
Dissertation

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By

Tiasha Barik Letostak, B.S., M.P.H.

Graduate Program in Public Health

The Ohio State University

2015

Dissertation Committee:

Thomas M. Wickizer, Advisor
Sandra Tanenbaum
Abigail Shoben
Marc Tassé
Abstract

Compared to children without special health care needs, children with special health care needs (CSHCN) typically utilize a wider range of health services and a higher quantity of those services due to the health conditions and health-related difficulties that CSHCN experience. CSHCN are also more likely to experience inadequacies in insurance coverage, to delay care, and to have unmet needs. These health services issues can lead to outcomes of care that are worse for CSHCN than for children without special health care needs. The medical home is a model of care delivery that has been promoted as being beneficial for CSHCN, particularly with respect to improving care coordination and providing more comprehensive care.

This dissertation involves three distinct, but related studies of health services issues experienced by CSHCN. Study 1 will assess whether particular aspects of a special health condition impact a child’s likelihood of having inadequate insurance coverage. Study 2 will examine whether the receipt of coordinated care is associated with reductions in unmet needs for various groups of CSHCN. Lastly, Study 3 will investigate how outcomes of care differ in a medical home versus a traditional setting of care delivery, and whether individual aspects of the medical home are positively associated with outcomes of care for CSHCN. All three studies were based on secondary analysis of data from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN), which is sponsored by the Maternal and Child Health Bureau, the U.S. Department of Health and Human Services, and the Health Resources and Services Administration.
Acknowledgments

I could not have completed my dissertation or my degree without the support of my committee, my classmates, and my family. My committee members have provided me with invaluable guidance, and the empathy and camaraderie of fellow students and their families have helped me throughout this entire process. My family, however, is by far the most important driving force in my academic and professional success.

I would first like to thank my parents for their unconditional love and sacrifice; they have always been there for me and are my biggest motivators. I would also like to thank my husband, Jim, who has been a pillar of encouragement and reassurance, showing me that the long-term gains would be worth the short-term hardships. His family has also been incredibly supportive, especially in caring for our daughter.

Lastly, I would like to thank my daughter, Maya, who has only ever known me as a student and working mother. She has grown up immersed in a world of academia: “studying” with me, coming to campus meetings, and attending a graduate course before she could even walk. She has accepted these unconventional circumstances since infancy, with a level of maturity and understanding beyond what would be expected at her age. Her strength continues to impress me every single day, and she has taught me more about my own abilities than she will ever know.
Vita

August 2009 .................................................. B.S. Biology, Emory University
August 2010 .................................................. M.P.H. Health Policy & Management, Emory University
2010 to 2012 .................................................. LEND Trainee, Nisonger Center, The Ohio State University Wexner Medical Center
2012 to 2014 .................................................. Graduate Teaching Associate, Health Services Management & Policy, The Ohio State University
2014 to present ............................................. Senior Strategist, Marketing & Public Relations, Nationwide Children’s Hospital

Publications


Fields of Study

Major Field: Public Health
Minor Field: Developmental Disabilities
# Table of Contents

Abstract ............................................................................................................................................ ii  
Acknowledgments ........................................................................................................................... iii  
Vita .................................................................................................................................................. iv  
List of Tables .................................................................................................................................. vii  
List of Figures .................................................................................................................................. ix  
Chapter 1. Key Terminology and Concepts ...................................................................................... 1  
Chapter 2. Specific Aims .................................................................................................................. 5  
Chapter 3. Context and Significance of Studies ............................................................................... 8  
Chapter 4. Literature Review ......................................................................................................... 10  
Chapter 5. Conceptual Frameworks .............................................................................................. 47  
Chapter 6. Study 1: Underinsurance .............................................................................................. 57  
  6.1 Study 1 Aims ........................................................................................................................ 57  
  6.2 Study 1 Background and Significance .................................................................................. 59  
  6.3 Study 1 Research Methods .................................................................................................. 60  
    6.3.1 Participants ................................................................................................................... 60  
    6.3.2 Data Source .................................................................................................................. 60  
    6.3.3 Variables ....................................................................................................................... 63  
    6.3.4 Statistical Methods ....................................................................................................... 71  
  6.4 Study 1 Results ..................................................................................................................... 75  
  6.5 Study 1 Discussion ............................................................................................................... 85  
    6.5.1 Limitations .................................................................................................................... 87  
Chapter 7. Study 2: Care Coordination .......................................................................................... 89  
  7.1 Study 2 Aims ........................................................................................................................ 89  
  7.2 Study 2 Background and Significance .................................................................................. 90  
  7.3 Study 2 Research Methods .................................................................................................. 91  
    7.3.1 Participants ................................................................................................................... 91  
    7.3.2 Data Source .................................................................................................................. 91  
    7.3.3 Variables ....................................................................................................................... 93  
    7.3.4 Statistical Methods ....................................................................................................... 99  
  7.4 Study 2 Results ................................................................................................................... 102  
  7.5 Study 2 Discussion ............................................................................................................. 115  
    7.5.1 Limitations .................................................................................................................. 116
Chapter 8. Study 3: The Medical Home ................................................................. 118
  8.1 Study 3 Aims ..................................................................................................... 118
  8.2 Study 3 Background and Significance ............................................................... 119
  8.3 Study 3 Research Methods ................................................................................ 120
    8.3.1 Participants ................................................................................................. 120
    8.3.2 Data Source ................................................................................................. 121
    8.3.3 Variables ..................................................................................................... 123
    8.3.4 Statistical Methods ..................................................................................... 126
  8.4 Study 3 Results ................................................................................................. 130
  8.5 Study 3 Discussion ........................................................................................... 142
    8.5.1 Limitations .................................................................................................. 144

Chapter 9. Dissemination ....................................................................................... 146

Works Cited ........................................................................................................... 147

Appendix A: Study 1 Survey Items ......................................................................... 164
Appendix B: Study 2 Survey Items ......................................................................... 170
Appendix C: Study 3 Survey Items ......................................................................... 178
List of Tables

Table 1. Study 1 Variables.................................................................................................................. 64
Table 2. NS-CSHCN Survey Items for Health Conditions and Condition Severity ......................... 65
Table 3. NS-CSHCN Survey Items for Functional Difficulties.......................................................... 67
Table 4. NS-CSHCN Survey Items for Financial Definition of Underinsurance.............................. 69
Table 5. NS-CSHCN Survey Items for Structural Definition of Underinsurance ............................. 70
Table 6. NS-CSHCN Survey Items for Attitudinal Definition of Underinsurance............................. 71
Table 7. Study 1 Descriptive Statistics for All Insured CSHCN ......................................................... 77
Table 8. Study 1 Demographics, Odds of Underinsurance for Insured CSHCN ............................... 79
Table 9. Study 1 Condition-Specific Characteristics ....................................................................... 83
Table 10. Study 2 Variables .............................................................................................................. 94
Table 11. NS-CSHCN Survey Items for Care Coordination ............................................................. 95
Table 12. NS-CSHCN Survey Items for Unmet Need ...................................................................... 97
Table 13. Study 2 Descriptive Statistics .......................................................................................... 102
Table 14. Study 2a Summary Statistics ......................................................................................... 106
Table 15. Study 2a Results .............................................................................................................. 108
Table 16. Study 2b Summary Statistics .......................................................................................... 109
Table 17. Study 2b Results ............................................................................................................. 114
Table 18. Study 3 Variables ............................................................................................................ 124
Table 19. NS-CSHCN Survey Items for Caregiver Burden ............................................................. 125
Table 20. NS-CSHCN Survey Items for Satisfaction with Care ...................................................... 126
Table 21. NS-CSHCN Survey Items for Transition Planning to Adult Care ................................. 126
Table 22. Study 3 Descriptive Statistics .......................................................................................... 132
Table 23. Study 3a Summary Statistics .......................................................................................... 134
Table 24. Study 3a Results: Odds of Experiencing Non-Clinical Outcomes of Care .................... 136
Table 25. Study 3a Results: Odds of Experiencing Non-Clinical Outcomes of Care, Based on Specific Covariates ............................................................................................................. 137
Table 26. Study 3b Summary Statistics .......................................................................................... 138
Table 27. Study 3b Results ............................................................................................................. 141
List of Figures

Figure 1. Health Insurance Coverage of the Total U.S. Population in 2011 ................................... 17
Figure 2. Role of Medicaid in Covering Selected U.S. Populations ................................................. 20
Figure 3. Conceptual Framework for Study 1 ................................................................................ 49
Figure 4. Conceptual Framework for Study 2a .............................................................................. 52
Figure 5. Conceptual Framework for Study 2b .............................................................................. 53
Figure 6. Conceptual Framework for Study 3 ................................................................................ 56
Figure 7. Study 1 Descriptive Statistics – All Types of Underinsurance and Overlap .................... 81
Figure 8. Study 2b Results ............................................................................................................ 111
Chapter 1. Key Terminology and Concepts

**Care Coordination (CC):** A process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of children and provide them with optimal health care (AAP, 2005). The literature indicates that care coordination is essential in increasing access to needed health care services for CSHCN, as it allows for more effective and efficient organization and provision of health services.

**Children with Special Health Care Needs (CSHCN):** Children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998). CSHCN typically have chronic health diseases and/or specific conditions that require them to utilize a greater number of services, when compared to children without special health care needs.

**Family-Centered Care (FCC):** The provision of health services to children that consider the active role and participation of families in health care decision-making in collaboration with health care professionals (DHHS, 2004). Using a family-centered care approach has been shown to improve the relationship between families of CSHCN and health care providers.

**Functional Ability:** The capacity or ability of a child to do things or activities that most children of the same age can do (CDC, 2005). In particular, the National Survey of Children with Special
Health Care Needs (NS-CSHCN) considers functional abilities to be activities that most children of the same age can generally perform, including physical and/or mental activities.

**Medical Home (MH):** A model for primary and pediatric health care provision in which children receive comprehensive, appropriate, and trustworthy services in an organized manner and in which families are considered an active participant in health care decision-making (AAP, 2002). The American Academy of Pediatrics has further clarified that a medical home does not refer to a house, building, or health care facility, but rather a concept of how health care should be provided to CSHCN to promote children’s healthy development toward adulthood.

**National Survey of Children with Special Health Care Needs (NS-CSHCN):** Sponsored by the Maternal and Child Health Bureau, the U.S. Department of Health and Human Services, and the Health Resources and Services Administration, the NS-CSHCN is a national telephone survey conducted for the third time in 2009-10. Previous administrations of the survey took place in 2000-2001 and 2005-2006. Independent random samples are taken in all 50 states and the District of Columbia, with a total of 40,242 detailed interviews collected, including at least 750 interviews conducted in each state and the District of Columbia.

**State and Local Area Integrated Telephone Survey (SLAITS):** An approach developed by the National Center for Health Statistics to quickly and consistently collect information on a variety of health topics at the state and local levels. The SLAITS mechanism is used for sampling and data collection for the NS-CSHCN, the National Survey of Children’s Health (NSCH), the National Survey of Early Childhood Health, the National Asthma Survey, and the National Survey of Adoptive Parents.
**Underinsurance**: a concept characterized as inadequate coverage, with multiple definitions. The Maternal and Child Health Bureau identified adequacy of health care insurance coverage as one of their core outcomes to target for CSHCN in their National Agenda, and Healthy People 2010 also incorporated this target (MCHB, 1995). Related items on the inadequacy of insurance (underinsurance) were subsequently incorporated in the National Survey of Children with Special Health Care Needs (NS-CSHCN) to address this core outcome.

*The following three definitions of underinsurance were used in Study 1, although researchers in the field have used many other definitions of underinsurance:*

- **Financial Underinsurance**: When out-of-pocket expenses for necessary medical care exceed a specified percent of the person’s income within a given time frame, or when a person delays health care due to out-of-pocket costs associated with the services. The “economic” definition of underinsurance defines a limit above which the expense of health care coverage becomes a burden and interferes with access to care. It emphasizes one’s ability to pay for health care and related services, including the cost of the insurance premiums, co-pays, and deductibles. Also known as “economic underinsurance.”

- **Structural Underinsurance**: When at least one benefit in the benchmark package (the benefits package used as a basis of comparison) is not covered by the individual’s health insurance plan. The “structural” definition of underinsurance considers the type of benefits offered by the program and the range of providers whose services are covered under the plan.
• **Attitudinal Underinsurance**: When at least one health benefit the person would prefer to receive is not covered by insurance, when there is at least one symptom that the person believed required treatment for which insurance coverage did not provide treatment, or when a person is dissatisfied with his/her insurance plan. The “attitudinal” definition of underinsurance emphasizes consumer satisfaction with and perceptions of coverage (Oswald et al., 2005).
Chapter 2. Specific Aims

The goal of this dissertation is to identify associations between specific characteristics of a child’s health condition and underinsurance, as well as the role of care coordination and the medical home in mitigating issues of care delivery for children with special health care needs (CSHCN). Study 1 examines how condition-specific characteristics are related to inadequate insurance coverage, with comparisons between publicly and privately insured CSHCN. Study 2 analyzes whether receipt of coordinated care is related to reductions in unmet needs for CSHCN. Study 3 explores how the medical home and individual components of the medical home are related to non-clinical outcomes of care for CSHCN.

The following specific aims are encompassed in the aforementioned three studies:

**Aim 1a:** For each definition of underinsurance (financial, structural, and attitudinal), determine the likelihood of underinsurance depending on condition-specific characteristics (e.g., condition complexity, condition severity, and number of functional limitations) for CSHCN who are insured, taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

**Aim 1b(1):** For each definition of underinsurance (financial, structural, and attitudinal), determine the likelihood of underinsurance for CSHCN who are publicly insured versus CSHCN who are privately insured, taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.
Aim 1b(2): For each definition of underinsurance (financial, structural, and attitudinal), determine the likelihood of underinsurance between CSHCN with severe health conditions who are privately insured versus CSHCN with severe health conditions who are publicly insured, taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

Aim 1b(3): For each definition of underinsurance (financial, structural, and attitudinal), determine the likelihood of underinsurance between CSHCN with functional limitations who are privately insured versus CSHCN with functional limitations who are publicly insured, taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

Aim 2a: Determine the percentage of CSHCN receiving care coordination depending on condition-specific characteristics (e.g., condition complexity, condition severity, number of health conditions, and number of functional difficulties), taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

Aim 2b: Examine if receipt of care coordination is associated with reductions in the following types of parent/guardian-reported unmet need for CSHCN: (1) any unmet need, (2) unmet need for preventive care, (3) unmet need for specialty care, (4) unmet need for therapeutic services, and (5) unmet need for support services, taking into account insurance status and demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.
**Aim 3a:** Determine the likelihood of CSHCN in medical homes experiencing the following parent/guardian-reported outcomes of care, as compared to CSHCN who are not in a medical home: (1) decreased caregiver burden, (2) increased satisfaction with care, and (3) receipt of transition planning to adult care, taking into account functional status, insurance status, and demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

**Aim 3b:** Determine if the following parent/guardian-reported outcomes of care (1) decreased caregiver burden, (2) increased satisfaction with care, or (3) receipt of transition planning to adult care differ between groups of CSHCN who are not in a medical home but who experience individual components of the medical home in the following combinations: (1) care that is accessible and comprehensive; (2) care that is family-centered and culturally sensitive; and (3) care that is coordinated.
Chapter 3. Context and Significance of Studies

Despite comprising only 13.9% of the overall child population in the U.S., CSHCN use more health care resources and account for a much greater proportion (42-50%) of all child health care costs, when compared to children without special needs (CAHMI 2008; Newacheck & Kim, 2005; Kogan & van Dyck, 2005). Studies demonstrate that CSHCN are less likely to be uninsured compared to children without special needs (4.8% vs. 8.3%), but are more likely to be underinsured (Tu & Cunningham, 2005). CSHCN are a vulnerable patient population that rely heavily on adequate health coverage and are adversely impacted by inadequacies or delays in care, and it is important to understand what factors may predispose CSHCN to being underinsured. An analysis of condition-specific characteristics and their association with underinsurance would yield valuable insight into which CSHCN are most likely to be underinsured and why this is the case. Ultimately, these findings may lead policymakers to begin viewing insurance less as a dichotomy of uninsured vs. insured, and more as a continuum of inadequacies experienced by individuals based on their varying health care needs.

Care coordination has been shown to be a necessary and beneficial mechanism in health services delivery, as it allows for continuity of care beyond the level of specific episodes of illness or disease (Haggerty et al, 2003). For CSHCN, the number of relationships among providers and between providers and families can multiply geometrically, as multiple caregivers must interact with the child and distinct family members (Bodenheimer, 2008). CSHCN have heterogeneous needs depending on the characteristics of their condition, but health care
legislation predominately addresses all CSHCN overall. An analysis of condition-specific characteristics, their impact on care coordination, and the association between care coordination and unmet needs would not only add to the current literature on CSHCN, but potentially inform the development of policy intended to address the complex needs of CSHCN.

Lastly, the medical home is a model of care delivery that has been shown to be beneficial with respect to improving care coordination and providing more comprehensive care for patients, particularly with respect to CSHCN. An examination of whether the presence of a medical home decreases unmet need, improves satisfaction with care, and reduces caregiver burden would contribute to the current literature on CSHCN. An assessment of particular medical home components may also identify which particular aspects of the medical home have a differential and/or positive impact on CSHCN, even when delivered outside of a medical home care setting. Additionally, privately insured CSHCN and publicly insured CSHCN may have differential access to a medical home or differential access to particular aspects of care, such as care coordination, outside of the medical home. Given that medical home programs for children are funded in nearly every state by both public and private insurers, an in-depth investigation of the medical home and its impact on CSHCN could provide additional evidence for insurers and policymakers to support the continuation or expansion of these medical home programs (Kaye & Takach, 2009; National Center for Medical Home Implementation, 2011b).
Chapter 4. Literature Review

The following literature review will discuss the health services needs of CSHCN and the barriers of care that CSHCN currently face, particularly with respect to obtaining necessary and affordable care. It will also underscore why a better understanding of inadequate insurance, care coordination, and the medical home – specifically, as they related to outcomes of care – are important for improving the health care delivery for CSHCN, especially CSHCN who have more severe or pervasive special health care needs.

Children with Special Health Care Needs (CSHCN)

A variety of factors contribute to the increased need for services and the requirement for types of services that CSHCN have beyond the scope of what is necessary for children without special needs. Firstly, CSHCN generally suffer from physical, mental, and/or emotional conditions that last for more than one year; it thus follows that both the breadth and duration of their health issues necessitate additional care (Denboba et al., 2006). Secondly, the term “special health care needs” may encompass children with relatively mild and manageable chronic conditions, to more complex and difficult to manage health conditions (Bethell, 2000). CSHCN also have variable health care needs with respect to both the type and severity of their health conditions (Perrin, 2002). The literature also indicates that, compared to children without special health needs, children with chronic health conditions need consistent access to high quality health care in order to maintain and promote their development and well-being.
(Erickson-Warfield & Gulley, 2006). Lastly, due to recent advancements in medicine and public health, both the survival rates and overall life expectancy of CSHCN have improved (Newacheck & Taylor, 1992; Boyle et al., 1994). These enhancements in survival and life expectancy mean the CSHCN patient population itself is expanding, as are their needs over time.

Reflecting the expanded CSHCN population, nearly 14% of children were found to have special health care needs according to the National Survey of Children with Special Health Care Needs (NS-CSHCN). The NS-CSHCN also indicates that 21.8% of U.S. households with children include at least one child with a special health care need (U.S. DHHS, 2008). It is important to note that the prevalence of CSHCN has increased modestly since estimates were last obtained from the 2001-2002 NS-CSHCN (U.S. DHHS, 2008). The Department of Health and Human Services attributes this increase in CSHCN prevalence to various reasons, including an increase in knowledge and awareness by health care professionals and parents about special needs, an increase in the number of CSHCN, and improvements in diagnosis (U.S. DHHS, 2008).

Persons with disabilities (PWD) and CSHCN constitute a significant proportion of the patient population that uses medical services/resources, with correspondingly high medical expenditures. Studies indicate CSHCN need numerous health care services and related services, which include but are not limited to, the following (U.S. DHHS, 2008):

- Specialized health services (52%)
- Specialized therapies (e.g., physical therapy, occupational therapy, speech-language pathology, etc.) (23%)
- Mental health/behavioral health services (25%)
- Family support services [including respite care (4.5%) and counseling (12%)]
- Medical supplies and equipment (11%)
• Early Intervention and special education services (n/a)
• Transportation (n/a)

These aforementioned services are essential to maintaining and/or improving the health of CSHCN, and some (e.g., transportation services) are even necessary for CSHCN to obtain access to the necessary health services (McPherson et al., 1998). Additionally, 86% of CSHCN also need prescriptions for their health conditions, which further results in increased health care costs for CSHCN (U.S. DHHS, 2008).

The amount of time and finances spent on CSHCN are important indicators of the impact of CSHCN on their families, and 18% of parents with CSHCN report that their child’s condition has caused them financial issues (U.S. DHHS, 2008). The literature has demonstrated that the service costs for CSHCN are three times greater than for children without special needs. In 2000, the average child with special needs incurred approximately $2,099 in health services costs, whereas a child without special needs incurred approximately $628 (Newacheck & Kim, 2005). These financial hardships are often exacerbated when parents must stop working or decrease work hours to take care of CSHCN. Twenty-four percent of families with CSHCN reported having to reduce work to accommodate the special needs of their child (U.S. DHHS, 2008). Researchers have estimated that total health care costs for CSHCN represent nearly 33.6% of total health care costs attributed to children in the U.S. (Newacheck & Kim, 2005).

Service Needs of CSHCN and Barriers to Care

Increased Unmet Need

The systems of care that provide services to CSHCN and their families include numerous providers, organizations, and agencies. Many of these entities significantly differ with respect to eligibility criteria, types of services offered, availability of services, and types of professionals
employed by the organization or agency (AAP, 2005). The 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) found that 16% of CSHCN had at least one unmet need for services. Additionally, 5.7% of CSHCN had no regular source of care and thus had to seek care through the emergency department, while 6.5% did not have a personal physician or nurse (U.S. DHHS, 2008).

In particular, an initial analysis of the first round of data from the NS-CSHCN revealed that 3.2% of CSHCN who needed routine care were unable to obtain that care, and 7.2% of CSHCN who needed specialty care were unable to obtain that care (Mayer, Skinner, & Slifkin, 2004). Moreover, although most families with CSHCN receive the services that they need – with respect to respite care, genetic counseling, and/or family counseling – 5% of parents of CSHCN reported having at least one unmet support service need (U.S. DHHS, 2008). A detailed secondary analysis of national data by Van Dyck et al. (2004) also corroborates that CSHCN have numerous unmet needs. This research indicates that 17.7% of CSHCN had an unmet need for any of 14 primary care and specialty care services, 21.9% had difficulties with referrals to providers, and 7.5% did not have a usual source of care. These findings are significant because the presence of a usual source of care, as well as a personal physician or nurse who knows the child and his/her particular needs, are important indicators of access to care.

