IMPACT OF MEDICAL HOME CHARACTERISTICS ON AVAILABILITY OF CARE: INFLUENCE OF SOCIAL CAPITAL AND INSURANCE STATUS

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DEDICATION

I would like to dedicate this dissertation to all of the children and families of children with special healthcare needs who deserve to be provided with the best healthcare possible. I hope that one day all children will be cared for in a comprehensive medical home that will allow for them to become healthy, happy, and compassionate human beings who thrive in the wonderful world in which we live.
LIST OF ABBREVIATIONS

AAP: American Academy of Pediatrics
ACA: Affordable Care Act
CDC: Centers for Disease Control and Prevention
CHIP: Children’s Health Insurance Program
CSHCN: Children with Special Healthcare Needs
ED: Emergency Department
FPL: Federal Poverty Level
HMO: Health Maintenance Organization
NS-CSHCN: National Survey for Children with Special Healthcare Needs
NSCH: National Survey of Children’s Health
OR: Odds Ratio
PCMH: Patient-Centered Medical Home
PCP: Primary Care Provider
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CHAPTER 1

INTRODUCTION

1.1 Overview of the Medical Home

As the population increases and the cost of health care becomes increasingly expensive, more children have become underinsured, noninsured, or are lacking resources to access quality preventive care. This is especially true for minority children and those with special health needs in urban and rural areas of the U.S., where these populations encounter unique barriers to care. As the step-wise implementation of the Affordable Care Act (ACA) unfolds, these unfortunate statistics may begin to normalize and hopefully begin to start a reverse trend for all children living in the U.S. The purpose of this research is to examine medical home characteristics within a large national dataset of children with chronic pediatric health conditions and evaluate how neighborhood social capital factors and insurance status play a role in the availability of medical care and mental health services in these potentially vulnerable children. Specifically, this research will examine independent medical home components within a medical practice and how they affect the availability of care, while accounting for the level of social capital and insurance status of the child.

Lack of access to preventive medical care is one of the greatest predictors of future chronic health-related conditions in children. Availability of medical care can be increased
within a model that fosters a supporting and caring environment with a “physician-family” partnership (AAP, 2002). This type of model is referred to as the “medical home”.

More specifically, the medical home model is a comprehensive approach to rendering high quality primary care services, which includes care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective (AAP, 2016). The American Academy of Pediatrics has advocated for this model since 1967, with an initial attempt to increase access to health care in children with special health care needs (CSHCN) but later to include all children (AAP, 2002). Recent research has shown that having a medical home may lead to higher perceived quality of care for all children as well as an increased likelihood of having had preventive health visits as and less emergency department and outpatient sick visits (Han et al. 2016 & Long et al. 2012).

Previous research has examined the impact of specific medical home components on time burden of families when taking care of their CSHCN, however, research is lacking on identifying specific components of the medical home that best predict availability of medical care and mental health services (Miller, et al., 2015). According to Miller and colleagues, care coordination, family-centered care, and obtaining needed referrals were the most predictive in lowering the odds of having increased time burden, however, having all five medical home components also resulted in less personal time caring for the child. Another study examining CSHCN has shown that having lower quality family-centeredness, as a component of the medical home, was most predictive of increased emergency department (ED) visits as compared to CSHCN with high quality family-centeredness. (Raphael, et al. 2011). This study did not specifically predict availability of care; however, the increased number of ED visits could be a response mechanism for lack of primary care availability.
Several researchers have hypothesized that social determinants of health (individual behaviors and environmental factors) largely contribute to decreased access to preventive health services, namely, inclusion into a medical home (Wong et al., 2012). Understanding this “third space” which is described as efforts to implement a medical home infrastructure along with recognizing the long range social determinants of health is crucial to the long-term success in accessing quality care (Wong et al., 2012). Included within social determinants of health include the level of social capital within the community that may influence access to a medical home and thus access to quality healthcare. By examining the level of social capital within communities, this will allow for a more robust understanding of how these specific factors influence the ability to secure quality health care services in the pediatric population for children with varying degrees of medical home inclusion within their primary care practice. This will allow us to gain a better understanding of how to increase the availability of care for children with barriers related in part to the neighborhood in which they live. This will also allow us to understand if the protective effects of the medical home are heightened or lessened depending on the level of social capital within the community. The understanding of these factors is crucial for maintaining the standard of care for all children, in order to decrease disease and increase quality of life across all pediatric populations.

1.2 Social Capital Factors

When examining the various factors that contribute to primary care availability for U.S. children, it is important to understand the social environment and neighborhood where they reside. Two social capital models that are important for the purposes of this research are bonding social capital and bridging social capital. The concept of bonding social capital describes social relationships within a community of shared values such as family or close friendships. Bridging social capital describes relationships between people from different communities,
neighborhoods, or groups (Narayan, 1999). These constructs can also be seen as vertical (bridging) or horizontal (bonding) relationships depending on the type of interaction. These models of social capital are extremely important when examining barriers to quality medical care services, as has been found in previous research. Many researchers in the past have described a direct inverse association between social class and health outcomes, which prompts a more detailed investigation into how social capital affects availability of care (Marmot, et al 1991, Wilkinson & Pickett 2009, Engstrom, et al. 2008). A systematic review published by Uphoff and colleagues (2013) examines three hypotheses in order to gain a broader insight into how neighborhood social capital factors may provide a buffer against poor self-rated health and health outcomes. The first model hypothesized by Uphoff and colleagues describes the buffer effect that increased levels of social capital may provide to low socioeconomic populations.

Figure 1.1 (Uphoff et al, 2013)
The second model by Uphoff and colleagues describes a possible dependency between social, economic, and cultural capital.

Figure 1.2 (Uphoff et al., 2013)

The third and final model by Uphoff and colleagues describes the possibility that all people within the same community may not equally obtain the same benefits, realizing a contextual component between area social capital (community) and self-rated health.

Figure 1.3 (Uphoff et al, 2013)

The authors from the above review found that there is strong evidence showing that individuals from a lower socioeconomic class typically have lower social capital or lack of social capital within their community or family unit. The authors also found that bonding social capital (close relationships or tight-knit communities) may buffer some of the negative effects of having a lower socioeconomic background on self-rated health (Uphoff et al, 2013). According to these above models, it is important to examine how the medical home model impacts availability of care in communities with varying levels of social capital.
Based on these findings, it is important to examine health in the context of care availability. The aforementioned review examined research largely surrounding self-reported health at the individual level, however, did not examine access or availability of medical care in general. By examining similar hypotheses for children who are cared for within and outside of a medical home (or some level in between), we can then begin to understand the impact of neighborhood social capital on availability of medical care and how these social capital factors influence or mediate access to these critical services. Another study examined the effects of neighborhood social capital (using similar constructs to the ones used within the current NSCH dataset (2011-2012)) on the decision of parents to vaccinate their children with the H1N1 vaccine. Parents who reported a high level of social capital within the neighborhood were more likely to vaccinate their children (Jung, et al, 2013). This dissertation will examine similar neighborhood bonding social capital factors as described in previous research (Iida & Rozier, 2013, Dauner, et al. 2015, Singh et al, 2008).

1.3 Health Disparities in Children

Access to quality health care in the United States has become more of a challenge for all age groups, especially in the adult Medicaid population and the uninsured (NHDR, 2014). Although access to care for children increased between 2002-2012, children with public insurance (Medicaid or Children’s Health Insurance Plan (CHIP)) coverage were still less likely to receive care when they wanted it during this time period (NHDR, 2014). In 2006, children made up 24.8% of the U.S. population (73.5 million individuals) and at this time, 40% of children belonged to a racial minority group and 17.6% of children lived below the federal poverty level (NHDR, 2008). In 2003, black children had a mortality rate 1.5 to 2 times higher than white children, and were less likely to survive their first year of life (NHDR, 2008). Children in these ethnic minority groups are at greater risk for developing poor health habits
early in life, which could lead to greater instances of health-related problems in adulthood (Jamerson et al, 2017).

Health status can be influenced by a range of factors, including: (a) socioeconomic status (SES), (b) race/ethnicity, (c) income level, (d) education level, (e) social and emotional support systems, (f) neighborhood factors, and (g) the status of health insurance (NIHCM, 2007). The attainment of health insurance in children is a large, influential factor in the overall accessibility of health care services. In 2002, 7.8 million children were uninsured, and one in five impoverished children lacked access to any type of health insurance (NIHCM, 2007). Minority children experience greater barriers to care due to cultural and geographic factors, even when insured at the same level as white children (Children’s Defense Fund, 2006). Children with mental, behavioral, and developmental disorders have been shown to have inadequate insurance coverage as well as lack a medical home and have decreased levels of neighborhood support and resources (Bitsko, et al., 2016). This research will attempt to quantify the relationship of medical home components on the availability of medical care and mental health services along with controlling for the level of neighborhood support (social capital) and insurance for children with special healthcare needs.

CSHCN have a wide range of chronic health conditions that encompass developmental and physical disabilities as well as learning disorders and mild conditions that may limit the child’s daily activities. The prevalence of CSHCN in the US is 15.1% and the total cost of healthcare for CSHCN accounts for 34% of all health-related costs for all children in the U.S. (HRSA, 2013; Newacheck & Kim, 2005). The source of funding for many of these under- or uninsured children comes largely from federal subsidies including Medicaid and CHIP programs. As of 2009, Medicaid and CHIP insured 59% of all low-income children, allowing them access to much needed medical care services (Kaiser Commission, 2011). With the creation of these
programs, 90% of children were insured by 2009. Despite these increases in access to subsidized insurance, eight million children were still uninsured in 2009, and five of these eight million children were actually eligible for Medicaid and CHIP (Kaiser Commission, 2011).

As federal and state programs fund more and more care for children, public health initiatives will play a greater role in providing preventive services and general medical care to this population in the future. Public health programs can bridge the gap and provide better health care for large populations of medically underserved children and therefore keep children healthier as they transition into later years. However, public health services suffer from a lack of funding and financial resources, and thus they are unable to adequately address the healthcare needs of the entire pediatric population. Public health and medical practitioners face a daunting task in trying to provide the best care to the most vulnerable segment of the pediatric population, including those with multiple chronic comorbid diseases. Public and private forces must join to create a model that continually meets all children’s’ health care needs. In order to address the largest barriers to health care access, all social factors must be considered, including those related to the level of social capital within the community. These factors should allow us to address where medical homes can best be utilized, along with understanding how social capital affects availability of care in this subset of the pediatric population.

1.4 Preventive Care Services: Factors to Be Considered

The National Healthcare Disparities Report (2008) measured access to child preventive services based on three categories: early childhood vaccinations, counseling about physical activity, and vision screening. According to the report, in 2006, African American children were less likely to have received all immunizations as compared to white children (77.0% vs. 81.6%). Also, in 2006, the rate of vaccination in high-income families was 86.3% as compared with poor families (76.5%) (NHDR 2008). Insured children were more likely to have received counseling
about physical activity as compared with non-insured children (36% and 28.5%, respectively) (NHDR 2008). Insured children were also more likely to have an annual vision-screening test than non-insured children; however, there were no racial or ethnic variations seen with vision screening practices (NHDR 2008). Access to the above preventive measures is an extremely important component of the medical home model. By having an accessible primary care provider, more effective counseling and treatment can take place while encouraging preventive strategies. Public health entities are integral in establishing preventive screening programs for children as well as establishing an entry point into a long-term relationship with a primary care provider. As more and more children are born into impoverished families, public health initiatives must take an active role at both the local and national levels in order to fill in the gaps where primary care providers are lacking resources. By examining the neighborhood level of social capital on the impact of availability of care within a medical home, public health programs can then be targeted toward these vulnerable communities.

1.5 Study Objectives

This study aims to:

- Examine the effects of medical home components on the availability of **all healthcare types** for children with special healthcare needs (CSHCN)
- Examine the effect of medical home components on the availability of **all health care types** while controlling for social capital and insurance coverage in children with special healthcare needs (CSHCN)
- Examine the effects of medical home components on the availability of **medical care** while controlling for social capital and insurance coverage in children with special healthcare needs (CSHCN)
• Examine the effects of medical home components on the availability of mental health services alone while controlling for social capital and insurance coverage in children with special healthcare needs (CSHCN)
CHAPTER 2

LITERATURE REVIEW

2.1 Importance of the Patient-Centered Medical Home

The medical home model was specifically designed for children with special physical, emotional, or developmental health care needs. However, the model now includes children who may remain vulnerable to disease because of other societal or environmental factors, as well as healthy children (Brito et al., 2008). The American Academy of Pediatrics describes the seven characteristics of the medical home as: “care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective” (Strickland et al., 2004). The medical home model is targeted toward: (a) children in high poverty areas; (b) children living in an area where health care is not accessible (such as rural areas); (c) psychosocially vulnerable children; (d) victims of domestic violence; (e) children with language barriers; and (f) children with low health literacy (Brito et al., 2008).

The medical home model was created to foster a sense of a “partnership of mutual responsibility” between patient, family, and the physician (AAP, 2002). However, not every pediatric practice has fully integrated these goals, and physicians may leave behind critical functions of the model due to financial or time constraints. This model also requires incorporation of other agencies and health care institutions, in order to function properly and to
attain the optimal and intended results. Components of the medical home as described by Strickland et al. (2004) include a “usual source of care, personal doctor or nurse, referrals for specialty care, coordinated care, and family-centered care.” If children have stable environments to receive care and the means to obtain care from providers, then this model can lead to a number of improvements in overall health. The medical home model can help the child remain healthy, foster a healthier family environment, and exhibit decreased emergency department visits and hospital admissions (Raphael, et al, 2015). Therefore, the medical home model can lead to lower costs overall with better coordination of care by the primary care provider (Singh et al., 2009).

One study has shown that physicians who are more active and involved in caring for children prior to and after hospital admission have helped to decrease overall hospital admission rates in three major U.S. cities (Perrin et al., 1996). Another study in the United Kingdom has found a strong correlation between the increased ratio of physicians to patients and decreased percentage of hospital mortality (Jarman et al., 1999). A stable primary care provider within a medical home (whether a physician or a nurse) can foster a long-term trusting relationship with the family, in addition to providing medical treatment and counseling advice. Children with a primary care provider are more likely to thrive in an active and healthy environment. A primary care provider can also coordinate care and provide crucial referrals to specialists, as well as foster a model of “family-centered care” (Strickland et al., 2004).

2.2 Medical Home Practice Variation for Medically Complex Children

Children with special health care needs (CSHCN) are defined by the Department of Health and Human Services 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” (HHS, 2011). According to previous research examining two prior versions of the National Survey of
Children’s Health, the prevalence of CSHCN in the U.S. is between 12.8 and 18% (Bethell et al. 2007). A study by Singh et al. (2009) showed that 53% of children with special health care needs in the U.S. did not have access to a medical home, with variation noted across states. Singh et al., (2009) also found that children aged 12-17 had a 26% higher chance of not having a true medical home as compared to children aged 0-5 years. Minority populations, on the other hand, were shown to have a 56% and 57% chance (Hispanic and Black children, respectively) of not having access to a medical home, as compared to their White counterparts. Children from non-English speaking households and children living below the poverty level also tend to lack access to a medical home (Singh et al. 2009).

