sambamoorthi, & St. Peter, 2014), family burden (DuPaul et al., 2013; Vohra et al., 2014), and healthcare transition (Cheak-Zamora, Yang, Farmer, & Clark, 2013). Specifically, children classified as having physical health conditions (PHCs) seem to experience better outcomes than those with other types of healthcare needs. For example, Nageswaran, Parish, Rose, and Grady (2011) found that compared to CSHCN with PHC, children with mental health conditions (MHC) or developmental disabilities (DD) were more likely to experience difficulty using community-based services. Similarly, in a study of the six Maternal & Child Health Bureau (MCHB) Core outcomes, Cheak-Zamora & Thullen (2017) found that children with PHC were statistically significantly more likely to report positive outcomes than children with MHCs, DDs, or multiple conditions on all six outcomes.

Among CSHCN in general, MH is linked to fewer unmet health care needs (Aysola, Bitton, Zaslavsky, & Ayanian, 2013; Hill, Freeman, Yucel, & Kuhlthau, 2008; Knapp, Hinojosa, Baron-lee, et al., 2012), fewer unmet needs for family support services (Hill et al., 2008; Miller, Nugent, Gaboda, & Russell, 2013; Strickland et al., 2009); reduced emergency department use (Diedhiou, Probst, Hardin, Martin, & Xirasagar, 2010; Lin, Younge, & Kleinman, 2017), less delayed or forgone care (Strickland et al., 2009), fewer missed school days (Knapp, Hinojosa, Baron-Lee, et al., 2012), improved shared decision-making (Butler, Elkins, Kowalkowski, & Raphael, 2015; Golnik, Scal, Wey, & Gaillard, 2012; Hubner, Feldman, & Huffman, 2016;

Smalley, Kenney, Denboba, & Strickland, 2014), and parental satisfaction (Golnik et al., 2012). Although the MH seems beneficial in reducing unmet needs for CSHCN in general, no studies to date have examined the role that MH care plays for children with different types of SHCN. It is not clear whether MH benefits are realized for all types of SHCN equally or if children with certain types of SHCN are more likely to benefit from care meeting MH criteria. This study addresses this gap and determines how the MH model may operate differently for children from different condition groups.

Method

Data Source and Sampling Procedures

This study used data from the 2009/2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), a cross-sectional survey administered by the National Center for Health Statistics (NCHS). Between July 2009 and March 2011, the NCHS screened 196,159 households for inclusion in the survey (Bramlett et al., 2014) using the children with special health care needs (CSHCN) screener developed to match the MCHB definition of CSHCN. To meet CSHCN status, children must meet one of five criteria: “need for or use of prescription medications; elevated need for or use of medical, mental health, or educational services; functional limitations; need for or use of special therapies; or emotional, developmental or behavioral conditions that require treatment” (Child and Adolescent Health Measurement Initiative [CAHMI], 2012, p.2). Initial screening resulted in 40,242 phone interviews with parents/caregivers of noninstitutionalized children ages 0-17 about service need, access, and utilization. Caregivers were interviewed by landlines or cell phones. Responses are weighted for representativeness at both the state and national levels; estimates are adjusted for non-response bias (2011/12 NSCH, Child and Adolescent Health Measurement Initiative [CAHMI], 2013).

Outcome Variables

I investigated six caregiver-reported outcomes to understand the relationship between the medical home, a child's health condition, and select health, community-based, educational, and family outcomes. Selected outcomes including the MCHB Core Outcomes, Indicators, and individual variables from the NS-CSHCN survey are outlined below (Child and Adolescent Health Measurement Initiative [CAHMI], 2012).

Health services. Health services outcomes include preventive services receipt and unmet need for care. Preventive services receipt is a combined measure defined as receipt of at least one preventive medical visit and at least one preventive dental visit in the last 12 months. The Child and Adolescent Measurement Initiative identifies this as MCHB Outcome #4, "Early and Continuous screening for special health care needs;" however, to avoid confusion with developmental screening, this dissertation refers to this outcome as "preventive services receipt."

In the NS-CSHCN, Indicator #6, "Unmet need for care," is created by examining discrepancies in services needed and those services received in the past 12 months. Caregivers are asked if their child had a need for 14 different healthcare services: 1) well-child checkups; 2) specialty care; 3) preventive dental care; 4) other dental care; 5) prescription medicine; 6) speech, physical, or occupational therapies; 7) mental health care or counseling; 8) substance abuse treatment or counseling; 9) home health care; 10) eyeglasses or vision care; 11) hearing aids or hearing care; 12) mobility aids or devices; 13) communication aids or devices; and 14) durable medical equipment. If caregivers answer affirmatively, they are asked if the child received all of the services he or she needed in the past 12 months. A child is considered to have unmet need if the caregiver indicates that one or more of the 14 services were needed but not received in the last 12 months.

Community-based services. MCHB Outcome #5, “Ease of use for community-based services” is a composite measure created by seven variables. Caregivers are asked about six potential difficulties in accessing community-based services for their children. Caregivers are also asked about their level of frustration in trying to acquire those services for their children. Children do not meet the outcome [that community-based services are easy to use] if their caregivers report difficulties in accessing one or more community-based services *and* report they are usually or always frustrated in their attempts to access services.

Educational services. One educational outcome was investigated: caregiver-reported receipt of special education services (Early Intervention or Special Education). Caregivers of children birth through two years old were asked if their child “receive[s] services from a program called Early Intervention Services” while caregivers of children ages three to seventeen were asked if their child “receive[s] services from a program called Special Education Services.” These two items were combined to create a composite measure of “Any Special Education Services.”

Family support. Indicator #7, “Unmet need for family support services,” is made up of six variables measuring need and receipt of family support services. Caregivers are asked about their need for three services because of their child’s special healthcare needs. These services include 1) respite care, 2) family genetic counseling, and 3) family mental health care/counseling. If caregivers report that they needed any one or more services and did not receive it in the past 12 months, the family is considered to have unmet need for family support services. If caregivers report a need and that they received the service in the past 12 months, the family is considered to have no unmet need.

MCHB Outcome #1, “Partner in Decision-Making” is a four-item composite measure. Caregivers are asked how frequently they feel they “1) discuss with providers a range of options to consider for their child's treatment; 2) are encouraged to ask questions or raise concerns; 3) it is easy to ask questions or raise concerns; and 4) their health care providers consider and respect what treatment choices the parent feels would be best for child.” To be considered as meeting “partner in decision-making,” caregivers must respond usually or always to all four items.

Predictor variables

The primary predictors of interest in this analysis were MH and child’s health condition type. The dichotomous MH measure is created from 21 NS-CSHCN survey items. The measure is designed to operationalize the American Academy of Pediatrics MH definition and includes five domains: 1) usual source of sick and well care; 2) personal doctor or nurse; 3) family-centered care; 4) no problems getting necessary referrals; and 5) effective care coordination when needed. Details about the construction of these five domains are displayed in Table 4.1 (2011/12 NSCH, Child and Adolescent Health Measurement Initiative [CAHMI], 2013).