Higher Health Services Utilization

With respect to health services utilization, the literature indicates that utilization differs depending on the characteristics of the family and child and insurance coverage. In particular, higher levels of education and household income are the primary family characteristics associated with increased utilization of services (Weller et al., 2003; Witt & Riley, 2003). The number and type of health conditions, as well as functional limitations in activity, are aspects of
the child that impact utilization of services (Kaiser Disability Survey, 2003; National Health Interview Survey, 2001). Specifically, the literature shows that CSHCN who have more specific health conditions, more complex conditions, and/or greater functional limitations utilize more services (Weller, Minkovitz, & Anderson, 2003; Shenkman et al., 2003).

Inadequate Insurance Coverage

Researchers have demonstrated that adequate health insurance coverage is essential for ensuring that CSHCN have access to necessary services (Hadley, 2003). However, the U.S. DHHS estimates that approximately 38% of CSHCN are either uninsured or underinsured. These CSHCN have inadequate public or private health insurance coverage for the services they need. CSHCN with adequate health insurance coverage were found to be two times more likely to have comprehensive, coordinated care, when compared to CSHCN with inadequate health insurance (Tippy et al., 2005). The literature also indicates that CSHCN who are underinsured or do not have adequate health insurance are three times more likely to report having difficulties using community-based services, when compared to CSHCN with adequate health insurance coverage (OR = 2.69, 95% CI: 1.31-5.50) (Baruffi et al., 2005). Additionally, studies have demonstrated that inadequate insurance (being underinsured), rather than lack of insurance (being uninsured) is a more prevalent issue for CSHCN than for the general population (Kogan et al., 2005; Kogan et al., 2010, NEJM; Honberg et al., 2009; Kogan et al., 2010, Pediatrics).

Researchers have demonstrated that the most common reasons for not being able to access necessary services include cost-related barriers, such as a lack of health insurance and having low household income (Hanson et al., 2003). For example, it was found that health insurance is a predictor of health care utilization by CSHCN, especially if CSHCN are covered by public insurance (Newacheck, McManus & Fox, 2000). In a secondary data analysis of the
National Health Interview Survey, Davidoff (2004) also found that nearly 14% of CSHCN who had health insurance also had at least one unmet service need. Additionally, underinsured CSHCN who have more severe conditions (and thus, have increased health services needs) were found to have an increased risk for experiencing difficulties when utilizing community-based services, as compared to CSHCN with less severe conditions (Baruffi et al., 2005).

The Role of Health Insurance and Its Significance for CSHCN

The role of health insurance is to mitigate financial risk for families and individuals, particularly in the event of an illness or accident. The literature indicates that being uninsured or inadequately insured (underinsured) is associated with decreased access to care and decreased likelihood of having a usual source of care, and, consequently, poorer health outcomes (Skinner & Mayer, 2007; Houtrow et al., 2008; Newacheck & Kim, 2005). In particular, uninsured or inadequately insured children and their families are more likely to delay or forgo care due to health care-related financial burdens (Wisk & Witt, 2012). Families with partial insurance are even more likely to delay or forgo necessary care because of its cost or due to issues with insurance, when compared to uninsured families.

CSHCN are a particularly vulnerable subpopulation at high risk of delaying or forgoing care if uninsured or underinsured. These disparities in care become increasingly pronounced for CSHCN with greater functional or activity limitations and CSHCN from middle-income families (DeVoe et al., 2011). This is because middle-income families often earn too much to qualify for public assistance, but too little to protect themselves from the high burden of costs incurred by CSHCN (DeVoe et al., 2011). Consequently, CSHCN in families who are uninsured or underinsured are more likely to use health care services inappropriately and seek more frequent
care at an emergency department because they lack a usual source of care (Hudman & O’Malley, 2003).

Uninsured and underinsured CSHCN and their families experience unmet needs, with negative economic and health implications (CDC, 2010). CSHCN may experience adverse health outcomes and missed school days, while parents/guardians may lose work time and have increased, otherwise avoidable out-of-pocket health care expenditures (Kullgren et al., 2010). At the societal level, delaying or forgoing care, and subsequently seeking care at the emergency department when a condition has deteriorated, results in avoidable long-term expenditures for the health care system (Rimsza, Butler & Johnson, 2007; Baicker & Chandra, 2008).

Health Insurance Overview

The United States health insurance system is comprised of both private, employer-sponsored insurers and publicly funded insurance programs, such as Medicaid and Medicare. The Kaiser Family Foundation provides information on health insurance coverage for the U.S. population. Its most recent report shows that approximately half of Americans were covered by private, employer-sponsored insurance plans, either through their own jobs or as dependents in 2011. Medicaid and uninsured estimates were each 16%, respectively, and 1% were covered by other public insurance plans, such as the military or Veterans Administration (U.S. Census Bureau, 2011 & 2012). Estimates of health insurance coverage information for the total U.S. population are shown in Figure 1.

Medicaid also encompasses the Children’s Health Insurance Program (CHIP), formerly known as the State Children’s Health Insurance Program (SCHIP). The Medicaid program and CHIP will both be discussed in further detail later. CSHCN are not eligible for Medicare nor are they eligible for Social Security Disability Insurance (SSDI).
**Private Health Insurance**

The most common form of health insurance coverage in general, and also the most common form of private health insurance in the United States, is employer-sponsored health insurance (Kaiser Family Foundation, 2013). Under employer-sponsored insurance, the employer covers a portion or the entirety of the plan premium as part of the employees' compensation package. Additionally, the employer negotiates rates for payments to physicians and hospitals, which results in decreased copayments and coinsurance for the insured consumer or employee (Blumenthal, 2006). Managed care plans are the most common type of private health insurance plan, although indemnity plans are also available for consumers (AHRQ, 2007).

Managed care plans include (1) health maintenance organizations (HMOs), (2) preferred provider organizations (PPOs), and point-of-service plans (POS). Although the organization, cost-sharing structure, and benefits for each type of managed care plan differs, all three types of

**Figure 1. Health Insurance Coverage of the Total U.S. Population in 2011 (Kaiser Family Foundation, 2013)**
managed care plans share one important feature. Except for group and staff model HMOs, most managed care plans have contracts with physicians, hospitals, or other providers that stipulate negotiated fees and higher costs for insured consumers when they receive out-of-network care. Managed care plans are more restrictive than indemnity plans with respect to the physicians or hospitals that are covered under the plan. However, costs are lower when insured consumers obtain care from physicians and other providers who are within network for the managed care plan. Out-of-pocket maximums and lifetime limits to benefits paid under the policy are not a feature of managed care plans, as is the case with indemnity plans (AHRQ, 2007).

A small percentage of individuals (5%) purchase individual, private insurance plans, either because they are self-employed or because they do not have access to group insurance through an employers for any other reason. However, when compared to employer-sponsored plans, these individual policies are typically not as affordable or as comprehensive with respect to benefits (Kaiser Family Foundation, 2013; Kaiser Family Foundation, 2013 Employer Health Benefits Survey; Davidoff, 2004). The costliness of individual plans is in part due to the fact that the consumer is responsible for paying the entire premium, whereas employers partially or fully cover premiums in employer-sponsored plans (Blumenthal, 2006).

Public Health Insurance: Medicaid

Medicaid is the primary publicly financed health coverage program for low-income Americans, and it provides coverage for more recipients than any other public health insurance program in the United States. It was enacted in 1965 as Title XIX of the Social Security Act, and its initial purpose was to provide health care to individuals and families that were receiving welfare. As an entitlement program, Medicaid provides assistance to all individuals who meet certain eligibility criteria, without enrollment freezes or waiting lists for benefits. The following
groups are covered under Medicaid: low-income individuals, pregnant women, children and some parents in both working and jobless families, children and adults with various physical and mental health conditions and disabilities (including CSHCN), and poor elderly and disabled Medicare beneficiaries (Kaiser Commission on Medicaid and the Uninsured, 2013).

Currently, Medicaid provides coverage to 62 million Americans, including 1 in 3 individuals with severe disabilities. Medicaid is the largest source of health insurance for children in the United States. In 2009, Medicaid covered nearly 31 million children. Along with the Children’s Health Insurance Program (CHIP), all children below 200% of the federal poverty level (FPL) are eligible for public health insurance coverage. As shown in Figure 2, Medicaid covers more than 1 in 3 children, nearly 70% of children below 100% FPL, and 41% of pregnant women. CHIP covers nearly 8 million children in low- and moderate-income families who make too much to qualify for Medicaid (Kaiser Commission on Medicaid and the Uninsured, 2013).

The literature demonstrates that children previously enrolled in Medicaid are more likely to enroll in CHIP for their state, and that CSHCN are more likely than other children to use hospital outpatient departments instead of doctor’s offices for primary care (Chen et al., 2011). Medicaid thus has a significant impact on CHIP enrollment and has been shown to be a determinant of inappropriate health services utilization for CSHCN, particularly those that have greater unmet needs than the general pediatric population (Chen et al., 2011). States use various strategies to pay for care for CSHCN and maximize the supports CSHCN receive. These include benefits counseling, consumer- and family-directed care, flexible funding, mandated benefits, and Medicaid buy-in programs. As health reform is implemented, researchers caution that policymakers at the state and federal level should consider which strategies are most cost-effective and beneficial for CSHCN, if ameliorating the financial hardships of CSHCN and their families is a priority (Bachman et al., 2012).
The Children’s Health Insurance Program (CHIP) provides health coverage to children in families that cannot afford private insurance coverage, but have incomes too high to qualify for Medicaid. CHIP was signed into law in 1997 and currently covers nearly 8 million children. Although the program is administered by the states, it receives federal matching funds or joint funding from the federal government, as well as broad guidance from the Centers for Medicare and Medicaid Services (CMS). Typically, the federal matching rate for CHIP is 15 percentage points higher than the Medicaid matching rate for any given state, so CHIP essentially fills a gap by covering children whose families would otherwise not be able to obtain public coverage through Medicaid (Centers for Medicare & Medicaid, 2013).


Figure 2. Role of Medicaid in Covering Selected U.S. Populations
States have three options for designing CHIP. The first is expansion of the Medicaid program, which is the option chosen by seven states, the District of Columbia, and five U.S. territories. The states that have used CHIP funds to expand Medicaid eligibility include Alaska, Delaware, Ohio, Maryland, New Hampshire, New Mexico, and South Carolina (Centers for Medicare & Medicaid, 2013). Children in these states are entitled to full benefits under Medicaid and must remain eligible for coverage even if all CHIP funds have been used. This option also means the federal match, or the federal share of financing for the state Medicaid and CHIP programs (also known as the Federal Medical Assistance Percentage), would not necessarily be 15 percentage points higher than the Medicaid matching rate. This is because CHIP funds would be used to expand Medicaid eligibility and CHIP would not exist as a separate state health insurance program (Kaiser Family Foundation, 2008).

A second option is for states to operate CHIP independently, as a separate state health plan. As of 2013, this is the program design for 15 states, including Alabama, Arizona, Colorado, Connecticut, Georgia, Kansas, Mississippi, Oregon, Rhode Island, Texas, Utah, Vermont, Washington, West Virginia, and Wyoming (Centers for Medicare & Medicaid, 2013). Operating CHIP separately from Medicaid allows states to receive the higher federal matching rate, which has been shown in the literature to be integral in ensuring gains in coverage for children (Patrick et al., 2012). States also have greater discretion as far as program design is concerned. In particular, states can offer differing delivery models for care as well as varying types of benefits. States that choose this option may also create eligibility criteria according to demographics such as income, disability status, age, or geographic area. Unlike the Medicaid expansion option, CHIP enrollees in states that operate CHIP as an independent program are not guaranteed services or benefits. As a result, states have waiting lists for coverage if demand exceeds available funds.
Additionally, states can also choose to specify how long that coverage lasts or when the coverage ends (Kaiser Commission on Medicaid and the Uninsured, 2010).

The remaining states have chosen a combination of the two approaches, which is the most common program design. Other program decisions, such as whether to provide entitlement services, provide a comprehensive benefits package, or charge premiums, are also up to the discretion of individual states. Given the flexibility that states have with respect to the design of CHIP, comparisons between states cannot be made easily. For instance, although two states may have the same income eligibility threshold with respect to FPL (e.g., 200% FPL), each state may permit different deductions when calculating income. Each state may also have a different eligibility limit based on whether CHIP operates as an independent program or whether CHIP funds are used to expand Medicaid, in which case the Medicaid eligibility limit that was in existence prior to the creation of CHIP may be used. This variability is of interest from a research and policy perspective, because delayed or forgone care significantly varies among CHSCN due to the differing Medicaid income eligibility levels and income thresholds that particular states set (Gnanasekaran et al., 2008). Additionally, the literature indicates that states with CHIP operating individually often do not have benefits that are as robust as those in Medicaid or coverage that is as comprehensive (Marcus, Rosenbaum, & Cyprien, 2004).

Many states have had to make cuts to Medicaid and CHIP due to recent fiscal pressures, particularly with respect to decreasing covered benefits and increasing cost-sharing for low-income beneficiaries (Smith et al., 2003). CSHCN are especially vulnerable to these cutbacks because they are more likely than other children to qualify for Medicaid or CHIP coverage (Davidoff et al., 2004). Given the critical role these programs play in health services utilization and benefitting children’s health, researchers recommend that policymakers should consider
enhancing federal matching funds so states can avert further cuts to Medicaid and CHIP (Kaiser Family Foundation, 2012).

In 2009, the Children’s Health Insurance Program Reauthorization Act (CHIPRA) was signed, reauthorizing and providing additional funding for CHIP, in addition to making improvements to Medicaid and CHIP. CHIPRA also authorized new federal funding for outreach efforts to children not enrolled in Medicaid or CHIP, despite meeting the eligibility criteria. This funding included $100 million for national outreach, grants to Indian Tribes and Indian health service providers, and grants to promote enrollment and retention in Medicaid and CHIP. The Affordable Care Act of 2010 maintains CHIP eligibility standards through 2019 and extends funding until October 1, 2015. At that time, the CHIP federal matching rate will increase by 23 percentage points, which would bring the average federal matching rate for CHIP to 93%. The Affordable Care Act also provided an additional $40 million in federal funds to continue promoting enrollment in Medicaid and CHIP (Centers for Medicare & Medicaid, 2013).

Since most public coverage for CSHCN is through state-sponsored programs like Medicaid and CHIP, gains in insurance enrollment and coverage from these programs are a valuable source of support for CSHCN and their families. However, research has shown that increases in enrollment and coverage do not necessarily imply that CSHCN are receiving adequate coverage for their needs (Kogan et al., 2010). Medicaid and CHIP have eligibility guidelines that often limit the income families can earn in order to retain benefits (Meyers et al., 1998). Many families must cutback or stop work altogether in order to keep their earnings low enough for CSHCN to receive essential Medicaid benefits (Meyers et al., 1998). Families may thus remain under financial distress, because state-sponsored programs do not mitigate the financial hardships associated with raising CSHCN (Lukemeyer, Meyers, & Smeeding, 2000). This
inadequacy of coverage for CSHCN has a number of negative consequences for CSHCN and their families, which is discussed further in the following section on underinsurance.

Underinsurance and CSHCN

Ward et al. (2002) developed three definitions to characterize underinsurance: economic, structural, and attitudinal. Economic definitions of underinsurance, also known as financial underinsurance in some of the CSHCN literature, emphasize the individual’s ability to pay for health care (Oswald et al., 2005). This includes the ability to pay the cost of insurance premiums, and copayments and deductibles, associated with the health plan. The economic definition of underinsurance specifies a limit above which the expense for health care coverage becomes burdensome and impedes access to care. An economically underinsured individual can thus be identified by whether or not out-of-pocket expenses for necessary care exceeds a specified percent of the individual’s income or by whether the individual delays care due to out-of-pocket expenses associated with the service (Oswald et al., 2005). Attitudinal definitions of underinsurance focus on consumer satisfaction with and perceptions of coverage with respect to health care. When at least one health benefit that the insured individual would prefer to receive is *not* covered by the insurance plan, when there is at least one symptom that the individual required treatment for which insurance did not provide coverage for, or when the insured individual is otherwise dissatisfied with their insurance plan, that individual is considered to be attitudinally underinsured in the literature (Oswald et al., 2005). Lastly, structural definitions of underinsurance emphasize the type of benefits offered by the program and the range of providers whose services are covered under the health plan. An individual is identified as being structurally underinsured if at least one health benefit in the benchmark
package (the benefits package used as a basis of comparison) is not covered by the individual’s health insurance plan (Oswald et al., 2005).

More generally, The Kaiser Family Foundation (2002) defines underinsured individuals as people who have health insurance but cannot access or pay for necessary care due to limits on benefits or unaffordable cost-sharing. In other words, the health plans that these individuals have do not cover all the services they need, or individuals cannot afford the cost-sharing associated with covered benefits. Additionally, due to benefit caps or the maximum amount that a health plan will pay over an individual’s lifetime, CSHCN may experience issues accessing health services and therefore postpone necessary care. These barriers to care disproportionately impact CSHCN given the vulnerability of this pediatric population, as limits in coverage and inadequacies in reimbursement can result in significant service gaps and place CSHCN at an increased risk for medical complications and compromised health outcomes (Aiken et al., 2004; Rewers et al., 2002; Newacheck et al., 2000). For this reason, underinsurance is a crucial aspect of determining the adequacy of health services for CSHCN.

As evidenced by the literature, CSHCN have higher levels of unmet need for both routine and specialty health care, when compared to the general pediatric population (Mayer et al., 2004; van Dyck, 2003). In particular, nearly 20% of low-income CSHCN experience some type of unmet health care need, and families of CSHCN incur significantly higher out-of-pocket costs for health care services as a result of their increased health needs (Davidoff, 2004). These unmet needs increase when a child’s special health care need is more severe or more pervasive. With respect to underinsurance, Oswald et al. (2005) demonstrated that the likelihood of being underinsured is directly associated with the pervasiveness of a child’s special health care needs. It was also shown that different definitions of underinsurance result in different groups of CSHCN being found to be underinsured.
Although there is no universally accepted definition of underinsurance or universally accepted benchmarks for what should be considered adequate insurance, a number of studies have attempted to conceptually clarify underinsurance and examine adequacy of health plans in concrete terms (Oswald et al., 2005). The issue of underinsurance has major implications for both the structure and budget of Medicaid and CHIP, as well as state Title V programs that serve CSHCN. In particular, because funds are limited for Title V programs, only certain types of specified medical services are covered by these programs for the uninsured and other children who lack insurance coverage for necessary services. A stronger understanding of the inadequacies of insurance for insured CSHCN would offer beneficial insight and allow policymakers to use evidence-based support to better structure public programs and the eligibility criteria that underlies those programs (Oswald et al., 2005).

**Care Coordination and Its Significance for CSHCN**

*Introduction to Care Coordination for CSHCN*

Care coordination is a necessary and beneficial mechanism in health services delivery, as it allows for continuity of care beyond the level of specific episodes of illness or disease (Haggerty et al, 2003). Although there is often a lack of clarity or consensus among policymakers, health plans, clinicians, researchers and even persons with disability about the meaning of care coordination, reviewing the literature on care coordination provides a clearer conceptualization of the term (Shortell, 1976; Fletcher et al., 1984; Siegel & Habel, 1996; Chen et al., 2000). Specifically, the framework for adequate care coordination consists of the following components (Antonelli RC, Stille & Antonelli DM, 2008):

- Development of a comprehensive plan of care through collaboration between the health provider and the family
• Establishment of a confidential, central record with the health and services information of the patient
• Sharing of information between the CSHCN, family members, and providers, including reasons for referrals
• Linking families to parent support groups
• Evaluation and discussion of information from specialists with families
• Implementation of recommendations from providers
• Coordination with educational services, public health services, financial assistance programs, and other community resources.

Research conducted by the Institute of Medicine (2001) has shown that the current lack of health services coordination in the U.S. health system is a major driving force for the absence of effective and efficient health services provision. However, care coordination that is offered in primary settings of care – for instance, primary care practices that are also considered medical homes – can aid families and patients in accessing and managing a myriad of health and related services in a more efficient, effective, and organized manner (AAP, 2005).

For young children with disabilities, the number of relationships among providers and between providers and families can multiply geometrically, as multiple caregivers must interact with the child and distinct family members (Bodenheimer, 2008). The literature shows that CSHCN have a complex array of health conditions, functional limitations, and other needs. All of these must be addressed by our current system of care to promote the health of CSHCN and improve their functionality, quality of life, and ability to integrate into the community (Stein & Silver, 2005). This provision of services includes specific health services provided primary care and specialty physicians. However, it also includes delivery at multiple care settings, through a
variety of health plans, and for multidisciplinary services. This necessitates a comprehensive understanding of resources offered in the health care arena as well as educational and community settings. The primary goal of the health care system is “to improve the health, functionality, and quality of people’s health, especially those with chronic health conditions.” For this reason, it is important that care is provided to patients with a comprehensive understanding of long-term, as well as short-term, health impacts (Eiser & Moore, 2001).

Without proper coordination of services between providers and patients’ families, individuals with disabilities may receive decreased quality of care as well as insufficient informational and emotional support for their disability. According to a 2004 survey of primary care patients, 18% of those with a physician visit during the previous 2 years reported receiving conflicting information from various doctors, and 24% reported leaving a visit with important questions unanswered (Schoen C et al., 2004). The survey also revealed physicians’ “missed opportunities to identify patient preferences or concerns, to communicate well, or to engage patients in care decisions.” Moreover, for every one of these three measures, rates of insufficient informational and emotional support for U.S. patients were higher than rates of the other countries in the study (Australia, Canada, New Zealand, and the United Kingdom) (Schoen C et al., 2004). Concurrently, when CSHCN are unable to receive the services that they need, their functional abilities and development are directly impacted. Additionally, research indicates that CSHCN who do not receive necessary services typically have poorer health, when compared to CSHCN who do receive necessary services (Benedict, 2006). Many studies have thus examined the effect of services on addressing unmet health care needs or family satisfaction, but only a handful have evaluated functional outcomes with respect to primary care service models for CSHCN (Cooley & McAllister, 2004).
Because of the increased needs of CSHCN and the number of providers they receive care from, it is important for the families of these children to understand the information provided to them by their physicians and to be an active participant in the delivery of health services. In a study of doctor-patient interaction, however, 50% of patients left their office visit without comprehending the information that their physician told them (Roter & Hall, 1989). Additionally, when physicians asked patients to restate the physician’s instructions, patients responded incorrectly 47% of the time (Schillinger et al., 2003). Based on another study of more than 1000 audiotaped visits with 124 physicians, patients and their families participated in medical decisions only 9% of the time (Braddock et al., 1999). Active patient or family participation has been shown to be a primary contributor to improved quality of care and care coordination, and it is a direct result of the clarity and completeness with which information is relayed from the physician to the patient and family (Heisler et al., 2002; Coleman et al., 2006).