Underserved and impoverished pediatric populations who lack access to a medical home suffer from the same health consequences as CSHCN. Many children from low-income families are considered to have special physical, emotional, or behavioral health care needs; however, some are not. Unfortunately, the environment in which the child lives may harbor inequities such that the child will develop social, behavioral, physical, or emotional disabilities as they grow. Newacheck et al. (1998) examined the quality of care and access to primary care services for children on Medicaid living in impoverished areas. The authors found that poor children on Medicaid, who do have access to primary care services, are still less likely to have a medical home than insured children (Newacheck et al. 1998). Another study conducted in Alabama found that only 11.8% of Medicaid-enrolled children had a formal medical home, characterized by a minimum of one visit in the preceding year (Peterson et al., 2002).

Homelessness is another factor that severely decreases access to pediatric primary care services. Homeless children have higher rates of chronic health conditions, higher numbers of emergency department visits, and greater need for specialty care (Redlener et al. 2005). Children with language and cultural barriers, immigrant children, and children in the foster system also
exhibit the same rates of primary care utilization use as homeless and impoverished children (Hansen et al., 2004; Huang et al., 2006). When examining each medical home component, further research has shown that the percentage of having a specific medical home component varies from 59% (care coordination) up to 93% (having a personal doctor or nurse) (Strickland, et al. 2009). Based on this finding, it is unknown which component or group of components has the greatest potential for children to receive quality medical or mental health care when needed.

2.3 Individual Social Capital vs. Aggregate

The association between social capital and health equity has been well established in the literature when examining multiple determinants of health (education, income, employment status). Individuals who live in socio-economically depressed areas of the U.S. tend to have worse health outcomes than individuals living in suburban or upper-scale communities (Whitehead, 1998, Marmot, et al., 1991, Wilkinson & Pickett 2009, Engstrom, et al., 2008). The phenomenon of social capital has had long lasting effects on communities, especially on how one or one’s group reports their physical and psychological health (Putnam, 2000). An earlier definition of social capital is “the ability to secure benefits through membership in networks and other social structures” (Portes, 1998). This definition can now be extrapolated to “health” benefits as a result of membership in a specific community as well as the social network in which people belong within the community in which they live. Early research examining social capital on health status was largely captured at the individual level without taking the community or neighborhood into account. A publication in 1992, challenged the notion that individual social capital (income, employment) was the sole factor in determining health status and found that health outcomes were more closely associated with the distribution of income within the country (Wilkinson, 1992). Despite this work, much debate has continued regarding the macro
level (community) versus the micro (individual) level factors and how these factors contribute to overall health and other outcomes within a specific neighborhood or community.

Another well-known component of social capital is civic participation as defined by Robert Putman (2000). Civic participation as described by Putnam (2000) includes trusting in others, which in turn facilitates cooperation and the development of working groups within the community to accomplish one collective goal. For the purposes this current research the collective goal is achieving greater availability of medical care and mental health services within the community. A study by Poortinga (2006) examines the health benefits of social capital and whether these benefits are due to individual factors or collective at the national level. This study examined 22 countries and found that that aggregate level variables were not associated with better self-rated health, however, individuals reporting good or very good health did reside in countries with high levels of social capital. This research suggests that communities reporting higher levels of social capital may report better self-rated health; however, it is unknown whether access to health care services are more prevalent in these areas. Further research has also shown that social capital is a good predictor of mortality and self-rated health in U.S. states when examining population health outcomes at the local, state, or national level (Kawachi et al. (1999, 2004). Another study has found, by reporting on individual level social capital factors, communities that lack trust or have lower levels of trust, report fair, bad, or very bad health by almost three times more than communities that report higher levels of trust. Findings from modeling on the aggregate level were also found to be similar to the individually reported outcomes (Poortinga, 2006). This study also found that individuals reporting higher levels of social support and civic participation within the community, were less likely to report poor health while individuals lacking social support were more likely to report a poorer health status (Poortinga, 2006).
2.4 Health Insurance

Health insurance remains one of the most important factors in the ability to obtain needed medical care. Multiple barriers exist even for children with Medicaid and Children’s Health Insurance Program (CHIP) coverage; however, children without any type of insurance face an even greater hardship. Newacheck et al., (1998) reported that an estimated 13% of children less than 18 years old were uninsured, and children without health insurance were six times more likely not to have a primary care provider or somewhere they can call a “usual source of care.” CSHCN who are also uninsured or underinsured face greater difficulties obtaining a regular source of care or a medical home. Newacheck and Kim (2005) have shown that CSHCN make up approximately 15% of the child population, however, account for almost half of all children’s medical related expenses. Kogan et al., (2005) have shown that 5.2% of CSHCN (according to the HHS definition) were uninsured and 32.3% were underinsured according to the National Survey of Children with Special Health Care Needs (NS-CSHCN). Families of CSHCN who were underinsured reported more access problems that directly affected the family infrastructure (Kogan et al., 2005). This information is important when creating a medical home because of the large amount of family involvement in the care of the child. If the family-centered approach is deficient, the medical home model will not be able to function properly.

2.5 Economic and Non-Economic Barriers to Services

Children face multiple barriers to health care, which include economic and non-economic factors. From the public health perspective, previous threats to population health in the U.S. arose from sanitation issues, poor living conditions and nutritional deficiencies. Many of these problems still exist; however, through advances in health-related technology and the increased availability of primary care providers and specialty care, many people can avoid these threats. A
large portion of the pediatric population in the country does not have access to a medical provider, particularly vulnerable children in underserved areas.

The majority of barriers arise because of the lack of insurance and/or the number of available health care providers in a particular area (Redlener, 2005). Children without private insurance, Medicaid or CHIP have difficulty obtaining access to primary and specialty healthcare services, and as exhibit higher rates of emergency room visits and hospitalizations (Brito, 2008). Research shows that 41% of children on Medicaid had two to four month gaps in insurance coverage during a given year (Fairbrother, 2007).

Non-economic barriers also prevent families from obtaining needed care. Rural physicians care for 20% of the U.S. population and yet comprise only 9% of all physicians (Brito, 2008). As health care providers tend to localize in higher populated areas, the rural population is becoming more distant from providers and finding themselves with inadequate access to care. Transportation continues to be a barrier in accessing primary care services, especially with the limited availability of public transportation in rural areas and the lack of household vehicles (Brito, 2008). According to a study conducted by Chan et al., (2006) geographical variation has a large impact on access to care, especially for rural residents. This research has shown that increased travel times lead to decreased physician visits and fewer medical specialist visits as compared to individuals living in urban areas (Chan et al., 2006). One study addressed transportation in an urban setting and found that transportation problems were significantly associated with missed appointments in poor urban children from Texas (Yang et al., 2006).

In addition to the economic and non-economic barriers described above when accessing a medical home, it is important to examine social capital factors within these communities to better understand the accessibility of a medical home within that community or neighborhood. Many
families with lack of transportation and health insurance will live in an impoverished community with varying levels of social capital within the community. It is known from previous literature that the level of social capital within a community affects multiple dimensions of one's health, including individual as well as family health (Dauner, et al., 2015, Iida & Rozier, 2013); however, little is known on how the level of neighborhood social capital effects availability of care when care is received within a medical home for CSHCN.
CHAPTER 3

METHODS

3.1 Data Source

The purpose of this research is to examine medical home characteristics within a large national dataset of children with chronic pediatric health conditions and evaluate how neighborhood social capital factors and insurance status play a role in the availability of medical care and mental health services in these potentially vulnerable children. Based on the applicability of this data set for this research, these data are taken from the National Survey of Children’s Health (2011-2012), which is a telephone survey conducted in English and Spanish during the years of 2010-2012. The Maternal and Child Health Bureau of the U.S. Department of Health and Human Services funded this survey. The National Center for Health Statistics provided oversight of the sampling and interviews for the survey (Child and Adolescent Health Measurement Initiative, 2012). This is the third and most recent iteration of the survey, which was previously administered in 2007-2008 and 2003-2004. Telephone numbers were selected at random for households that had one or more children under the age of 18. When the call was made, only one child in the household was selected at random as the subject of the interview. Survey questions were then asked to the parent or guardian about the selected child. A total of 95,677 surveys were completed in 2010-2012, with 1811-2200 surveys collected per state. The survey results are weighted, in order to represent children ages 0-17 years in the U.S. and in each state that are non-institutionalized. (Child and Adolescent Health Measurement Initiative, 2012).
3.2 Study Population

The study population of interest includes all children from the telephone interviews whose parent or guardian answered all questions included for the variables of interest (social capital, insurance status, availability of medical care and mental health services and medical home components) (n=32,496). Detailed descriptions of the variables are listed in the next section. Inclusion criteria include all children in the survey who are between the ages of 0 and 17 years and have been selected by the interviewee as the child for whom the questions were asked and who have identified with at least one disease or illness listed in the survey (Figure 3.1). Exclusion criteria are children whose parents or guardians did not answer questions assessing the specified variables selected for inclusion into this study.

The specific population are children whose parents have identified them with having at least one disease or illness from the survey are considered children with special healthcare needs (CSHCN) for the purposes of this research. These specific disorders/illnesses are as follows: attention deficit disorder or attention deficit hyperactivity disorder, depression, anxiety problems, behavior or conduct problems, Autism, Asperger’s Disorder, pervasive development disorder, or other autism spectrum disorders, any developmental delay, intellectual disability or mental retardation, cerebral palsy, speech or other language problems, Tourette Syndrome, epilepsy or seizure disorder, hearing problems, vision problems that cannot be corrected with standard glasses or contact lenses, bone, joint, or muscle problems, brain injury or concussion, asthma, and diabetes. Respondents were asked whether their child has been diagnosed with one of these disorders in the past. In order to include disorders that characterize children as having special health care needs, the NSCH followed a screening tool (CSHCN Screener©) developed in prior research as the basis for disease selection (Bethell et al., 2002). Previous research using the NSCH has also incorporated this screening tool when categorizing CSHCN (Toomey et al.,
Within the sample population of this survey, 19.8% of children are considered CSHCN based on the number of children whose parents have identified them with one or more of the selected diseases/illnesses.

**Figure 3.1. List of Diseases NSCH 2011-2012**

<table>
<thead>
<tr>
<th>Disease</th>
<th>Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder</td>
<td>Asthma</td>
</tr>
<tr>
<td>Depression</td>
<td>Diabetes</td>
</tr>
<tr>
<td>Anxiety problems</td>
<td>Epilepsy or seizure disorder</td>
</tr>
<tr>
<td>Behavior or conduct problems</td>
<td>Hearing problems</td>
</tr>
<tr>
<td>Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder</td>
<td>Vision problems that cannot be corrected with standard glasses or contact lenses</td>
</tr>
<tr>
<td>Any developmental delay</td>
<td>Bone, joint, or muscle problems</td>
</tr>
<tr>
<td>Intellectual disability or mental retardation</td>
<td>A brain injury or concussion</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td></td>
</tr>
<tr>
<td>Speech or other language problems</td>
<td></td>
</tr>
<tr>
<td>Tourette Syndrome</td>
<td></td>
</tr>
</tbody>
</table>

**3.3 Study Variables**

After applying the study inclusion and exclusion criteria, the sample consisted of 32,496 children. Data were collected via a complex sampling design that involved primary sampling units, stratification by state and phone type (landline versus cell phones), and unequal selection probabilities. The analysis therefore used the complex samples module in SPSS version 24 to correctly weight the data and adjust standard errors for the non-random nature of the sampling. All reported $p$-values have been adjusted for the sampling design. The weights are used to make inferences about the population, while the $p$-values are used to determine the probability that the estimates were chance results due to repeated sampling under the null hypothesis. The analysis is interested in whether social capital mediates any of the relationships regarding a specific medical home component and the availability of health care. Following Baron and
Kenney (1986), mediation can be inferred if variables that are significant in a regression without the mediator become non-significant in a model with the mediator. Partial mediation occurs if the variable remains significant, but its effect size (e.g. odds ratio), is substantially reduced. Thus, all of the dependent variables have been analyzed with two different models, one that excludes social capital and one that includes it. The models will all be logistic regressions given that the outcomes are binary. Unadjusted comparisons are presented prior to the logistic regressions in order to get a sense of associations before adding controls. The significance of the unadjusted comparisons will be assessed using an F-test that is an adjustment to the usual chi-square test to account for the complex sampling.

**Independent Variable- Medical Home Item**

The presence of medical home characteristics within the child’s primary care practice, listed below:

- Usual source of care coded as “yes”, “no”, “there is more than one place”, and “don’t know”.
  - Is there a place that (child) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?
- Personal provider coded as “yes”, yes, more than one person”, “no”, and “don’t know”.
  - A personal doctor or nurse is a health professional who knows your child and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, nurse practitioner, or physician assistant. Do you have one or more persons you think of as (child's) personal doctor or nurse?
- Care coordination coded as “yes”, “no”, and “don’t know”.

---

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• (During the past 12 months/ Since (his/her) birth), have you felt that you could have used extra help arranging or coordinating (child's) care among the different health care providers or services?

• Communication coded as “very satisfied”, “somewhat satisfied”, “somewhat dissatisfied”, “very dissatisfied”, “no communication needed or wanted”, and “don’t know”.

• Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among (child's) doctors or other health care providers?

• Family-Centered Care coded as “never”, “sometimes”, “usually”, “always”, and “don’t know”.

• (During the past 12 months/ Since (his/her) birth, how often did (child's) doctors or other health care providers help you feel like a partner in (his/her) care? Would you say never, sometimes, usually, or always?

The above variables are chosen based on the American Academy of Pediatrics’ (AAP) definition of a medical home which includes: care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (AAP, 2002). The same or similar variables using the 2011-2012 and prior versions of the NSCH have been used in the past for other research assessing AAP defined medical home characteristics (Balistreri, 2015; Stevens & Kim, 2016; Zickafoose & Davis, 2013; Zickafoose et al, 2012). Balistreri further states that the child is considered as having a medical home if only the first three components are met which are defined as having a personal doctor or nurse, having a usual source of care, and having family-centered care (2015). Prior researchers have also used similar variables from other datasets based on the AAP definition of a medical home. According to Han et al, to qualify as
having a medical home, the child is required to have a usual source of care as well as have components of care that is accessible, comprehensive, family-centered, and compassionate (Han et al, 2016). These data were taken from Medical Expenditure Panel Survey (MEPS) with similar variables used as in the NSCH. Other studies examining the NS-CSHCN dataset uses similar variable to describe the medical home model based on the AAP definition (Strickland et al, 2009, Miller et al, 2015). The main medical home variables described in this prior research involve the child having a usual source of care, a personal doctor or nurse, help with coordination of care, and family-centered care which are again, the same variables used in this current study to assess the most critical medical home components. Each variable will be examined in the regression model in order to assess the most predictive medical home characteristic on the availability of medical care and mental health services.

**Mediating Variable- Social Capital**

Social capital will be assessed using four variables in the data set that describe the bonding social capital characteristics within the child’s neighborhood or community. These specific variables are similar to neighborhood bonding social capital factors described in previous research (Iida, H & Rozier, R.G., 2013; Dauner, et al, 2015; Singh et al, 2008; Jung et al., 2013). The variables being used are below and are codes as “definitely agree”, “somewhat agree”, “somewhat disagree”, “and definitely disagree”.