Following the example of past studies using the NS-CSHCN (Cheak-Zamora et al., 2013; DuPaul et al., 2013; Nageswaran, Parish, Rose, & Grady, 2011), health conditions were categorized into four mutually exclusive groups. Physical health conditions (PHC) included allergies, asthma, blood problems, cystic fibrosis, diabetes, epilepsy/seizure disorder, heart problems, arthritis/joint problems, migraines/frequent headaches, and muscular dystrophy. Mental health conditions (MHC) included ADHD, anxiety, behavioral/conduct disorder, and depression. Developmental disabilities (DD) included autism spectrum disorder, cerebral palsy, Down syndrome, developmental delay, intellectual disability, and traumatic brain injury. Children with any combination of PHC, MHC, and DD were defined as having multiple condition types. To ensure appropriate condition grouping of ADHD, which can also be defined as a developmental disability in the pediatric literature, a research assistant performed a cluster analysis on all included conditions. ADHD clustered with other MHCs such as anxiety, depression, and behavioral problems; as a result, I classified ADHD as a MHC rather than a DD (see supporting information Appendix 4.1).

Choice of additional predictors was guided by Andersen's Behavioral Model of Health Services Utilization (Figure 4.1), which is frequently used to study the MH's impact on health outcomes (Andersen 1995). This model recognizes in addition to health system factors like the MH, additional need-based, predisposing, and enabling factors will also contribute to a patient/family's ability to access needed care and services. Health system factors include the ways care is delivered (i.e. models or approaches), service delivery locations, and physician and health care provider behaviors. Need-based factors contribute to a child's need for health care services and supports and frequently include functional status, presence of complex conditions, and health status. Predisposing traits are immutable characteristics like age, race/ethnicity, and sex. Enabling factors are characteristics that enable or hinder access to services and can include socio-economic status, household language, and insurance variables.

Besides condition type, two additional *need-based* factors were included in the models. First, all children in the NS-CSHCN have a qualifying primary need, which makes them an appropriate survey participant (prescription medication use only, service use only, prescription medication and service use, functional limitations with any other category). A second need-based factor was how frequently the child's condition impacted his or her daily activities (never affected, moderately affected, consistently affected). *Predisposing* variables included age (0-5, 6-11, 12-17), sex (male, female), and race/ethnicity (White, Black, Hispanic, Multi-racial/Other).

Enabling variables included poverty status as measured by the Federal Poverty Level (FPL) designations (<100%, 100-199%, 200-399%, 400% or more FPL); primary household language (English/non-English); highest form of parental education achieved (less than high school [HS], HS graduate, more than HS); insurance status (public, private, both, uninsured); consistency of insurance in past year (yes, no); family structure (two parent biological or adopted; two parent step-family, single mother household, other family structure); and HRSA region (Regions 1-10) as a geographic control variable.

Statistical analysis

In the model building process, I performed diagnostic procedures to check for outliers and multicollinearity. I first used SAS survey frequency procedures to obtain descriptive percentages of the total sample, to describe the children in all four condition groups, to produce bar graphs of proportions of children according to covariates, and to produce bar graphs of relationships among the children in the condition groups and the outcomes. A research assistant used Cook's distance to check the data for outliers; no influential observations were identified. Bivariate chi-square analyses were conducted to examine associations between the two primary predictors (MH and condition type) and each of the six outcome variables. A research assistant and I conducted a collinearity analysis, examining variance inflation factors (VIFs) and collinearity in the final models. All VIFs were below two, and collinearity measures were well below three, suggesting that multicollinearity was not a problem. Scatterplots of pairwise relationships and residuals among the covariates did not suggest outliers or collinearity.

The first set of multi-variable analyses included six logistic regression models with MH and condition type as primary predictors and need-based, predisposing, and enabling factors described above as covariates. The second set of multi-variable analyses were four separate multi-variable logistic regression models per outcome variable stratified by condition type (PHC, MHC, DD, multiple conditions) to understand how the MH model may operate differently for children with different conditions, while controlling for need-based, predisposing, and enabling factors (24 models total: 4 conditions x 6 outcomes). To facilitate easy interpretation, only the outcomes and their relationships to MH are reported for each condition type in this paper. Observations with missing values were excluded from the final multivariable logistic models.

All statistical analyses were conducted in SAS 9.4. I used SAS survey procedures to weight and stratify the data in all analyses to account for the complex nature of the NS-CSHCN. Domain analyses were used for the 24 weighted stratified models to correctly obtain accurate subpopulation estimates. In these domain analyses, the stratified subgroup analyses revealed large estimates and large confidence intervals for children with DDs (n=1,630) and with MHCs (n=5,373) for certain outcomes. The outcome, "No Unmet Need for family support" also produced large confidence intervals for some condition groups. As a result, I ran unweighted versions of all stratified models, which yielded more conservative estimates with smaller confidence intervals and slightly reduced standard errors. It is likely that the smaller sample sizes for children with MHCs and children with DDs (Table 4.2) resulted in less precise adjusted odds ratio estimates, indicated by the wide confidence intervals in Table 4.5.

Results

Table 4.2 displays descriptive characteristics of the sample of children whose caregivers participated in the 2009/2010 National Survey of Children with Special Health Care Needs. Almost 43% of all caregivers reported care consistent with MH criteria. The largest condition group was PHCs followed by multiple conditions, MHCs, and DDs. Over 70% of caregivers reported successful receipt of preventive services, no unmet need for health care services, and shared decision-making with their health care provider. The majority of parents also reported community-based services were easy to use (65.1%) and no unmet need for family support services (63.1%). Approximately 27% of parents reported their child utilized some type of special education service.

Unadjusted Analyses

Bivariate chi square analyses indicated that both medical home and condition type were statistically significantly associated with all six outcomes ($p<.0001$). Between 78 and 83% of children with PHC, MHC, and multiple conditions experienced receipt of preventive services in the past year compared to just 70.3% of children with DD only. Children with DD or multiple conditions experienced the lowest rates of shared decision-making, community services being easy to use, no unmet need for health care services, and no unmet need for family support services (Table 4.3). The pattern for special education services was reversed with children with caregivers of children with DD and multiple conditions reporting the highest rates of special education receipt, 70.8% and 72.7% respectively.

Adjusted Analyses

Table 4.4 outlines results for the six separate adjusted models investigating the effect of condition type and MH on the six chosen outcomes. MH was positively predictive of all outcomes ($p<.0001$) *except* special education services. Children whose caregivers reported MH-consistent care were at a slightly reduced odds of special education receipt (aOR: .88, CI: .79, .98, $p<.05$) when compared to those without a MH.

The impact of condition type on the six outcomes varied. PHC served as the reference group for all outcomes. Children with MHC, DD, and multiple condition types were all at increased odds of special education services ($p<.0001$) compared to children with PHCs.