Care coordination is thus an integral part of health care outcomes for CSHCN, as it allows for more effective and efficient organization and provision of health services. A review of the literature indicates that effective and efficient care coordination has a beneficial impact on the following aspects of health and health services delivery (Devers, 1995; Seigel, 1996; Van Achterberg, 1996; Bennett, 1997; Watson, 1997; Hughes, 1999; Ronder, 1999):

- Improved patient experience
- Improved family experience
- Decreased family caregiving burden
- Improved provider experience
- Maintenance/improvement of functional status*
- Improved independence and community participation
• Maintained/improved health status
• Prevention of secondary complications

Research has also demonstrated that care coordination can improve family satisfaction with services. Despite these recognized benefits, both families and health care providers commonly report barriers to the provision of coordinated services. Subsequent sections will address the value of care coordination for caregivers/parents and health care providers, and will also discuss the barriers impeding care coordination for both parties.

Family Caregivers and Parents

Family caregivers, particularly parents, “are often thrust into the role by circumstances” and “[this] role keeps expanding in its demands” (Coleman et al., 2006). The scenario “imposes a constant state of stress and flux,” and “any transition from one health care setting to another, therefore, adds a complex layer of adjustment” to the responsibilities of the family and the child’s experience of his or her disability (Martire et al., 1997). With decreases in continuity of care, increases in the number of part-time physicians, and widening separation between inpatient and outpatient practitioners, care coordination and family-centered care have a crucial role in ensuring CSHCN receive quality care and their families are satisfied with that care.

Care coordination is any activity that helps ensure that the patient’s needs and preferences for health services, as well as sharing of information across people, functions, and sites, are met over time (National Quality Forum, 2006). As mentioned earlier, the effectiveness of the care coordination process primarily depends upon how effectively medical providers and families communicate with one another (McAllister et al., 2007). However, the data indicate that adequate and effective care coordination is a significant issue for families of CSHCN; 31.8% reported a lack of one or more aspects of care coordination in the 2005-2006 NS-CSHCN
The research in this area further corroborates the importance of care coordination for CSHCN. Because families of CSHCN have difficulty understanding what services their children need, what services they qualify for, and how to access those necessary services, care coordination is vital in guiding parents and families through the process of navigating and accessing both the health care system and resources in the community (AAP, 2005).

Despite the importance of care coordination for CSHCN and their families, most research on the topic has solely emphasized barriers that impeded care coordination or factors that may promote care coordination. For instance, Antonelli et al. (2008) found that care coordination for CSHCN in pediatric settings results in cost savings by preventing unnecessary negative health outcomes, via reduced pediatric or clinic visits, emergency room visits, subspecialist visits, hospitalizations, and specialized therapies. Researchers also found that use of care coordination was more likely for families with social stressors or related complications, compared to families without additional social stressors. Very few studies have examined the impact that care coordination has on health outcomes for CSHCN, and none of these studies have evaluated its impact on functional abilities as a health outcome for CSHCN.

Palfrey et al. (2004) found a significant decrease in children’s hospitalizations (58% at baseline vs. 43.2% post-intervention; p < 0.01) as well as a decrease in the rate of parental workdays lost (26% at baseline vs. 14.1% post-intervention; p = 0.02) for children who received care coordination and integrated services while hospitalized, versus those children who did not. This project, titled “Pediatric Alliance for Coordinated Care (PACC)”, involved six pediatric offices and approximately 150 CSHCN and their families. Palfrey et al. (2004) also found that families with CSHCN who had more severe conditions were more likely to utilize care coordination services and also more likely to be satisfied with the services they had obtained with the help of the practitioner providing the care coordination. It is important to note that researchers did not look
at other benefits of care coordination or integrated services, particularly with respect to related health outcomes, nor did they examine the impact of care coordination on functional ability. For this reason, Palfrey et al. specifically recommend the replication of the project at additional facilities, so as to be able to generalize the findings to a broader population of CSHCN and to gain further insight on the positive impact that care coordination and family-centered care may have on CSHCN outcomes.

Care Coordination in Primary Care Settings

Healthcare providers, and, in particular, pediatricians, have a different perception of care coordination and of barriers impeding the provision of health services to CSHCN. Considering the views of healthcare providers is important for comprehensively evaluating the effectiveness of care coordination. In 2000, the AAP conducted a survey of pediatricians (also members of the AAP) to obtain information on care coordination services that these pediatricians had provided to CSHCN (Bhushan-Gupta et al., 2004). The survey showed that CSHCN comprised approximately 26.9% of the patient population in primary practice settings. Furthermore, pediatricians who provided services to CSHCN reported providing a higher frequency of services to CSHCN compared to non-CSHCN, to a statistically significant degree. These services included, but were not limited to, the following:

- Integrating the medical care plan with other providers’ care plans (49.1% for CSHCN vs. 41.0% for non-CSHCN; \( p < 0.001 \))
- Assisting the family in obtaining an appointment with a specialty provider (61.4% for CSHCN vs. 59.1% for non-CSHCN; \( p < 0.001 \))
- Spending enough time with the child’s family to discuss the results from specialty provider visits (18.8% for CSHCN vs. 15.0% for non-CSHCN; \( p < 0.001 \))
• Meeting with the discharge planning team when the child was hospitalized (23.7% for CSHCN vs. 19.3% for non-CSHCN; p < 0.001)
• Contacting the school to discuss the child’s health and educational needs (23.7% for CSHCN vs. 17.8% for non-CSHCN; p < 0.001)
• Discussing other needs of the family (40.5% for CSHCN vs. 31.2% for non-CSHCN; p < 0.001)

The AAP survey also obtained information on specific barriers pediatricians encountered when providing care coordination services to CSHCN. The following were reported by pediatricians to be barriers impeding provision of services for care coordination (Bhushan-Gupta et al., 2004):

• Lack of time
• Insufficient staff (medical staff and office staff)
• Lack of community and government services in the area
• Difficulties communicating effectively when developing an integrated medical care plan
• Inadequate payment or reimbursement for [care coordination] services
• Lack of training on care coordination and on identifying the potential needs for other services that families may have

Because primary care is typically the main setting for provision of pediatric services for most CSHCN, primary care practices can play an essential role in coordinating care for CSHCN (AAP, 2005). Given the breadth of functions involved for successful care coordination, the American Academy of Pediatrics (2005) recommends that primary physicians designate an individual to be a care coordinator for their office. This individual can be a nurse, social worker, therapist, or other professional with experience working with CSHCN. Ideally, he/she aids in
developing a plan of services to meet the needs of CSHCN and families and provides follow-up with other health care professionals, as well as payers and community resources.

The literature, however, indicates that primary care practices for children generally focus only on preventive and acute care, and lack the integration and coordination necessary to integrate care with specialists and community resources, such as therapists and educators (Cooley & McAllister, 2004). Despite the fact that the literature clearly demonstrates the importance of care coordination for maintaining health and well-being and improving the aforementioned health outcomes for CSHCN, there is a distinct absence of studies with respect to its impact on functional abilities. This is a significant area of interest for health services research on CSHCN and individuals with disabilities, in general, given that functional abilities/limitations are a primary indicator of an individual’s ability to perform self-care, conduct daily activities, and participate in his/her household and the greater community. The American Academy of Pediatrics (2005) has identified numerous barriers that prevent the provision of care coordination services, ranging from the absence of a single point of entry and evaluation into the health system to socioeconomic and cultural factors. The following section will discuss some recommendation and best practices that have been demonstrated to improve or alleviate the barriers that prevent provision of care coordination services, for individuals with disabilities and CSHCN in particular.

**Care Coordination Best Practices**

Parents and family members of an individual with a disability can greatly benefit from care coordination. Most individuals with disabilities have ongoing needs for multiple services through their lifetimes and truly comprehensive care should address the full spectrum of these needs (Sofaer, Kreling, & Carmel, 2000). It is important to isolate major barriers to coordination,
in order to further understand the difficulties faced by family caregivers of individuals with disabilities and support these caregivers. A study based on applications submitted by 28 New York City hospitals summarizes the following obstacles to serving family caregivers, as recognized by health professionals at the administrative and clinical level (Levine, 1998):

- Hospitals lack the time and financial resources necessary to address caregivers’ needs.
- In their focus on the patient’s clinical condition [child’s disability], health care providers often overlook the caregiver.
- Information systems fail to collect and share about social and emotional aspects of care.
- Language, cultural, and educational differences can create challenges when families and health care professionals come from different backgrounds.
- Families’ emotional responses to illness [disability] can make it challenging for hospital staff to provide support in meaningful way.

It thus follows that best practices at the practitioner and health management level should involve mechanisms of care that improve upon these deficiencies. Specifically, the National Quality Forum defines five domains for developing performance measures or indicators of care coordination: (1) healthcare (medical) “home”, (2) proactive plan of care and follow-up, (3) communication, (4) information systems, and (5) transitions or “hand-offs”. Traditional hospital infrastructures lack the time and resources necessary to address the family or caregiver’s needs, but a medical home acts a central point of access, and promotes and guarantees a system of continuous, comprehensive care for particular conditions. In the second domain, best practices include joint creation, management, and assessment of goals as part of a proactive plan of care with the patient/family caregiver. This plan also includes community
services and resources, in addition to standard health services for the patient’s needs (National Quality Forum, 2006).

Through the third domain of communication, all team members – including providers, patients, and families – work within this shared plan of care and are held co-accountable for contributing to and achieving the patient’s goals. Ideal communication additionally entails shared decision-making with the patient and family, as this form of support is equally important as communication among providers. HIPAA-compliant communications, access to, and availability of information can be made possible through interoperable information systems that include decision support tools, provider alerts, and patient reminders, which are all part of the fourth domain. In the fifth domain, transitions between care settings can be improved through increased use of electronic records, for more timely transfer of health information, and involvement of the team during hospitalizations, nursing home stays, etc. Furthermore, patient-family surveys, administered within close proximity to the health care event, are crucial to measuring the effectiveness, efficiency, and timeliness of care coordination best practices (National Quality Forum, 2006).

The Role of Medical Homes and Their Significance for CSHCN

Overview of Medical Homes

The American Academy of Pediatrics (AAP) has published a number of public policies with recommendation on how to improve the provision of health care services for CSHCN, many of which speak to the significance of the medical home and related concepts of care. Specifically, the AAP defines a medical home as a model for primary and pediatric health care services provision, in which children receive comprehensive, appropriate, and trustworthy services in an organized manner, and in which families are considered an active participant in
health care decision-making. Because of confusion surrounding the concept of a medical home, the AAP also released a policy that made clear that the medical home does not refer to “a house, building, or health care facility”, but rather to the concept of how health care should be provided to CSHCN to promote their healthy development toward adulthood (AAP, 2002). Further, the AAP policy on medical homes outlined services needed for a primary practice setting to be considered a medical home for CSHCN:

- Accessible
- Family-Centered
- Comprehensive
- Continuous
- Coordinated
- Compassionate
- Culturally effective

These aspects of care were described in-depth by the AAP for improving services provision for CSHCN and are considered desirable characteristics of a medical home (AAP, 2002). The AAP also notes, “Physicians should strive to provide these services and incorporate these values into the way they deliver care to all children.”

The literature indicates that a medical home model of care is beneficial for CSHCN in a variety of ways. A review of the research studies and interventions on the effect of medical homes on health care and health outcomes for CSHCN revealed that the medical home can decrease school absences and improve mental health as well as general health status (Homer et al., 2008). Additionally, in a study of a medical home intervention, researchers found that children with chronic conditions who received care based on the medical home model had improved mental health status after 6 months, 1 year, and 4-5 years of follow-up, when compared to children with chronic conditions who received standard care in an ambulatory care setting (Stein & Jessop, 1991). Researchers also examined the level of psychological adjustment
following the medical home care intervention, and found that participants of the medical home intervention experienced significantly better psychological adjustment at 6 months ($p = 0.041$), 1 year ($p = 0.076$), and 4-5 years ($p = 0.026$) of follow-up, compared to CSHCN who received standard care. The results from these studies demonstrate the benefit that the medical home may have in improving health status and outcomes for CSHCN.

**Accessible Care**

The literature provides various definitions for accessible care, many of which have similarities. One comprehensive definition states accessible care is “care with no delays as a result of cost or insurance, transportation, office hours, or physician availability” (Benedict, 2008). This is comparable to another definition, which explains accessible care should be “health care that is not barred by financial constraints, geographical constraints, temporal or cultural constraints” and should involve “no delays, transportation problems or physical barriers” (Vest et al., 2010; Minden et al., 2007).

With respect to the medical home, the AAP defines accessible care as care that is provided in the child’s community, where all insurance (including Medicaid) is accepted and insurance changes are accommodated. The health care practice should also be accessible by public transportation, if available in that location, and the practice itself should be physically accessible and should meet the requirements outlined in the Americans with Disabilities Act. Lastly, families or CSHCN should be able to speak directly to the physician when necessary.

Accessible care has also been identified as an essential component of care for CSHCN, as indicated by various studies that demonstrate how having accessible care contributes to better outcomes of care. Teach et al. (2006) showed that patients that had higher spatial accessibility to primary care services made more scheduled visits for asthma care and, relatedly, fewer visits
for urgent care. With respect to financial constraints, poor or near-poor families of CSHCN were more likely to have unmet needs and delay seeking care for conditions due to cost concerns, when compared to CSHCN in higher income families (Bloom et al., 2009). CSHCN in lower income families were also more likely to rely on emergency departments as their usual source of care (U.S. DHHS, 2000). This is related not only to temporal constraints these families face, such as not being able to see a primary care physician during office hours, but also delays in care as a result of lack of insurance or inadequate insurance. Financial and temporal constraints are integral aspects of care that need not be present for CSHCN to receive accessible care.

**Family-Centered Care**

Family-centered care (FCC) is an essential component of care for CSHCN, and has been demonstrated to be a valuable contributor to improving child health outcomes, improving resource allocation, and increasing satisfaction with care. Specifically, family-centered care underscores the importance of families being active participants in the health care decision-making process and being informed of children's health conditions by health care providers. The underlying assumption is that, because parents are the primary experts with respect to their children's health and needs and because all families operate under differing circumstances, children's functioning is optimized if families collaborate in the health care process alongside providers (King et al., 2004). The American Academy of Pediatrics (2003) corroborates this, as demonstrated in their policy statement on family-centered care. In particular, the AAP asserts that information brought to the care process by families and the role of families in decision-making are important in achieving better health outcomes for children, as well as improving allocation of resources and improving satisfaction.
Pediatric practices that provide family-centered care do so in the following ways, according to the AAP (2003):

- By considering families as key partners in the care of children;
- By showing respect for their culture, customs, traditions, and expertise;
- By providing flexibility according to the needs and preferences of families.

Having this type of partnership, communication, sharing of information, and more effective decision-making enhances the quality of care, while simultaneously improving the health and general functioning of the child. The use of family-centered care can improve the satisfaction that both families and professionals have with the care that is provided to children, as well as enhance confidence, promote more effective use of services, and decrease health care costs for the family and the provider (AAP, 2003). For these reasons, the Institute of Medicine (2001) recommends that patients and families, in general, participate in the health care process and be informed about it. In addition to integrating family-centered care in pediatric practices, however, family-centered care should also be incorporated in hospitals, community settings and clinics, since CSHCN receive services in a variety of care settings.

The literature indicates that family-centered care is important and beneficial for addressing the health services needs of CSHCN. A study of 2,100 families of CSHCN from 20 different states (representative of all main U.S. Census regions: Northeast, Midwest, South, and West) examined the unmet needs and barriers to access that CSHCN experienced, as well as the perceptions that parents had of health care services (Erickson, Warfield & Gulley, 2006). Researchers found that CSHCN had higher needs for health services if they were in poorer health, had severe conditions, or had a less stable health status. Parents reported a variety of unmet needs, including the need for additional specialized services (3%) and the need for mental health services (12%). When comparing CSHCN with changing needs to CSHCN with
more stable needs for services or comparing CSHCN with severe limiting conditions to CSHCN with more mild conditions, the number of unmet needs increase significantly with the increase in needs for services (OR = 3.39 and OR = 2.34, respectively).

Studies demonstrate that families are more satisfied with the care their children receive when health providers consider them to be active partners in the health care decision-making process for their children. Ngui & Flores (2006) conducted a secondary data analysis of a national survey and found that nearly 8% of CSHCN families overall were dissatisfied with health care services. A significantly higher rate of dissatisfaction was reported for families who had children with the following characteristics or had other barriers impeding care coordination:

- Families with children with severe conditions, compared to families with children with less severe conditions (OR = 1.14, 95% CI 1.06-1.22; p < 0.05)
- Families with uninsured children, compared to families with insured children (OR = 1.71, 95% CI 1.04-2.82)
- Families interviewed in Spanish, compared to families interviewed in another language (OR = 2.25, 95% CI 1.06-4.76)

Non-minority parents were more likely to report having received family-centered care than minority parents. In particular, minority parents reported the following complaints (p < 0.001), which indicate that their child did not receive care that was family-centered:

- Providers sometimes or never spent enough time with their child
- Providers did not listen to the family carefully
- Providers were not sensitive to the customs and values of the family
- Providers did not provide enough information to the family
- Providers did not help the family feel like partners in their child’s care
A second study also found that families that did not receive family-centered care were more likely to be dissatisfied with the services they received, when compared to families that were considered partners in care and when adjusting for race, age, poverty status, gender, and health insurance status (Denboba et al., 2006).

The literature also indicates that family-centered care is associated with positive outcomes for CSHCN, ranging from unmet needs to missed school days due to health conditions. Specifically, Denboba et al. (2006) found that, compared to families that were always or usually considered partners in their children’s care, families that never or sometimes felt like partners were significantly more at risk for having children who missed school days due to their health conditions (OR_{adj} = 1.22, 95% CI: 1.01-1.46). These families were also at an increased risk for having children with unmet health needs (OR_{adj} = 2.54, 95% CI: 2.19-2.95) and unmet family needs (OR_{adj} = 2.69, 95% CI: 2.16-3.36), adjusting for race/ethnicity, age, poverty, gender, and health insurance.

However, results from a previous NS-CSHCN indicate that approximately 34.5% of CSHCN did not receive care that is considered to be family-centered (CAHMI, 2005-2006). Furthermore, despite the literature on the benefits of family-centered care for CSHCN, there is very little research with respect to the impact of family-centered care on health outcomes. The literature on the impact of family-centered care has predominately looked at only two outcomes for CSHCN: (1) psychological health and (2) development of skills, the latter of which was only measured for children with cerebral palsy (King et al., 2004; Law et al., 1998). Specifically, family-centered care has been shown to promote healthy psychosocial development in children with chronic health conditions who participated in a service program that focused on the family, when compared to children who received services from a standard health care program (King et al., 2004). Some studies have looked specifically at parental
outcomes, and results from these studies show that the provision of family-centered care has benefits with respect to improved psychological health in mothers of CSHCN. This is primarily due to the fact that a more active participation in the health care process enhances the sense of competency, control, and well-being that a parent has overall (King et al., 2004).

**Continuous Care**

Continuous care occurs when the same primary pediatric health care professionals are available to provide care to CSHCN from infancy through adolescence and young adulthood. These professionals would ideally provide CSHCN and their families with assistance with transitions, particularly with respect to developmentally appropriate health assessments and counseling. Often, a child with special health care needs may be hospitalized, or the child may receive care at another facility or from another health care provider. In these events, the medical home physician is expected to participate to the fullest extent allowed in care and discharge planning (American Academy of Pediatrics, 2002). Unlike comprehensive care, continuous care emphasizes the linearity of patient care with one provider and when the patient is transferred or referred to another provider.

**Comprehensive Care**

Comprehensive care refers to the scope of care that CSHCN receive, and includes addressing all preventive, primary, and tertiary health care service needs in a medical home model. The AAP characterizes comprehensive care as care that is “delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care” (2002). This means that the medical, educational, developmental, psychosocial, and other services needs of the child and family are identified and addressed. Comprehensive care also
involves ensuring that ambulatory and inpatient care for ongoing and acute illnesses are available “24 hours a day, 7 days a week, [and] 52 weeks a year.” With respect to preventive care, comprehensive care involves providing the entire range of services related to illness prevention. This includes immunizations, assessments of growth and development, appropriate screenings, and patient and parent counseling about health, safety, nutrition, and psychosocial issues.

In the medical home, the physician is expected to advocate for the child, youth, and family in obtaining comprehensive care, and the physician also shares responsibility for the care that is provided. Information needs to be made available about private insurance, as well as public resources, such as Supplemental Security Income, Medicaid, CHIP, waivers, early intervention programs, and Title V State Programs for CSHCN. Lastly, it may be necessary to schedule extra time for an office visit with CSHCN, in order to provide comprehensive care (American Academy of Pediatrics, 2002). In the literature, receipt of comprehensive care is assessed based on whether the patient and/or family have difficulty obtaining necessary care, obtaining specialized services, or obtaining prescription medications (Bethell et al., 2004). Two studies on CSHCN who received comprehensive care have demonstrated its benefits with respect to health outcomes, but these CSHCN were either not part of a medical home (Weller et al., 2003) or were only residing in rural areas (Farmer et al., 2005).

**Coordinated Care**

For background and more details, see section on Care Coordination and Its Significance for CSHCN. With respect to medical homes that operate based on the care coordination model, more than 30 states have initiated projects to build and advance medical homes for children enrolled in Medicaid and CHIP (Kaye & Takach, 2009).
Compassionate and Culturally Effective/Sensitive Care

In a medical home, compassionate care is provided when “concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions” and “efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth” (AAP, 2002). Similarly, culturally effective or culturally sensitive care involves efforts to understand the child and family in a respectful manner. The child and family’s “cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan” (AAP, 2002). Culturally effective care also means that all efforts are made to ensure that the child and family understand the results of the medical encounter and the care plan, and that (para) professional translators or interpreters are provided if needed. Written materials should also be provided in the family’s primary language for care in the medical home to be culturally effective.