- “people in the neighborhood help each other out”
- “we watch out for each other’s children in this neighborhood”
- “there are people I can count on in this neighborhood”
- “if my child were outside playing and got hurt or scared, there are adults nearby who I trust to help my child”
A social capital index (SCI) was created based on review of previous research by Singh et al, 2008 and Iida and Rozier, 2013 who have used similar variables to represent social capital within their research. The response codes for all four variables will be added for a total score of 4 (highest) to 16 (lowest). The SCI scores will then be grouped into 4 categories (4= highest, 5-7= higher, 8-10 =lower, and ≥ or equal to 11 = lowest). This grouping was based on the frequency distribution of the scores for each variable as was performed in previous research using the same variables (Iida and Rozier, 2013). This identical composite score methodology was used in the prior research as above. This composite score cannot necessarily be translated across all social capital research examining health outcomes, however, these variables do represent bonding social capital and thus are utilized in the same manner for this current research. The SCI will then be used in the regression analysis as a continuous variable.

**Mediating Variable- Insurance Status**

The first question is defined as having any kind of health coverage, including health insurance, health maintenance organizations (HMO’s), or government insurance plans such as Medicaid. The second question addresses if there was any time in the past 12 months that the child was not covered by ANY health insurance. Previous research has used similar variables when assessing type and adequacy of insurance coverage when analyzing the NSCH 2007 dataset (Bethell et al., 2011; Zickafoose et al., 2012; Kogan et al., 2010). It is important to understand the percentage of children receiving Medicaid as well as the number of children who lost insurance coverage in the past 12 months when examining the availability of care. This will assist in the understanding of the effects of Medicaid and loss of insurance on the ability to access medical care or mental health services. The specific questions are below and are coded as “yes”, “no”, and “don’t know”.

Does (child) have any kind of health care coverage, including health insurance, prepaid plans such as HMO’s or government plans such as Medicaid?

(During the past 12 months/ since (his/her) birth, was there any time when (he/she) was not covered by ANY health insurance?

**Other Mediating Variables**

**Poverty Status**- This variable is defined by the enrollment in Medicaid or CHIP health insurance plans.

- If YES to the above question regarding insurance status, [Is that coverage/Is (he/she) insured by] Medicaid or the Children’s Health Insurance Program, CHIP?

There are multiple ways in which poverty can be defined when examining child health outcomes, however, many are not standardized across the U.S. Even though Medicaid and CHIP are administered through the states, a child is only eligible for these benefits if they live at a certain percentage below the poverty level for that particular state. In this way, all children who are eligible for Medicaid or CHIP are considered to be living in poverty at some level.

**Ethnicity**- This variable is defined by the following questions:

- Is (child) of Hispanic, Latino or Spanish origin?
- Is [S.C.] White, Black or African American, American Indian, Alaska Native, Asian, or Native Hawaiian or other Pacific Islander?

**Dependent Variable- Availability of Care**

This variable is defined by asking the respondent if there was any time during the past 12 months when the child needed health care but it was delayed or not received. This specific variable assesses availability of all types of care including medical, dental, vision, and mental health services. For this research, the main focus is medical care and mental health services.
Prior research has utilized similar variables from the NSCH dataset. (Bethell et al., 2011). The specific questions are below.

- Sometimes people have difficulty getting health care when they need it. By health care, I mean medical care as well as other kinds of care like dental care, vision care, and mental health services. (During the past 12 months/ since (his/her) birth, was there any time when (child) needed health care but it was delayed or not received?

- What type of care was delayed or not received? Was it **medical care**, dental care, vision care, **mental health services**, or something else?

Figure 3.2 below shows the conceptual model of the relationship between five medical home components and the availability of medical care and mental health services with the addition of the possible confounding effects of the mediating variables including social capital, insurance status, ethnicity, and poverty status.

Figure 3.2- Conceptual Model
<table>
<thead>
<tr>
<th>Variable</th>
<th>Code Name</th>
<th>Response Name</th>
<th>Question to Assess Variable</th>
<th>Miss Set Responses</th>
<th>New Label Responses</th>
<th>Composite</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Home Items</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K4Q01</td>
<td>usual</td>
<td></td>
<td>Is there a place that (child) usually goes when (he/she) is sick or you need advice about (his/her) health?</td>
<td>0) Yes</td>
<td>1) No</td>
<td>2) There is more than one place 6) Don't know</td>
</tr>
<tr>
<td>K4Q04</td>
<td>usualprov</td>
<td></td>
<td>A personal doctor or nurse is a health professional who knows your child and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, nurse practitioner, or physician assistant. Do you have one or more persons you think of as (child)'s personal doctor or nurse?</td>
<td>1) Yes, one person</td>
<td>2) Yes, more than one person 3) No</td>
<td>4) Don't know</td>
</tr>
<tr>
<td>Personal Provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K5Q21</td>
<td>usualcare</td>
<td></td>
<td>(During the past 12 months, since (his/her) birth), have you felt that you could have used extra help arranging or coordinating (child)'s care among the different health care providers or services?</td>
<td>0) Yes</td>
<td>1) No</td>
<td>6) Don't know</td>
</tr>
<tr>
<td>Care Coordination</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K5Q30</td>
<td>usualcomm</td>
<td></td>
<td>Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among (child)'s doctors or other health care providers?</td>
<td>1) Very satisfied</td>
<td>2) Somewhat satisfied 3) Somewhat dissatisfied</td>
<td>4) Very dissatisfied</td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K5Q44</td>
<td>usualfam</td>
<td></td>
<td>(During the past 12 months, since (his/her) birth, how often did (child)'s doctors or other health care providers help you feel like a partner in (his/her) care? Would you say never, sometimes, usually, or always?</td>
<td>1) Never</td>
<td>2) Sometimes 3) Usually 4) Always</td>
<td>6) Don't know</td>
</tr>
<tr>
<td>Family-Centered Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mediating Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K10Q10</td>
<td>usual</td>
<td></td>
<td>People in this neighborhood help each other out?</td>
<td>0) Definitely agree 1) Somewhat agree 3) Somewhat disagree 4) Definitely disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Capital Items</td>
<td>social_composite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K10Q31</td>
<td>usual</td>
<td></td>
<td>(We watch out for each other's children in this neighborhood)</td>
<td>0) Definitely agree 1) Somewhat agree 3) Somewhat disagree 4) Definitely disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighborhood and Community Questions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K10Q32</td>
<td>usual</td>
<td></td>
<td>There are people I can count on in this neighborhood?</td>
<td>0) Definitely agree 1) Somewhat agree 3) Somewhat disagree 4) Definitely disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>K10Q34</td>
<td>usual</td>
<td></td>
<td>If my child were outside playing and got hurt or scared, there are adults nearby who I trust to help my child?</td>
<td>0) Definitely agree 1) Somewhat agree 3) Somewhat disagree 4) Definitely disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K3Q01</td>
<td>usual</td>
<td></td>
<td>Does (child) have any kind of health care coverage, including health insurance, prepaid plans such as HMO's or government plans such as Medicaid?</td>
<td>1) Yes</td>
<td>0) No</td>
<td>6) Don't know</td>
</tr>
<tr>
<td>Poverty Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K3Q02</td>
<td>usual</td>
<td></td>
<td>(YES, is that coverage is (the she) insured by Medicaid or the Children's Health Insurance Program, CHIP?)</td>
<td>1) Yes</td>
<td>0) No</td>
<td>6) Don't know</td>
</tr>
<tr>
<td>K3Q03</td>
<td>usual</td>
<td></td>
<td>During the past 12 months, since (his/her) birth, was there any time when (he/she) was not covered by ANY health insurance?</td>
<td>1) Yes</td>
<td>0) No</td>
<td>6) Don't know</td>
</tr>
<tr>
<td>Lack of Insurance Measure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K11Q01</td>
<td>usual</td>
<td></td>
<td>Is (child) of Hispanic, Latino or Spanish origin?</td>
<td>1) Yes</td>
<td>0) No</td>
<td>6) Don't know</td>
</tr>
<tr>
<td>K11Q02</td>
<td>usual</td>
<td></td>
<td>Is (child) White, Black or African American, American Indian, Alaska Native, Asian, or Native Hawaiian or other Pacific Islander?</td>
<td>1) White/African American 2) Black/African-American 3) American Indian/ Native American 4) Alaska Native 5) Asian 6) Native Hawaiian 7) Pacific Islander 8) Other 9) Don't Know</td>
<td>10) Refused</td>
<td></td>
</tr>
</tbody>
</table>
3.4 Statistical Analysis Plan

Preliminary Screening Procedures

Missing values

Only cases with complete data (i.e., cases that have responses to all the study variables) were included in the analysis (n= 32,496). Cases with missing values were excluded. The data were coded so that non-concrete responses (“don’t know”) were eliminated from the analyses.

Normality

Univariate normality was assessed via the skewness and kurtosis indices of the study variables and all variables were found to have a normal distribution allowing for parametric analyses to be performed.

Recoding of Data (medical home)

The medical home variables in question (table 1) have been re-coded to eliminate missing values as well as responses that are equivocal in nature (i.e. “don’t know”, or “mostly”). The variables are then labeled as a new variable in the dataset. Responses are only included if the participant answered “yes” or “no” for each medical home variable.

3.5 Research Questions

R (1): What components of the medical home predict availability of all health care types?

Statistical analysis plan (1):

1. Sample: CSHCN
2. Independent variables:
   1. Usual source of care- K4Q01
   2. Personal provider- K4Q04
   3. Care coordination- K5Q21
   4. Communication- K5Q30
   5. Family-centered care- K5Q44

3. Dependent variable:
   1. Availability of health care; measured using a nominal scale- K4Q27

Statistical test: Logistic regression analysis to predict availability of all healthcare types for each independent medical home item.

Statistical analysis plan (2):
1. Sample: CSHCN
2. Independent variables:
   1. Usual source of care- K4Q01
   2. Personal provider- K4Q04
   3. Care coordination- K5Q21
   4. Communication- K5Q30
   5. Family-centered care- K5Q44
3. Mediating variables:
   1. Social capital composite (K10Q30, K10Q31, K10Q32, K10Q34)
   2. Insurance status ( K3Q01, K3Q02, K2Q03)
3. Dependent variable:
   1. Availability of health care; measured using a nominal scale- K4Q27
4. Statistical test: Logistic regression analysis to predict availability of all healthcare types for each independent medical home item while controlling for social capital and insurance status.

**R(2):** What components of the medical home predict availability of **medical care** at varying levels of social capital and insurance coverage?

**Statistical analysis plan (1):**

1. Sample: CSHCN

2. Independent variables:
   1. Usual source of care- K4Q01
   2. Personal provider- K4Q04
   3. Care coordination- K5Q21
   4. Communication- K5Q30
   5. Family-centered care- K5Q44

3. Dependent variable:
   1. Availability of medical care; measured using a nominal scale- K4Q28

4. Statistical test: Logistic regression analysis to predict availability of medical care for each independent medical home item.

**Statistical Analysis Plan (2):**

5. Sample: CSHCN

6. Independent variables:
   1. Usual source of care- K4Q01
   2. Personal provider- K4Q04
   3. Care coordination- K5Q21
   4. Communication- K5Q30
5. Family-centered care- K5Q44

3. Mediating variables:
   1. Social capital composite (K10Q30, K10Q31, K10Q32, K10Q34)
   2. Insurance status (K3Q01, K3Q02, K3Q03)

7. Dependent variable:
   1. Availability of medical care; measured using a nominal scale- K4Q28

8. Statistical test: Logistic regression analysis to assess predictability of availability of medical care for each independent medical home item while including social capital and insurance status.

R (3): What components of the medical home predict availability of mental health services at varying levels of social capital and insurance coverage?

Statistical analysis plan (1):

1. Sample: CSHCN

2. Independent variables:
   1. Usual source of care- K4Q01
   2. Personal provider- K4Q04
   3. Care coordination- K5Q21
   4. Communication- K5Q30
   5. Family-centered care- K5Q44

3. Dependent variable:
   1. Availability of mental health services; measured using a nominal scale- K4Q28

4. Statistical test: Logistic regression analysis to predict availability of mental health services for each independent medical home item.
Statistical Analysis Plan (2):

1. Sample: CSHCN

2. Independent variables:
   1. Usual source of care- K4Q01
   2. Personal provider- K4Q04
   3. Care coordination- K5Q21
   4. Communication- K5Q30
   5. Family-centered care- K5Q44

3. Mediating variables:
   1. Social capital composite- K10Q30, K10Q31, K10Q32, K10Q34
   2. Insurance status- K3Q01, K3Q02, K3Q03

3. Dependent variable:
   1. Availability of mental health services; measured using a nominal scale-K4Q28

4. Statistical test: Logistic regression analysis to predict availability of mental health services for each independent medical home item while including social capital and insurance status.
CHAPTER 4

FINDINGS

4.1 Demographics of Study Participants

Table 4.2 displays summary statistics for the variables used in the study. Unweighted Ns
and percentages are presented along with weighted percentages to demonstrate both the
characteristics of the sample and how the distributions change after weighting. The following
percentages are reported as the weighted percentage for each variable. For example, minorities
and Hispanics were under-sampled relative to their population distribution, but the weights
increase the percentage of Hispanics, African Americans, and other minorities. Non-Hispanic
respondents represented 80.5% of the sample population and White respondents represented
66.9% of the sample population.

4.2 Descriptives of Study Variables

For the medical home variables, the vast majority of cases had a single location for
receiving care (91.9%, weighted), a single primary care physician (90.9%), did not feel a need
for extra help coordinating care (81.8%), and were somewhat or very satisfied with the
provider’s communication (93.6%). 20.1% of the population felt that their health care provider
usually makes the parent feel like a partner, and 66.9% always felt that way. Most (95.4%) of
population has health insurance, with 42.7% receiving public insurance in the form of Medicaid
or CHIP. 6.7% of the population went without insurance in the past month.

The social capital variable was created as a composite of four items, and the scale had
high internal consistency (Cronbach’s alpha = .848). The variable was calculated as the sum of
the four items and then discretized into four ordered categories. The modal score in the population was the “higher” category (36.0%) followed by “highest” (30.9%).