Caregivers of children with multiple conditions reported reduced odds of shared decision-making (aOR: .76, CI: .66, .87, $p<.001$), community services being easy to use (aOR: .67, CI: .59, .75, $p<0001$), no unmet need for health care services (aOR: .72, CI: .63, .83, $p<.0001$), and no unmet need for family support services (aOR: .64, CI: .46, .89, $p<.05$) compared to children with PHC. Children with multiple conditions had increased odds of preventive services receipt in the past year compared to children with PHC (aOR: 1.39, CI: 1.21, 1.60, $p<.0001$). While children with MHC and DD were at reduced odds for several of the outcomes studied in these six models, no significant effects between these conditions types and the six outcomes emerged in the adjusted models.

The twenty-four stratified models allowed a more nuanced look at the ways that children with different types of conditions may benefit from receiving care that meets MH criteria. For most outcomes and conditions, the effect sizes and results remained similar for weighted and unweighted analyses (Table 4.5 & Table 4.6). As mentioned in the methods section, unweighted analyses yielded smaller effect sizes, narrower confidence intervals, and smaller standard errors for the stratified models, potentially producing more precise estimates.

The small number of children with DDs and MH-consistent care is notable (n=511). It is possible that the small number of observations in this group combined with the overweighting of certain groups in the NS-CSHCN produced an exaggeration of the positive effects that do exist. For example, although the percentages of non-white racial & ethnic groups are consistent across condition types (Table 4.2), the low numbers of minority children in the DD group and in the MHC group is noteworthy. Variables used to create the child-level weights in the NS-CSHCN include race/ethnicity, age, gender, and metropolitan statistical area status (2011/12 NSCH, Child and Adolescent Health Measurement Initiative [CAHMI], 2013). Low numbers for any groups making up these variables may have affected our results. This issue combined with the already small number of children with DDs and a MH may be responsible for the large effects and CIs displayed in Table 4.5. As an alternative to these potentially exaggerated results, Table 4.6 displays results from the unweighted stratified analyses.

In these unweighted analyses, the MH's impact on two outcomes was similar for all four condition groups: preventive services receipt and special education services. Odds of preventive services receipt ranged from 1.24 for children with MHCs to 1.56 for children with DDs. The MH's impact on preventive services receipt was statistically significant for all conditions ($p<.05$ – $p<.0001$). The MH's impact on special education receipt was statistically significant for children with PHCs and mconditions ($p<.001$). Children with MH-consistent care in these groups were at .78 and .85 reduced odds (respectively) of special education receipt. Children with MHCs and DDs and MH-consistent care were also at reduced odds, but these associations were not significant.

MH seemed to have a larger effect on the remaining four outcomes. Caregivers of children with DDs and multiple conditions who reported MH-consistent care had between 3.2 and 3.4 greater odds of reporting community services being easy to use compared to caregivers of children w/o MH care. The effect of MH was less pronounced for children with PHCs and MHCs; however, those with MH-consistent care were still had between 2.5 and 2.8 greater odds of reporting community services being easy to use when compared to children without MH. For shared decision-making, the benefits of the MH model were again greatest for children with DDs and multiple conditions, followed by children with MHCs and children with PHCs. Caregivers of children with DDs and multiple conditions and MH-consistent care in these groups had 7.6 to 8.2 greater odds of experiencing shared decision-making, while caregivers of children with PHCs and MHCs had only 5.4 to 6.1 greater odds of reporting shared decision-making in the MH. This pattern continued for the MH's impact on unmet need for health care. Children with DDs and multiple conditions experienced a more pronounced effect of MH on unmet need for health care services; those with MH-consistent care had between 2.8 and 2.9 greater odds of reporting no unmet need for health care compared to those without MH. Caregivers of children with PHCs and MHCs reporting MH-consistent care had 2.1 and 2.2 greater odds of reporting no unmet need for health care compared to similar caregivers reporting no MH.

For no unmet need for family support services (FSS), the effect of MH-consistent care was beneficial for all conditions; however, children with PHCs experienced the lowest impact of MH on no unmet need for FSS followed by children with multiple conditions, MHCs, and DDs. The benefits of MH-consistent care seemed greatest for children with MHCs and DDs, who had between 4.5 and 4.7 greater odds of reporting no unmet FSS need compared to children without MHs. MH was also positively predictive of no unmet FSS need for children with PHCs and multiple conditions; however, the odds of no unmet need were reduced for children in these condition groups (aOR: 2.6 – 3.1).

Discussion

To my knowledge this is the first study that has investigated the differential impacts of MH-consistent care on pediatric outcomes for children with PHCs, MHCs, DDs, and multiple conditions. While MH-consistent care was statistically significantly associated with all six outcomes investigated in models including the full sample, the effect of condition type was largely only significant for children with multiple conditions. Confirming the findings of past research, children with multiple conditions experienced reduced odds of shared decision-making, community services being easy to use (Cheak-Zamora & Thullen, 2017; Nageswaran et al., 2011), and preventive services receipt (Nageswaran et al., 2011). These children were also less likely to report no unmet need for both health care and family support services. These results in the context of past research is a reminder of the challenges faced by families of children experiencing multiple conditions. These children may have unique needs that individual providers, community-based agencies, and communities themselves simply may not have the capacity to meet. Caregivers of children with MHCs, DDs, and multiple conditions were all significantly more likely to report special education receipt than caregivers of children with PHCs, as might be expected since many PHCs (besides orthopedic impairments) alone would not qualify a child for special education services (Individuals with Disabilities Education Improvement Act, 2004).

In models including the total sample and in stratified models, our findings are consistent with past research investigating associations between MH-consistent care and preventive services receipt (Jaudes, Champagne, Harden, Masterson, & Bilaver, 2012; Romaire, Bell, & Grossman, 2012); shared decision-making (Butler et al., 2015; Golnik et al., 2012; Hubner et al., 2016; Smalley et al., 2014); community services being easy to use (Baruffi, Miyashiro, Prince, & Heu, 2005); unmet need for family support services (Hill et al., 2008; Miller et al., 2013; Strickland et al., 2009); and unmet need for health care services (Aysola et al., 2013; Hill et al., 2008; Knapp, Hinojosa, Baron-Lee, et al., 2012). In the six logistic regression models investigating the total sample and in the 24 stratified models investigating the condition subgroups, MH-consistent care had the most dramatic effects on shared decision-making (aOR: 5.78; Stratified aORs: 5.36-8.21); unmet need for family support services (aOR: 3.39; Stratified aORs: 2.58-4.65); and community services being easy to use (aOR: 2.99; Stratified aORs: 2.52-3.42). The effects were less pronounced for traditional health care variables like preventive services receipt and no unmet need for health care, suggesting that MH-consistent care may be especially effective at promoting family-centered outcomes.