With respect to the medical home model of care delivery, the literature indicates that care that is compassionate and culturally effective are both integral components of care for CSHCN. However, very few studies have examined the impact of these aspects of care for CSHCN who are not in a medical home. Researchers also have not thoroughly studied the effect of compassionate and/or culturally effective care on outcomes for CSHCN. In one study that did investigate care experiences for CSHCN who were not part of a medical home, researchers found that providers reported increases in preventive care provision, patient satisfaction, and positive health outcomes as a result of culturally effective care delivery (Denboba et al., 2006). The study measured whether providers utilized culturally and linguistically competent
approaches and whether they took the time to better understand the sociocultural influences and preferences of CSHCN and their families.
Chapter 5. Conceptual Frameworks

Figure 3 is a graphical depiction of the conceptual framework for Study 1, which examines the impact of various condition-specific characteristics on underinsurance. The dependent variable or outcome for Study 1 is adequacy of insurance, as assessed by three definitions of underinsurance – (1) financial underinsurance, (2) structural underinsurance, and (3) attitudinal underinsurance. The independent variables for Study 1 include four condition-specific characteristics: (1) the severity of the child’s condition, (2) the complexity of the child’s condition, (3) number of health conditions experienced by the child, and (4) number of functional difficulties experienced by the child.

Other variables in the model include control variables such demographic characteristics and financial characteristics. Based on the literature, demographics may influence the financial characteristics of CSHCN, as well as their likelihood of being underinsured (the dependent variable): (1) race/ethnicity, (2) parental education, (3) family structure, and (4) residence. All demographic characteristics – age of the child, gender of the child, race/ethnicity, parental education, family structure, and residence – are also indicated in the literature to be related to condition-specific characteristics (the independent variables). Since the age and gender of the child with special health care needs are not related to that child’s likelihood of being underinsured (the dependent variable), only race/ethnicity, parental education, family structure, and residence were considered as potential confounders in this model.
Financial characteristics, such as household income, have been demonstrated in the literature to be related to the likelihood of CSHCN of being underinsured (the dependent variable) and may also influence condition-specific characteristics such as the number of functional difficulties experienced by CSHCN (an independent variable). For this reason, household income is also included in the statistical model and analyzed as a potential confounder for Study 1. Because Study 1 focuses on adequacy of insurance, only CSHCN who were continuously insured for 12 months prior to the NS-CSHCN interview were included in the analysis. All insured groups (privately insured only, public insured only, and both publicly and privately insured) were analyzed for Aim 1a. Comparisons between CSHCN who are privately insured and CSHCN who are publicly insured were analyzed for Aim 1b, (1)-(3).
Figure 3. Conceptual Framework for Study 1 (Underinsurance)
Conceptual Frameworks, continued: Study 2a and Study 2b (Care Coordination)

Figure 4 is a graphical depiction of the conceptual framework for Study 2a, which examines the impact of various condition-specific characteristics on care coordination. Figure 5 is a graphical depiction of the conceptual framework for Study 2b, which analyzes the impact of care coordination on unmet need. The AHRQ suggests the effects or experiences of care coordination mechanisms will be perceived differently depending on who is asked to evaluate those effects: patient and/or family, health care professional(s), or system representative(s). The perspective reflected by the NS-CSHCN is the family perspective, which will be used to measure coordination activities and adequacy of that coordination based on satisfaction scores.

The dependent variable or outcome for Study 2a is care coordination, as assessed by the patient/family perspective from the 2009/10 NS-CSHCN. The independent variables for Study 2a are the following condition-specific characteristics of the child with special health care needs: (1) the severity of the child’s condition, (2) the complexity of the child’s condition, (3) the number of health conditions experienced by the child, and (4) number of functional difficulties experienced by the child. All demographic characteristics – age of the child, gender of the child, race/ethnicity, parental education, family structure, and residence – were analyzed as potential confounders in Study 2a. Both financial characteristics – household income and insurance status – were also treated as potential confounders in Study 2a since the literature has shown that they may be related to both the condition-specific characteristics (the independent variables) and the likelihood of receiving care coordination (the dependent variable). Based on the literature, the following demographics may influence financial characteristics of CSHCN: (1) race/ethnicity, (2) parental education, (3) family structure, and (4) residence. Lastly, because Study 2a focused on care coordination as the outcome, only CSHCN who used more than one
type of service or saw more than one specialty doctor in the 12 months prior to the NS-CSHCN interview were included in the study sample.

The dependent variable or outcome for Study 2b is unmet need. Specifically, likelihood of any unmet need was assessed overall and then individually, for four types of unmet need – (1) unmet need for preventive care, (2) unmet need for specialty care, (3) unmet need for therapeutic services, and (4) unmet need for support services. The independent variable for Study 2b is care coordination, based on the patient/family perspective assessed in the 2009/10 NS-CSHCN. According to the literature, financial characteristics (household income and insurance status) may influence both care coordination (the independent variable) and unmet need (the dependent variable) and were thus considered as potential confounders in Study 2b. Demographic characteristics, such as age, gender, race/ethnicity, parental education, family structure, and residence – may be related to care coordination (the independent variables) and the likelihood of having unmet need(s) (the dependent variable), and were also considered as potential confounders for Study 2b analyses. Since Study 2b focused on unmet need as an outcome, only CSHCN who had an unmet need (for some or all services) in the 12 months prior to the NS-CSHCN interview were included in the study sample.
The AHRQ describes that the effects or experiences of care coordination mechanisms will be perceived differently depending upon who is asked to evaluate those effects: patient and/or family, health care professional(s), or system representative(s). The perspective reflected by the data source (in this case, the family perspective is assessed in the NS-CSHCN) can be used to measure coordination activities and adequacy of that coordination based on satisfaction scores.

*Figure 4. Conceptual Framework for Study 2a (Care Coordination)*
The AHRQ describes that the effects or experiences of care coordination mechanisms will be perceived differently depending upon who is asked to evaluate those effects: patient and/or family, health care professional(s), or system representative(s). The perspective reflected by the data source (in this case, the family perspective is assessed in the NS-CSHCN) can be used to measure coordination activities and adequacy of that coordination based on satisfaction scores.

Figure 5. Conceptual Framework for Study 2b (Care Coordination)
Conceptual Frameworks, continued: Study 3 (The Medical Home)

Figure 6 is a graphical depiction of the conceptual framework for Study 3. Study 3a examines the likelihood of CSHCN in medical homes experiencing the following parent/guardian-reported non-clinical outcomes of care, compared to non-medical home CSHCN: (1) decreased caregiver burden, (2) increased care satisfaction, and (3) receipt of transition planning to adult care. These are the dependent variables for Study 3a; the independent variable is medical home status.

All demographic characteristics – age of the child, gender of the child, race/ethnicity, parental education, family structure, and residence – may influence both the likelihood of being in a medical home (the independent variable) and the likelihood of experiencing the outcomes of care (the dependent variables), and are thus considered potential confounders for Study 3a analyses. Based on the literature, the following demographics influence financial characteristics of CSHCN: (1) race/ethnicity, (2) parental education, (3) family structure, and (4) residence. Lastly, only CSHCN who were part of a medical home for 12 months prior to the NS-CSHCN interview are included in the study sample for Study 3a.

Study 3b examines the likelihood of CSHCN experiencing the following parent/guardian reported non-clinical outcomes of care: (1) decreased caregiver burden, (2) increased satisfaction with care, and (3) receipt of transition planning to adult care. The analyses in Study 3b are between groups of CSHCN who are not in a medical home but who experience individual components or groups of components that constitute a medical home. Specifically, comparisons were made between (1) CSHCN who received accessible and comprehensive care, (2) CSHCN who received family-centered and culturally sensitive care, and (3) CSHCN who received coordinated care. These medical home components are independent variables for Study 3b.
All demographic characteristics – age of the child, gender of the child, race/ethnicity, parental education, family structure, and residence – may influence both the likelihood of receiving particular types of care that are associated with the medical home (the independent variables) and the likelihood of experiencing the outcomes of care (the dependent variables), and were thus be considered potential confounders for Study 3b analyses. Additionally, the following demographics have been shown in the literature to be related to financial characteristics of CSHCN: (1) race/ethnicity, (2) parental education, (3) family structure, and (4) residence. Lastly, because the analyses for Study 3b focused on CSHCN who are not in a medical home but experience components of care that constitute a medical home (either individually or in groups), only CSHCN who were not part of a medical home for 12 months prior to the NS-CSHCN interview were included in the study sample for Study 3b.
For Aim 3b, individual non-clinical outcomes of care were compared between groups of CSHCN who are not in a medical home, but who experience individual components or clusters of components of the medical home as follows: (1) care that is accessible and comprehensive; (2) care that is family-centered and culturally sensitive; and (3) care that is coordinated.

Figure 6. Conceptual Framework for Study 3 (The Medical Home)
Chapter 6. Study 1: Underinsurance

6.1 Study 1 Aims

Aim 1a: For each definition of underinsurance (financial, structural, and attitudinal), determine the likelihood of underinsurance in relation to condition-specific characteristics (e.g., condition complexity, condition severity, number of health conditions, and number of functional difficulties) for insured CSHCN, taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

Hypothesis 1a – Condition Complexity: Among CSHCN who are insured (public, private, or both), CSHCN who have “any other needs” will be more likely to be underinsured than CSHCN who have a disability that requires “medication only,” which is indicative of a less complex condition.

Hypothesis 1a – Condition Severity: Among insured CSHCN, CSHCN who have higher condition severity will be more likely to be underinsured than CSHCN who have lower condition severity.

Hypothesis 1a – Health Conditions: Among CSHCN who are insured (public, private, or both), CSHCN who have more than one health condition will be more likely to be underinsured than CSHCN who have only one health condition.

Hypothesis 1a – Functional Difficulties/Limitations: Among CSHCN who are insured (public, private, or both), CSHCN who have functional limitations or difficulties will be more likely to be underinsured than CSHCN who do not have functional limitations.
**Aim 1b:** For each definition of underinsurance (financial, structural, and attitudinal), determine the likelihood of underinsurance for CSHCN who are publicly insured versus CSHCN who are privately insured, taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

**Hypothesis 1b(1) – Private vs. Public Insurance:** Among those who are insured either privately or publicly, CSHCN who are privately insured will be more likely to be underinsured than CSHCN who are publicly insured.

**Hypothesis 1b(1) – Private vs. Both:** Among those who are insured either privately or both publicly and privately, CSHCN who are privately insured will be more likely to be underinsured than CSHCN who are both privately and publicly insured.

**Hypothesis 1b(1) – Public vs. Both:** Among those who are insured either publicly or both publicly and privately, CSHCN who are publicly insured will be more likely to be underinsured than CSHCN who are both publicly and privately insured.

**Aim 1b(2):** For each definition of underinsurance (financial, structural, and attitudinal), determine the likelihood of underinsurance between CSHCN with severe health conditions who are privately insured versus CSHCN with severe health conditions who are publicly insured, taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

**Hypothesis 1b(2) – Severity:** Among those who are insured, CSHCN who have “any other needs” will be more likely to be underinsured than CSHCN if they are (1) privately insured as opposed to publicly insured, (2) privately insured as opposed to both publicly and privately insured, and (3) publicly insured as opposed to both publicly and privately insured.
**Aim 1b(3):** For each definition of underinsurance (financial, structural, and attitudinal), determine the likelihood of underinsurance between CSHCN with functional limitations who are privately insured versus CSHCN with functional limitations who are publicly insured, taking into account demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

**Hypothesis 1b(3) – Functional Difficulties/Limitations:** Among those who are insured, CSHCN who have functional limitations will be more likely to be underinsured than CSHCN who do not if they are (1) privately insured as opposed to publicly insured, (2) privately insured as opposed to both publicly and privately insured, and (3) publicly insured as opposed to both publicly and privately insured.

**6.2 Study 1 Background and Significance**

Despite comprising only 13.9% of the overall child population in the U.S., CSHCN use more health care resources and account for a much greater proportion (42-50%) of all child health care costs, when compared to children without special needs (CAHMI 2008; Newacheck & Kim, 2005; Kogan & van Dyck, 2005). Studies have also demonstrated that CSHCN are less likely to be uninsured compared to children without special needs (4.8% vs. 8.3%), but are more likely to have inadequate insurance coverage (i.e., be underinsured) (Tu & Cunningham, 2005). As a result of the cost-sharing that typically occurs with most health insurance plans, the literature indicates that CSHCN are also more likely to delay care and have unmet needs.

Because CSHCN are such a vulnerable patient population with respect to relying heavily on having adequate coverage and with respect to being adversely impacted by inadequacies or delays in care, it is important to understand what factors may predispose CSHCN to being underinsured. An analysis of condition-specific characteristics, such as condition severity and
functional limitations experienced by CSHCN, along with their association with particular types of underinsurance, would yield valuable insight into which CSHCN are most likely to be underinsured and why this may be the case. Ultimately, these findings may provide information to improve health services delivery for CSHCN who are currently inadequately insured.

6.3 Study 1 Research Methods

6.3.1 Participants

The overall study population for this dissertation included CSHCN from 0 to 17 years of age whose parents or caregivers were surveyed in the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN). Of the 372,698 children screened, 59,941 were identified with special health care needs, and in-depth interviews were subsequently completed for a total of 40,242 CSHCN. This total includes approximately 750 interviews per state and the District of Columbia, with a range of 751 in the District of Columbia to 878 in Texas. For Study 1, only CSHCN who were continuously or consistently insured for 12 months prior to the NS-CSHCN interview were included in the study sample. The study population for Study 1 is 90.7% of the overall study population, with n = 37,043 CSHCN.

6.3.2 Data Source

All data for this study was obtained from the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN), sponsored by the Maternal and Child Health Bureau, U.S. Department of Health and Human Services, and Health Resources and Services Administration. The NS-CSHCN is a national telephone survey, conducted for the third time in 2009-10. Previous administrations occurred in 2000-2001 and 2005-2006. Independent random samples are taken in all 50 states and the District of Columbia, with at least 750 interviews conducted in each state and D.C. Its primary goal is to assess the prevalence and impact of
special health care needs among children under age 18 in all 50 states and the District of Columbia.

A SLAITS approach, developed by the National Center for Health Statistics to quickly and consistently collect information on a variety of health topics at the state and local levels, is used for sampling and data collection for the NS-CSHCN. This mechanism is also used for sampling and data collection for the National Survey of Children’s Health (NSCH), the National Survey of Early Childhood Health, the National Asthma Survey, and the National Survey of Adoptive Parents. The SLAITS study design involves random-digit dialing (RDD) and computer-assisted telephone interviewing (CATI) to annually contact and identify children between ages 0-17. Only landline phone numbers have been included in the study design in previous years; however, for the 2009/10 NS-CSHCN, the sample of landline telephone numbers was supplemented by an independent RDD sample of cell phone numbers. This cell phone sampling was a new feature of the NS-CSHCN, and information is included on whether the respondent was interviewed via landline or cell phone number. SLAITS surveys use the sampling frame from the National Immunization Survey (NIS) for purposes of efficiency and economy.

The following sections are included in the NS-CSHCN interview:

- Section 1: NIS/SLAITS (qualifying question on household having a child less than 18 years old)
- Section 2: Initial Screening (to determine if child has special health care needs)
- Section 3: Health and Functional Status
- Section 4: Access to Care – Use of Services and Unmet Needs
- Section 5: Care Coordination
- Section 6A: Family Centered Care and Shared Decision Making
Data from the NS-CSHCN are publicly available, at no cost, from the Data Resource Center of the CDC. This data is provided in SAS and SPSS formats, and the original SAS version of the data set (without constructed indicators) is also downloadable at no cost from the CDC’s website for the National Children’s Health Survey (NCHS). In order to provide estimates that are representative of CSHCN or households with CSHCN at the state and national level, sampling weights are provided in the publicly released data files.

The sampling weights adjust responses from the survey using population data from the U.S. Census counts of children and are stratified by sex, age, and race/ethnicity as the reference population. The weighting variable, WEIGHT_I, is included in the Interview File and adjusts survey responses to reflect the population of CSHCN age 0-17 years in each state and the District of Columbia. As recommended by CAHMI, this weight variable was applied to all analyses using the Interview File. Similar sampling weights were also provided for the household interview and child screener.
6.3.3 Variables

In Study 1, the outcome of interest or dependent variable was inadequate insurance coverage, as measured by three different definitions of underinsurance (financial, structural, and attitudinal). The primary independent variables were condition-specific characteristics of CSHCN, which included condition complexity, condition severity, number of health conditions, and number of functional limitations. Demographic characteristics, such as age of the child, gender of the child, race/ethnicity, parental education, family structure, and residence, were also included in analyses as control variables or covariates. In addition, race/ethnicity, parental education, family structure, and residence were considered potential confounders, as they were shown in the literature to be related to both the independent and dependent variables.

Financial characteristics – specifically, household income and insurance status (public only, private only, or both public and private) – were also part of the analyses in Study 1 as control variables. Because Study 1 focused on adequacy of insurance coverage, uninsured status (not having any insurance coverage) was not part of the financial characteristics included in the analyses. Household income was considered as a potential confounder as well, since the literature indicated that income influences the likelihood of CSHCN of being underinsured (the dependent variable) and condition-specific characteristics such as the number of functional difficulties experienced by CSHCN (an independent variable).

A complete list of all variables, as well as a description of each variable, is provided below in Tables 1-6. Table 1 presents an overview of all variables for Study 1, a description of each of these variables or survey items, and the role of each variable in the study (control variable, confounder, independent variable, or dependent variable). Table 2 shows the 2009/10 NS-CSHCN survey items for health conditions and condition severity, while Table 3 shows the
survey items for functional difficulties. Tables 4, 5, and 6 show the survey items for the definitions of financial, structural and attitudinal underinsurance, respectively.

<table>
<thead>
<tr>
<th>Variable/Survey Item(s)</th>
<th>Description</th>
<th>Role(s) in Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE_X</td>
<td>Age of child</td>
<td>Control variable</td>
</tr>
<tr>
<td>C2Q03_X</td>
<td>Gender of child</td>
<td>Control variable</td>
</tr>
<tr>
<td>HISPANIC C10Q32_X</td>
<td>Race/ethnicity of child</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>EDUCR_IMP</td>
<td>Highest education level attained by any parent in household</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>FAMSTRUCT (*derived from responses to C11Q01_A through C10Q05)</td>
<td>Family structure (biological or adopted child, step-family, mother-only, other)</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>C10Q41</td>
<td>Residence</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>POVLEVEL_IMP C11Q11 C11Q12 C11Q13</td>
<td>Household income (by FPL) Receipt of welfare Receipt of SSI SSI for disability</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>TYPEINS (*derived from Section 7 survey questions)</td>
<td>Insured status (private and/or public coverage)</td>
<td>Control variable</td>
</tr>
<tr>
<td>CSHCN1, CSHCN1A_X, CSHCN1_B_X; CSHCN5, CSHCN5_A_X</td>
<td>Condition complexity (qualification reason from Screener – Rx medication only or other)</td>
<td>Independent variable</td>
</tr>
<tr>
<td>C3Q02, C3Q03; K2Q31_A/B/C through K2Q27_A/B/C; K2Q40_A/B/C through K2Q52_A/B/C</td>
<td>Condition severity (how often the condition affects the child’s daily life; severity level as indicated by health care provider)</td>
<td>Independent variable</td>
</tr>
<tr>
<td>K2Q31_A/B through K2Q52_A/B</td>
<td>Number of current health conditions (from a list of 20)</td>
<td>Independent variable</td>
</tr>
<tr>
<td>C3Q21 through C3Q34</td>
<td>Number of current functional difficulties (from a list of 14)</td>
<td>Independent variable</td>
</tr>
<tr>
<td>C4Q03_D, C4Q05_1/1A/1B, C4Q05_2/2A/2B, C4Q05_3/3A/3B &amp; C4Q05_32/32A/32B, C4Q05_4/4A/4B through C4Q05_7/7A/7B; C4Q06_1/1A/1B through C4Q06_3/3A/3B; C9Q05</td>
<td>Financial underinsurance</td>
<td>Dependent variable</td>
</tr>
</tbody>
</table>

Table 1. Study 1 Variables
Table 1 continued

<table>
<thead>
<tr>
<th>Variable/Survey Item(s)</th>
<th>Description</th>
<th>Role(s) in Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>C4Q03_A; C4Q05_1/1A/1B, C4Q05_2/2A/2B, C4Q05_31/31A/31B &amp; C4Q05_32/32A/32B, C4Q05_4/4A/4B through C4Q05_7/7A/7B; C4Q06_1/1A/1B through C4Q06_3/3A/3B</td>
<td>Structural underinsurance</td>
<td>Dependent variable</td>
</tr>
<tr>
<td>C8Q01_A, C8Q01_B, C8Q01_C</td>
<td>Attitudinal underinsurance</td>
<td>Dependent variable</td>
</tr>
</tbody>
</table>

*Responses for individual questions were suppressed to protect the confidentiality of respondents.