<table>
<thead>
<tr>
<th>Table 4.1 Social Capital Composite</th>
<th>Scale Mean if Item Deleted</th>
<th>Scale Variance if Item Deleted</th>
<th>Corrected Item-Total Correlation</th>
<th>Cronbach's Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>People in this neighborhood help each other out.</td>
<td>4.70</td>
<td>5.227</td>
<td>0.668</td>
<td>0.815</td>
</tr>
<tr>
<td>We watch out for each other's children in this neighborhood.</td>
<td>4.80</td>
<td>5.069</td>
<td>0.696</td>
<td>0.803</td>
</tr>
<tr>
<td>There are people I can count on in this neighborhood.</td>
<td>4.88</td>
<td>5.028</td>
<td>0.726</td>
<td>0.790</td>
</tr>
<tr>
<td>If my child were outside playing and got hurt or scared, there are adults nearby who I trust to help my child.</td>
<td>4.96</td>
<td>5.291</td>
<td>0.654</td>
<td>0.820</td>
</tr>
</tbody>
</table>

The first dependent variable is whether any health care for the child had been delayed or not received in the prior year. This includes medical care, dental care, vision care, mental health services, or other health care services. Just fewer than eleven percent (10.9%) of the population reported that this indeed occurred; the remaining dependent variables were asked only of these respondents. Of those experiencing a delay or lack of access, a little under half (47.5%) reported that it was medical care that was difficult to access. Thirty-seven percent reported that accessing dental care was a problem. Just over thirteen percent said the same about vision care, 19.4% said mental health care access was problematic, and 9.0% reported other types of health care services were delayed or not received.
<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
<th>Weighted %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Hispanic</td>
<td>28,133</td>
<td>88.1%</td>
<td>80.50%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3,791</td>
<td>11.9%</td>
<td>19.50%</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>23,451</td>
<td>73.8%</td>
<td>66.9%</td>
</tr>
<tr>
<td>African American</td>
<td>3,584</td>
<td>11.3%</td>
<td>16.5%</td>
</tr>
<tr>
<td>Other</td>
<td>4,729</td>
<td>14.9%</td>
<td>16.7%</td>
</tr>
<tr>
<td><strong>R has Single Usual Source of Care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2,343</td>
<td>7.2%</td>
<td>8.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>30,102</td>
<td>92.8%</td>
<td>91.9%</td>
</tr>
<tr>
<td><strong>R has Personal Provider</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2,225</td>
<td>6.9%</td>
<td>9.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>30,218</td>
<td>93.1%</td>
<td>90.9%</td>
</tr>
<tr>
<td><strong>Felt Need for Extra Help Coordinating Care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>24,754</td>
<td>86.0%</td>
<td>81.8%</td>
</tr>
<tr>
<td>Yes</td>
<td>4,019</td>
<td>14.0%</td>
<td>18.2%</td>
</tr>
<tr>
<td><strong>Satisfaction with Communication among Child's Health Care Providers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very or Somewhat Dissatisfied</td>
<td>1,580</td>
<td>5.6%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Somewhat or Very Satisfied</td>
<td>26,857</td>
<td>94.4%</td>
<td>93.6%</td>
</tr>
<tr>
<td><strong>How Often Health Care Providers Make R Feel Like a Partner</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>896</td>
<td>2.8%</td>
<td>3.8%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>2,556</td>
<td>8.0%</td>
<td>9.2%</td>
</tr>
<tr>
<td>Usually</td>
<td>6,825</td>
<td>21.4%</td>
<td>20.1%</td>
</tr>
<tr>
<td>Always</td>
<td>21,626</td>
<td>67.8%</td>
<td>66.9%</td>
</tr>
<tr>
<td><strong>Social Capital</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lowest</td>
<td>3,047</td>
<td>9.5%</td>
<td>12.0%</td>
</tr>
<tr>
<td>Lower</td>
<td>5,962</td>
<td>18.6%</td>
<td>21.1%</td>
</tr>
<tr>
<td>Higher</td>
<td>11,798</td>
<td>36.8%</td>
<td>36.0%</td>
</tr>
<tr>
<td>Highest</td>
<td>11,241</td>
<td>35.1%</td>
<td>30.9%</td>
</tr>
<tr>
<td><strong>Does Child have Health Insurance?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1,120</td>
<td>3.5%</td>
<td>4.60%</td>
</tr>
<tr>
<td>Yes</td>
<td>31,328</td>
<td>96.5%</td>
<td>95.40%</td>
</tr>
<tr>
<td><strong>Is Insurance Medicaid/CHIP?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>20,085</td>
<td>64.7%</td>
<td>57.3%</td>
</tr>
<tr>
<td>Yes</td>
<td>10,976</td>
<td>35.3%</td>
<td>42.7%</td>
</tr>
</tbody>
</table>
Table 4.2 Continued

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
<th>Weighted %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any time Past 12 Months Child Not Insured?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>29,630</td>
<td>91.2%</td>
<td>93.3%</td>
</tr>
<tr>
<td>Yes</td>
<td>1,576</td>
<td>4.8%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Any Time Past 12 Months Child's Health Care Delayed/Not Received?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>29,280</td>
<td>90.2%</td>
<td>89.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>3,173</td>
<td>9.8%</td>
<td>10.9%</td>
</tr>
<tr>
<td>Was Medical Care Delayed/Not Received?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1,686</td>
<td>53.3%</td>
<td>52.5%</td>
</tr>
<tr>
<td>Yes</td>
<td>1,479</td>
<td>46.7%</td>
<td>47.5%</td>
</tr>
<tr>
<td>Was Dental Care Delayed/Not Received?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2,055</td>
<td>64.9%</td>
<td>62.7%</td>
</tr>
<tr>
<td>Yes</td>
<td>1,110</td>
<td>35.1%</td>
<td>37.3%</td>
</tr>
<tr>
<td>Was Vision Care Delayed/Not Received?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2,763</td>
<td>87.3%</td>
<td>86.6%</td>
</tr>
<tr>
<td>Yes</td>
<td>402</td>
<td>12.7%</td>
<td>13.4%</td>
</tr>
<tr>
<td>Was Mental Health Care Delayed/Not Received?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2,454</td>
<td>77.5%</td>
<td>80.6%</td>
</tr>
<tr>
<td>Yes</td>
<td>711</td>
<td>22.5%</td>
<td>19.4%</td>
</tr>
<tr>
<td>Was Other Care Delayed/Not Received?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2,879</td>
<td>91.0%</td>
<td>91.0%</td>
</tr>
<tr>
<td>Yes</td>
<td>286</td>
<td>9.0%</td>
<td>9.0%</td>
</tr>
</tbody>
</table>

Note. Total sample size = 32,496.

4.3 Research question 1: What components of the medical home predict availability of care for all healthcare types?

Bivariate analysis

The first part of the research question asks about the characteristics of those reporting a delay or non-receipt of any health care access versus those who did not report delays/no receipt of care. Table 4.3 presents unadjusted comparisons of all independent variables. The percentages refer to the number of patients within each level of the dependent variable. For example, of those who said receiving health care had not been a problem, 92.7% had a single
source of care while 86.3% of those saying health care access was a problem had a single usual
source of care. This difference is statistically significant, \( p < 0.001 \). In fact, all of the
comparisons except for ethnicity and race are significant. Those who had experienced a delay or
not received health care were less likely to have a personal provider, much more likely to feel a
need for extra help with care coordination, less likely to be satisfied with communication, less
likely to say the care provider always made them feel like a partner, more likely to have low
social capital, less likely to have insurance, more likely to receive public insurance, and much
more likely to have gone without insurance in the prior year. These comparisons were all
significant with \( p < 0.001 \).
### Table 4.3
Cross-Tabulations of Individual Variables by Availability of Care

<table>
<thead>
<tr>
<th>Child's Health Care Delayed/Not Received?</th>
<th>No</th>
<th>Yes</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>R has Single Usual Source of Care</td>
<td>92.7%</td>
<td>86.3%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>R has Personal Provider</td>
<td>91.6%</td>
<td>86.7%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Felt Need for Extra Help Coordinating Care</td>
<td>14.0%</td>
<td>51.9%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Very or Somewhat Satisfied with Communication</td>
<td>95.6%</td>
<td>77.0%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>How Often Health Care Providers Make R Feel Like a Partner</td>
<td></td>
<td></td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Never</td>
<td>3.0%</td>
<td>9.3%</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>7.8%</td>
<td>20.8%</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td>19.6%</td>
<td>24.3%</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>69.6%</td>
<td>45.6%</td>
<td></td>
</tr>
<tr>
<td>Social Capital</td>
<td></td>
<td></td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Lowest</td>
<td>11.10%</td>
<td>20.00%</td>
<td></td>
</tr>
<tr>
<td>Lower</td>
<td>20.6%</td>
<td>24.5%</td>
<td></td>
</tr>
<tr>
<td>Higher</td>
<td>36.2%</td>
<td>34.3%</td>
<td></td>
</tr>
<tr>
<td>Highest</td>
<td>32.1%</td>
<td>21.1%</td>
<td></td>
</tr>
<tr>
<td>Child has Health Insurance</td>
<td>96.5%</td>
<td>86.7%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Insurance is Medicaid/CHIP</td>
<td>40.9%</td>
<td>58.4%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Child Not Insured Any Time Past 12 Months</td>
<td>4.7%</td>
<td>24.3%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Hispanic</td>
<td>19.1%</td>
<td>22.1%</td>
<td>0.115</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td>0.077</td>
</tr>
<tr>
<td>White</td>
<td>67.3%</td>
<td>63.5%</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>16.4%</td>
<td>16.7%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>16.3%</td>
<td>19.8%</td>
<td></td>
</tr>
</tbody>
</table>

Note. Percentages determined within values of care delayed. p-value from F-test adjusted for weights, strata, and PSUs.
Multivariate analysis

Table 4.4 places the independent variables into the logistic regression models simultaneously. The child’s current health care status was left out because of perfect multicollinearity with the question asking about insurance status in the last year (if a respondent is uninsured now, he or she was necessarily not insured at some point in the last year). The first model excludes social capital. It finds that the odds of having delayed health care or care not provided are 33.9% lower for those with a single source of care compared to those without. There was also a very large association between health care delays and feeling a need for extra help coordinating care, with odds being 4.7 times higher for those needing help compared to those who did not. Satisfaction with communication reduced the odds by 58.1%, and each increase on the ordinal scale asking if providers make the respondent feel like a partner reduces the odds by 30.7%. Receiving Medicaid/CHIP assistance increases the odds of problems (care coordination, communication, partner with care, single source of care, and personal provider) by 67.4%, and uninsured status during the prior year increases the odds more than six-fold. Hispanics, previously non-significant, are now actually less likely to report problems with delays, $OR = .517$. Race has also become significant, with African Americans less likely than whites to report a delay, $OR = .688$.

These inferences are retained when adding social capital to the model. That is, social capital is not a complete mediator of any of the significant relationships but does have a statistically significant direct effect overall. Each increase on the social capital scale reduces the odds of experiencing a delay or no access to health care by 12.5%. 
Table 4.4
Logistic Regressions for Health Care Delayed/Not Received

<table>
<thead>
<tr>
<th></th>
<th>Model 1</th>
<th>Model 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>95% CI for</td>
<td>95% CI for</td>
</tr>
<tr>
<td></td>
<td>Exp(B) Lower</td>
<td>Exp(B) Lower</td>
</tr>
<tr>
<td></td>
<td>Upper Sig.</td>
<td>Upper Sig.</td>
</tr>
<tr>
<td>(Odds ratio)</td>
<td>0.461 0.234</td>
<td>0.631 0.302</td>
</tr>
<tr>
<td></td>
<td>0.906 0.025</td>
<td>1.317 0.220</td>
</tr>
<tr>
<td>R has Single Usual Source of Care</td>
<td>0.665 0.444</td>
<td>0.448 0.302</td>
</tr>
<tr>
<td></td>
<td>0.997 0.048</td>
<td>1.317 0.172</td>
</tr>
<tr>
<td>R has Personal Provider</td>
<td>1.317 0.849</td>
<td>0.448 0.302</td>
</tr>
<tr>
<td></td>
<td>2.042 0.219</td>
<td>1.317 0.172</td>
</tr>
<tr>
<td>Felt Need for Extra Help Coordinating Care</td>
<td>4.770 3.831</td>
<td>4.685 3.768</td>
</tr>
<tr>
<td></td>
<td>5.940 0.000</td>
<td>5.825 0.000</td>
</tr>
<tr>
<td>Very or Somewhat Satisfied with Communication</td>
<td>0.419 0.304</td>
<td>0.422 0.307</td>
</tr>
<tr>
<td></td>
<td>0.577 0.000</td>
<td>0.580 0.000</td>
</tr>
<tr>
<td>How Often Health Care Providers Make R Feel Like a Partner</td>
<td>0.693 0.614</td>
<td>0.707 0.626</td>
</tr>
<tr>
<td></td>
<td>0.783 0.000</td>
<td>0.798 0.000</td>
</tr>
<tr>
<td>Insurance is Medicaid/CHIP</td>
<td>1.674 1.361</td>
<td>1.602 1.302</td>
</tr>
<tr>
<td></td>
<td>2.059 0.000</td>
<td>1.970 0.000</td>
</tr>
<tr>
<td></td>
<td>8.405 0.000</td>
<td>8.261 0.000</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.517 0.376</td>
<td>0.369 0.291</td>
</tr>
<tr>
<td></td>
<td>0.710 0.000</td>
<td>0.695 0.000</td>
</tr>
<tr>
<td>Race = African American</td>
<td>0.688 0.509</td>
<td>0.491 0.391</td>
</tr>
<tr>
<td></td>
<td>0.929 0.015</td>
<td>0.897 0.008</td>
</tr>
<tr>
<td>Race = Other</td>
<td>0.950 0.716</td>
<td>0.939 0.710</td>
</tr>
<tr>
<td></td>
<td>1.260 0.722</td>
<td>1.243 0.660</td>
</tr>
<tr>
<td>Social Capital</td>
<td>0.875 0.794</td>
<td>0.963 0.006</td>
</tr>
</tbody>
</table>

Note. Baseline category for outcome = No. Reference category for race = white.
4.4 Research Question 2: What components of the medical home predict availability of medical care while controlling for social capital and insurance coverage?

Bivariate analysis

The following tables summarize predictors of delays in access to medical care. The sample here is reduced to only those that answered affirmatively to the prior dependent variable, which makes the sample size much smaller ($n = 3,173$).

Table 4.5 presents unadjusted results looking at each predictor’s effect on whether any medical care was delayed or not received. Those that answered “yes” were significantly less likely to have a personal health care provider, less likely to feel a need for extra help coordinating care, more likely to say the health care provider never makes him or her always feel like a partner, less likely to have health insurance, more likely to have been uninsured at any point in the prior 12 months, and more likely to be African American.
Table 4.5
Cross-Tabulations of Individual Variables by Medical Care Delayed/Not Received

<table>
<thead>
<tr>
<th>Child's Medical Care Delayed/Not Received?</th>
<th>No</th>
<th>Yes</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>R has Single Usual Source of Care</td>
<td>86.4%</td>
<td>86.3%</td>
<td>0.976</td>
</tr>
<tr>
<td>R has Personal Provider</td>
<td>90.0%</td>
<td>82.9%</td>
<td>0.014</td>
</tr>
<tr>
<td>Felt Need for Extra Help Coordinating Care</td>
<td>56.1%</td>
<td>47.4%</td>
<td>0.029</td>
</tr>
<tr>
<td>Very or Somewhat Satisfied with Communication</td>
<td>80.0%</td>
<td>74.2%</td>
<td>0.08</td>
</tr>
<tr>
<td>How Often Health Care Providers Make R Feel Like a Partner</td>
<td></td>
<td></td>
<td>0.005</td>
</tr>
<tr>
<td>Never</td>
<td>5.5%</td>
<td>13.1%</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>22.0%</td>
<td>19.6%</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td>25.3%</td>
<td>23.2%</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>47.1%</td>
<td>44.1%</td>
<td></td>
</tr>
<tr>
<td>Social Capital</td>
<td>0.523</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lowest</td>
<td>19.8%</td>
<td>20.4%</td>
<td></td>
</tr>
<tr>
<td>Lower</td>
<td>26.1%</td>
<td>22.9%</td>
<td></td>
</tr>
<tr>
<td>Higher</td>
<td>32.2%</td>
<td>36.9%</td>
<td></td>
</tr>
<tr>
<td>Highest</td>
<td>22.0%</td>
<td>19.8%</td>
<td></td>
</tr>
<tr>
<td>Child has Health Insurance</td>
<td>90.8%</td>
<td>82.1%</td>
<td>0.002</td>
</tr>
<tr>
<td>Insurance is Medicaid/CHIP</td>
<td>56.0%</td>
<td>61.0%</td>
<td>0.207</td>
</tr>
<tr>
<td>Child Not Insured Any Time Past 12 Months</td>
<td>17.8%</td>
<td>32.4%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Hispanic</td>
<td>24.4%</td>
<td>19.7%</td>
<td>0.224</td>
</tr>
<tr>
<td>Race</td>
<td>0.041</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>67.4%</td>
<td>59.4%</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>13.2%</td>
<td>20.3%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>19.4%</td>
<td>20.3%</td>
<td></td>
</tr>
</tbody>
</table>