The relationship between MH and special education services receipt in the total sample and in the four stratified models is interesting. MH was a significant predictor of reduced EI services in the model investigating the total sample (Table 4.4). When I stratified and split out the data for special education services, I discerned which groups may have been driving the significant association between MH and special education (Table 4.6). Children with PHCs and multiple conditions were the only groups that experienced significant associations between MH-consistent care and Special Education receipt. These condition groups also had the largest number of observations (16,169 and 12,079 respectively), suggesting that these significant effects of MH on special education in the total sample and for children with PHCs and multiple conditions may be a result of large sample sizes rather than a meaningful relationship. This is one limitation of using large national cross-sectional data sets; as a result, this finding should be interpreted with caution.

As demonstrated for special education receipt, the 24 stratified models illustrated that the relationship between MH-consistent care and condition type can produce outcomes differing by the child's condition and subsequent needs. Children with PHCs experienced the highest rates of all outcomes except preventive service receipt and special education services (Table 4.3), which is consistent with past research demonstrating better outcomes for children with PHCs (Cheak-Zamora & Thullen, 2017; Nageswaran et al., 2011). Models for children with PHCs produced the smallest effect sizes for MH's relationship to all outcomes (Table 4.6).

Children with DDs and multiple conditions seemed to benefit the most from receiving MH-consistent care. The increased positive impact of MH for children with DDs and multiple conditions validates the importance of this model for children in these groups; however, Cheak-Zamora & Thullen (2017) found that children with DDs and multiple conditions experienced consistent disparities in all six MCHB core outcomes including access to MH-consistent care. The relatively low nationwide prevalence of MH-consistent care (57%) and these disparities are disappointing because it means that the very children who might most likely benefit from MH-consistent care are those who may have the most difficult time accessing it.

Nevertheless, the impact of MH-consistent care for all groups was positive and is a reminder of the importance of accessible, comprehensive, coordinated, family-centered care for all families with CSHCN. The differential impacts of MH-consistent care for children with different types of conditions may have important policy implications for local, state, and federal Maternal and Child Health initiatives and future research. Much of the MH research on children with various health conditions frequently refers to the population in aggregate as CSHCN (Kuo et al., 2013); children with medical complexity (Cady et al., 2015; Klitzner, Rabbitt, & Chang, 2010; Looman et al., 2015); or high-risk children (Mosquera et al., 2014). Actual MH interventions often implement blanket programs with features like care coordination, multi-disciplinary teams, and a care plan (Cady et al., 2015; Farmer, Clark, Drewel, Swenson, & Ge, 2011; Kuo et al., 2013). The greater impacts of MH-consistent care for children with DDs, multiple conditions, and at times MHCs may indicate a need for states and funders to incentivize condition-specific medical home models and care coordination networks (Domino, Humble, Lawrence, & Wegner, 2009; Golnik et al., 2012). More research is needed to determine efficient, effective MH models that meet the unique needs of *all* CSHCN and their families.

Limitations

Some limitations of this study include recall bias, the subjective nature of some questions, and the use of cross-sectional data. As with all variables in the NS-CSHCN, all predictors and outcomes were caregiver-reported and are subject to recall bias. Furthermore, variables like shared decision-making, community services being easy to use, and the MH measure itself are created using subjective, opinion-based questions asked of caregivers. As a result, they reflect caregiver perceptions, which may or may not reflect reality. Reported child health conditions are also subject to caregiver understanding, which may result in over or under reporting of certain conditions. Finally, the use of cross-sectional data limits the ability to determine a truly causal relationship.

Conclusion

The data reported in this study indicate differential effects of the MH model of care for children with PHCs, MHCs, DDs, and multiple conditions. MH-consistent care had the largest effects on shared decision-making, caregivers reporting community services being easy to use, and no unmet need for family support services, with children with DDs and multiple conditions seeming to benefit the most. To ensure CSHCN of all types get the care and resources needed, particularly those children with increased needs for community support and resources, targeted policies and programs are needed to fully realize the benefit of the MH for these children and to improve access to MH-consistent care in the U.S.

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Table 4.1 Medical Home Measure Domains

Domains	Criteria to meet Medical Home status [a]
Usual source for sick care	Yes, besides emergency department
Personal doctor or nurse	Yes, has at least one personal doctor or nurse
Family-centered care	Provider usually/always:
	• Spends enough time
	• Listens carefully
	• Is sensitive to family values and customs
	• Provides needed information
No problems getting referrals (when needed)	No problems getting referral, when needed
Effective care coordination (when needed)	Caregiver usually/always:
	• gets help coordinating care when needed
	• satisfied with communication among child's providers
	• satisfied with communication between child's providers, school, and other programs

[a] Children must meet all five domains for their care to meet medical home criteria.

Figure 4.1 Andersen's Behavioral Model of Health Services Utilization (Andersen 1995)