<table>
<thead>
<tr>
<th>Survey Item Description*</th>
<th>Coding of Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often does [CHILD’S NAME]’s health condition affect [his/her] ability to do age-appropriate things? (C3Q02)</td>
<td>1 = Never, 2 = Sometimes, 3 = Usually, 4 = Always</td>
</tr>
<tr>
<td>If so, how much limitation does your child experience? (C3Q03)</td>
<td>1 = A great deal, 2 = Some, 3 = Very little</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Survey Item Description*</th>
<th>Ever? (Yes)</th>
<th>Current? (Yes)</th>
<th>Mild, Moderate, or Severe? (Severe)</th>
</tr>
</thead>
<tbody>
<tr>
<td>For the following list of conditions, has 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? If yes, does [CHILD’S NAME] currently have the condition? Is that condition mild, moderate, or severe?</td>
<td>N/A</td>
<td>K2Q31A</td>
<td>K2Q31B</td>
</tr>
<tr>
<td>Attention Deficit Disorder or Attention Deficit Hyperactive Disorder (ADD or ADHD)</td>
<td>K2Q32A</td>
<td>K2Q32B</td>
<td>K2Q32C</td>
</tr>
<tr>
<td>Depression</td>
<td>K2Q33A</td>
<td>K2Q33B</td>
<td>K2Q33C</td>
</tr>
<tr>
<td>Anxiety problems</td>
<td>K2Q34A</td>
<td>K2Q34B</td>
<td>K2Q34C</td>
</tr>
<tr>
<td>Behavioral or conduct problems</td>
<td>K2Q35A</td>
<td>K2Q35B</td>
<td>K2Q35C</td>
</tr>
<tr>
<td>Autism, Asperger’s Disorder, pervasive developmental disorder, or other autism spectrum disorder</td>
<td>K2Q36A</td>
<td>K2Q36B</td>
<td>K2Q36C</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>Intellectual disability or mental retardation</td>
<td>N/A</td>
<td>K2Q37A</td>
</tr>
</tbody>
</table>

Table 2. NS-CSHCN Survey Items for Health Conditions and Condition Severity

Continued
### Table 2. continued

<table>
<thead>
<tr>
<th>Survey Item Description*</th>
<th>Ever? (Yes)</th>
<th>Current? (Yes)</th>
<th>Mild, Moderate, or Severe? (Severe)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>K2Q40A</td>
<td>K2Q40B</td>
<td>N/A</td>
</tr>
<tr>
<td>Diabetes</td>
<td>K2Q41A</td>
<td>K2Q41B</td>
<td>N/A</td>
</tr>
<tr>
<td>Epilepsy or seizure disorder</td>
<td>K2Q42A</td>
<td>K2Q42B</td>
<td>K2Q42C</td>
</tr>
<tr>
<td>Migraine or frequent headaches</td>
<td>K2Q43A</td>
<td>K2Q43B</td>
<td>N/A</td>
</tr>
<tr>
<td>Head injury, concussion, or traumatic brain injury</td>
<td>K2Q44A</td>
<td>K2Q44B</td>
<td>K2Q44C</td>
</tr>
<tr>
<td>A heart problem, including congenital heart disease</td>
<td>K2Q45A</td>
<td>K2Q45B</td>
<td>N/A</td>
</tr>
<tr>
<td>Blood problems such as anemia or sickle cell disease</td>
<td>K2Q46A</td>
<td>K2Q46B</td>
<td>N/A</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>K2Q47A</td>
<td>K2Q47B</td>
<td>N/A</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>K2Q48A</td>
<td>K2Q48B</td>
<td>N/A</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>K2Q49A</td>
<td>K2Q49B</td>
<td>N/A</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>K2Q50A</td>
<td>K2Q50B</td>
<td>N/A</td>
</tr>
<tr>
<td>Arthritis or other joint problems</td>
<td>K2Q51A</td>
<td>K2Q51B</td>
<td>N/A</td>
</tr>
<tr>
<td>Allergies</td>
<td>K2Q52A</td>
<td>K2Q52B</td>
<td>N/A</td>
</tr>
</tbody>
</table>

*If ≥ 1 of these items is severe, then the child’s health condition was classified as being severe.
<table>
<thead>
<tr>
<th>Survey Item Description</th>
<th>Survey Item</th>
<th>Survey Response*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you say [he/she] experiences a lot, a little, or no difficulty with any of the following:</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Breathing or other respiratory problems, such as wheezing or shortness of breath?</td>
<td>C3Q23</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Swallowing, digesting food, or metabolism?</td>
<td>C3Q24</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Blood circulation?</td>
<td>C3Q25</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Repeated or chronic physical pain, including headaches?</td>
<td>C3Q26</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Seeing even when wearing glasses or contact lenses?</td>
<td>C3Q21</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Hearing even when using a hearing aid or other device?</td>
<td>C3Q22</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Compared to other children [his/her] age, would you say he/she experiences a lot, a little, or no difficulty with any of the following?</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Taking care of [himself/herself], for example, doing things like eating, dressing and bathing? (Children 3-17 years only)</td>
<td>C3Q27</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Coordination or moving around?</td>
<td>C3Q28</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Using [his/her] hands?</td>
<td>C3Q29</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Learning, understanding, or paying attention? (Children 1-17 years only)</td>
<td>C3Q30</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Speaking, communicating, or being understood? (Children 1-17 years only)</td>
<td>C3Q31</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>With feeling anxious or depressed? (Children 18 months-17 years only)</td>
<td>C3Q32</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>With behavior problems, such as acting out, fighting, bullying, or arguing? (Children 18 months-17 years only)</td>
<td>C3Q33</td>
<td>A lot, a little</td>
</tr>
<tr>
<td>Making and keeping friends? (Children 3-17 years only)</td>
<td>C3Q34</td>
<td>A lot, a little</td>
</tr>
</tbody>
</table>

*If the survey response for any of the above items is either “a lot” or “a little” difficulty (as opposed to “no difficulty”), then the child was classified as having that functional difficulty.

**Table 3. NS-CSHCN Survey Items for Functional Difficulties**

**Underinsurance**

Underinsurance is a concept characterized as inadequate coverage, with multiple definitions. The Maternal and Child Health Bureau identified adequacy of health care insurance coverage as a core outcome for CSHCN in their National Agenda, and Healthy People 2010 also incorporated this target (MCHB, 1995). Items related to underinsurance were subsequently
incorporated in the National Survey of Children with Special Health Care Needs (NS-CSHCN) to address this goal. The following definitions of underinsurance were used in Study 1:

1. **Financial Underinsurance:** When out-of-pocket expenses for necessary medical care exceed a specified percent of the person’s income within a given time frame, or when a person delays health care due to out-of-pocket costs associated with the services. This economic definition of underinsurance defines a limit above which the expense of health care coverage becomes a burden and interferes with access to care. It emphasizes one’s ability to pay for health care and related services, including the cost of insurance premiums, co-pays, and deductibles.

2. **Structural Underinsurance:** When at least one benefit in the benchmark package (the benefits package used as a basis of comparison) is not covered by the individual’s health insurance plan. Structural underinsurance considers the type of benefits offered by the program and the range of providers whose services are covered under the plan.

3. **Attitudinal Underinsurance:** When at least one health benefit the person would prefer to receive is not covered by insurance; when there is at least one symptom the person believed necessitated treatment, for which insurance coverage did not provide treatment; or when a person is dissatisfied with his/her insurance plan. Emphasizes consumer satisfaction with and perceptions of coverage (Oswald et al., 2005).

As shown in Table 4, financial underinsurance was measured by four survey questions: C4Q03_D, C4Q05_1/1A/1B, C4Q05_2/2A/2B, C4Q05_31/31A/31B & C4Q05_32/32A/32B, C4Q05_4/4A/4B through C4Q05_7/7A/7B; C4Q06_1/1A/1B through C4Q06_3/3A/3B; C9Q05.
<table>
<thead>
<tr>
<th>Survey Item Description**</th>
<th>Needed Services? (Yes)</th>
<th>Received all needed care? (No)</th>
<th>Reasons for not receiving care? (1)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>During the past 12 months, did you have any difficulties or delays because of issues related to cost? (C3Q03_D)</td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>During the past 12 months, was there any time when [CHILD’S NAME] needed the following services: (C4Q05)</td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Well child check up</td>
<td>C4Q05_1</td>
<td>C4Q05_1A</td>
<td>C4Q05_1B</td>
</tr>
<tr>
<td>Specialty care</td>
<td>C4Q05_2</td>
<td>C4Q05_2A</td>
<td>C4Q05_2B</td>
</tr>
<tr>
<td>Preventive dental care</td>
<td>C4Q05_31</td>
<td>C4Q05_31A</td>
<td>C4Q05_31B</td>
</tr>
<tr>
<td>Other dental care</td>
<td>C4Q05_32</td>
<td>C4Q05_32A</td>
<td>C4Q05_32B</td>
</tr>
<tr>
<td>Prescription medications</td>
<td>C4Q05_4</td>
<td>C4Q05_4A</td>
<td>C4Q05_4B</td>
</tr>
<tr>
<td>Physical, occupational, or speech therapy</td>
<td>C4Q05_5</td>
<td>C4Q05_5A</td>
<td>C4Q05_5B</td>
</tr>
<tr>
<td>Mental health care/counseling</td>
<td>C4Q05_6</td>
<td>C4Q05_6A</td>
<td>C4Q05_6B</td>
</tr>
<tr>
<td>Substance abuse treatment or counseling (children 8-17 years)</td>
<td>C4Q05_7</td>
<td>C4Q05_7A</td>
<td>C4Q05_7B</td>
</tr>
<tr>
<td>During the past 12 months, was there any time when you or other family members needed the following: (C4Q06)</td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Respite care</td>
<td>C4Q06_1</td>
<td>C4Q06_1A</td>
<td>C4Q06_1B</td>
</tr>
<tr>
<td>Genetic counseling</td>
<td>C4Q06_2</td>
<td>C4Q06_2A</td>
<td>C4Q06_2B</td>
</tr>
<tr>
<td>Mental health care/counseling</td>
<td>C4Q06_3</td>
<td>C4Q06_3A</td>
<td>C4Q06_3B</td>
</tr>
<tr>
<td>Has [CHILD’S NAME]’s health conditions caused financial problems for your family? (C9Q05)</td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

*16 different reasons listed for not receiving all the needed care – of interest for the financial definition of underinsurance is (1) [because] COST WAS TOO MUCH

**If > 1 of these items above were true, then the child was classified as underinsured according to the financial definition of underinsurance.

Table 4. NS-CSHCN Survey Items for Financial Definition of Underinsurance
Table 5 shows that structural underinsurance was measured by the following survey items: C4Q03_1; C4Q05_1/1A/1B, C4Q05_2/2A/2B, C4Q05_31/31A/31B & C4Q05_32/32A/32B, C4Q05_4/4A/4B through C4Q05_7/7A/7B; C4Q06_1/1A/1B through C4Q06_3/3A/3B.

<table>
<thead>
<tr>
<th>Survey Item Description**</th>
<th>Needed Services? (Yes)</th>
<th>Received all needed care? (No)</th>
<th>Reasons for not receiving care? (3, 4)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>During the past 12 months, did you have any difficulties or delays getting services for [CHILD’S NAME] because [he/she] was not eligible for the services? (C4Q03_A)***</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>During the past 12 months, was there any time when [CHILD’S NAME] needed the following services: (C4Q05)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Well child check up</td>
<td>C4Q05_1</td>
<td>C4Q05_1A</td>
<td>C4Q05_1B</td>
</tr>
<tr>
<td>Specialty care</td>
<td>C4Q05_2</td>
<td>C4Q05_2A</td>
<td>C4Q05_2B</td>
</tr>
<tr>
<td>Preventive dental care</td>
<td>C4Q05_31</td>
<td>C4Q05_31A</td>
<td>C4Q05_31B</td>
</tr>
<tr>
<td>Other dental care</td>
<td>C4Q05_32</td>
<td>C4Q05_32A</td>
<td>C4Q05_32B</td>
</tr>
<tr>
<td>Prescription medications</td>
<td>C4Q05_4</td>
<td>C4Q05_4A</td>
<td>C4Q05_4B</td>
</tr>
<tr>
<td>Physical, occupational, or speech therapy</td>
<td>C4Q05_5</td>
<td>C4Q05_5A</td>
<td>C4Q05_5B</td>
</tr>
<tr>
<td>Mental health care/counseling</td>
<td>C4Q05_6</td>
<td>C4Q05_6A</td>
<td>C4Q05_6B</td>
</tr>
<tr>
<td>Substance abuse treatment or counseling (children 8-17 years)</td>
<td>C4Q05_7</td>
<td>C4Q05_7A</td>
<td>C4Q05_7B</td>
</tr>
<tr>
<td>During the past 12 months, was there any time when you or other family members needed the following: (C4Q06)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Respite care</td>
<td>C4Q06_1</td>
<td>C4Q06_1A</td>
<td>C4Q06_1B</td>
</tr>
<tr>
<td>Genetic counseling</td>
<td>C4Q06_2</td>
<td>C4Q06_2A</td>
<td>C4Q06_2B</td>
</tr>
<tr>
<td>Mental health care/counseling</td>
<td>C4Q06_3</td>
<td>C4Q06_3A</td>
<td>C4Q06_3B</td>
</tr>
</tbody>
</table>

*16 different reasons listed for not receiving all the needed care – of interest for the structural definition of underinsurance are (3) HEALTH PLAN PROBLEM (plan would not cover service) and (4) CAN’T FIND PROVIDER WHO ACCEPTS CHILD’S INSURANCE

**If > 1 of these items above is true, then the child was underinsured according to the structural definition of underinsurance.

***Eligibility for services implies that the health care service was not covered by the health plan and/or the child could not get approval from his/her doctor or health plan.

Table 5. NS-CSHCN Survey Items for Structural Definition of Underinsurance

Attitudinal insurance was also measured by three survey questions, which are shown below in Table 6. These included survey items C8Q01_A, C8Q01_B, and C8Q01_C. Note that it
was possible for CSHCN to be classified as underinsured in more than one way (e.g., financially underinsured and structurally underinsured) due to the fact that the categories of underinsurance are not mutually exclusive.

<table>
<thead>
<tr>
<th>Survey Item Description</th>
<th>Survey Item</th>
<th>Survey Response*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does [CHILD’S NAME]’s health insurance offer benefits or cover services that meet [his/her] needs? <em>(only children with current insurance)</em></td>
<td>C8Q01_A</td>
<td>No</td>
</tr>
<tr>
<td>Are the costs not covered by [CHILD’S NAME]’s health insurance reasonable? <em>(only children with current insurance)</em> [Never or Sometimes]</td>
<td>C8Q01_B</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Does [CHILD’S NAME]’s health insurance company allow [him/her] to see the health care providers he/she needs? <em>(only children with current insurance)</em> [Never or Sometimes]</td>
<td>C8Q01_C</td>
<td>Sometimes</td>
</tr>
</tbody>
</table>

*If > 1 of these survey responses above are true, then the child is underinsured according to the attitudinal definition of underinsurance.

Table 6. NS-CSHCN Survey Items for Attitudinal Definition of Underinsurance

Coding of responses for survey items was binary. Responses of “Yes” for a Yes/No question, “Never” (1) or “Sometimes” (2) were coded as “1” for qualifying as being underinsured. All other responses (“No”, “Usually”, “Always” and “Other”) were coded as “0” and did not qualify CSHCN as being underinsured.

6.3.4 Statistical Methods

Prior to determining any associations, univariate analyses were performed to obtain descriptive statistics. The primary purpose of these univariate analyses was to describe the CSHCN population that was continuously insured for the last 12 months, which is the sample of interest for Study 1. These descriptive statistics are shown in Table 7. Specifically, descriptive statistics for the following variables were obtained for all insured CSHCN, which is the population of interest for Study 1 analyses of underinsurance: each type of insurance status (public, private, both public and private, or other), household income, age, gender, race/ethnicity, family structure (single mother or other), parental education, condition...
complexity (prescription medication usage only or other), condition severity (low, moderate or high), number of health conditions reported (1, 2, 3, or 4 or more up to 20 total), number of functional difficulties (any, 1, 2, 3, or 4 or more up to 14 total), no conditions and no difficulties reported, no difficulties and 1 or more conditions reported, no conditions and 1 or more difficulties reported, and both conditions and difficulties reported.

Bivariate analyses were used to investigate associations between the condition-specific indicators of interest and insurance status, in order to explain how condition-specific characteristics and demographics vary depending on insurance status. Bivariate analysis included cross-tabulations between type of insurance (private only, public only, or both private and public) and the following independent variables: (1) demographic variables (race/ethnicity, family structure, and parental education), (2) financial variables (household income), and (3) specific condition characteristics (condition complexity, condition severity, number of health conditions, and number of functional limitations). The results of these bivariate analyses are shown in Table 33, with separate columns for each type of insurance coverage (private only, public only, or both private and public insurance coverage).

All three types of underinsurance (the three dependent variables) were binary responses (yes/no dummy coded 0, 1) and all independent variables were categorical or continuous. Binary logistic regression (LOGIT) techniques were used to examine the relationship of interest between condition-specific characteristics and underinsurance. An alternative model is a linear probability model (ordinary least squares approach). This approach is less desirable because it would (1) not have addressed issues of heteroskedasticity, (2) would have resulted in a non-normal distribution of errors, and (3) would have yielded predicted probabilities that could be greater than 1 or less than 0. Logistic regression is employed when the dependent variable (Y) is dichotomous, rather than continuous and approximately normal with respect to
its distribution. Logistic regression models are a form of generalized linear models \[ g(E(y|x) = B0 + B1x + ...), \] where the link function, \( g(\mu) \), is defined as the logit.

Multiple logistic regression was also used to examine if two or more independent variables in the model for Study 1 were predictors for the dependent variable, underinsurance. Additionally, collinearity between two predictor variables and multicollinearity between more than two predictor variables was determined by whether there was a non-zero correlation between the variables by examining the following two diagnostic factors as part of the collinearity statistics: tolerance and Variance Inflation Factor (VIF). Specifically, a tolerance statistic \( (1-R^2) \) below 0.20 was the threshold used to determine if further investigation would be warranted. This value is interpreted as indicating that at least 80% of the variance of the independent variable is being shared with other independent variables.

Typically, situations in which the tolerance value is low and accompanied by large standard errors and non-significance indicate an almost perfect linear combination of the independent variables in the model and imply that the independent variable should not be added to the regression equation. Secondly, the VIF \( (1/Tolerance) \) measures the impact of collinearity in a regression model and is always greater than or equal to one. Although there is no formal VIF value for determining the presence of multicollinearity, the literature generally assumes that values of VIF above 10 may indicate multicollinearity (Regression with SPSS, Chapter 2). Because of problems related to multicollinearity in Study 1, no single LOGIT model contained all of the independent variables in the study. In order to examine all potentially significant variables, different models (a-d) were used for different sets of variables if multicollinearity was an issue (Hosmer et al., 2013). Appendix A has additional details on these separate models, which were used for the results reported in Tables 8 and 9.
Statistical analyses for Study 1 encompassed a number of formal comparisons, and when multiple statistical tests or comparisons are being performed simultaneously on a single data set, this increases the chances of obtaining false-positive results (Type I errors). This problem of multiple comparisons is commonly compensated for through the use of the Bonferroni method or correction, which is an adjustment made to the p-values to mitigate this risk of false positives when a large number of significance tests are involved in a study. However, due to the large sample size for Study 1, a p-value < 0.001 was used for the significance level for each aim and sub-aim despite the number of comparisons involved. This p-value was deemed to be appropriate because, even if up to 50 comparisons were conducted, 0.001 would still be a conservative estimate (standard p-value < 0.05/50 = 0.001).

Survey weights were used rather than using unweighted data since the 2009/10 NS-CSCN oversampled based on multiple demographics and preliminary data analyses demonstrated that estimates were not equivalent when using survey weights versus unweighted data. Another rationale for utilizing survey weights was that the study sample was not large enough to provide estimates specific to the U.S. population, so conclusions may be drawn about the general population of CSHCN from study results.

The initial model that was tested for each type of underinsurance in Study 1 is presented below and included all aforementioned independent variables, demographics, and financial characteristics described for CSHCN.

\[
g(E(\text{underinsurance})) = \beta_0 + \beta_1(\text{condition complexity}) + \beta_2(\text{condition severity}) + \beta_3(\text{health conditions}) + \beta_4(\text{functional difficulty}) + \beta_5(\text{age}) + \beta_6(\text{gender}) + \beta_7(\text{parental education}) + \beta_8(\text{family structure}) + \beta_9(\text{residence}) + \beta_{10}(\text{household income}) + \beta_{11}(\text{insurance status}) + \beta_{12}(\text{welfare recipient}) + \beta_{13}(\text{SSI recipient})
\]
Each parameter (β) is presented as \( \text{exp}(β) \) or odds ratio (OR), since odds ratios provide an estimate of the likelihood of a given outcome relative to a reference category for the independent variable. The results are presented in terms of odds ratios (exponential coefficient), 95% confidence intervals and p-values. For example, when considering financial underinsurance (1 = yes; 0 = no) as the dependent variable and condition severity as the independent variable (with categories of low condition severity, moderate condition severity, and high condition severity and the reference category as low severity), an adjusted odds ratio of 1.396 for high condition severity would be interpreted as the likelihood of being financially underinsured for CSHCN with high condition severity versus CSHCN with low condition severity.

6.4 Study 1 Results

*Descriptive Statistics – Financial Independent Variables*

The descriptive statistics in Table 7 show that the sample of CSHCN who were continuously or consistently insured during the past 12 months constituted 90.7% of the entire CSHCN survey population. With respect to insurance coverage, more than half (62.9%) of the sample of continuously insured CSHCN had private insurance only, while nearly one-third (27.6%) had public insurance only. A much smaller percentage of continuously insured CSHCN had both public and private insurance combined (7.5%). Tables 7 and 8 show a breakdown of health insurance coverage by type for the entire population of CSHCN, including those who were not consistently or continuously insured in the last 12 months. A comparison between the sample of continuously insured CSHCN and the overall CSHCN survey population showed that slightly more CSHCN in the overall survey population were publicly insured (35.9% overall vs. 27.6% for continuously insured CSHCN) or had both public and private insurance coverage (8.2% overall vs. 7.9% for continuously insured CSHCN).
Descriptive Statistics – Family Structure and Parental Education (Independent Variables)

Descriptive statistics about family structure and parental education are also summarized in Table 7. In terms of family structure, nearly one-third of households for continuously insured CSCHN were single mother households, also known as “mother-only”, with no second parent/guardian present in the household. All other family structures (two-parent household or other non-single mother households) comprised 71.2% of the continuously insured CSHCN sample. Similarly, nearly one-third of parents (28.6%) for the sample of continuously insured CSHCN had attained a high school education or less as the highest level of parental education.