Note. Question only asked of those who answered health care had been delayed/not received. Percentages determined within values of care delayed. p-value from F-test adjusted for weights, strata, and PSUs.
Multivariate analysis

Table 4.6 presents the logistic regressions. Two variables are significant before adding in social capital. First, the odds of experiencing a delay/no receipt of medical care were 36.8% lower among those who felt they needed extra help coordinating care. The odds of experiencing a delay/no receipt of medical care were 2.57 times higher for children that had gone without health insurance in the prior year. These variables are also significant in the second model. Social capital did not have a direct effect on the outcome of medical care alone as it did in the previous model when examining availability of all health care types.
**Table 4.6**  
Logistic Regressions for Medical Care Delayed/Not Received

<table>
<thead>
<tr>
<th></th>
<th>Model 1</th>
<th></th>
<th>Model 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Exp(B)</strong></td>
<td><strong>95% CI for</strong></td>
<td><strong>95% CI for</strong></td>
<td><strong>95% CI for</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Exp(B)</strong></td>
<td><strong>Lower</strong></td>
<td><strong>Upper</strong></td>
<td><strong>Sig.</strong></td>
</tr>
<tr>
<td>(Odds Ratio)</td>
<td>2.005</td>
<td>0.721</td>
<td>5.577</td>
<td>0.182</td>
</tr>
<tr>
<td>R has Single Usual Source of Care</td>
<td>1.383</td>
<td>0.751</td>
<td>2.549</td>
<td>0.298</td>
</tr>
<tr>
<td>R has Personal Provider</td>
<td>0.619</td>
<td>0.332</td>
<td>1.157</td>
<td>0.133</td>
</tr>
<tr>
<td>Felt Need for Extra Help Coordinating Care</td>
<td>0.632</td>
<td>0.447</td>
<td>0.892</td>
<td>0.009</td>
</tr>
<tr>
<td>Very or Somewhat Satisfied with Communication</td>
<td>0.685</td>
<td>0.434</td>
<td>1.080</td>
<td>0.103</td>
</tr>
<tr>
<td>How Often Health Care Providers Make R Feel Like a Partner</td>
<td>0.866</td>
<td>0.712</td>
<td>1.053</td>
<td>0.149</td>
</tr>
<tr>
<td>Insurance is Medicaid/CHIP</td>
<td>0.966</td>
<td>0.688</td>
<td>1.356</td>
<td>0.841</td>
</tr>
<tr>
<td>Child Not Insured Any Time Past 12 Months</td>
<td>2.565</td>
<td>1.656</td>
<td>3.973</td>
<td>0.000</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.752</td>
<td>0.471</td>
<td>1.201</td>
<td>0.232</td>
</tr>
<tr>
<td>Race = African American</td>
<td>1.410</td>
<td>0.854</td>
<td>2.328</td>
<td>0.180</td>
</tr>
<tr>
<td>Race = Other</td>
<td>1.459</td>
<td>0.922</td>
<td>2.308</td>
<td>0.107</td>
</tr>
<tr>
<td>Social Capital</td>
<td>1.103</td>
<td>0.934</td>
<td>1.303</td>
<td>0.247</td>
</tr>
</tbody>
</table>

Note. Question only asked of those who answered health care had been delayed/not received. Baseline category for outcome = No. Reference category for race = white.
4.5 Research Question 3: What components of the medical home predict availability of mental health services while controlling for social capital and insurance coverage?

Bivariate analysis

The following tables summarize predictors of delays in access to mental health services. The sample here is reduced to only those that answered affirmatively to the prior dependent variable, which makes the sample size much smaller ($n = 3,173$).

Table 4.7 looks at unadjusted associations with mental health care. Those that had experienced a delay/no receipt of mental health care were more likely to have a personal provider, more likely to feel that they need extra help coordinating care, more likely to have insurance, less likely for that insurance to be Medicaid/CHIP, less likely to have been uninsured in the previous year, and less likely to be Hispanic.
### Table 4.7
Cross-Tabulations of Individual Variables by Mental Health Care Delayed/Not Received

<table>
<thead>
<tr>
<th>Child's Mental Health Care Delayed/Not Received?</th>
<th>No</th>
<th>Yes</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>R has Single Usual Source of Care</td>
<td>85.4%</td>
<td>90.2%</td>
<td>0.118</td>
</tr>
<tr>
<td>R has Personal Provider</td>
<td>85.1%</td>
<td>92.8%</td>
<td>0.008</td>
</tr>
<tr>
<td>Felt Need for Extra Help Coordinating Care</td>
<td>48.7%</td>
<td>63.4%</td>
<td>0.001</td>
</tr>
<tr>
<td>Very or Somewhat Satisfied with Communication</td>
<td>78.4%</td>
<td>72.8%</td>
<td>0.129</td>
</tr>
<tr>
<td>How Often Health Care Providers Make R Feel Like a Partner</td>
<td></td>
<td></td>
<td>0.088</td>
</tr>
<tr>
<td>Never</td>
<td>9.3%</td>
<td>8.5%</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>19.1%</td>
<td>28.2%</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td>25.0%</td>
<td>21.5%</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>46.6%</td>
<td>41.9%</td>
<td></td>
</tr>
<tr>
<td>Social Capital</td>
<td></td>
<td></td>
<td>0.911</td>
</tr>
<tr>
<td>Lowest</td>
<td>20.3%</td>
<td>18.9%</td>
<td></td>
</tr>
<tr>
<td>Lower</td>
<td>24.9%</td>
<td>23.4%</td>
<td></td>
</tr>
<tr>
<td>Higher</td>
<td>34.0%</td>
<td>36.4%</td>
<td></td>
</tr>
<tr>
<td>Highest</td>
<td>20.8%</td>
<td>21.4%</td>
<td></td>
</tr>
<tr>
<td>Child has Health Insurance</td>
<td>85.3%</td>
<td>92.4%</td>
<td>0.014</td>
</tr>
<tr>
<td>Insurance is Medicaid/CHIP</td>
<td>60.6%</td>
<td>49.6%</td>
<td>0.012</td>
</tr>
<tr>
<td>Child Not Insured Any time Past 12 Months</td>
<td>27.3%</td>
<td>13.3%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Hispanic</td>
<td>24.8%</td>
<td>11.2%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td>0.08</td>
</tr>
<tr>
<td>White</td>
<td>61.8%</td>
<td>71.1%</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>17.8%</td>
<td>11.6%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>20.5%</td>
<td>17.3%</td>
<td></td>
</tr>
</tbody>
</table>

Note. Question only asked of those who answered health care had been delayed/not received. Percentages determined within values of care delayed. p-value from F-test adjusted for weights, strata, and PSUs.
Multivariate analysis

Table 4.8 presents the logistic regressions. Looking first at significant associations in the model without social capital, the odds of experiencing a delay/no access for mental health care more than doubled for those with a personal care provider. The odds increase by 89.7% among those feeling like they need extra help coordinating care but decreased by 61% among Hispanics. The results are the same in the second model, which did not find a significant effect when social capital was included.
<table>
<thead>
<tr>
<th></th>
<th>Model 1 95% CI for Exp(B)</th>
<th>Model 2 95% CI for Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Exp(B)  Lower  Upper  Sig.</td>
<td>Exp(B)  Lower  Upper  Sig.</td>
</tr>
<tr>
<td><strong>(Odds Ratio)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R has Single Usual Source of Care</td>
<td>0.085  0.028  0.257  0.000</td>
<td>0.085  0.026  0.278  0.000</td>
</tr>
<tr>
<td>R has Personal Provider</td>
<td>1.339  0.676  2.652  0.402</td>
<td>1.341  0.677  2.656  0.400</td>
</tr>
<tr>
<td>Felt Need for Extra Help Coordinating Care</td>
<td>2.802  1.456  5.393  0.002</td>
<td>2.793  1.446  5.397  0.002</td>
</tr>
<tr>
<td>Very or Somewhat Satisfied with Communication</td>
<td>1.897  1.246  2.886  0.003</td>
<td>1.894  1.245  2.882  0.003</td>
</tr>
<tr>
<td>How Often Health Care Providers Make R Feel Like a Partner</td>
<td>0.967  0.599  1.560  0.889</td>
<td>0.966  0.598  1.560  0.888</td>
</tr>
<tr>
<td>Insurance is Medicaid/CHIP</td>
<td>1.019  0.810  1.281  0.875</td>
<td>1.019  0.810  1.282  0.872</td>
</tr>
<tr>
<td>Child Not Insured Any Time Past 12 Months</td>
<td>0.839  0.567  1.240  0.378</td>
<td>0.839  0.568  1.238  0.376</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.641  0.375  1.098  0.105</td>
<td>0.644  0.376  1.101  0.108</td>
</tr>
<tr>
<td>Race = African American</td>
<td>0.399  0.231  0.689  0.001</td>
<td>0.398  0.229  0.692  0.001</td>
</tr>
<tr>
<td>Race = Other</td>
<td>0.656  0.343  1.253  0.202</td>
<td>0.655  0.342  1.252  0.200</td>
</tr>
<tr>
<td>Social Capital</td>
<td>0.883  0.517  1.505  0.647</td>
<td>0.882  0.516  1.507  0.645</td>
</tr>
<tr>
<td></td>
<td>0.999  0.836  1.195  0.995</td>
<td></td>
</tr>
</tbody>
</table>

Note. Question only asked of those who answered health care had been delayed/not received. Baseline category for outcome = No. Reference category for race = white.
CHAPTER 5

DISCUSSION LIMITATIONS, POLICY IMPLICATIONS AND CONCLUSION

5.1 Discussion

This research provides important insight not only in regards to medical home status and availability of care, but also targets a specific medical home characteristic that is more likely to make the greatest impact on availability of care in children with special healthcare needs. By identifying one or more specific medical home items that make a large impact in accessing care, policies can then be developed surrounding these targeted initiatives. As many health systems continue to see an increase in CSHCN coupled with the movement toward value-based reimbursement structures, this type of knowledge is important for the fund allocation process.

Care Coordination

When examining the first model (research question 1), it appears that lack of care coordination is the most significant factor associated with delays in care or care that is not received (OR = 4.77). This means that CSHCN who have delays in receiving care are 4.7 times more likely to have problems with care coordination as opposed to the group who reported no delays in care. A 2015 study examining time burden on families, showed that three of the five medical home components in the study were associated with increased time burden on families (care coordination, family-centered care, and no problems obtaining needed referrals). This research also shows that families of CSHCN who only reported care coordination as a lacking component of their medical home, had 1.6 times the adjusted odds of a time burden as compared
with CSHCN’s who exhibited all 5 medical home components (Miller et al, 2015). Care coordination within this study reduced the odds of spending more than 4 hours/week arranging or coordinating care (Miller et al, 2015). Another study found that care coordination within a medical home environment was associated with decreased unmet needs regarding specialty care by one-third (Boudreau, et al, 2014). In a prior study examining the 2005-2006 NSCH, it was found that only 47.1% of CSHCH had access to a medical home, however, only about half of these children were found to have achieved all five medical home components. Only 59.2% received effective care coordination within this study, which was the lowest percentage category of the five medical home items included within the study (Strickland et al, 2009).

Among those CSHCN who exhibited delays in care or received no care, they are also less likely to identify with a primary care provider (PCP), less likely to be satisfied with communication from the provider, less likely to feel a partnership in care delivery, less likely to have insurance, more likely to receive state Medicaid assistance and much more likely (OR=6.13) to have gone without insurance at some point in the past 12 months. These findings are significant because all components listed are important aspects of the medical home model. Although insurance status is not a medical home item, this has proven to be a critical component when trying to access primary care for children (Newacheck et al, 2011). Although these other factors are significant within the first model, care coordination seems to have had the greatest impact in children who have reported delays or non-receipt of care.

When availability of medical care alone is examined, similar relationships are discovered. The odds of experiencing delay/no receipt of medical care were 36.8% lower among those respondents who felt they needed extra help coordinating care. This relationship is counterintuitive, however, could be result of children who have more health care needs actually receive appropriate care but need greater assistance with care coordination between specialists.
Those who had experienced a delay/no receipt of mental health services were more likely to have a personal provider and were also more likely to feel that they need extra help with care coordination, which is similar to the first model examining all healthcare types.

Social Capital

In addition to the medical home items already discussed, social capital was also examined as a possible mediator between the relationships of the medical home on the availability of care in CSHCN. In the first model, regarding overall care availability/delay, each increase on the social capital scale, reduced the odds of experiencing delay in care or access to healthcare by 12.5%. This, however, did not hold true in the subsequent analyses when examining only medical care (research question 2) and mental health services (research question 3) alone. To date, there has been no specific research examining how social capital contributes to the availability of healthcare within a medical home environment. This is largely due to the variability in the definition of social capital within the community as well as the variability in how the medical home is defined. An attempt to find a relationship between social capital and availability of care within a medical home environment is also difficult to find in this research. The 12.5% decrease in delay of care cannot be adequately explained by this relationship affecting one single medical home variable or a group of variables. Respondents reporting that their child’s health care was not delayed exhibited higher social capital scores than respondents who reported their child’s health care was delayed/not received. This could be a result of the community in which the child lives regardless of medical home status within the child’s primary care practice. To date, there has been no research into the association between availability of care within a medical home and the influence of social capital, making it difficult to know if these results are significant compared to other datasets examining similar social capital variables.
Social capital had no significant effect on the availability of medical care or mental health services for any medical home variable.

**Ethnicity**

Prior research has shown that the Hispanic population is least likely to receive care within a medical home (32.2%) as opposed to Non-Hispanic White (52.8%), and Non-Hispanic Black (36.6%) (Strickland et al, 2009). Because of these findings, this research examined the Hispanic population in CSHCN and it was found that Hispanics are actually less likely to report problems with delays in health care (OR=.517) for all healthcare types and (OR=.399) for mental health services. African Americans are also less likely than whites to report a delay (OR=.688) for all health care types, but are more likely to experience delay of medical care. Although these results are promising for minority children, this does not address the actual percentage of minority CSHCN who are actually cared for within a medical home environment.

**Insurance Status**

When examining the first model, CSHCN were less likely to have insurance, more likely to have Medicaid or CHIP, and more likely to have gone without health insurance in the prior year. For the second model (medical care), these children are also less likely to have insurance and are more likely to have gone without insurance at some point within the past year. For the third model (mental health services), these children are now more likely to have insurance, less likely for that insurance to be Medicaid or CHIP, and less likely to have gone without insurance during the prior year.

**Mental Health**

The odds of experiencing a delay in mental health services more than doubled for those with a personal provider. The odds also increase by 89.7% among those who feel like they need extra help coordinating care, but decreased by 61% among Hispanics. Examining the
availability of mental health services for CSHCN produces results that appear to be counterintuitive. Previous research analyzing data from the 2007 NSCH has also shown that having a medical home was associated with being less likely to have received mental health care (Knapp, et al, 2012). This type of relationship is possible because not all primary care providers are as knowledgeable or are as willing to treat children with mental health disorders as effectively as other primary care complaints. This may prompt discussion regarding a specific mental health medical home infrastructure to better care for these children.