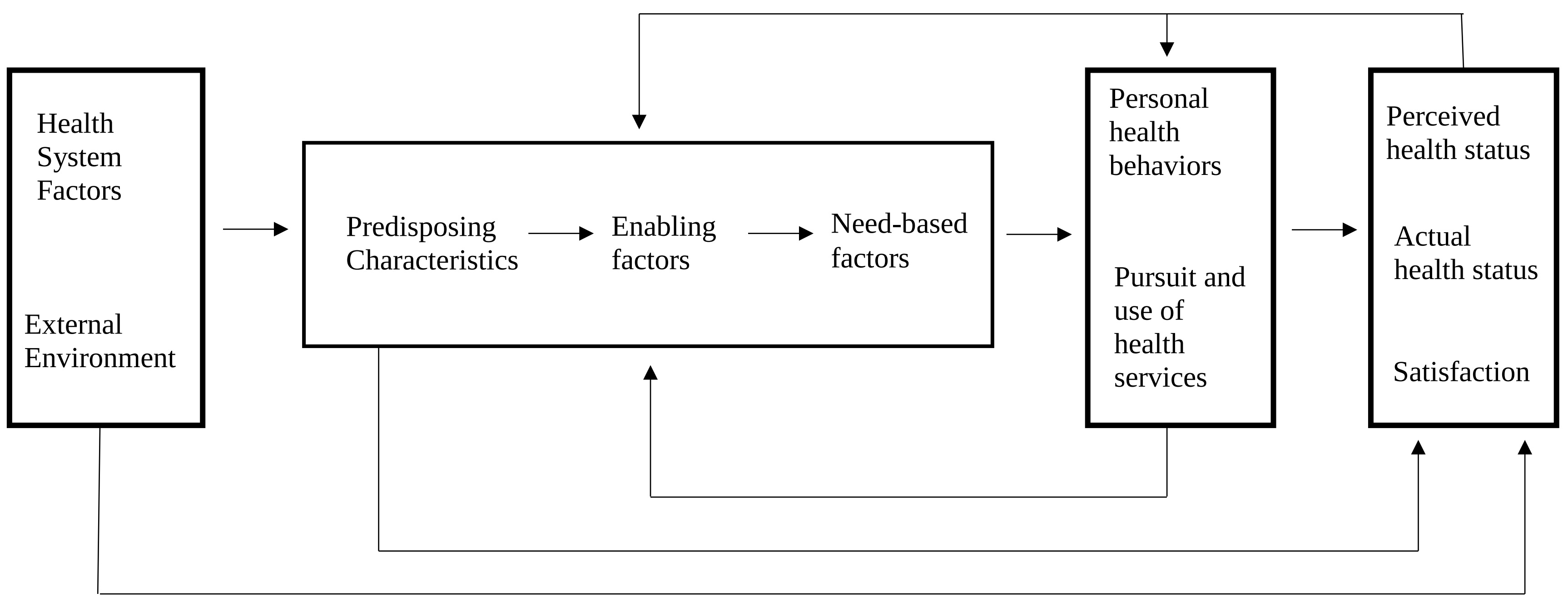

Table 4.2. Study Population Characteristics by Key Variables

Condition Group	PHC Only N (%)	MHC Only N (%)	DD Only N (%)	Multiple N (%)	Total N (%)
		Unweighted N (Weighted %)			
	16,169 (45.2)	5,373 (14.2)	1,630 (4.4)	12,079 (36.2)	35,251
Health system					
Medical home status					
No	6,901 (48.5)	2,796 (56.4)	1,040 (71.6)	7,529 (67.3)	18,266 (57.4)
Yes	8,837 (51.5)	2,384 (43.6)	511 (28.4)	4,158 (32.7)	15,890 (42.6)
Need					
Primary Need					
RX Meds Only	10,834 (65.3)	1,732 (29.6)	14 (1.1)	1,854 (15.2)	14,434 (39.3)
Service Use Only	950 (6.7)	963 (21.1)	602 (37.2)	1,678 (14.6)	4,193 (12.9)
RX + Service Use	2,366 (15.3)	2,167 (38.0)	66 (3.6)	3,657 (28.8)	8,256 (22.9)
Functional limits	2,019 (12.8)	511 (11.3)	948 (58.1)	4,890 (41.4)	8,368 (24.9)
Daily Activities					
Never affected	7,863 (46.0)	2,031 (36.1)	147 (11.5)	2,049 (15.7)	12,090 (32.1)
Moderately affected	6,761 (42.7)	2,182 (39.8)	537 (29.7)	4,551 (36.6)	14,031 (39.5)
Consistently affected	1,520 (11.4)	1,140 (24.2)	940 (58.9)	5,440 (47.8)	9, 040 (28.4)
Predisposing					
Age					
0-5 y	3,736 (26.7)	154 (3.3)	520 (37.4)	1,167 (11.7)	5,577 (18.4)
6-11 y	6,332 (38.0)	2,345 (44.2)	685 (40.8)	4,968 (40.6)	14,330 (40.0
12-17 y	6,101 (35.2)	2,874 (52.5)	425 (21.8)	5,944 (47.7)	15,344 (41.6)
Sex					
Female	7,139 (45.0)	1,803 (65.1)	552 (31.0)	4,081 (35.4)	13,575 (39.5)
Male	8,992 (55.0)	3,562 (34.9)	1,076 (69.0)	7,982 (64.6)	21,612 (60.5)
Race/Ethnicity					
White	10,905 (55.7)	4,107 (69.4)	1,084 (57.9)	8,376 (60.0)	24,472 (59.3)
Black	1,918 (19.8)	383 (11.8)	147 (12.9)	1,191 (15.3)	3,639 (16.7)
Hispanic	1,785 (16.5)	489 (13.5)	240 (22.3)	1,323 (15.9)	3,837 (16.1)

Multi-racial/Other	1,561 (8.0)	394 (5.3)	159 (6.9)	1,189 (8.8)	3,303 (7.9)
Enabling					
Insurance status					
Any private	11,414 (66.4)	3,457 (62.2)	1,040 (60.2)	6,920 (51.6)	22,831 (60.2)
Public only	3,717 (30.3)	1,531 (34.9)	485 (36.0)	4,424 (44.6)	10,157 (36.4)
Uninsured	406 (3.3)	152 (2.9)	55 (3.8)	352 (3.8)	965 (3.4)
Consistently Insured					
Yes	15,028 (91.5)	4,938 (92.4)	1,491 (90.5)	11,027 (89.5)	32,484 (90.9)
No	1,105 (8.5)	407 (7.6)	131 (9.5)	1,017 (10.5)	2,660 (9.1)
Household language					
English	15,615 (93.7)	5,245 (95.1)	1,521 (88.7)	11,727 (94.6)	34,108 (94.0)
Non-English	554 (6.3)	128 (4.9)	109 (11.3)	352 (5.4)	1,143 (6.0)
Parental education					
More than HS	13,336 (72.6)	4,206 (67.3)	1,292 (68.2)	9,224 (65.4)	28,058 (69.0)
HS graduate	2,167 (19.0)	890 (21.6)	239 (21.5)	2,064 (21.3)	5,360 (20.3)
Less than HS	666 (8.4)	277 (11.0)	99 (10.3)	791 (13.3)	1,833 (10.6)
Household income					
400% or more FPL	5,855 (30.8)	1,791 (28.2)	473 (25.8)	3,174 (21.9)	11,293 (27.0)
200-399% FPL	5,179 (29.6)	1,681 (29.1)	523 (29.0)	3,620 (26.8)	11,003 (28.5)
100-199% FPL	2,876 (21.0)	1,041 (22.4)	340 (24.3)	2,623 (23.5)	6,880 (22.2)
<100% FPL	2,259 (18.6)	860 (20.3)	294 (20.9)	2,662 (27.8)	6,075 (22.3)
Family Structure					
Two parents	11,150 (63.4)	2,850 (46.3)	1,181 (70.2)	6,402 (47.5)	21,583 (55.5)
Two parents step	1,071 (7.1)	744 (15.5)	100 (6.1)	1,400 (12.1)	3,315 (10.1)
Single mother	2,883 (24.2)	1,076 (26.5)	217 (16.4)	2,883 (30.4)	7,059 (26.5)
Other	816 (5.3)	624 (11.6)	107 (7.4)	1,243 (10.0)	2,790 (8.0)
HRSA region					
Region 1	1,770 (4.7)	697 (6.2)	196 (5.6)	1,459 (5.2)	4,122 (5.2)
Region 2	645 (8.7)	194 (7.3)	107 (12.5)	493 (8.7)	1,439 (8.7)
Region 3	1,970 (10.0)	615 (9.7)	170 (9.2)	1,425 (10.3)	4,180 (10.0)
Region 4	2,640 (21.4)	853 (21.0)	202 (17.2)	2,003 (21.5)	5,698 (21.2)
Region 5	1,854 (17.5)	670 (20.5)	197 (18.5)	1,396 (17.5)	4,117 (18.0)

Region 6	1,631 (14.1)	501 (12.7)	113 (8.7)	1,333 (13.9)	3,578 (13.6)
Region 7	1,309 (5.0)	437 (5.0)	114 (4.8)	875 (4.8)	2,735 (4.9)
Region 8	1,843 (3.3)	683 (3.3)	208 (3.8)	1,276 (3.1)	4,010 (3.3)
Region 9	1,382 (11.8)	330 (10.3)	155 (14.5)	881 (11.2)	2,748 (11.5)
Region 10	1,125 (3.3)	393 (4.0)	168 (5.2)	938 (3.9)	2,624 (3.7)

Abbreviations: PHC, Physical Health Condition; MHC, Mental Health Condition; DD, Developmental Disability; RX, Prescription; FPL, Federal Poverty Level; HRSA, Health Resources & Services Administration; HS, High school.