Descriptive Statistics – Specific Condition Characteristics (Independent Variables)

As shown in the descriptive statistics for Table 7, more than half of continuously insured CSHCN had a condition of low severity (58.0%), at a complexity level that consisted of qualifying for special health care needs due to prescription medication usage only (79.4%). One-third of continuously insured CSHCN had a condition of moderate severity (32.4%), while 20.6% qualified for special health care needs due to other elevated service use or needs. One health condition (34.5%) was most frequently reported, followed by two health conditions (32.5%). Most continuously insured CSHCN also reported one functional difficulty (31.2%), although slightly more than one-fourth (26.3%) reported four or more functional difficulties. The majority of continuously insured CSHCN (81.7%) had at least one health condition and one functional difficulty (both conditions and difficulties).
<table>
<thead>
<tr>
<th>Survey Item†</th>
<th>% CSHCN in survey</th>
<th>n***</th>
<th>Pop. Est.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance status: consistently insured for past 12 months (items below from this sample)</td>
<td>90.7%</td>
<td>37,043</td>
<td>10,031,355</td>
</tr>
<tr>
<td>→ Private insurance only (financial characteristic)</td>
<td>62.9%</td>
<td>23,300</td>
<td>6,309,722</td>
</tr>
<tr>
<td>→ Public insurance only (financial characteristic)</td>
<td>27.6%</td>
<td>10,224</td>
<td>2,768,654</td>
</tr>
<tr>
<td>→ Both public and private insurance (financial characteristic)</td>
<td>7.5%</td>
<td>2,778</td>
<td>752,352</td>
</tr>
<tr>
<td>→ Other insurance (financial characteristic)</td>
<td>2.0%</td>
<td>741</td>
<td>200,627</td>
</tr>
<tr>
<td>→ Financial - income level: At or above 300% FPL (vs. below 300% FPL)</td>
<td>55.0%</td>
<td>20,374</td>
<td>5,517,245</td>
</tr>
<tr>
<td>→ Demographic – age of child: 0-5 years</td>
<td>20.8%</td>
<td>7,294</td>
<td>2,307,940</td>
</tr>
<tr>
<td>→ Demographic – age of child: 6-11 years</td>
<td>38.7%</td>
<td>15,834</td>
<td>4,292,126</td>
</tr>
<tr>
<td>→ Demographic – age of child: 12-17 years</td>
<td>40.5%</td>
<td>17,114</td>
<td>4,501,684</td>
</tr>
<tr>
<td>→ Demographic – gender of child: male (vs. female)</td>
<td>59.4%</td>
<td>22,004</td>
<td>5,958,625</td>
</tr>
<tr>
<td>→ Demographic – race/ethnicity of child: White, non-Hispanic</td>
<td>66.3%</td>
<td>24,559</td>
<td>6,650,788</td>
</tr>
<tr>
<td>→ Demographic – race/ethnicity of child: Black, non-Hispanic</td>
<td>15.7%</td>
<td>5,816</td>
<td>1,574,923</td>
</tr>
<tr>
<td>→ Demographic – race/ethnicity of child: Hispanic</td>
<td>10.9%</td>
<td>4,038</td>
<td>1,093,418</td>
</tr>
<tr>
<td>→ Demographic – race/ethnicity of child: Other minority, non-Hispanic</td>
<td>6.6%</td>
<td>2,445</td>
<td>662,069</td>
</tr>
<tr>
<td>→ Demographic – family structure: mother-only (vs. all other households)</td>
<td>28.8%</td>
<td>10,668</td>
<td>2,889,030</td>
</tr>
<tr>
<td>→ Demographic – parental education: ≤ high school (vs. &gt; high school)</td>
<td>28.6%</td>
<td>10,594</td>
<td>2,868,967</td>
</tr>
<tr>
<td>→ Condition complexity: Other reason§ (vs. Rx medication usage only)</td>
<td>20.6%</td>
<td>7,631</td>
<td>2,066,459</td>
</tr>
<tr>
<td>→ Condition severity: Low severity (3-5) (based on summary score^)</td>
<td>58.0%</td>
<td>21,485</td>
<td>5,818,186</td>
</tr>
<tr>
<td>→ Condition severity: Moderate severity (6-9) (based on summary score^)</td>
<td>32.4%</td>
<td>12,002</td>
<td>3,250,159</td>
</tr>
<tr>
<td>→ Condition severity: High severity (≥ 10) (based on summary score^)</td>
<td>9.6%</td>
<td>3,556</td>
<td>963,010</td>
</tr>
<tr>
<td>→ No. of health conditions reported: None</td>
<td>9.0%</td>
<td>3,334</td>
<td>902,822</td>
</tr>
<tr>
<td>→ No. of health conditions reported: 1</td>
<td>34.5%</td>
<td>12,780</td>
<td>3,460,817</td>
</tr>
<tr>
<td>→ No. of health conditions reported: 2</td>
<td>32.5%</td>
<td>12,039</td>
<td>3,260,190</td>
</tr>
<tr>
<td>→ No. of health conditions reported: 3</td>
<td>13.8%</td>
<td>5,112</td>
<td>1,384,327</td>
</tr>
<tr>
<td>→ No. of health conditions reported: ≥ 4 (up to 20)</td>
<td>10.2%</td>
<td>3,778</td>
<td>1,023,198</td>
</tr>
<tr>
<td>→ No. of functional difficulties: Any</td>
<td>16.0%</td>
<td>5,927</td>
<td>1,605,017</td>
</tr>
<tr>
<td>→ No. of functional difficulties: 1</td>
<td>31.2%</td>
<td>11,557</td>
<td>3,129,783</td>
</tr>
</tbody>
</table>

Table 7. Study 1 Descriptive Statistics for All Insured CSHCN (Univariate Analysis)
Table 7 continued

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>% CSHCN in survey</th>
<th>n ***</th>
<th>Pop. Est.</th>
</tr>
</thead>
<tbody>
<tr>
<td>→ No. of functional difficulties: 2</td>
<td>15.5%</td>
<td>5,742</td>
<td>1,554,860</td>
</tr>
<tr>
<td>→ No. of functional difficulties: 3</td>
<td>11.0%</td>
<td>4,075</td>
<td>1,103,449</td>
</tr>
<tr>
<td>→ No. of functional difficulties: ≥ 4 (up to 14)</td>
<td>26.3%</td>
<td>9,742</td>
<td>2,638,246</td>
</tr>
<tr>
<td>No conditions and no difficulties</td>
<td>2.9%</td>
<td>1,304</td>
<td>319,434</td>
</tr>
<tr>
<td>No difficulties, 1 or more conditions</td>
<td>6.0%</td>
<td>2,586</td>
<td>662,726</td>
</tr>
<tr>
<td>No conditions, 1 or more difficulties</td>
<td>9.4%</td>
<td>3,687</td>
<td>1,044,019</td>
</tr>
<tr>
<td>Both conditions and difficulties</td>
<td>81.7%</td>
<td>32,665</td>
<td>9,075,571</td>
</tr>
</tbody>
</table>

Note: Survey weights were utilized to derive all calculations of n for each of the above survey items. Unweighted calculations were not equivalent to weighted calculations, partly due to the fact that the survey oversampled based on particular demographic characteristics such as race/ethnicity.

Subset of those CSHCN consistently insured for last 12 months

*Insurance coverage status AT TIME OF SURVEY

Total n = 40,242 (entire CSHCN population included in 2009/10 NS-CSHCN). Totals may not always sum to 40,242 since unknown values (responses coded as “refused”, “don’t know”, or system missing) are not included in the denominator count. Missing data counts for each variable were found to be less than 5% of the overall value for each variable; multiple imputation will therefore be unnecessary.

Other reasons could include (1) elevated service use or needs; (2) functional limitations; (3) use of special therapies; or (4) ongoing emotional, developmental, or behavioral conditions. Children may have qualified under multiple reasons, so totals (if reported separately) do not add up to 100%.

Based on preliminary analyses, approximately 1% of respondents had missing data with respect to the variables of interest. See Appendix A for details.

Summary score is a combination of the following three variables: (1) the amount of time the child is affected by the condition, (2) the severity rating of the difficulties caused by the condition, and (3) the pervasiveness of the condition (pervasiveness is defined by the number of qualifying reasons the child had for being included in the survey). See Appendix A for additional details on measurement of the summary score.

**Regression Factors Associated with Underinsurance**

Table 8 shows odds ratios for underinsurance (financial, structural and attitudinal) based on Study 1 covariates: age, gender, race/ethnicity, family structure, education, income, and insurance. Table 9 has unadjusted and adjusted odds for underinsurance based on (1) condition severity, (2) condition complexity, (3) health conditions, and (4) functional difficulties.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds of Underinsurance by Definition*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(95% Confidence Interval for Odds: LL-UL)</td>
</tr>
<tr>
<td>Age of child: Mean = 10.2 years**</td>
<td>1.029 (CI: 0.929-1.129)</td>
</tr>
<tr>
<td>Gender: Male (ref) vs. Female**</td>
<td>0.906 (CI: 0.759-1.093)</td>
</tr>
<tr>
<td>Race/Ethnicity of child*: White, non-Hispanic (ref)</td>
<td></td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>1.166 (CI: 0.895-1.236)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.185 (CI: 0.938-1.432)</td>
</tr>
<tr>
<td>Other minority, non-Hispanic</td>
<td>1.123 (CI: 0.933-1.213)</td>
</tr>
<tr>
<td>Family structure: Mother-only (ref) vs. others**</td>
<td>1.169 (CI: 0.804-1.434)</td>
</tr>
<tr>
<td>Parental education: ≤ HS (ref) vs. &gt; HS**</td>
<td>1.097 (CI: 0.823-1.371)</td>
</tr>
<tr>
<td>Income: &lt; 300% FPL (ref) vs. ≥ 300% FPL^+</td>
<td>1.322 (CI: 0.991-1.653)</td>
</tr>
<tr>
<td>Type of Insurance*: Public (ref)/private/both</td>
<td></td>
</tr>
<tr>
<td>Private Only (vs. public only)</td>
<td>2.376 (CI: 2.053-2.699)</td>
</tr>
<tr>
<td>Both Private &amp; Public (vs. public only)</td>
<td>1.815 (CI: 1.403-2.227)</td>
</tr>
</tbody>
</table>

Table 8. Study 1 Demographics – Odds of Underinsurance for Insured CSHCN
Footnotes for Table 8:
*Based on these definitions of underinsurance, n = 14,817 for CSHCN who were not underinsured in any way –40.0% of CSHCN who were continuously insured during the past 12 months were adequately insured/not underinsured based on the three definitions of underinsurance utilized in this study.
* Original coding from survey retained; all coded as binary variables exc. age (continuous variable)
^ Original coding presented all possibilities in one variable; levels were recoded into dummy variables for each category of race/ethnicity.
^ Original coding presented all types of insurance status in one variable, including uninsured (not relevant to this study). Insured categories were recoded into dummy variables for each category (binary): private (includes military coverage), public only (includes Medicaid, SCHIP, Medicare, and Medigap), and both private & public (includes other comprehensive, in which interviewer was unable to determine sources of various coverage).

>> Notes: 1) Each parameter (βeta) is presented as (expβeta), since it can be interpreted more easily as the odds of being underinsured (the dependent variable) related to a “one unit increase” in the independent variable (e.g., the difference between being male or female, in the case of a binary variable like gender; or an additional level of severity or an additional health condition, in the case of a continuous variable that has been split into multiple levels).
2) Because of problems related to multicollinearity (more than one independent variable; VIF scores obtained after regression to identify degree of collinearity), no single LOGIT model contained all of the independent variables below. In order to examine all potentially significant variables, different models (a-d) were used for different sets of variables if multicollinearity was an issue (Hosmer et al., 2013). See Appendix A for model details, used in Tables 8 and 9.

Descriptive Statistics – Underinsurance (Dependent Variable)

Figure 7 shows the results for CSHCN who were classified as underinsured. Approximately one-third (32.2% or 11,928 CSHCN) were attitudinally underinsured, while approximately one-fourth (23.0% or 8,520 CSHCN) were financially underinsured. Only 4.8% of the continuously insured CSHCN sample was structurally underinsured. The definitions for each type of underinsurance are provided earlier in the Methods section.
Figure 7. Study 1 Descriptive Statistics – All Types of Underinsurance and Overlap

Notes: Only those CSHCN who were continuously insured (90.7%) were included. All totals for number of insured CSHCN for each demographic summed to 37,043, the total number of insured CSHCN. If ≥ 1 of the underinsurance items for any category (see above) is true, then the child is underinsured according to that particular definition of underinsurance. The Methods section includes an overall definition of underinsurance and definitions of the three types of underinsurance.
**Condition-Specific Characteristics and Association with Underinsurance**

Table 9 shows unadjusted and adjusted odds ratios for condition-specific characteristics, with separate columns for financial, structural, and attitudinal underinsurance. The adjusted odds ratios for the relationship between condition-specific characteristics and the likelihood of any type of underinsurance were very similar to unadjusted odds ratios for any given condition-specific characteristic, in that there was a less than 10% difference between the adjusted and unadjusted odds ratios. This is likely due to the limited amount of confounding by variables in the multiple regression model utilized for Study 1 (age, gender, race/ethnicity, parental education, and household income).

High condition severity was associated with higher odds of financial and attitudinal underinsurance, when compared to the lowest category of severity (ORs approximately 1.3-1.4; Table 9). For financial underinsurance, adjusted odds ratios for the following variables were statistically significant at p < 0.001: high condition severity (vs. low), other condition complexity (vs. prescription medication usage only), moderate number of health conditions (2-3, vs. low/only one health condition), and high number of health conditions (4 or more, vs. low/only one health condition). For structural underinsurance, none of the four condition-specific characteristics were significant at p < 0.001. Lastly, for attitudinal underinsurance, high condition severity was also found to be statistically significant at p < 0.001.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds of Underinsurance by Definition and 95% Confidence Intervals (p-value &lt; 0.001)**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Financial</strong></td>
</tr>
<tr>
<td></td>
<td>Unadjusted (CI)</td>
</tr>
<tr>
<td><strong>Condition severity:</strong> Low (ref)</td>
<td></td>
</tr>
<tr>
<td>Moderate (vs. low)</td>
<td>1.225 (CI: 1.109-1.341)</td>
</tr>
<tr>
<td>High (vs. low)</td>
<td><strong>1.396</strong> (CI: 1.184-1.608)</td>
</tr>
<tr>
<td><strong>Condition complexity:</strong> Rx only (ref)/Other</td>
<td></td>
</tr>
<tr>
<td>Other (Rx +)</td>
<td><strong>1.611</strong> (CI: 1.466-1.756)</td>
</tr>
<tr>
<td><strong>Health conditions (0-20)</strong>: Low (1 health condition reported) (ref)</td>
<td></td>
</tr>
<tr>
<td>Moderate (2-3) (vs. low)</td>
<td><strong>1.157</strong> (CI: 1.039-1.275)</td>
</tr>
<tr>
<td>High (≥ 4) (vs. low)</td>
<td><strong>1.264</strong> (CI: 1.146-1.382)</td>
</tr>
<tr>
<td><strong>No. of functional difficulties (0-14)</strong>: None (ref)</td>
<td></td>
</tr>
<tr>
<td>Low (1) (vs. none)</td>
<td>0.932 (CI: 0.769-1.095)</td>
</tr>
<tr>
<td>Moderate (2-3) (vs. none)</td>
<td><strong>1.077</strong> (CI: 0.914-1.240)</td>
</tr>
<tr>
<td>High (≥ 4) (vs. none)</td>
<td><strong>1.126</strong> (CI: 0.963-1.289)</td>
</tr>
</tbody>
</table>

*Adjusted for age, gender, race/ethnicity, family structure, parental education, income and insurance status (identified as potential confounders for Study 1). As demonstrated above, adjusted results were less than 10% different compared to unadjusted results, suggesting limited confounding due to these variables.

**Result is statistically significant at p < 0.001.

Note: Based on these definitions of underinsurance, 14,817 CSHCN were not underinsured in any way – in other words, 40.0% of CSHCN who were continuously insured during the past 12 months were adequately insured/not underinsured based on the three definitions of underinsurance.

Table 9. Study 1 Condition-Specific Characteristics (Unadjusted vs. Adjusted* Odds)
Bivariate Analysis – Insurance Type and Selected Variables

Bivariate analysis of independent variables included cross-tabulations between type of insurance (private only, public only, or both private and public) and (1) selected demographic variables (race/ethnicity, family structure, and parental education), (2) financial variables (household income), and (3) specific condition characteristics (condition complexity, condition severity, number of health conditions, and number of functional limitations). The results of these bivariate analyses are shown in Table 33, with separate columns for each type of insurance coverage (private only, public only, or both private and public insurance coverage).

Results revealed that CSHCN who had private insurance only were more likely to be White, non-Hispanic CSHCN (76.7% of CSHCN). CSHCN of a racial/ethnic minority (Black, non-Hispanic; or Hispanic) were more likely to have public insurance (29.2% of publicly insured CSHCN vs. 8.7% of privately insured CSHCN were Black; and 17.9% of publicly insured CSHCN vs. 7.8% of privately insured CSHCN were Hispanic). Overall, CSHCN who had public insurance only or both public and private insurance combined were also more likely than CSHCN with private insurance only to be in single mother households, to be in households where the highest level of parental education was high school or less, and to be of Black or Hispanic descent.

A very small percentage of privately insured CSHCN were from single mother households (9.6% of CSHCN), with the vast majority of privately insured CSHCN being part of all other, non-single mother households (90.4%). These non-single mother households consisted primarily of two-parent, biological or adoptive families (68.8% with private insurance) or two parent families with at least one step-parent (45.5% with private insurance), which is noted in the footnotes for Table 33 since analyses were not conducted on separate categories of non-single mother households. Parental education revealed a similar breakdown with respect to type of insurance coverage. Nearly 84.3% of privately insured CSHCN came from households
where the parental education was greater than high school level. These results for family structure and parental education, in addition to details about condition-specific characteristics and their relation to insurance coverage, are also summarized in Table 33 in Appendix A.

The adjusted odds ratios and corresponding confidence intervals for all covariates and condition-specific characteristics are presented in Table 9, which summarizes the main findings for Study 1. Specifically, the odds of being underinsured in any way – either financially, structurally, or attitudinally – are adjusted for all of the aforementioned covariates: age, gender, race/ethnicity, family structure, parental education, income and insurance status and are presented for the four condition-specific characteristics in Study 1: condition severity, condition complexity, number of health conditions, and number of functional difficulties. These odds of underinsurance revealed the following trend with respect to condition-specific characteristics: as condition severity, condition complexity, number of health conditions, and number of functional difficulties increased or worsened, the odds of underinsurance also increased for each of the four condition-specific characteristics.

### 6.5 Study 1 Discussion

By examining underinsurance within subgroups of CSHCN with condition-specific characteristics and stratifying CSHCN based on type of insurance (public, private, and other), results from Study 1 add to the body of literature on underinsurance for CSHCN and identified specific risk factors for CSHCN that may contribute to their likelihood of underinsurance. In particular, findings from Study 1 demonstrated a positive correlation between financial underinsurance and the following condition-specific characteristics: condition severity, condition complexity and the number of health conditions. Based on information from this national dataset, as condition severity, condition complexity (any needs greater than
prescription medication) and number of health conditions increase, the odds of being financially underinsured also increased for CSHCN. Another statistically significant finding was the positive correlation between condition severity and attitudinal underinsurance, such that the odds of being attitudinally underinsured increased for CSCHN as their condition severity increased.

With respect to specific demographic characteristics, such as income, Study 1 examined whether living below 300% FPL may influence the likelihood of underinsurance. Within a particular subgroup of insurance, particularly those CSHCN who have private insurance, CSHCN are more likely to be underinsured if they are in families with incomes below 300% of the FPL. Additionally, CSHCN who are non-Hispanic or in families with incomes at or above 300% of the FPL were less likely to be underinsured based on any of the three definitions of underinsurance. These results indicate that race/ethnicity and income are factors for underinsurance.

Overall, Study 1 findings underscore the importance of looking at CSHCN not simply as insured or uninsured, but as a vulnerable population that experiences underinsurance due to variations in many other factors, including condition-specific characteristics such as condition severity, complexity, health conditions and functional difficulties/limitations. Previous research has demonstrated that health services obstacles faced by underinsured children are similar in burden to those encountered by uninsured children, and that CSHCN have a higher risk of underinsurance than other children (Kogan et al., 2010). In this study, even CSHCN with consistent insurance for the entire year prior to survey interview experienced gaps in care, with respect to being able to adequately meet health service needs. Thus, an important finding is that CSHCN with particular condition-specific characteristics, such as increased condition severity, were more likely to be underinsured than other CSHCN.

Earlier studies have found that publicly insured CSHCN also had a lower rate of underinsurance compared to privately insured CSHCN, which may be due to the fact that
Medicaid provides better coverage of long-term benefits such as specialized therapies, with little or no copayment required (Kogan et al., 2010). Findings from this study demonstrated a similar relationship between public insurance and odds of underinsurance, in that publicly insured CSHCN from the NS-CSHCN were also less likely to be underinsured, compared to privately insured CSHCN. Additionally, the literature indicates that higher health care utilization results in higher unreimbursed costs of care and that current reimbursement policies do not adequately support physician time and effort required to develop partnerships with families and other health care providers (Antonelli et al., 2008; Bodenheimer, 2008). At the point of care level, this is a disincentive for motivated providers to comprehensively address the myriad of needs for CSHCN who may be underinsured due to the complexity, severity or magnitude of health conditions and functional limitations that they experience.

6.5.1 Limitations

Since respondents of the NS-CSHCN are parents/guardians and not health care providers of CSHCN, the integrity of the data provided by the NS-CSHCN may be affected by recall bias, as well as other forms of respondent bias due to a parent respondent’s inability to answer a question accurately or unwillingness to respond honestly about their child’s health condition or functional abilities. The results from the survey are weighted to reflect the population of CSHCN ages 0-17, at the state and national level. Therefore, further subsetting of the survey data to a specific population subgroup, such as a particular racial/ethnic group or poverty level, would lead to incorrect standard error estimation. For this reason, conclusions can not be drawn at a subpopulation level, aside from generalizations for an entire state or nationally.

Also, a major limitation of the cross-sectional data derived from the NS-CSHCN is that it is does not allow for causal inferences, since measurements were taken only at one point in
time. Therefore, all results from the three studies are presented solely as associations, because causal relationships cannot be substantiated. Additionally, as is the case with many other national surveys of this scale, only non-institutionalized CSHCN and those who have permanent residences were interviewed for the NS-CSCHN. For this reason, families with CSHCN living in institutions or families who are homeless or migrants are underrepresented in the survey data. Results from the studies are representative only of non-institutionalized CSHCN ages 0-17.

Lastly, errors in the measurement of underinsurance may also have contributed to some of the observed variances in underinsurance rates across different groups of CSHCN that were analyzed for Study 1. In particular, since there is no one consistently utilized definition of underinsurance, it is possible that alternative definitions of underinsurance may lead to different results. Additionally, because there was no evaluation of actual insurance policies that CSHCN had, only parent-report was used to determine underinsurance, including structural underinsurance (which involves the coverage and benefits of the insurance policy or plan). A more accurate and comprehensive examination of insurance policies would be beneficial when determining the true extent of structural underinsurance for CSHCN.
Chapter 7. Study 2: Care Coordination

7.1 Study 2 Aims

**Aim 2a:** Determine the percentage of CSHCN receiving care coordination depending on condition-specific characteristics (e.g., condition complexity, condition severity, number of health conditions, and number of functional difficulties), taking into account demographics such as age, gender, race/ethnicity, and household income.

**Hypothesis 2a(1) – Condition Complexity:** Among CSHCN with the same type of insurance coverage, there will be fewer CSHCN with “any other needs” who receive care coordination, compared to CSHCN with a disability that requires “medication only,” which is indicative of a less complex condition.

**Hypothesis 2a(2) – Condition Severity:** Among CSHCN with the same type of insurance coverage, there will be fewer CSHCN who have higher condition severity that receive care coordination, compared to CSHCN who have lower condition severity.