5.2 Limitations of Data

NSCH is a cross-sectional dataset, which is representative of a snapshot in time and does not represent a longitudinal assessment regarding outcomes of patients who utilize a medical home model. There are very few missing values for the variables that are being used for this research. There are a few limitations that warrant further examination and are described in this section.

Telephone Surveying

The overall response rate of the survey was 54.2% for landline and 41.2% for cell phone for the respondents who fully completed the survey. The inherent limitation of using telephones (landline or cellular) to contact study participants is the potential for contacting only respondents who are of a higher socioeconomic status and who could live in higher income areas. This not only eliminates children in lower socioeconomic categories, but also children in urban areas which may already not be well represented by the study sample. Prior research examined the effectiveness of telephone surveys in Ireland and has concluded that land-line surveys may not be as effective as they have been in the past, mostly related to survey fatigue and the general notion of individuals moving solely to a cellular phone as their primary means of communication (Boland et al, 2006).
Medicaid Eligibility among States

The NSCH sample represents respondents from each state in the U.S. and ranges from 1811 (South Dakota) to 2200 (Texas) respondents for each state. The poverty thresholds for children 6-18 years of age for states vary from 133% of federal poverty level (FPL) (17 states) to 319% of FPL (D.C). Twenty-two states do allow for a higher poverty threshold for children from 0-1 year of age. The state differences in poverty thresholds for Medicaid could have resulted in missing children who could otherwise be living in poverty according to another standardized measure (Medicaid, 2016). Based on the sampling framework in this study, the proportion of state representation is unknown and could represent bias towards individuals in states who only responded to all variables included in the study design.

Social Capital: Urban vs. Rural

Based on the sampling framework for these data, much of the respondents may live in rural areas according to the National Center for Health Statistics who administered the original survey. There are distinct differences in the literature when attempting measure social capital in urban and rural environments. Rural communities, in general, typically have higher levels of social capital according to prior research (Glendinning, et al, 2003; Turcotte, M, 2005). One study found that residents who live in rural areas reported higher levels of social capital related to civic activities and cohesion as compared to urban residents. In the same study, rural residents reported better mental health which could be attributed to higher levels of social capital which is evidenced by higher levels of trust and increased access to help when needed and cohesive relationships (Ziersch, et al, 2009). In this current research, 67% individuals reported social capital in the highest 2 quartiles, while 34% responded with social capital levels in the lower 2 quartiles. Although most respondents reported higher levels of social capital, this did not seem to affect availability of medical care or mental health services. The level of social capital, did
however, reduce the odds of experiencing a delay in care for all health care types. This limitation is not well understood in the context of these findings, but could possibly show increased availability of care amongst healthcare types that were not included within these models (dental, vision, other) if examined independently of one another.

**State Representation of Children’s Hospitals**

Individual state representation of children’s hospitals may be an important limitation regarding further policy actions that could result based on this research. According to data from the Children’s Hospital Association, there are 222 children’s hospitals or hospital systems in the United States. The range of hospitals per state is 1 to 19 with the mean number of hospitals per state in the U.S. at 4.6 (Children’s Hospital Association, 2018). For this research, specific variables were selected based on the research questions and the possibility exists that all states were not represented equally in the sample. When examining policy implications, this could limit generalizability to all states especially if there is lack of a strong pediatric health care presence within the state. Initially policy recommendations as a result of this study, may also not be possible in all states due to financial stability of pediatric hospitals as well as the extent of existing community partnerships.

**Types of Childhood Diseases Reported**

Another limitation of this research is the types of chronic diseases reported in the survey. The diseases and illness included within the survey are based on the CSHCN Screener ® and have been used in previous research (Bethell et al, 2002). There have been, however, published changes made from the 2007 version. A list of illnesses that have been deleted from the 2011/2012 survey are as follows: hay fever or respiratory allergy, food or digestive allergy, eczema or any type of skin allergy, migraine headache, ear infections, problems with bones, joints, or muscles, and dental health. The two illnesses that have been added to the 2011/2012
survey are the presence of an intellectual disability and cerebral palsy (CDC, 2013). The rationales for deletions or additions are not published in the literature. The severity of the disease or illness is also not addressed within this research and categorizes all children with one or more diseases as a child with special healthcare needs. The methodology was specifically structured in this way due to the author’s preference to include all possible children with a healthcare need; however, it is possible that all CSHCN are not equally in need of the same medical or mental health resources.

**Methodology and Analysis**

Logistic regression is being used to the exploratory nature of this research and will not imply causality or to generate theory testing within this area of research. This procedure will only be valid for this particular dataset and will not claim to necessarily further replicate these procedures in future datasets with similar variables, however, would be valid for further research utilizing this same dataset. These results will however, assist in developing an initial strategy aimed at increasing availability of care for children with special healthcare needs (CSHCN) based on the extent of medical home characteristics within their current medical practice as well as the neighborhood in which they live.

The sample size for this research is adequate for the research question being answered as well as the methodology that is employed considering this is an observational study. The entire dataset contains 96,677 children, including children with special healthcare needs (CSHCN). The sample population for this research is a subset of the total, which contains only those children who identify with one or more chronic illnesses as listed in figure 2. For research question #1, total research sample is 32,496 or approximately 34% of the total sample size. For the subsequent research questions, the sample size is dramatically less (3,173) due to using only the respondents that answered affirmatively to the dependent variable in the first research
question (availability or non-receipt of care). A power calculation was performed assuming a 5% margin of error and 95% confidence interval and the current sample size is well beyond appropriate levels (Raosoft, 2004). The current dissertation committee as well as a consulting statistician also approved the sample size for this type of research design.

Impact of ACA/NSCH 2016 Data

Since the writing of this research study, a new 2016 version of the NSCH has been published. Since the Affordable Care Act has been incrementally implemented over the past few years, there is a possibility of differences in findings, largely related to Medicaid expansion if the new 2016 data set was used examining the same variables. At the time these current data were collected (2011-2012), Medicaid expansion was not signed into law, and therefore, the effects of the increased eligibility may not have been captured. Although Medicaid expansion did go into effect until 2014, many of the eligible children in the U.S. were also previously eligible under their respective state Medicaid policy as Medicaid expansion largely expanded care for childless adults. There are however, increased eligibility thresholds, which have allowed for a greater number of children who may not have been previously eligible for Medicaid to now be covered up to 133% of FPL in each state (Kaiser Family Foundation, 2014). In addition to increased eligibility under Medicaid, the Children’s Health Insurance Program (CHIP) also received authorization through fiscal year 2015 as well as further increased financing for fiscal years 2016-2019 (Kaiser Family Foundation, 2014). As more children are enrolled into state Medicaid programs, it will be continually important to assess medical home access and availability of care in all pediatric primary and specialty care practices.
5.3 Policy Implications

As more health systems recognize the importance of the medical home model within their primary care practices, it will be extremely important to understand what individual components are the most effective at producing the greatest return. As care becomes more risk-based, hospitals will need to more effectively budget their resources by providing more cost-effective care without sacrificing quality. At the same time, low-income areas within the hospital catchment area cannot suffer as many children in these depressed areas need a level of care that can only be provided by a medical home or a practice that encompasses the most important components of a medical home. By understanding how social capital impacts CSHCN within the surrounding communities, more targeted interventions can be employed in order to make the medical home model most effective at providing quality care for the nation's most vulnerable children. It appears from this research that care coordination is an important factor when considering creating a medical home structure. This component along with the four other medical home components would provide the best outcomes, however, this task is often cost-prohibitive for small practices or even larger organizations. Spending time and effort enhancing care coordination within the practice would provide benefit to CSHCN even if the other variables are lacking. At the same time, assessing social capital in a specific area of the community may also assist in the decision making on the location of new primary care clinics. If hospitals can partner with community organizations to clean up socioeconomically disadvantaged areas and increase the level of social capital, CSHCN will receive care that is more available as well as be provided with more effective care coordination within the medical home practice.

This survey was administered during the early implementation period of the Affordable Care Act, which may or may not have an impact on the overall availability of
medical care or mental health services that the child receives. Now, in the year 2018, when most of the changes affecting children’s healthcare have been implemented, it may be reasonable to expect a more positive response when addressing care coordination or the other areas critical areas of the medical home structure. A new version of the survey was completed in 2016 and was combined with the National Survey of Children with Special Healthcare Needs (NS-CSHCN), however, the data are not publically available as of this time. Further research examining these same medical home characteristics on the availability of care using the more recent 2016 survey may provide greater insight into the effects of the Affordable Care Act on this specific population of children to allow for further policy changes in the future.

5.4 Conclusion

This is a cross-sectional study examining the availability of care for children with special health care needs and how social capital plays a role in this relationship. When all healthcare types are examined, it appears that lack of care coordination is the most significant factor associated with delays in care or care that is not received (OR= 4.77). Social capital does have an influence within this larger relationship and does contribute to reduced odds of having delayed care or no receipt of care. When medical care alone is analyzed, social capital does not have significant effects in this patient population and is not a mediator of any of the significant relationships that are found. In regards to mental health services, social capital also did not have any mediating effect on the relationships between the medical home and availability of care. Social capital research is difficult to perform mainly due to how this concept is defined and how respondents interpret the variables describing various forms of social capital. As referenced previously, the third model of social capital described by Uphoff and colleagues (2013) describes the possibility that all people within the same community may not equally obtain the same
benefits, realizing a contextual component between social capital and self rated health. This is important for researchers as they devise research questions appropriate for the particular setting as well as important for individuals when interpreting how social capital effects them and their family within their community or neighborhood environment. Further research must be conducted to address multiple types of social capital that exist within communities as well as attempting to find patterns that are associated with greater health outcomes for CSHCN and all children who live in these communities. Furthermore, specific health services may need to be broken down further to specific diseases or illnesses to better address the health care inadequacies within the community and allow better appropriation of funding or assistance with the populations that could benefit the most.
APPENDIX A- IRB LETTER OF EXEMPTION

From: RAGS Research Compliance researchcompliance@kent.edu
Subject: IRB DETERMINATION - Project determined to be exempt from review
Date: December 8, 2016 at 10:47 AM
To: jpennin5@kent.edu
Cc: Alemagno, Sonia salemagn@kent.edu

Thank you for submitting the IRB DETERMINATION FORM to our office for review. We have determined that your project is exempt from the Federal Policy for the Protection of Human Subjects and does not require IRB Review.

Once a project has been deemed “exempt” continuing IRB review is not required, unless changes are made that would disqualify the study for exemption. It is the investigator’s responsibility to notify the IRB if any changes are made in the project’s design, procedures, etc. Exempting an activity from review does not absolve the investigator(s) from ensuring that the welfare of subjects is protected. Projects should be in line with the ethical standards put forth in the Belmont Report and still need to comply with the guidelines and ethics codes of academic disciplines.

We have assigned your application the following IRB number: 16-587. Please be sure to reference this number for future correspondences with our office about this determination.

Should you have additional questions, please feel free to contact us. Thank you.
Thanks, Kevin
Kevin McCreary
Assistant Director, Research Compliance
330-672-8058

For links to obtain general information, access forms, and complete required training, visit our website at www.kent.edu/research.
APPENDIX B- NSCH 2011-2012 TOPICS AND SURVEY QUESTIONS

National Survey of Children’s Health (NSCH), 2011/2012

www.childhealthdata.org

The Data Resource Center (DRC) is a project of the Child and Adolescent Health Measurement Initiative at Oregon Health & Science University.

The DRC is sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration.

Initial Screening and Sampling

The interviewer begins by asking how many children live in the household and the age of each person under 18 years old living in the household. (S_UNDR18)

After the initial screening is completed, a single child is randomly selected from households with one or more children, ages 0-17.

The selected child is the subject of the National Survey of Children’s Health Interview questions asked in Sections 1 – 12 of the survey.

SECTION 1: Initial Demographics

1. Child’s sex (K1Q01)
2. Respondent’s relationship to the child (K1Q02)
3. What is the primary language spoken in your home? (K1Q03)

SECTION 2: Child’s Health and Functional Status

1. In general, how would you describe [CHILD’S NAME] health? (K2Q01)
2. How would you describe the condition of [CHILD’S NAME] teeth? (K2Q01_D)
3. How tall is [CHILD’S NAME] now? (K2Q02)
4. How much does [CHILD’S NAME] weigh now? (K2Q03)
5. What was [CHILD’S NAME] birth weight? (K2Q04)
6. Was [CHILD’S NAME] born premature? (K2Q05) ±
7. Does [CHILD’S NAME] currently need or use medicine prescribed by a doctor, other than vitamins? (K2Q10-K2Q12)
8. Does [CHILD’S NAME] need or use more medical care, mental health, or educational services than is usual for most children of the same age? (K2Q13-K2Q15)
9. Is [CHILD’S NAME] limited or prevented in any way in (his/her) ability to do the things most children of the same age can do? (K2Q16-K2Q18)
10. Does [CHILD’S NAME] need or get special therapy, such as physical, occupational, or speech therapy? (K2Q19-K2Q21)
11. Does [CHILD’S NAME] have any kind of emotional, developmental, or behavioral problem for which (he/she) needs treatment or counseling? (K2Q22-K2Q23)

If YES to any of the above items 7-11 above, two follow up questions are asked:
- Is this because of a medical, behavioral, or other health condition?
- Has this condition lasted or is it expected to last for 12 months or longer?

12. Has a doctor, health care provider, teacher, or school official ever told you [CHILD’S NAME] has a learning disability? (K2Q30A) (ages 3-17 years)
- Does [CHILD’S NAME] currently have a learning disability? (K2Q30B)
- Would you describe (his/her) learning disability as mild, moderate, or severe? (K2Q30C)

13. For each condition, please tell me if a doctor or other health care provider ever told you that [CHILD’S NAME] had the condition, even if (he/she) does not have the condition now. Has a doctor or health professional ever told you that [CHILD’S NAME] has any of the following conditions?