Table 4.3. Proportions of Six Pediatric Outcomes by Condition Type and Presence of Medical Home

	Medical Home [a] Weighted % (SE)	Condition Type [a] Weighted % (SE)				
		PHC	MHC	DD	Multiple	Total
Weighted % (SE)	57.0 (.45)	45.2 (.48)	14.2 (.33)	4.4 (.18)	36.2 (.47)	
Preventive Services Receipt						
Yes	82.6 (.51)	78.4 (.61)	81.1 (1.0)	70.3 (2.05)	81.2 (.64)	78.6 (.39)
No	17.4 (.51)	21.6 (.61)	18.9 (1.0)	29.7 (2.05)	18.8 (.64)	21.4 (.39)
Shared Decision-making						
Yes	89.9 (.44)	75.9 (.63)	71.5 (1.20)	61.8 (2.13)	63.2 (.84)	70.3 (.44)
No	10.1 (.44)	24.1 (.63)	28.5 (1.20)	38.2 (2.13)	36.8 (.84)	29.7 (.44)
Community Services Easy to Use						
Yes	81.6 (.51)	73.7 (.66)	70.2 (1.15)	58.0 (2.09)	51.0 (.84)	65.1 (.45)
No	18.4 (.51)	26.3 (.66)	29.8 (1.15)	42.0 (2.09)	49.0 (.84)	34.9 (.45)
Unmet Need: Health Care						
No	87.8 (.47)	83.9 (.56)	79.1 (1.11)	70.3 (1.91)	65.7 (.82)	76.4 (.41)
Yes	12.2 (.47)	16.1 (.56)	20.9 (1.11)	29.7 (1.91)	34.3 (.82)	23.6 (.42)
Unmet Need: Family Support						
No	83.1 (1.61)	75.8 (2.79)	67.7 (2.83)	57.0(4.11)	58.0 (1.45)	63.1 (1.09)
Yes	16.9 (1.61)	24.2 (2.79)	32.3 (2.83)	43.0 (4.11)	42.0 (1.45)	36.9 (1.09)
Any Special Education						
No	79.6 (.52)	7.5 (.37)	28.2 (1.14)	70.8 (2.05)	51.9 (.84)	27.3 (.41)
Yes	20.4 (.52)	92.5 (.37)	71.8 (1.14)	29.2 (2.05)	48.1 (.84)	72.7 (.41)

Abbreviations: PHC, Physical Health Condition; MHC, Mental Health Condition; DD, Developmental Disability.

[a] $P < .0001$ Between all outcomes & both predictors

Table 4.4. Adjusted Associations Between Medical Home, Condition Type & Six Pediatric Outcomes

	Preventive Services Receipt OR (95% CI)	Shared Decision Making OR (95% CI)	Community Services Easy to Use OR (95% CI)	No Unmet Need – Health Care OR (95% CI)	No Unmet Need – Family Support OR (95% CI)	Any Special Education Services OR (95% CI)
Health system						
Medical home status						
No	1.00	1.00	1.00	1.00	1.00	1.00
Yes	1.44 (1.29, 1.60) [a]	5.78 (5.13, 6.50) [a]	2.99 (2.71, 3.30) [a]	2.47 (2.20, 2.77) [a]	3.39 (2.57, 4.49) [a]	.88 (.79, .98) [c]
Need						
Condition Type						
PHC only	1.00	1.00	1.00	1.00	1.00	1.00
MHC only	1.09 (0.91, 1.30)	0.87 (0.74, 1.03)	1.04 (0.89, 1.22)	1.01 (0.85, 1.12)	0.73 (0.49, 1.09)	3.07 (2.55, 3.69) [a]
DD only	1.07 (0.84, 1.36)	0.89 (0.70, 1.12)	1.16 (0.93, 1.46)	0.93 (0.74, 1.16)	0.80 (0.50, 1.25)	13.01 (10.18, 16.63) [a]
Multiple	1.39 (1.21, 1.60) [a]	0.76 (0.66, 0.87) [b]	0.67 (0.59, 0.75) [a]	0.72 (0.63, 0.83) [a]	0.64 (0.46, 0.89) [c]	7.01 (5.97, 8.23) [a]
Primary Need						
RX Meds Only	1.00	1.00	1.00	1.00	1.00	1.00
Service Use Only	0.73 (0.61, 0.88) [b]	0.88 (0.73, 1.06) [b]	0.58 (0.49, 0.70) [a]	0.55 (0.46, 0.67) [a]	1.09 (0.69, 1.71)	3.21 (2.60, 3.95) [a]
RX + Service Use	1.01 (0.87, 1.17)	1.29 (1.11, 1.49)	0.72 (0.63, 0.82) [a]	0.72 (0.62, 0.85) [a]	1.47 (0.96, 2.26)	2.22 (1.87, 2.65) [a]
Functional limits	0.78 (0.65, 0.93)	0.95 (0.81, 1.12)	0.53 (0.46, 0.62) [a]	0.56 (0.47, 0.66) [a]	0.93 (0.60, 1.44)	3.80 (3.17, 4.57) [a]
Daily Activities						
Never affected	1.00	1.00	1.00	1.00	1.00	1.00
Moderately affected	1.03 (0.90, 1.17)	0.73 (0.64, 0.83) [b]	0.62 (0.55, 0.70)	0.76 (0.65, 0.88)	0.94 (0.63, 1.39)	1.14 (.97, 1.33) [c]
Consistently affected	0.91 (0.75, 1.09)	0.74 (0.63, 0.87)	0.43 (0.37, 0.50)	0.48 (0.41, 0.58) [a]	0.52 (0.34, 0.77) [a]	1.78 (1.49, 2.13) [a]
Predisposing						
Age						
0-5 y	1.00	1.00	1.00	1.00	1.00	1.00
6-11 y	2.84 (2.47, 3.26) [a]	1.09 (0.94, 1.27)	1.07 (0.93, 1.23)	0.80 (0.69, 0.94)	0.63 (0.46, 0.86) [c]	2.04 (1.71, 2.44) [a]
12-17 y	2.21 (1.93, 2.55) [a]	1.14 (0.98, 1.33)	1.05 (0.91, 1.22)	0.65 (0.55, 0.77) [a]	0.63 (0.46, 0.86) [c]	2.08 (1.74, 2.49) [a]
Sex						
Female	1.00	1.00	1.00	1.00	1.00	1.00
Male	1.03 (0.93, 1.15)	0.96 (0.86, 1.06)	1.19 (1.08, 1.31) [c]	1.20 (1.08, 1.33) [c]	0.97 (0.79, 1.20)	1.49 (1.33, 1.67) [a]