**Hypothesis 2a(3) – Health Conditions:** Among CSHCN with the same type of insurance coverage, there will be fewer CSHCN who have more than one health condition who receive care coordination, compared to CSHCN who have only one health condition.

**Hypothesis 2a(4) – Functional Difficulties/Limitations:** Among CSHCN with the same insurance coverage, there will be fewer CSHCN who have functional limitations who receive care coordination, compared to CSHCN who do not have functional limitations.
Aim 2b: Examine if receipt of care coordination is associated with reductions in (1) any unmet need, (2) unmet need for preventive care, (3) unmet need for specialty care, (4) unmet need for therapeutic services, and (5) unmet need for support services, accounting for insurance status and demographics such as age, gender, race/ethnicity, and household income.

Hypothesis 2b: Among CSHCN with the same type of insurance coverage, CSHCN who receive care coordination will be less likely to have (1) any unmet need overall, (2) unmet need for preventive care, (3) unmet need for specialty care, (4) unmet need for therapeutic services, and (5) unmet need for support services.

7.2 Study 2 Background and Significance

Care coordination is a necessary and beneficial mechanism in health services delivery, as it allows for continuity of care beyond the level of specific episodes of illness or disease (Haggerty et al, 2003). Research conducted by the Institute of Medicine (2010) has also shown that the current lack of health services coordination in the U.S. health system is a major driving force for the absence of effective and efficient health services provision. For CSHCN, the number of relationships among providers and between providers and families can multiply geometrically, as multiple caregivers must interact with the child and distinct family members (Bodenheimer, 2008). Consequently, care coordination that is offered in primary care settings can aid families and CSHCN in accessing and managing a myriad of health and related services in a more efficient, effective, and organized manner (AAP, 2005).

The literature demonstrates that CSHCN have a complex array of health conditions, functional limitations, and other needs, all of which must be addressed by our current system of care to promote the health of CSHCN and improve their functionality, quality of life, and ability to integrate into the community (Stein & Silver, 2005). An analysis of condition-specific
characteristics and their association with care coordination would therefore add to the current literature on CSHCN. An analysis of care coordination as it relates to unmet need for CSHCN would show whether coordination of care alone is associated with reductions of unmet need.

7.3 Study 2 Research Methods

7.3.1 Participants

The overall study population for this dissertation included children with special health care needs (CSHCN) from 0 to 17 years of age whose parents or caregivers were surveyed in the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN). Of the 372,698 children screened, 59,941 were identified with special health care needs, and in-depth interviews were subsequently completed for a total of 40,242 CSHCN. This total included approximately 750 interviews per state and the District of Columbia, with a range of 751 in the District of Columbia to 878 in Texas. For Study 2a, CSHCN were compared based on whether or not they received care coordination, since the study questions involved determining whether condition-specific characteristics were associated with the receipt of effective care coordination. For Study 2b, the outcome of interest was whether or not CSHCN receiving effective care coordination – which was defined as receiving care coordination when needed if CSHCN received two or more services – were more or less likely to have unmet needs.

7.3.2 Data Source

All data for this study was obtained from the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN), sponsored by the Maternal and Child Health Bureau, the U.S. Department of Health and Human Services, and the Health Resources and Services Administration. The NS-CSHCN is a national telephone survey that was conducted for the third time in 2009-10. Previous administrations of the survey took place in 2000-2001 and 2005-2006.
Independent random samples were taken in all 50 states and the District of Columbia, with at least 750 interviews conducted in each state and the District of Columbia. Its primary goal was to assess the prevalence and impact of special health care needs among children under age 18 in all 50 states and the District of Columbia.

A SLAITS approach, developed by the National Center for Health Statistics to quickly and consistently collect information on a variety of health topics at the state and local levels, is used for sampling and data collection for the NS-CSHCN. This mechanism is also used for sampling and data collection for the National Survey of Children’s Health (NSCH), the National Survey of Early Childhood Health, the National Asthma Survey, and the National Survey of Adoptive Parents. The SLAITS study design involves random-digit dialing (RDD) and computer-assisted telephone interviewing (CATI) to annually contact and identify children between ages 0-17. Only landline phone numbers have been included in the study design in previous years; however, for the 2009/10 NS-CSHCN, the sample of landline telephone numbers was supplemented by an independent RDD sample of cell phone numbers. This cell phone sampling was a new feature of the NS-CSHCN, and information is included on whether the respondent was interviewed via landline or cell phone number. SLAITS surveys use the sampling frame from the National Immunization Survey (NIS) for purposes of efficiency and economy.

The following sections are included in the NS-CSHCN interview:

- Section 1: NIS/SLAITS (qualifying question on household having a child less than 18 years old)
- Section 2: Initial Screening (to determine if child has special health care needs)
- Section 3: Health and Functional Status
- Section 4: Access to Care – Use of Services and Unmet Needs
- Section 5: Care Coordination
- Section 6A: Family Centered Care and Shared Decision Making
- Section 6B: Transition Issues
- Section 6C: Developmental Screening
- Section 7: Health Insurance
7.3.3 Variables

Table 10 provides a complete list of all Study 2 variables and their detailed descriptions.

Study 2a: Condition-Specific Characteristics and Care Coordination

The outcome of interest, or dependent variable, in Study 2a was care coordination, as assessed by the patient/family perspective. The study sample included CSHCN whose families used multiple health care services or health care providers and reported a need for care coordination, whether or not they received effective care coordination or not. Table 11 lists NS-CSHCN survey items for care coordination, a dependent variable in Study 2a and an independent variable in Study 2b. The primary independent variables were condition-specific characteristics of CSHCN, which include condition complexity, condition severity, number of health conditions, and number of functional limitations. Table 2 lists survey items from the NS-CSHCN for health
conditions and condition severity, while Table 3 lists survey items for functional difficulties (independent variables for Study 2a).

Demographic characteristics, such as age, gender, race/ethnicity, and parental education, were included in analyses as control variables and as potential confounders. These demographics have been shown in the literature to be related to the independent and dependent variables. Financial characteristics – specifically, household income and insurance status (public only, private only, or both public and private) – were part of the analyses in Study 2a as control variables. Household income was considered a potential confounder, since the literature indicated income influences the likelihood of CSHCN of receiving coordinated care (the dependent variable) and may also influence condition-specific characteristics, such as the number of functional difficulties a CSHCN has (an independent variable).

<table>
<thead>
<tr>
<th>Variable/Survey Item(s)</th>
<th>Description</th>
<th>Role(s) in Study*</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE_X</td>
<td>Age of child</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>C2Q03_X</td>
<td>Gender of child</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>HISPANIC C10Q32_X</td>
<td>Race/ethnicity of child</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>EDUCR_IMP</td>
<td>Highest education level attained by any parent in household</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>FAMSTRUCT (*derived from responses to C11Q01_A thru C10Q05)</td>
<td>Family structure (biological or adopted child, step-family, mother-only, other)</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>C10Q41</td>
<td>Residence</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>POVLEVEL_IMP</td>
<td>Household income (by FPL)</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>C11Q11</td>
<td>Receipt of welfare</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>C11Q12</td>
<td>Receipt of SSI</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>C11Q13</td>
<td>SSI for disability</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>TYPEINS (*derived from Section 7 survey questions)</td>
<td>Insured status (uninsured, private and/or public coverage)</td>
<td>Control variable</td>
</tr>
<tr>
<td>CSHCN1, CSHCN1A_X, CSHCN1B_X; CSHCN5, CSHCN5_A_X</td>
<td>Condition complexity (based on qualification reason from Screener – Rx medication only or other)</td>
<td>Independent variable (Study 2a only)</td>
</tr>
</tbody>
</table>

Table 10. Study 2 Variables

Continued

94
### Table 10 continued

<table>
<thead>
<tr>
<th>Variable/Survey Item(s)</th>
<th>Description</th>
<th>Role(s) in Study*</th>
</tr>
</thead>
<tbody>
<tr>
<td>C3Q02, C3Q03; K2Q31_A/B/C through K2Q27_A/B/C; K2Q40_A/B/C through K2Q52_A/B/C</td>
<td>Condition severity (how often the condition affects the child’s daily life; severity level as indicated by health care provider)</td>
<td>Independent variable (Study 2a only)</td>
</tr>
<tr>
<td>K2Q31_A/B through K2Q52_A/B</td>
<td>Number of current health conditions (from a list of 20 different conditions)</td>
<td>Independent variable (Study 2a only)</td>
</tr>
<tr>
<td>C3Q21 through C3Q34</td>
<td>Number of current functional difficulties (from a list of 14 different difficulties)</td>
<td>Independent variable (Study 2a only)</td>
</tr>
<tr>
<td>C5Q01; C5Q05-C5Q07; C5Q09-C5Q13; C5Q15-C5Q17</td>
<td>Care coordination</td>
<td>Dependent variable (Study 2a); independent variable (Study 2b)</td>
</tr>
<tr>
<td>C4Q05_1/A/B &amp; C4Q05_2/A/B; C4Q05_4/A/B through C4Q05_7/A/B; C4Q05_31/A/B &amp; C4Q05_32/A/B; C4Q06_1/A/B through C4Q06_3/A/B</td>
<td>Unmet need</td>
<td>Dependent variable (Study 2b only)</td>
</tr>
</tbody>
</table>

*Unless otherwise noted, all study variables were used in both Study 2a and Study 2b.

### Table 11. NS-CSHCN Survey Items for Care Coordination

**Survey Item Description**

<table>
<thead>
<tr>
<th>Survey Item Description</th>
<th>Survey Item</th>
<th>Survey Response*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did [CHILD’S NAME] use any other health-related medical, educational, or social services in the past 12 months? <em>(Qualifying question for CSHCN who reported receiving less than two services on K4Q20-21, C4Q05_1A-14A, C4Q05_2C-14C, C3Q12-13, and C3Q15)</em></td>
<td>C5Q01</td>
<td>Yes</td>
</tr>
<tr>
<td>During the past 12 months, did [CHILD’S NAME] need a referral to see any doctors or receive any services?</td>
<td>C5Q11</td>
<td>Yes</td>
</tr>
<tr>
<td>If YES: Was getting referrals a big problem, a small problem, or not a problem?</td>
<td>C4Q07</td>
<td>Not a problem</td>
</tr>
<tr>
<td>If the child received &gt; 2 of these in the past 12 months:</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Does anyone help you arrange or coordinate [CHILD’S NAME]’s care among the different doctors or services that (he/she) uses?</td>
<td>C5Q12</td>
<td>Yes</td>
</tr>
<tr>
<td>If YES: Does a doctor or someone in a doctor’s office provide this help arranging or coordinating [CHILD’S NAME]’s care?</td>
<td>C5Q13</td>
<td>Yes</td>
</tr>
<tr>
<td>If YES to both: Is there anyone else who helps arrange or coordinate [CHILD’S NAME]’s care?</td>
<td>C5Q15</td>
<td>Yes</td>
</tr>
</tbody>
</table>
### Table 11 continued

<table>
<thead>
<tr>
<th>Survey Item Description</th>
<th>Survey Item</th>
<th>Survey Response*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who does provide help arranging or coordinating [CHILD’S NAME]’s care?</td>
<td>C5Q16</td>
<td>N/A</td>
</tr>
<tr>
<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 NAME]’s care among these different health care providers or services?</td>
<td>C5Q17</td>
<td>Yes</td>
</tr>
<tr>
<td>During the past 12 months/Since (his/her) birth, how often did you get as much help as you wanted with arranging or coordinating [CHILD’S NAME]’s care? Would you say never, sometimes, or usually?</td>
<td>C5Q09</td>
<td>Sometimes or usually</td>
</tr>
<tr>
<td>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?</td>
<td>C5Q10</td>
<td>Very/somewhat satisfied</td>
</tr>
<tr>
<td>Do [CHILD’S NAME]’s doctors or other health care providers need to communicate with (his/her) school, early intervention program, child care providers, vocational education or rehabilitation program?</td>
<td>C5Q05</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>If YES:</strong> Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?</td>
<td>C5Q06</td>
<td>Very/somewhat satisfied</td>
</tr>
</tbody>
</table>

*Survey response of interest. If > 1 is true (in addition to “Yes” to the qualifying question, other than responses about needing referrals or needing help), then the child has received coordinated care.

**Study 2b: Care Coordination and Unmet Needs**

The outcome of interest, or dependent variable, in Study 2b was unmet need, measured as either any unmet need or unmet need for one of four types of services (preventive care, specialty care, therapeutic services, and support services). Because Study 2b focuses on CSHCN who have unmet needs, each unmet need was coded as “0” if a parent responded “No” to the question about the particular unmet need or “1” if a parent responded “Yes” to the question about the particular unmet need. Table 12 lists the NS-CSHCN survey items for parent-reported unmet need. The primary independent variable was care coordination, as assessed by the
Table 11 lists NS-CSHCN survey items for care coordination, a dependent variable in Study 2a and an independent variable in Study 2b.

Demographic characteristics and financial characteristics were similar to the analysis for Study 2a. Potential confounders in Study 2b were adjusted for in analyses and included demographic controls such as age, gender, race/ethnicity, parental education, family structure, and socioeconomic status. For example, CSHCN of minority race/ethnicity who reside in a mother-only household, have incomes below the 300% FPL, and/or have parents who have attained less than a high school education, would be more likely to be publicly insured due to those demographic and socioeconomic characteristics.

<table>
<thead>
<tr>
<th>Survey Item Description</th>
<th>Needed Services? (Yes)</th>
<th>Received all needed care? (No)*</th>
<th>Reasons for not receiving care? (Any)</th>
</tr>
</thead>
<tbody>
<tr>
<td>During the past 12 months, was there any time when [CHILD’S NAME] needed the following services: (C4Q05)</td>
<td></td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Well child check up (preventive care)</td>
<td>K4Q20; C4Q05_1</td>
<td>C4Q05_1A</td>
<td>C4Q05_1B</td>
</tr>
<tr>
<td>Specialty care</td>
<td>C4Q05_2</td>
<td>C4Q05_2A</td>
<td>C4Q05_2B</td>
</tr>
<tr>
<td>Preventive dental care</td>
<td>C4Q05_31</td>
<td>C4Q05_31A</td>
<td>C4Q05_31B</td>
</tr>
<tr>
<td>Other dental care</td>
<td>C4Q05_32</td>
<td>C4Q05_32A</td>
<td>C4Q05_32B</td>
</tr>
<tr>
<td>Prescription medications</td>
<td>C4Q05_4</td>
<td>C4Q05_4A</td>
<td>C4Q05_4B</td>
</tr>
<tr>
<td>Physical, occupational, or speech therapy</td>
<td>C4Q05_5</td>
<td>C4Q05_5A</td>
<td>C4Q05_5B</td>
</tr>
<tr>
<td>Mental health care/counseling</td>
<td>C4Q05_6</td>
<td>C4Q05_6A</td>
<td>C4Q05_6B</td>
</tr>
<tr>
<td>Substance abuse treatment/counseling (children 8-17 years)</td>
<td>C4Q05_7</td>
<td>C4Q05_7A</td>
<td>C4Q05_7B</td>
</tr>
<tr>
<td>Home health care</td>
<td>C4Q05_8</td>
<td>C4Q05_8A</td>
<td>C4Q05_8B</td>
</tr>
<tr>
<td>Vision care or eyeglasses</td>
<td>C4Q05_9</td>
<td>C4Q05_9A</td>
<td>C4Q05_9B</td>
</tr>
<tr>
<td>Hearing aids or hearing care</td>
<td>C4Q05_10</td>
<td>C4Q05_10A</td>
<td>C4Q05_10B</td>
</tr>
<tr>
<td>Mobility aids or devices (children 3-17 years)</td>
<td>C4Q05_11</td>
<td>C4Q05_11A</td>
<td>C4Q05_11B</td>
</tr>
</tbody>
</table>

Table 12. NS-CSHCN Survey Items for Unmet Need Continued
Table 12 continued

<table>
<thead>
<tr>
<th>Survey Item Description</th>
<th>Needed Services? (Yes)</th>
<th>Received all needed care? (No)*</th>
<th>Reasons for not receiving care? (Any)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication aids or devices <em>(children 3-17)</em></td>
<td>C4Q05_12</td>
<td>C4Q05_12A</td>
<td>C4Q05_12B</td>
</tr>
<tr>
<td>Durable medical equipment</td>
<td>C4Q05_14</td>
<td>C4Q05_14A</td>
<td>C4Q05_14B</td>
</tr>
<tr>
<td>During the past 12 months, was there any time when you or other family members needed the following: <em>(C4Q06)</em></td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respite care</td>
<td>C4Q06_1</td>
<td>C4Q06_1A</td>
<td>C4Q06_1B</td>
</tr>
<tr>
<td>Genetic counseling</td>
<td>C4Q06_2</td>
<td>C4Q06_2A</td>
<td>C4Q06_2B</td>
</tr>
<tr>
<td>Mental health care/counseling</td>
<td>C4Q06_3</td>
<td>C4Q06_3A</td>
<td>C4Q06_3B</td>
</tr>
</tbody>
</table>

*If > 1 of these survey responses above is true, then the child was classified as having a parent-reported unmet need. **CSHCN who responded “No” to receiving all needed care, but “Yes” to receiving any care were classified as having “moderate unmet need”; CSHCN who responded “No” to receiving all needed care and “No” to receiving any needed care were classified as having “high unmet need.”
7.3.4 Statistical Methods

Prior to determining any associations, univariate analyses were performed to obtain descriptive statistics. These initial analyses allowed for a thorough description of the sample of CSHCN who received care coordination. It also allowed for an examination of differences in the sample with respect to important covariates such as demographics and insurance status.

Statistical analyses for Study 2 encompassed a number of formal comparisons, and when multiple statistical tests or comparisons are being performed simultaneously on a single data set, this increases the chances of obtaining false-positive results (Type I errors). This problem of multiple comparisons is commonly compensated for through the use of the Bonferroni method or correction, which is an adjustment made to the p-values to mitigate this risk of false positives when a large number of significance tests are involved in a study. However, due to the large sample size for Study 2, a p-value < 0.001 was used for the significance level for each aim and sub-aim despite the number of comparisons involved. This p-value was deemed to be appropriate because, even if up to 50 comparisons were conducted, 0.001 would still be a conservative estimate (standard p-value < 0.05/50 = 0.001).

In Study 2a, the dependent variable, care coordination, was dichotomous (yes/no dummy coded 0, 1 variable) and all independent variables were categorical or continuous. Binary logistic regression (LOGIT) techniques were used to examine the relationship of interest between condition-specific characteristics and care coordination. An alternative model is a linear probability model (ordinary least squares approach). This approach is less desirable because it would (1) not have addressed issues of heteroskedasticity, (2) would have resulted in a non-normal distribution of errors, and (3) would have yielded predicted probabilities that could be greater than 1 or less than 0. Logistic regression is employed when the dependent
variable (Y) is dichotomous, rather than continuous and approximately normal with respect to its distribution. Logistic regression models are a form of generalized linear models \( g(E(y|x) = B_0 + B_1x + \ldots) \), where the link function, \( g(\mu) \), is defined as the logit.

In Study 2b, multiple logistic regression was used to examine if two or more independent variables in the model were predictors of the dependent variable, unmet need. Additionally, collinearity between two predictor variables and multicollinearity between more than two predictor variables was determined by whether there was a non-zero correlation between the variables by examining the following two diagnostic factors as part of the collinearity statistics: tolerance and Variance Inflation Factor (VIF). Specifically, a tolerance statistic \((1-R^2)\) below 0.20 was the threshold used to determine if further investigation was warranted. This value indicates that at least 80% of the variance of the independent variable is being shared with other independent variables.

Typically, situations in which the tolerance value is low and accompanied by large standard errors and non-significance indicate an almost perfect linear combination of the independent variables in the model and imply that the independent variable should not be added to the regression equation. However, neither low tolerance statistics nor large standard errors were found to be significant issues for the independent variables included in the multiple regression models for Study 1. Secondly, the VIF \((1/Tolerance)\) measures the impact of collinearity in a regression model and is always greater than or equal to one. Although there is no formal VIF value for determining the presence of multicollinearity, the literature generally assumes that values of VIF above 10 may indicate multicollinearity (Regression with SPSS, Chapter 2). When compared to the individual \( R^2 \) values (separate from the overall \( R^2 \) of the model) for Study 2b, neither the \( R^2 \) nor the VIF values for any of the independent variables were
higher than the threshold of 10, thus indicating that although multicollinearity was present to a
small degree (as is to be expected for a multiple regression model), it was not cause for concern.

The weighting variable, WEIGHT_I, was included in the Interview File and adjusts survey
responses to reflect the population of CSHCN age 0-17 years in each state and the District of
Columbia. As recommended by CAHMI, this weight variable was applied to all analyses using the
Interview File. Survey weights were used rather than using unweighted data since the 2009/10
NS-CSHCN oversampled based on multiple demographics and preliminary data analyses
demonstrated that estimates were not equivalent when using survey weights versus
unweighted data. Another rationale for utilizing survey weights is that the study sample was not
large enough to provide estimates specific to the U.S. population, so conclusions could be drawn
about the general population of CSHCN from study results.

The initial model tested for care coordination in Study 2a is presented below and
includes all aforementioned independent variables, demographics, and financial characteristics.

\[
g(E(\text{care coordination})) = \beta_0 + \beta_1(\text{condition complexity}) + \beta_2(\text{condition severity}) +
\beta_3(\text{health conditions}) + \beta_4(\text{functional difficulty}) + \beta_5(\text{age}) + \beta_6(\text{gender}) + \beta_7(\text{parental education}) + \beta_8(\text{family structure}) + \beta_9(\text{residence}) + \beta_{10}(\text{household income}) +
\beta_{11}(\text{insurance status}) + \beta_{12}(\text{welfare recipient}) + \beta_{13}(\text{SSI recipient})
\]
The initial model tested for any unmet need and each type of unmet need (preventive care,
specialty care, therapeutic services, and support services) in Study 2b is below, and it also
includes all aforementioned independent variables, demographics, and financial characteristics.

\[
g(E(\text{unmet need})) = \beta_0 + \beta_1(\text{care coordination}) + \beta_2(\text{age}) + \beta_3(\text{gender}) + \beta_4(\text{parental education}) + \beta_5(\text{family structure}) + \beta_6(\text{residence}) + \beta_7(\text{household income}) + \beta_{11}(\text{insurance status}) + \beta_{12}(\text{welfare recipient}) + \beta_{13}(\text{SSI recipient})
\]
Each parameter (βeta) is presented as exp(βeta) or odds ratio (OR), since odds ratios provide an estimate of the likelihood of a given outcome relative to a reference category for the independent variable. The results are presented in terms of odds ratios (exponential coefficient), 95% confidence intervals and p-values.