Ages 2-17
- Attention Deficit Disorder or Attention Deficit Hyperactive Disorder * (K2Q31A)
- Is [CHILD’S NAME] currently taking medication for ADD or ADHD? (K2Q31D)
- Depression (K2Q32A)
- Anxiety Problems (K2Q33A)
- Behavior or conduct problems (K2Q34A)
- Autism, Asperger’s Disorder, pervasive development disorder, or other autism spectrum disorder (K2Q35A)
- Any developmental delay (K2Q36A)
- Intellectual disability or mental retardation (K2Q60A) ±
  - Cerebral palsy (K2Q61A) ±
  - How would you describe (his/her) ability to walk? (K2Q61C)
- Speech or other language problems (K2Q37A)
- Tourette Syndrome (K2Q38A) Ages 0-17
- Asthma (K2Q40A)
- Diabetes (K2Q41A)
- Epilepsy or seizure disorder (K2Q42A)
- Hearing problems (K2Q43A)
- Vision problems that cannot be corrected with standard glasses or contact lenses? (K2Q44A)
- Bone, joint, or muscle problems (K2Q45A)
- A brain injury or concussion (K2Q46A)

If YES to any of the conditions above (K2Q31A-K2Q46A), two follow up questions are asked:
- Does [CHILD’S NAME] currently have condition? (K2Q31B – K2Q46B)
- Would you describe (his/her) condition as mild, moderate, or severe? (K2Q31C – K2Q46C)

If YES to any of the following conditions: ADD/ADHD, Depression, Anxiety Problems, Behavior/Conduct Problems, Autism or ASD, Developmental Delay, Intellectual Disability or Mental Retardation, Cerebral Palsy, Speech Problems, or Tourette Syndrome (K2Q31A,
K2Q34A-K2Q43A, K2Q45A-K2Q61A), one follow up question is asked:

- How old was [CHILD’S NAME] when you were first told by a doctor or other health care provider that (he/she) had [CONDITION]? (NEW4Q31, NEW4Q34–NEW4Q43, NEW4Q45-NEW4Q61) ±If YES to item K2Q35A above, four follow up questions are asked:
  - What type of doctor or other health care provider first told you that [CHILD’S NAME] had autism or ASD? (K2Q35D) ±
  - To the best of your knowledge, did [CHILD’S NAME] ever have autism or ASD? (K2Q35E) ±
  - The Data Resource Center (DRC) is a project of the Child and Adolescent Health Measurement Initiative at Oregon Health & Science University.
  - The DRC is sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration. 3
  - Reasons why [CHILD’S NAME] may no longer have autism or ASD (K2Q35F) ±
    - Do any of the following apply? Response Options:
      - Treatment helped condition go away
      - Condition seemed to go away on its own
      - Behaviors or symptoms changed
      - A doctor or health care provider changed the diagnosis
      - Other reason(s)? (Verbatim response recorded) (K2Q35G) ±
  - Reasons why a doctor, health care provider, or school professional may have told you that [CHILD’S NAME] had a condition that (he/she) never had (K2Q35H) ±
    - Do any of the following apply? Response Options:
      - With more information, the diagnosis changed
      - The diagnosis was given so [CHILD’s NAME] could receive needed services
      - You disagree with the doctor or other health provider about their opinion that [CHILD’s NAME] has autism or ASD
      - Other reason(s)? (Verbatim response recorded) (K2Q35J) ±

SECTION 3: Health Insurance Coverage

1. Does [CHILD’S NAME] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid? (K3Q01) ±If YES, [Is that coverage/Is (he/she) insured by] Medicaid or the Children’s Health Insurance Program, CHIP? (K3Q02) ±If YES, During the past 12 months, was there any time when (he/she) was not covered by ANY health insurance? (K3Q03) ±If NO, During the past 12 months, was there any time when (he/she) had health care coverage? (K3Q04) ±
2. The next four questions are asked for insured children only.
   - Does [CHILD’S NAME] health insurance offer benefits or cover services that meet (his/her) needs? (K3Q20) ±
   - Does [CHILD’S NAME] health insurance allow (him/her) to see the health care providers (he/she) needs? (K3Q22) ±
   - Not including health insurance premiums or costs that are covered by insurance, do you pay any money for [CHILD’S NAME] health care? (K3Q21A) ±
   - How often are these costs reasonable? (K3Q21B) ±
3. In the past 12 months, did your family have problems paying or were unable to pay any of [CHILD’S NAME]’s medical bills? (K3Q25) ±
4. During the past 12 months, how often have you been frustrated in your efforts to obtain health care services for [CHILD’S NAME]? (C4Q04)

SECTION 4: Health Access and Utilization

1. Is there a place that [CHILD’S NAME] USUALLY goes when (he/she) is sick or you need advice about (his/her) health? (K4Q01)
   - Is it a doctor’s office, emergency room, hospital outpatient department, clinic, or some other place? (K4Q02)
2. A personal doctor or nurse is a health professional who knows your child well and is familiar with your child’s health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician’s assistant. Do you have one or more persons you think of as [CHILD’S NAME] personal doctor or nurse? (K4Q04)
3. During the past 12 months, did [CHILD’S NAME] see a doctor, nurse, or other health care professional for any kind of medical care including sick-child care, well-child checkups, physical exams, and hospitalizations? (S4Q01)
4. During the past 12 months, how many times did [CHILD’S NAME] see a doctor, nurse, or other health care provider for preventive medical care such as a physical exam or well-child checkup? (K4Q20)
5. During the past 12 months, did [CHILD’S NAME] see a dentist for any kind of dental care, including check-ups, dental cleanings, x-rays, or filling cavities? (K4Q30)
6. During the past 12 months, how many times did [CHILD’S NAME] see a dentist for preventive dental care, such as check-ups and dental cleanings? (K4Q21)
7. During the past 12 months, did [CHILD’S NAME] have a toothache, decayed teeth, or unfilled cavities? (K4Q39) (ages 1-17 years)
8. Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers. During the past 12 months has [CHILD’S NAME] received any treatment or counseling from a mental health professional? (K4Q22) (ages 2-17 years)
9. During the past 12 months, has [CHILD’S NAME] taken any medication because of difficulties with (his/her) emotions, concentration, or behavior? (K4Q23) *asked only for children who are not taking medication for ADD/ADHD
10. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care. During the past 12 months, did [CHILD’S NAME] see a specialist (other than a mental health professional)? (K4Q24)
   - If NO, during the past 12 months, did you or a doctor think that (he/she) needed to see a specialist? (K4Q25)
   - If YES, during the past 12 months, how much of a problem, if any, was it to get the care from the specialists that [CHILD’S NAME] needed? (K4Q26)
11. Has [CHILD’S NAME] [ever (0-5 years)/in the past two years (6-17 years)] had (his/her) vision tested with pictures, shapes, or letters? (K4Q31)
   - If YES, What kind of place did [CHILD’S NAME] have (his/her) vision tested? (K4Q32)
12. Sometimes people have difficulty getting health care when they need it. By health care, I mean medical care as well as other kinds of care like dental care, vision care and mental health services. During the past 12 months, was there any time when [CHILD’S NAME] needed health care?
care but it was delayed or not received? (K4Q27)  
- If YES, What type of care was delayed or not received? (K4Q28)  
13. Some new parents are helped by programs that send nurses, healthcare workers, social workers, or other professionals to their home to help prepare for the new baby or take care of the baby or mother. Between the time [you were (his/her) mother was] pregnant with [CHILD’S NAME] and up until the present day, did someone from such a program visit your home? (K4Q35) ±*asked only for children 0-3 years old  
- If YES, How many different professionals came to your home? (K4Q35A) ±  
- If YES, Please tell me if the [the professional / any of the professionals] who visited your home talked about parental concerns about their children and families (K4Q35B) ± Response Options: (1) the care giver’s emotional well-being; (2) smoking or alcohol use in the home; (3) building a close relationship with child; (4) the use of toys or activities for learning, growth and development; (5) how to make sure [CHILD’S NAME] is safe; (6) how to get needed health care; (7) other services that may help your family, such as public assistance or job training  
14. Earlier you told me that you had been told by a doctor or other health care provider that [CHILD’S NAME] had (a condition / conditions) that affected (his/her) learning or development. Has [CHILD’S NAME] ever received therapy services to meet (his/her) developmental needs, such as Early Intervention, occupational therapy, or behavioral therapy? (K4Q36) ± *asked only for children who have been diagnosed with autism/ASD etc. or Developmental Delay  
- If YES, How old was [CHILD’S NAME] when (he/she) began receiving services? (K4Q37) ±  
- If YES, Is [CHILD’S NAME] currently receiving therapy services? (K4Q38) ±  

SECTION 5: Medical Home  
1. During the past 12 months, did [CHILD’S NAME] need a referral to see any doctors or receive any services? (K5Q10)  
- Was getting referrals a big problem, small problem, or not a problem? (K5Q11)  
2. Does anyone help you arrange or coordinate [CHILD’S NAME]’s care among the different doctors or services that (he/she) uses? (K5Q20) *asked for children who used more than two services  
3. During the past 12 months, have you felt that you could have used extra help arranging or coordinating [CHILD’S NAME]’s care among the different health care providers or services? (K5Q21) *asked for children who used more than two services  
- If YES, during the past 12 months, how often did you get as much help as you wanted with arranging or coordinating [CHILD’S NAME]’s care? (K5Q22) *asked for children who used more than two services  
4. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [CHILD’S NAME]’s doctors and other health care providers? (K5Q30)*asked for children who used more than two services  
5. Do [CHILD’S NAME]’s doctor or other health care providers need to communicate with (his/her) child care providers, school, or other programs? (K5Q31)  
- Overall, are you very satisfied, somewhat satisfied, or very dissatisfied with that communication? (K5Q32)  
6. During the past 12 months, how often did [CHILD’S NAME]’s doctors and other health care providers spend enough time with (him/her)? (K5Q40)  
7. During the past 12 months, how often did [CHILD’S NAME]’s doctors and other health care providers listen carefully to you? (K5Q41)
8. When [CHILD’S NAME] is seen by doctors and other health care providers, how often are they sensitive to your family’s values and customs? (K5Q42)

9. Information about a child’s health or health care can include things such as the causes of any health problems, how to care for a child now, and what to expect in the future. During the past 12 months, how often did you get the specific information you needed from [CHILD’S NAME]’s doctors and other health care providers? (K5Q43)

10. During the past 12 months, how often did [CHILD’S NAME]’s doctors or other health care providers help you feel like a partner in (his/her) care? (K5Q44)

SECTION 6: Early Childhood (0–5 years)

1. Do you have any concerns about [CHILD’S NAME] learning, development, or behavior? (K6Q01)

2. Are you concerned about how (he/she):
   - Talks and makes speech sounds? (K6Q02) (ages 4 months – 5 years)
   - Understands what you say? (K6Q03) (ages 4 months – 5 years)
   - Uses (his/her) hands and fingers to do things? (K6Q04) (ages 4 months – 5 years)
   - Uses (his/her) arms and legs? (K6Q05) (ages 4 months – 5 years)
   - Behaves? (K6Q06) (ages 4 months – 5 years)
   - Gets along with others? (K6Q07) (ages 4 months – 5 years)
   - Is learning to do things for (himself/herself) (K6Q08) (ages 10 months to 5 years)
   - Is learning pre-school or school skills? (K6Q09) (ages 18 months - 5 years)

3. During the past 12 months did [CHILD’S NAME]’s doctors or other health care providers ask if you have concerns about (his/her) learning, development, or behavior? (K6Q10) *asked for children who used at least one service in past year

4. Sometimes a child’s doctor or other health care providers will ask a parent to fill out a questionnaire at home or during their child’s visit. During the past 12 months, did a doctor or other health care provider have you fill out a questionnaire about specific concerns or observations you may have about [CHILD’S NAME]’s development, communication, or social behaviors?
   - Did this questionnaire ask you about your concerns or observations about how [CHILD’S NAME] talks or makes speech sounds (K6Q13A) (ages 10-23 months only)
   - Did this questionnaire ask you about your concerns or observations about how [CHILD’S NAME] interacts with you and others? (K6Q13B) (ages 10-23 months only)
   - Did this questionnaire ask you about your concerns or observations about words and phrases [CHILD’S NAME] uses and understands? (K6Q14A) (ages 24-71 months only)
   - Did this questionnaire ask you about your concerns or observations about how [CHILD’S NAME] behaves and gets along with you and others (K6Q14B) (ages 24-71 months only)

5. Does [CHILD’S NAME] have any developmental problems for which (he/she) has a written intervention plan called an Individual Family Services Plan (IFSP) or Individualized Education Program (IEP)? (K6Q15)

6. Does [CHILD’S NAME] receive care for at least 10 hours per week from someone not related to (him/her)? This could be a day care center, preschool, Head Start program, nanny, au pair, or any other non-relative. (K6Q20)

7. During the past 12 months, did you or anyone in the family have to quit a job, not take a job,
or greatly change your job because of problems with child care for [CHILD’S NAME]? (K6Q27)
8. Was [CHILD’S NAME] ever breastfed or fed breast milk? (K6Q40)
   − If YES, how old was [CHILD’S NAME] when [he/she] completely stopped breastfeeding or
     being fed breast milk? (K6Q41)
   − If YES, how old was [CHILD’S NAME] when [he/she] was first fed formula? (K6Q42)
   − This next question is about the first thing [CHILD’S NAME] was given other than breast milk
     or formula. Please include juice, cow’s milk, sugar water, baby food, or anything else that
     [CHILD’S NAME] might have been given, even water. How old was [CHILD’S NAME] when
     [he/she] was first fed anything other than breast milk or formula? (K6Q43)
9. I am going to read a list of items that sometimes describe children. For each item, please tell
   me how often this was true for [CHILD’S NAME] during the past month:
   − (He/She) is affectionate and tender with you. (K6Q70) ± (ages 6 months – 5 years)
   − (He/She) bounces back quickly when things don’t go (his/her) way. (K6Q73) ± (ages 6 months
     – 5 years)
   − (He/She) shows interest and curiosity in learning new things. (K6Q71) ± (ages 6 months – 5
     years)
   − (He/She) smiles and laughs a lot. (K6Q72) ± (ages 6 months – 5 years)
10. On an average weekday, about how much time does [CHILD’S NAME] usually spend in
    front of a TV watching TV programs, videos, or playing video games? (K6Q65A)
11. On an average weekday, about how much time does [CHILD’S NAME] usually spend with
    computers, cell phones, handheld video games, and other electronic devices? (K6Q65B)
12. During the past week, how many days did you or other family members read to [CHILD’S
    NAME]? (K6Q60)
13. During the past week, how many days did you or other family members tell stories or sing
    songs to [CHILD’S NAME]? (K6Q61)
14. During the past week, how many days did [CHILD’S NAME] play with other children
    [his/her] age? (K6Q63)
15. During the past week, how many days did you or any family member take [CHILD’S
    NAME] on any kind of outing, such as to the park, library, zoo, shopping, church, restaurants, or
    family gatherings? (K6Q64)

SECTION 7: Middle Childhood and Adolescence (6-17 years)

1. What kind of school is [CHILD’S NAME] currently enrolled in? (K7Q01)
   − If NOT ENROLLED, at any time during the past 12 months, was [CHILD’S NAME] enrolled
     in a public school, a private school, or home school? (K7Q01F)
2. During the past 12 months, about how many days did [CHILD’S NAME] miss school because
    of illness or injury? (K7Q02)
3. During the past 12 months, how many times has [CHILD’S NAME] school contacted you or
    another adult in your household about any problems [he/she] is having with school? (K7Q04)
4. Since starting kindergarten, has [he/she] repeated any grades? (K7Q05)
   − If YES, which grade or grades did (he/she) repeat? (K7Q05_A) ±
5. Does [CHILD’S NAME] have a health problem, condition, or disability for which [he/she] has
    a written intervention plan called an Individualized Education Program or IEP? (K7Q11)
6. During the past 12 months, was [CHILD’S NAME] on a sports team or did [he/she] take
sports lessons after school or on weekends? (K7Q30)

7. During the past 12 months, did [CHILD’S NAME] participate in any clubs or organizations after school or on weekends? (K7Q31)

8. During the past 12 months, did [CHILD’S NAME] participate in any other organized activities or lessons, such as music, dance, language, or other arts? (K7Q32)

9. During the past 12 months, how often did you attend events or activities that [CHILD’S NAME] participated in? (K7Q33) *asked for children who participated in one or more extracurricular activities (K7Q30-K7Q32)

10. Regarding [CHILD’S NAME]’s friends, would you say that you have met all, most, some or none of [his/her] friends? (K7Q34)