Race/Ethnicity						
White	1.00	1.00	1.00	1.00	1.00	1.00
Black	1.34 (1.16, 1.59) [b]	0.89 (0.76, 1.04)	1.06 (0.91, 1.23)	0.91 (0.77, 1.15)	0.93 (0.68, 1.27)	1.09 (.90, 1.32)
Hispanic	1.32 (1.09, 1.60) [c]	1.03 (0.86, 1.22)	0.92 (0.78, 1.10)	0.95 (0.79, 1.15)	1.14 (0.80, 1.62)	.95 (.79, 1.15)
Multi-racial/Other	1.12 (0.93, 1.36)	0.99 (0.82, 1.19)	0.91 (0.77, 1.07)	0.94 (0.78, 1.12)	1.08 (0.76, 1.54)	1.09 (.91, 1.31)
Enabling						
Insurance status						
Any Private	1.00	1.00	1.00	1.00	1.00	1.00
Public Only	1.17 (1.00, 1.37)	0.88 (0.76, 1.02)	1.03 (0.89, 1.18)	0.93 (0.80, 1.07)	0.95 (0.73, 1.24)	1.07 (.93, 1.25)
Uninsured	0.53 (0.38, 0.74) [c]	1.02 (0.70, 1.49)	0.82 (0.57, 1.18)	0.65 (0.46, 0.92)	0.44 (0.22, 0.89)	.56, (.35, .89) [c]
Consistently Insured						
Yes	1.00	1.00	1.00	1.00	1.00	1.00
No	0.60 (0.49, 0.73) [a]	0.72 (0.58, 0.89) [b]	0.29 (0.23, 0.36) [a]	0.43 (0.34, 0.53) [a]	0.69 (0.47, 1.02)	.93 (.66, 1.30)
Household language						
English	1.00	1.00	1.00	1.00	1.00	1.00
Non-English	0.70 (0.53, 0.93)	0.94 (0.70, 1.27)	0.89 (0.67, 1.18)	1.21 (0.90, 1.62)	1.76 (0.96, 3.20)	1.07 (.78, 1.48)
Parental education						
More than HS	1.00	1.00	1.00	1.00	1.00	1.00
HS graduate	0.85 (0.73, 0.99)	0.94 (0.81, 1.07)	1.40 (1.22, 1.59) [a]	1.32 (1.14, 1.54) [b]	1.89 (1.39, 2.55) [a]	1.08 (.93, 1.27)
Less than HS	0.74 (0.60, 0.92)	0.89 (0.72, 1.10)	1.82 (1.48, 2.24) [a]	1.52 (1.22, 1.90) [b]	1.96 (1.31, 2.94) [b]	.85 (.68, 1.07)
Household income						
400% or more FPL	1.00	1.00	1.00	1.00	1.00	1.00
200-399% FPL	0.65 (0.56, 0.74) [a]	0.90 (0.79, 1.02)	0.77 (0.68, 0.87) [a]	0.54 (0.46, 0.62) [a]	0.69 (0.52, 0.91)	1.06 (.93, 1.22)
100-199% FPL	0.58 (0.48, 0.69) [a]	0.92 (0.78, 1.09)	0.68 (0.58, 0.79) [a]	0.47 (0.40, 0.56) [a]	0.72 (0.52, 0.99)	1.14 (.96, 1.35)
<100% FPL	0.56 (0.45, 0.70) [a]	0.92 (0.75, 1.12)	0.73 (0.61, 0.88) [b]	0.41 (0.33, 0.50) [a]	0.65 (0.45, 0.96)	1.05 (.84, 1.30)
Family Structure						
Two parents	1.00	1.00	1.00	1.00	1.00	1.00
Two parents step	1.03 (0.85, 1.25)	0.91 (0.78, 1.08)	0.99 (0.84, 1.16)	0.93 (0.78, 1.11)	1.34 (0.95, 1.90)	.77 (.64, .93) [c]
Single Mother	0.88 (0.77, 1.01)	0.89 (0.78, 1.02)	0.89 (0.79, 1.01)	0.87 (0.76, 1.00)	1.13 (0.87, 1.47)	.81, (.70, .93) [c]
Other	1.02 (0.82, 1.28)	0.95 (0.78, 1.16)	0.93 (0.77, 1.14)	1.08 (0.88, 1.33)	1.22 (0.85, 1.75)	1.14 (.92, 1.40) [b]
HRSA region						

Region 1	1.00	1.00	1.00	1.00	1.00	1.00
Region 2	0.89 (0.61, 1.04)	0.84 (0.66, 1.05)	1.08 (.87, 1.33)	1.13 (0.87, 1.46)	0.70 (0.43, 1.12)	1.09 (.88, 1.36)
Region 3	0.68 (0.55, 0.86) [b]	1.13 (0.92, 1.38)	1.07 (0.89, 1.28)	1.02 (0.82, 1.28)	1.18 (0.79, 1.77)	.76 (.62, .94) [c]
Region 4	0.52 (0.43, 0.64) [a]	1.08 (0.90, 1.29)	1.16 (0.99, 1.36)	0.95 (0.78, 1.16)	0.92 (0.64, 1.32)	.51 (.42, .61) [a]
Region 5	0.57 (0.46, 0.69) [a]	1.11 (0.92, 1.34)	1.01 (0.85, 1.19)	0.93 (0.75, 1.14)	0.80 (0.55, 1.16)	.72 (.60, .87) [b]
Region 6	0.51 (0.40, 0.65) [a]	1.03 (0.83, 1.27)	0.82 (0.68, 0.99)	0.81 (0.64, 1.02)	0.66 (0.44, 1.00)	.48 (.37, .62) [a]
Region 7	0.51 (0.40, 0.64) [a]	1.06 (0.87, 1.31)	1.09 (0.90, 1.31)	1.03 (0.82, 1.30)	0.67 (0.44, 1.03)	.76 (.62, .93) [b]
Region 8	0.48 (0.38, 0.60) [a]	0.88 (0.70, 1.09)	0.86 (0.71, 1.04)	0.81 (0.64, 1.03)	0.59 (0.40, 0.89)	.71 (.57, .88) [c]
Region 9	0.57 (0.44, 0.73) [a]	0.74 (0.58, 0.94)	1.03 (0.83, 1.28)	0.82 (0.63, 1.06)	0.60 (0.39, 0.92)	.70 (.55, .89) [c]
Region 10	0.51 (0.40, 0.64) [a]	1.06 (0.86, 1.31)	0.95 (0.79, 1.14)	0.85 (0.68, 1.07)	0.69 (0.47, 1.04)	.67 (.54, .84) [b]

Abbreviations: CSHCN, Children with Special Healthcare Needs; FPL, Federal Poverty Level; HRSA, Health Resources & Services Administration; HS, High school; PHC, Physical Health Condition; MHC, Mental Health Condition; DD, Developmental Disability; RX, Prescription.