11. During the past 12 months, how often has [CHILD’S NAME] been involved in any type of community service or volunteer work at school, church, or in the community? Would you say once a week or more, a few times a month, a few times a year, or never? (K7Q37) (ages 12-17 years only)

12. During the past week, did [CHILD’S NAME] earn money from any work, including regular jobs as well as babysitting, cutting grass or other occasional work? (K7Q38) (ages 12-17 years only)

- If YES, during the past week, how many hours did [CHILD’S NAME] work for pay? (K7Q39)

13. During the past week, on how many nights did [CHILD’S NAME] get enough sleep for a child [his/her] age? (K7Q40)

14. During the past week, on how many days did [CHILD’S NAME] exercise, play a sport, or participate in physical activity for at least 20 minutes that made [him/her] sweat and breathe hard? (K7Q41)

15. On an average weekday, about how much time does [CHILD’S NAME] usually spend reading for pleasure? (K7Q50)

16. On an average weekday, about how much time does [CHILD’S NAME] usually spend in front of a TV watching TV programs, videos, or playing video games? (K7Q60A)

17. On an average weekday, about how much time does [CHILD’S NAME] usually spend with computers, cell phones, handheld video games, and other electronic devices, doing things other than schoolwork? (K7Q60B)

18. Do you monitor the content of what [CHILD’S NAME] watches on TV, plays on the computer, or does on electronic devices? (K7Q61)

19. Do you limit the amount of time [CHILD’S NAME] spends watching TV, playing on the computer, or using electronic devices? (K7Q61A)

20. Does [CHILD’S NAME] have a TV, computer, or access to electronic devices in [his/her] bedroom? (K7Q62)

I am going to read a list of items that sometimes describe children. For each item, please tell me how often this was true for [CHILD’S NAME] during the past month:

- [He/She] argues too much. (K7Q70)
- [He/She] bullies or is cruel or mean to others. (K7Q71)
- [He/She] is unhappy, sad, or depressed. (K7Q79)
- [He/She] cares about doing well in school. (K7Q82)
- [He/She] does all required homework. (K7Q83)
- [He/She] finishes the tasks [he/she] starts and follows through with what [he/she] says [he’ll/she’ll] do. (K7Q84) ±
- [He/She] stays calm and in control when faced with a challenge. (K7Q85) ±
- [He/She] shows interest and curiosity in learning new things. (K7Q86) ±
SECTION 8: Family Functioning

1. About how often does [CHILD’S NAME] attend a religious service? (K8Q12)
2. During the past week, how many days did all the family members who live in the household eat a meal together? (K8Q11)
3. How well can you and [CHILD’S NAME] share ideas or talk about things that really matter? (K8Q21) (ages 6-17 years)
4. In general, how well do you feel you are coping with the day to day demands of (parenthood/raising children)? (K8Q30)
5. During the past month, how often have you felt [CHILD’S NAME] is much harder to care for than most children (his/her) age? (K8Q31)
6. During the past month, how often have you felt (he/she) does things that really bother you a lot? (K8Q32)
7. During the past month, how often have you felt angry with (him/her)? (K8Q34)
8. Is there someone that you can turn to for day-to-day emotional help with [parenthood/raising children]? (K8Q35)

SECTION 9: Parental Health

1. Including the adults and all the children, how many people live in this household? (K9Q00)**
2. How old are you [MOTHER TYPE]? (K9Q16)**±
3. What is the age of the oldest adult living in the household? (C10Q14)** ±
4. Earlier you told me you are [CHILD’S NAME] (Mother/Father). Are you [CHILD’S NAME] biological, adoptive, step, or foster (mother/father)? (K9Q10)**
5. Does [CHILD’S NAME] have any (other) parents, or people who act as (his/her) parents, living here? (K9Q11)**
   - What is their relationship to [CHILD’S NAME]? (K9Q12)**
6. Are you and [CHILD’S NAME] [FATHER TYPE] or [MOTHER TYPE] currently married or living together as partners? (C10Q10)**
   *asked for children who live in household with both mother and father type
   - If NOT MARRIED, Are you [MOTHER TYPE] currently married, separated, divorced, widowed, or never married? (C10Q10A)** asked only when the respondent is the mother
7. Would you say that your relationship is completely happy, very happy, fairly happy, or not too happy? (K9Q18)
8. Would you say that, in general, ([CHILD’S NAME] [MOTHER TYPE]/your) health is excellent, very good, good, fair, or poor? (K9Q20)
9. Would you say that, in general, ([CHILD’S NAME] [FATHER TYPE]/your) health is excellent, very good, good, fair, or poor? (K9Q21)
10. Would you say that, in general, ([CHILD’S NAME] [MOTHER TYPE]/your) mental and emotional health is excellent, very good, good, fair, or poor? (K9Q23)
11. Would you say that, in general, ([CHILD’S NAME] [FATHER TYPE]/your) mental and emotional health is excellent, very good, good, fair, or poor? (K9Q24)
12. Does anyone living in your household use cigarettes, cigars, or pipe tobacco? (K9Q40)
   - Does anyone smoke inside [CHILD’S NAME]’s home? (K9Q41)
13. Since [CHILD’S NAME] was born, how often has it been very hard to get by on your family’s income – hard to cover the basics like food or housing? Would you say very often,
somewhat often, often, rarely, or never? (ACE1) ±
14. Did [CHILD’S NAME] ever live with a parent or guardian who got divorced or separated after [CHILD’S NAME] was born? (ACE3) ±
15. Did [CHILD’S NAME] ever live with a parent or guardian who died? (ACE4) ±
16. Did [CHILD’S NAME] ever live with a parent or guardian who served time in jail or prison after [CHILD’S NAME] was born? (ACE5) ±
17. Did [CHILD’S NAME] ever see or hear any parents or adults in (his/her) home slap, hit, kick, punch, or beat each other up? (ACE6) ±
18. Was [CHILD’S NAME] ever the victim of violence or witness any violence in (his/her) neighborhood? (ACE7) ±
19. Did [CHILD’S NAME] ever live with anyone who was mentally ill or suicidal, or severely depressed for more than a couple of weeks? (ACE8) ±
20. Did [CHILD’S NAME] ever live with anyone who had a problem with alcohol or drugs? (ACE9) ±
21. Was [CHILD’S NAME] ever treated or judged unfairly because of (his/her) race or ethnic group? (ACE10) ±
- During the past year, how often was [CHILD’S NAME] treated or judged unfairly? Would you say very often, somewhat often, rarely, or never? (ACE11) ±
22. Other than adults in your home or [CHILD’S NAME]’s parents, is there at least one other adult in [CHILD’S NAME]’s school, neighborhood, or community who knows [CHILD’S NAME] well and who (he/she) can rely on for advice or guidance? (K9Q96) ± (ages 0 – 6 years)

SECTION 10: Neighborhood and Community Characteristics

1. Please tell me if the following places and things are available to children in your neighborhood, even if [CHILD’S NAME] does not actually use them:
- Sidewalks or walking paths? (K10Q11)
- A park or playground area? (K10Q12)
- A recreation center, community center, or boys’ or girls’ club? (K10Q13)
- A library or bookmobile? (K10Q14)
2. In your neighborhood, is there litter or garbage on the street or sidewalk? (K10Q20)
3. How about poorly kept or rundown housing? (K10Q22)
4. How about vandalism such as broken windows or graffiti? (K10Q23)
5. Now, for the next four questions, I am going to ask you how much you agree or disagree with each of these statements about your neighborhood or community:
- “People in this neighborhood help each other out.” (K10Q30)
- “We watch out for each other’s children in this neighborhood.” (K10Q31)
- “There are people I can count on in this neighborhood.” (K10Q32)
- “If my child were outside playing and got hurt or scared, there are adults nearby who I trust to help my child.” (K10Q34)
6. How often do you feel [CHILD’S NAME] is safe in your community or neighborhood? (K10Q40)
7. How often do you feel (he/she) is safe at school? (K10Q41)

SECTION 11: Additional Demographics

1. Is [CHILD’S NAME] of Hispanic, Latino or Spanish origin? (K11Q01)
2. Is [CHILD’S NAME] White, Black or African American, American Indian, Alaska Native, Asian, or Native Hawaiian or other Pacific Islander? (K11Q02)**

3. At any time during the past 12 months, did [CHILD’S NAME] receive services from any Indian Health Service hospital or clinic? (K11Q03) *asked only for American Indian or Alaska Native children

4. What is the highest grade or year of school ( [MOTHER TYPE/FATHER TYPE/OTHER] ) has completed? (K11Q20-K11Q21)**

5. Thinking back to who you lived with when you were about 13 years old, what was the highest grade or year of school completed by your mother, father, or main guardian? If you lived with more than one parent or guardian, please tell me about the one who had the most education? (K11Q22A)** ±

   - How long has [CHILD/ CHILD’S MOTHER/ CHILD’S FATHER] been in the United States? (K11Q34A-K11Q37A)

7. How many times has [CHILD’S NAME] ever moved to a new address? (K11Q43)

8. Was anyone in the household employed at least 50 weeks out of the 52 weeks? (K11Q50)

9. Do you own or rent your home? (C10Q41)

10. At any time during the past 12 months, even for one month, did anyone in this household receive any cash assistance from a state or a county welfare program? (K11Q60)

11. During the past 12 months, did ([CHILD’S NAME]/any child in the household) receive Food Stamps or Supplemental Nutrition Assistance Program benefits? (K11Q61)

12. During the past 12 months, did ([CHILD’S NAME]/any child in the household) receive free or reduced-cost breakfasts or lunches at school? (K11Q62)

13. Does anyone who lives in the household currently receive benefits from the Women, Infants, and Children (WIC) Program? (S9Q34) ±

SECTION 12: Additional Health Insurance Questions

1. What is the main reason [CHILD’S NAME] does not have health insurance now? (K12Q01)

2. About how long has it been since [CHILD’S NAME] last had any kind of health insurance? (K12Q02) IF child has been insured in the past or respondent answered DK/REF, two follow up question are asked
   - Has [CHILD’S NAME] ever been covered by health insurance that was provided through: an employer/union ? (K12Q03) an insurance company? (K12Q04)
   3. Before today, had you ever heard of Medicaid/CHIP? (K12Q11/K12Q21)
   IF NO to (K12Q11 OR K12Q21), skip to #7 (K12Q30)
   IF NO to (K12Q11 AND K12Q21) skip to #12 (K12Q40)

4. Has [CHILD’S NAME] ever been enrolled in Medicaid/CHIP? (K12Q12/K12Q22)
   IF YES to (K12Q12/K12Q22), two follow up question are asked
   - When was the last time [CHILD’S NAME] was enrolled in Medicaid/CHIP? (K12Q13/K12Q23)
   - What is the main reason that [CHILD’S NAME] enrollment ended? (K12Q14/K12Q24)
   - IF NO or DK/REF, have you ever applied for Medicaid/CHIP? (K12Q15/K12Q25)
   IF YES to (K12Q15/K12Q25), two follow up question are asked:
   - When was the last time that you applied? (K12Q16/K12Q26)
   - What is the reason that you were unable to enroll [CHILD’S NAME] in
Medicaid/CHIP? (K12Q17/K12Q27)
5. K12Q21-K12Q24 ONLY IF respondent’s state uses different names for their Medicaid and CHIP programs: Before today, had you ever heard of [STATE CHIP NAME]? (K12Q21) IF NO to (K12Q21), but respondent has heard of Medicaid (YES to K12Q11), skip to #7 (K12Q30) IF respondent has not heard of CHIP and Medicaid (NO to K12Q11 and K12Q21) skip to #12 (K12Q40)
6. IF YES to (K12Q21), has [CHILD’S NAME] ever been enrolled in [STATE CHIP NAME]? (K12Q22) IF YES to (K12Q22), two follow up question are asked:
- When was the last time [CHILD’S NAME] was enrolled in [STATE CHIP NAME]? (K12Q23)
- What is the main reason that [CHILD’S NAME] enrolment ended? (K12Q24) IF NO or DK to (K12Q22), have you ever applied for [STATE CHIP NAME]? (K12Q25) IF YES to (K12Q25), two follow up questions are asked:
- When was the last time that you applied? (K12Q26)
- What is the reason that you were unable to enroll [CHILD’S NAME] in [STATE CHIP NAME]? (K12Q27)
K12Q30-K12Q37 ONLY IF respondent has heard of either Medicaid or CHIP (YES to K12Q11 or K12Q21):
7. If you wanted to get more information about [either Medicaid or STATE CHIP NAME], do you know where to go to get that information? (K12Q30)
8. If you wanted to enroll [CHILD’S NAME] in [either Medicaid or STATE CHIP NAME], do you know how to do that? (K12Q31)
9. Based on what you know about Medicaid/CHIP, how easy or difficult do you think it is to… (K12Q32/K12Q33) - re-enroll [IF child has ever been enrolled in Medicaid] or complete an application [IF respondent has heard of Medicaid and child has never been enrolled]?
10. Based on what you know about [either Medicaid or STATE CHIP NAME], do you think [CHILD’S NAME] is eligible now? (K12Q34)
11. If you were told that [CHILD’S NAME] was eligible for [either Medicaid or STATE CHIP NAME], would you want to enroll him/her? (K12Q35)
- IF NO to K12Q35, what is the main reason you would NOT want to enroll [CHILD’S NAME]? (K12Q36)
- IF YES to K12Q35 and NO to K12Q34, what is the main reason you think [CHILD’S NAME] is not eligible for [either Medicaid or STATE CHIP NAME]? (K12Q38)
- IF YES to (K12Q34 AND K12Q35), what is the main reason [CHILD’S NAME] is not enrolled? (K12Q37)
12. At this time, does [MOTHER TYPE/FATHER TYPE/OTHER] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid or Medicare? (K12Q40/K12Q50/K12Q60)
IF YES to (K12Q40/50/60), is that health insurance provided through [her/his/your] current employer, former employer, union, or some other source? (K12Q41/K12Q51/K12Q61) IF NO to (K12Q40/50/60), skip to #13 (K12Q42/52/62)
13. At this time is [MOTHER TYPE/FATHER TYPE/OTHER] eligible for health insurance through [her/his/your] current employer or union? (K12Q42/K12Q52/K12Q62) IF NO or RF, skip to next section K12Q43/53/63 - K12Q47/57/67 ONLY IF respondent’s health insurance is provided by (or available through) their employer and/or union:
14. Does this [employer/union] offer health insurance that could help pay for doctor visits and hospital stays for [CHILD’S NAME]? (K12Q43/K12Q53/K12Q63)
IF NO or DK, skip to #17 (K12Q46/56/66)
K12Q44/54/64 - K12Q45/55/65 ONLY IF employer /union health insurance covers child (K12Q43):
15. If [CHILD’S NAME] was covered by insurance provided through this [employer/union], would this [employer/union] pay for all, some, or none of (his/her) health insurance premium? (K12Q44/K12Q54/K12Q64)
16. What is the main reason that [CHILD’S NAME] is not covered by insurance provided through this [employer/union]? (K12Q45/K12Q55/K12Q65)
K12Q46/56/66 - K12Q47/57/67 ONLY IF respondent uses insurance offered through her/his employer:
17. Would you say that the total number of persons who work for this employer is above or below 100? (K12Q46/K12Q56/K12Q66)
  - IF response is under 100, is the total number of persons who work for [your/her] employer above or below 50? (K12Q47/K12Q57/K12Q67)
References

American Academy of Pediatrics (2016). National Center for Medical Home Implementation. What is Medical Home?