[a] $P < .0001$. [b] $P < .001$. [c] $P < .05$

Table 4.5. Weighted Adjusted Associations Between Six Pediatric Outcomes & Medical Home, Stratified by Condition Type

	PHC OR (95% CI)	MHC OR (95% CI)	DD OR (95% CI)	Multiple OR (95% CI)
Preventive Services Receipt (n=32,078)				
MH Yes	1.47 (1.26, 1.71)[a]	1.29 (.95, 1.77)	1.50 (.96, 2.35)	1.45 (1.20, 1.75)[b]
No	1.00	1.00	1.00	1.00
Shared Decision-Making (n=32,111)				
MH Yes	4.96 (4.21, 5.84)[a]	6.56 (4.75, 9.08)[a]	8.76 (5.18, 14.83)[a]	6.56 (5.31, 8.10)[a]
No	1.00	1.00	1.00	1.00
Community Services Easy to Use (n=32,142)				
MH Yes	2.65 (2.29, 3.07)[a]	2.61 (1.98, 3.46)[a]	3.50 (2.29, 5.37)[a]	3.61 (3.10, 4.20)[a]
No	1.00	1.00	1.00	1.00
No Unmet Need – Health Care (n=31,889)				
MH Yes	1.94 (1.62, 2.34)[a]	2.69 (1.92, 3.78)[a]	3.06 (2.01, 4.67)[a]	2.88 (2.41, 3.42)[a]
No	1.00	1.00	1.00	1.00
No Unmet Need – Family Support (n=6,150)				
MH Yes	3.27 (1.74, 6.13)[b]	5.86 (3.04, 11.29)[a]	7.23 (2.54, 20.60)[b]	3.09 (2.13, 4.48)[a]
No	1.00	1.00	1.00	1.00
Any Special Education Services (n =32,299)				
MH Yes	.86 (.68, 1.10)	.80, (.63, 1.02)	.97 (.64, 1.48)	.90 (.77, 1.05)
No	1.00	1.00	1.00	1.00

Note. Controlling for Need-based, Predisposing, and Enabling covariates. n = total number of observations for whom data was available for that outcome

Abbreviations: PHC, Physical Health Condition; MHC, Mental Health Condition; DD, Developmental Disability.

[a] $P < .0001$. [b] $P < .001$. [c] $P < .05$.

Table 4.6. Unweighted Adjusted Associations Between 6 Pediatric Outcomes & Medical Home, Stratified by Condition Type

	PHC OR (95% CI)	MHC OR (95% CI)	DD OR (95% CI)	Multiple OR (95% CI)
Preventive Services Receipt (n=32,078)				
MH Yes	1.24 (1.14, 1.36) [a]	1.29 (1.09, 1.52) [c]	1.56 (1.19, 2.05) [c]	1.27 (1.14, 1.43) [a]
No	1.00	1.00	1.00	1.00
Shared Decision-Making (n=32,111)				
MH Yes	5.36 (4.87, 5.89) [a]	6.13 (5.15, 7.28) [a]	8.21 (5.82, 11.60) [a]	7.63 (6.76, 8.61) [a]
No	1.00	1.00	1.00	1.00
Community Services Easy to Use (n = 32,142)				
MH Yes	2.52 (2.31, 2.74) [a]	2.78 (2.40, 3.22) [a]	3.20 (2.48, 4.13) [a]	3.42 (3.13, 3.75) [a]
No	1.00	1.00	1.00	1.00
No Unmet Need – Health Care (n = 31,889)				
MH Yes	2.12 (1.91, 2.36) [a]	2.17 (1.82, 2.60) [a]	2.93 (2.20, 3.91) [a]	2.79 (2.52, 3.09) [a]
No	1.00	1.00	1.00	1.00
No Unmet Need – Family Support (n =6,150)				
MH Yes	2.58 (1.79, 3.73) [a]	4.50 (2.91, 6.96) [a]	4.65 (2.45, 8.82) [a]	3.13 (2.59, 3.78) [a]
No	1.00	1.00	1.00	1.00
Any Special Education Services (n =32,299)				
MH Yes	.78 (.69, .89) [b]	.94 (.82, 1.07)	.89 (.68, 1.16)	.85 (.78, .93) [b]
No	1.00	1.00	1.00	1.00

Note. Controlling for Need-Based, Predisposing, and Enabling covariates. n = total number of observations for whom data was available for that outcome

Abbreviations: PHC, Physical Health Condition; MHC, Mental Health Condition; DD, Developmental Disability.

[a] $P < .0001$. [b] $P < .001$. [c] $P < .05$.

APPENDICES

Appendix 2.1 Agreement for individual items extracted and coded in the systematic review process

	N Agreed	% Agreed
Total Items	228	87%
Medical Home (MH) Setting	18	90%
Study Design	16	80%
Sample Population	19	95%
Sample Age	17	85%
Number of participants/observations	18	90%
Definition & Measurement of MH detailed	17	85%
Definition & Measurement of MH - categorical	18	90%
Main predictors	20	100%
Outcome source	19	95%
Outcomes	17	85%
Objective or Subjective Outcome	14	70%
Traditional or Non-Traditional Outcome	16	80%
Length of follow-up	19	95%

Appendix 2.2 Descriptive statistics of included studies by age

Sample Age	N	%
<=2 y	1	1.22%
<5 mo	1	1.22%
0 to 12+ y	1	1.22%
0 to 17 y (<18)	38	46.34%
0 to 18 y	5	6.10%
0 to 19 y	1	1.22%
0 to 20 y	1	1.22%
0 to 21 y	2	2.44%
0 to 5 y	2	2.44%
1 to 13 y	1	1.22%
1 to 16 y	1	1.22%
1 to 17 y	2	2.44%
1 to 19 y	1	1.22%
1 to 20 y, at follow up	1	1.22%
1 to 26 mo, at enrollment	1	1.22%
12 to 17 y	5	6.10%
2 to 15 y	2	2.44%
2 to 17 y	1	1.22%
2 to 17 y (<18)	1	1.22%
2 to 18 y	2	2.44%
24 mo	1	1.22%
3 to 17 y	2	2.44%
4 to 17 y	1	1.22%
4 to 17 y (<18)	1	1.22%
5 to 17 y	1	1.22%
6 mo to 12 y	1	1.22%
6 to 17 y	3	3.66%
Not Reported	2	2.44%
Grand Total	**82**	**100.00%**

Appendix 2.3 References for all studies in Systematic Review, APA Style

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Appendix 4.1 Cluster Analysis Output