7.4 Study 2 Results

Descriptive Statistics – Care Coordination (Study 2a)

Table 13 shows descriptive statistics for demographic, condition-specific and financial characteristics examined in Study 2, as well as a summary of components of care coordination and the overall percentage of unmet need in the entire population CSHCN that was surveyed for the 2009/10 NS-CSHCN. In particular, 24.4% (n = 9,815) of survey respondents stated that they did not need care coordination on behalf of their CSHCN. 33.3% (n = 12,455) of all CSHCN whose parents or guardians were surveyed stated that they needed care coordination, but that the care coordination they received was not effective, meaning it did not meet one or more of the elements of care coordination used to defined “effective care coordination.” Families who did receive help arranging or coordinating their child’s health care amounted to 21.4% (n = 8,328) of all CSHCN whose parents or guardians were surveyed. Of all CSHCN whose parents or guardians were surveyed for the 2009/10 NS-CSHCN, 16.0% (n = 6,186) reported that the child’s doctor or office staff at the doctor’s office helped the family coordinate the child’s health care, and 5.4% (n = 2,111) reported that someone other than the child’s doctor or office staff helped the family.

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>% CSHCN</th>
<th>n</th>
<th>Pop. Est.</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN who needed care coordination (CC)</td>
<td>75.6%</td>
<td>29,845</td>
<td>8,253,333</td>
</tr>
<tr>
<td>All items below are calculated based on a sample size of n = 29,845 and reflect statistics for only the population of CSHCN who needed care coordination (i.e., 75.6% of total CSHCN):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN who received effective CC, among all CSHCN who needed it – includes the following 3 items:</td>
<td>58.3%</td>
<td>17,390</td>
<td>4,618,391</td>
</tr>
<tr>
<td>Survey Item</td>
<td>% CSHCN</td>
<td>n</td>
<td>Pop. Est.</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------</td>
<td>---------</td>
<td>--------</td>
<td>-----------</td>
</tr>
<tr>
<td>→ (1) Received direct help when needed for CC</td>
<td>26.6%</td>
<td>7,945</td>
<td>2,188,567</td>
</tr>
<tr>
<td>→ (2) Very satisfied with communication among doctors and other health care providers when needed for CC</td>
<td>56.5%</td>
<td>16,853</td>
<td>4,535,422</td>
</tr>
<tr>
<td>→ (3) Very satisfied with communication between child’s doctor(s) and school when needed for CC</td>
<td>20.7%</td>
<td>6,179</td>
<td>1,755,648</td>
</tr>
<tr>
<td>Financial - income level: 0-99% FPL</td>
<td>17.5%</td>
<td>5,216</td>
<td>1,866,994</td>
</tr>
<tr>
<td>Financial - income level: 100-199% FPL</td>
<td>19.6%</td>
<td>5,838</td>
<td>1,834,025</td>
</tr>
<tr>
<td>Financial - income level: 200-399% FPL</td>
<td>31.8%</td>
<td>9,504</td>
<td>2,391,821</td>
</tr>
<tr>
<td>Financial - income level: 400% FPL or more</td>
<td>33.1%</td>
<td>9,865</td>
<td>2,300,084</td>
</tr>
<tr>
<td>Demographic – age of child: 0-5 years</td>
<td>18.5%</td>
<td>5,514</td>
<td>1,744,803</td>
</tr>
<tr>
<td>Demographic – age of child: 6-11 years</td>
<td>40.1%</td>
<td>11,971</td>
<td>3,244,847</td>
</tr>
<tr>
<td>Demographic – age of child: 12-17 years</td>
<td>43.4%</td>
<td>12,938</td>
<td>3,403,273</td>
</tr>
<tr>
<td>Demographic – gender of child: male</td>
<td>61.2%</td>
<td>18,249</td>
<td>4,968,991</td>
</tr>
<tr>
<td>Demographic – gender of child: female</td>
<td>40.6%</td>
<td>12,121</td>
<td>3,408,830</td>
</tr>
<tr>
<td>Demographic – race/ethnicity: White, non-Hispanic</td>
<td>70.9%</td>
<td>21,160</td>
<td>4,974,384</td>
</tr>
<tr>
<td>Demographic – race/ethnicity: Black, non-Hispanic</td>
<td>10.2%</td>
<td>3,032</td>
<td>1,353,913</td>
</tr>
<tr>
<td>Demographic – race/ethnicity: Hispanic</td>
<td>11.4%</td>
<td>3,386</td>
<td>1,406,069</td>
</tr>
<tr>
<td>Demographic – race/ethnicity: Minority, non-Hispanic</td>
<td>9.5%</td>
<td>2,846</td>
<td>658,558</td>
</tr>
<tr>
<td>Demographic – family structure: mother-only</td>
<td>19.8%</td>
<td>5,899</td>
<td>2,125,307</td>
</tr>
<tr>
<td>Demographic – family structure: all other households</td>
<td>80.7%</td>
<td>24,084</td>
<td>6,136,943</td>
</tr>
<tr>
<td>Demographic – parental education: ≤ high school</td>
<td>20.7%</td>
<td>6,163</td>
<td>2,602,730</td>
</tr>
<tr>
<td>Demographic – parental education: &gt; high school</td>
<td>81.3%</td>
<td>24,260</td>
<td>5,790,193</td>
</tr>
<tr>
<td>Condition severity: Low severity (3-5)</td>
<td>24.6%</td>
<td>7,356</td>
<td>2,265,440</td>
</tr>
<tr>
<td>Condition severity: Moderate severity (6-9)</td>
<td>39.5%</td>
<td>11,802</td>
<td>3,224,407</td>
</tr>
<tr>
<td>Condition severity: High severity (&gt;10)</td>
<td>37.5%</td>
<td>11,185</td>
<td>2,877,663</td>
</tr>
<tr>
<td>No. of health conditions reported: None</td>
<td>12.6%</td>
<td>3,771</td>
<td>1,030,491</td>
</tr>
<tr>
<td>No. of health conditions reported: 1</td>
<td>32.6%</td>
<td>9,739</td>
<td>2,571,848</td>
</tr>
<tr>
<td>No. of health conditions reported: 2</td>
<td>29.3%</td>
<td>8,740</td>
<td>2,350,629</td>
</tr>
<tr>
<td>No. of health conditions reported: 3</td>
<td>12.4%</td>
<td>3,710</td>
<td>1,047,117</td>
</tr>
<tr>
<td>No. of health conditions reported: ≥ 4 (up to 20)</td>
<td>14.9%</td>
<td>4,460</td>
<td>1,392,559</td>
</tr>
<tr>
<td>No. of functional difficulties experienced: None</td>
<td>9.8%</td>
<td>2,941</td>
<td>742,513</td>
</tr>
<tr>
<td>No. of functional difficulties experienced: Any</td>
<td>91.2%</td>
<td>27,219</td>
<td>7,649,655</td>
</tr>
<tr>
<td>No. of functional difficulties experienced: 1</td>
<td>21.3%</td>
<td>6,372</td>
<td>1,612,761</td>
</tr>
<tr>
<td>No. of functional difficulties experienced: 2</td>
<td>15.3%</td>
<td>4,558</td>
<td>1,179,810</td>
</tr>
<tr>
<td>No. of functional difficulties experienced: 3</td>
<td>12.4%</td>
<td>3,709</td>
<td>1,034,088</td>
</tr>
<tr>
<td>No. of functional difficulties: ≥ 4 (up to 14)</td>
<td>43.0%</td>
<td>12,842</td>
<td>3,822,996</td>
</tr>
<tr>
<td>CSHCN with no unmet need for 14 health services†</td>
<td>79.6%</td>
<td>23,757</td>
<td>6,280,496</td>
</tr>
<tr>
<td>CSHCN with 1 unmet need for health services/equipment†</td>
<td>13.4%</td>
<td>3,994</td>
<td>1,220,902</td>
</tr>
<tr>
<td>CSHCN with &gt; 2 unmet needs for 14 health services†</td>
<td>7.1%</td>
<td>2,110</td>
<td>721,223</td>
</tr>
</tbody>
</table>

Note: Survey weights used in all calculations of n. Unweighted calculations not equivalent to weighted calculations, partly because the survey oversampled based on particular demographics. Percentages reported are weighted to population characteristics.

Yellow = Predictor/independent variable  Gray = not of interest; included as a reference

*Insurance coverage status AT TIME OF SURVEY – “both” indicates public & private at same time
Table 13 Notes continued

**All descriptive statistics presented are only for the sample of interest, which include CSHCN who needed care coordination (n = 29,845).

^ The summary score is a combination of the following variables: (1) amount of time the child is affected by the condition, (2) severity rating of the difficulties caused by the condition, and (3) pervasiveness of the condition (pervasiveness is defined by the number of qualifying reasons the child had for being included in the survey). See Appendix B for details on measurement of the summary score for Study 2.

§ Unmet need for 14 specific health care services or equipment in the past 12 months was combined to include the following specific unmet needs for health care services or equipment: (1) preventive medical care among CSHCN who needed it; (2) specialty care among CSHCN who needed it; (3) preventive dental care among CSHCN who needed it; (4) other dental care among CSHCN who needed it; (5) prescription medications among CSHCN who needed it; (6) physical, occupational, or speech therapy among CSHCN who needed it; (7) mental health care or counseling among CSHCN who needed it; (8) substance abuse treatment among CSHCN age 8-17 years who needed it; (9) home health care; (10) vision care or eyeglasses; (11) hearing aids or hearing care; (12) mobility aids or devices, CSHCN age 3-17 years only; (13) communication aids or devices, CSHCN age 3-17 years only; and (14) durable medical equipment. See Appendix B for details on the level of unmet need for each of the specific health care services or equipment.

Additional percentages for CSHCN and effective care coordination (out of all CSHCN):

- Did not need care coordination: 24.4% (n = 9,815)
- Needed care coordination, but care coordination received was not effective (did not meet 1 or more elements of care coordination): 33.3% (n = 12,455)
- Needed care coordination, and care coordination that was received was effective (met all needed components of care coordination): 42.3% (n = 17,390)

Additional percentages for receiving help arranging/coordinating child’s care:

- Nobody helps family with coordinating child’s health care: 78.6% (n = 31,380)
- Families who receive help arranging/coordinating child’s care: 21.4% (n = 8,328)
  - Child’s doctor or office staff at doctor’s office help family coordinate child’s health care: 16.0% (n = 6,186)
  - Someone other than the child’s doctor or office staff helps family: 5.4% (n = 2,111)

Descriptive Statistics – Care Coordination (Study 2a)

Table 14 reports summary statistics for Study 2a, for the percentage of CSHCN receiving effective CC and being satisfied with each component of CC. These elements included the following, when needed for CC: (1) whether CSHCN received direct help; (2) whether they were very satisfied with the communication among doctors and other health care providers; and (3) whether they were very satisfied with the communication between the child’s doctor(s) and school or special education programs. In the 2009/10 NS-CSHCN, 75.6% of all parents/guardians surveyed or n = 29,845 reported needing CC. Of those parents who reported needing CC, only
42.3% (n = 17,390) reported that the CC their CSHCN received was effective, indicating that it met all three of the aforementioned components of CC.

**Descriptive Statistics – Care Coordination (Study 2a)**

Results from Study 2a demonstrated some differences between uninsured and insured CSHCN with respect to receiving CC when needed. Table 15 shows summary statistics by insurance type (public, private or both public and private), for each component of effective CC. Privately insured CSHCN were more likely to have received CC when needed and to be satisfied with communication for the individual aspects of care communication (when needed for CC, between doctors and other health care providers, and between doctors and school/special education programs).

**Care Coordination and Unmet Need (Study 2b)**

Study 2b examined the relationship between CC and unmet need. Summary statistics for Study 2b are in Table 16. Figure 8 expands upon the percentages of unmet need for specific services, which include preventive, specialty, therapy, and support services. Additional details on each of these categories are in the Variables section of Study 2, as well as in Appendix B.
<table>
<thead>
<tr>
<th>Variable</th>
<th>% CSHCN receiving effective CC*</th>
<th>% of CSHCN receiving help for CC or being satisfied with communication, among CSHCN needing the service</th>
</tr>
</thead>
<tbody>
<tr>
<td>12,898 CSHCN needed CC help</td>
<td>42.3% of all CSHCN (n = 17,390)</td>
<td>Received all needed help with direct CC¹ 57.8% (n = 7,945) Satisfied with communication of doctors² 62.7% (n = 16,853) Satisfied with doctors' communication to school or special ed. programs³ 53.1% (n = 6,179)</td>
</tr>
<tr>
<td>26,415 CSHCN needed doctors and other providers to communicate for CC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11,523 CSHCN doctors &amp; school/special ed. programs to communicate for CC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of child (mean = 10.2 years old)</td>
<td></td>
<td>^Interpretation: 65.3% of CSHCN 0-5 years (n = 1,874) received all needed help with direct CC.</td>
</tr>
<tr>
<td>0-5 years</td>
<td>44.9% (n = 3,295)</td>
<td>65.3% (n = 1,874)</td>
</tr>
<tr>
<td>6-11 years</td>
<td>41.5% (n = 6,739)</td>
<td>55.1% (n = 3,032)</td>
</tr>
<tr>
<td>12-17 years</td>
<td>41.7% (n = 7,356)</td>
<td>55.8% (n = 3,039)</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>42.0% (n = 10,328)</td>
<td>57.0% (n = 4,741)</td>
</tr>
<tr>
<td>Female</td>
<td>42.7% (n = 7,030)</td>
<td>58.9% (n = 3,187)</td>
</tr>
<tr>
<td>Race/Ethnicity of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>45.1% (n = 12,606)</td>
<td>61.1% (n = 5,301)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>36.6% (n = 1,552)</td>
<td>52.1% (n = 862)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>39.8% (n = 1,726)</td>
<td>54.2% (n = 920)</td>
</tr>
<tr>
<td>Other minority, non-Hispanic</td>
<td>38.0% (n = 1,506)</td>
<td>56.4% (n = 862)</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother-only</td>
<td>37.9% (n = 3,081)</td>
<td>47.3% (n = 1,547)</td>
</tr>
<tr>
<td>All other</td>
<td>43.8% (n = 14,080)</td>
<td>56.8% (n = 6,398)</td>
</tr>
<tr>
<td>Parental education (highest education of adult in household)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school</td>
<td>40.2% (n = 3,348)</td>
<td>55.4% (n = 1,138)</td>
</tr>
<tr>
<td>&gt; High school</td>
<td>43.2% (n = 14,042)</td>
<td>59.3% (n = 6,807)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 300% FPL</td>
<td>40.6% (n = 8,653)</td>
<td>56.2% (n = 4,479)</td>
</tr>
<tr>
<td>At or above 300% FPL</td>
<td>44.3% (n = 8,737)</td>
<td>61.7% (n = 3,466)</td>
</tr>
</tbody>
</table>

Table 14. Study 2a Summary Statistics
Table 14 continued

<table>
<thead>
<tr>
<th>Variable</th>
<th>% CSHCN receiving effective CC*</th>
<th>% of CSHCN receiving help for CC or being satisfied with communication, among CSHCN needing the service</th>
</tr>
</thead>
<tbody>
<tr>
<td>12,898 CSHCN needed CC help</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26,415 CSHCN needed doctors and other providers to communicate for CC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11,523 CSHCN doctors &amp; school/special ed. programs to communicate for CC</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>42.3% of all CSHCN</strong> (n = 17,390)</td>
<td><strong>Received all needed help with</strong></td>
<td><strong>Satisfied with</strong></td>
</tr>
<tr>
<td></td>
<td><strong>direct CC</strong></td>
<td><strong>communication of doctors</strong></td>
</tr>
<tr>
<td></td>
<td>57.8% (n = 7,945)</td>
<td>62.7% (n = 16,853)</td>
</tr>
<tr>
<td></td>
<td>68.4% (n = 11,096)</td>
<td>53.1% (n = 6,179)</td>
</tr>
<tr>
<td></td>
<td>68.5% (n = 5,285)</td>
<td>50.3% (n = 4,799)</td>
</tr>
<tr>
<td></td>
<td>68.4% (n = 11,096)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>67.3% (n = 1,380)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>67.3% (n = 1,380)</td>
<td></td>
</tr>
<tr>
<td><strong>Condition complexity (qualification reason from screener)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rx med usage only</td>
<td>39.2% (n = 6,776)</td>
<td>68.5% (n = 5,285)</td>
</tr>
<tr>
<td></td>
<td>68.4% (n = 11,096)</td>
<td>68.4% (n = 11,096)</td>
</tr>
<tr>
<td>Other reason</td>
<td>44.3% (n = 10,614)</td>
<td>44.1% (n = 2,660)</td>
</tr>
<tr>
<td></td>
<td>54.3% (n = 5,757)</td>
<td>50.3% (n = 4,799)</td>
</tr>
<tr>
<td><strong>Condition severity (mode = 4)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low severity (3-5)</td>
<td>39.8% (n = 8,820)</td>
<td>64.5% (n = 5,251)</td>
</tr>
<tr>
<td></td>
<td>63.5% (n = 9,527)</td>
<td>57.9% (n = 1,840)</td>
</tr>
<tr>
<td>Moderate severity (6-9)</td>
<td>47.7% (n = 6,548)</td>
<td>53.0% (n = 1,302)</td>
</tr>
<tr>
<td></td>
<td>64.7% (n = 4,502)</td>
<td>55.1% (n = 3,405)</td>
</tr>
<tr>
<td>High severity (≥ 10)</td>
<td>37.8% (n = 2,022)</td>
<td>42.6% (n = 1,392)</td>
</tr>
<tr>
<td></td>
<td>59.7% (n = 2,824)</td>
<td>47.3% (n = 934)</td>
</tr>
<tr>
<td><strong>No. of health conditions (mode = 1)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>43.5% (n = 12,432)</td>
<td>68.4% (n = 3,507)</td>
</tr>
<tr>
<td></td>
<td>68.8% (n = 7,467)</td>
<td>59.4% (n = 1,959)</td>
</tr>
<tr>
<td>2</td>
<td>39.6% (n = 2,679)</td>
<td>60.6% (n = 1,744)</td>
</tr>
<tr>
<td></td>
<td>65.0% (n = 3,966)</td>
<td>56.1% (n = 1,427)</td>
</tr>
<tr>
<td>3</td>
<td>38.7% (n = 1,440)</td>
<td>53.0% (n = 1,302)</td>
</tr>
<tr>
<td></td>
<td>59.8% (n = 2,821)</td>
<td>51.1% (n = 1,278)</td>
</tr>
<tr>
<td>≥ 4 (up to 20)</td>
<td>41.0% (n = 839)</td>
<td>42.6% (n = 1,392)</td>
</tr>
<tr>
<td></td>
<td>51.1% (n = 2,599)</td>
<td>46.3% (n = 1,515)</td>
</tr>
<tr>
<td><strong>No. of functional difficulties (mode = 1)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any</td>
<td>45.4% (n = 1,871)</td>
<td>89.5% (n = 587)</td>
</tr>
<tr>
<td></td>
<td>78.3% (n = 1,633)</td>
<td>75.9% (n = 311)</td>
</tr>
<tr>
<td>1</td>
<td>41.5% (n = 3,678)</td>
<td>79.2% (n = 1,329)</td>
</tr>
<tr>
<td></td>
<td>74.6% (n = 3,042)</td>
<td>69.9% (n = 814)</td>
</tr>
<tr>
<td>2</td>
<td>47.7% (n = 2,874)</td>
<td>73.0% (n = 1,126)</td>
</tr>
<tr>
<td></td>
<td>73.1% (n = 2,516)</td>
<td>70.1% (n = 735)</td>
</tr>
<tr>
<td>3</td>
<td>47.4% (n = 2,294)</td>
<td>66.0% (n = 1,000)</td>
</tr>
<tr>
<td></td>
<td>68.8% (n = 2,169)</td>
<td>60.8% (n = 762)</td>
</tr>
<tr>
<td>≥ 4 (up to 14)</td>
<td>39.0% (n = 6,673)</td>
<td>48.3% (n = 3,903)</td>
</tr>
<tr>
<td></td>
<td>54.3% (n = 7,493)</td>
<td>46.8% (n = 3,557)</td>
</tr>
</tbody>
</table>

*Note: Whether or not CSHCN received effective care coordination was the independent variable/variable of interest for Study 2a – therefore, this group (CSHCN who needed care coordination and received effective care coordination) was compared against all other CSHCN, which included CSHCN who needed care coordination but did not receive effective care coordination and included CSHCN whose parents/caregivers reported not receiving care coordination at all.
<table>
<thead>
<tr>
<th>Type of Insurance Coverage</th>
<th>% CSHCN receiving effective CC</th>
<th>% of CSHCN receiving help for CC or being satisfied with communication, among CSHCN needing the service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 12,898 CSHCN needed CC help 26,415 CSHCN needed doctors and other providers to communicate for CC 211,523 CSHCN doctors &amp; school/special ed. programs to communicate for CC</td>
<td>42.3% of all CSHCN (n = 17,390)</td>
<td>Received all needed help with direct CC 57.8% (n = 7,945)</td>
</tr>
<tr>
<td>No insurance (uninsured CSHCN)</td>
<td>24.9% (n = 296)</td>
<td>34.7% (n = 132)</td>
</tr>
<tr>
<td>Any insurance (all insured CSHCN)</td>
<td>42.9% (n = 17,079)</td>
<td>58.7% (n = 7,797)</td>
</tr>
<tr>
<td>Private insurance only</td>
<td>44.4% (n = 10,478)</td>
<td>62.5% (n = 4,080)</td>
</tr>
<tr>
<td>Public insurance only</td>
<td>40.4% (n = 4,739)</td>
<td>55.4% (n = 2,701)</td>
</tr>
<tr>
<td>Both private &amp; public</td>
<td>44.8% (n = 1,244)</td>
<td>55.6% (n = 748)</td>
</tr>
</tbody>
</table>

Table 15. Study 2a Results – Percentage of CSHCN Receiving Care Coordination (CC) and Being Satisfied*
<table>
<thead>
<tr>
<th>Variable</th>
<th>Overall %</th>
<th>% of CSHCN with unmet needs for specific health services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Any Unmet Need: 23.6% (n = 8,074)</td>
<td>Unmet Need for Preventive Services*: 14.0% (n = 4,778)</td>
</tr>
<tr>
<td></td>
<td>Unmet Need for Specialty Care^: 9.1% (n = 3,113)</td>
<td>Unmet Need for Therapeutic Services**: 11.0% (n = 3,768)</td>
</tr>
<tr>
<td></td>
<td>Unmet Need for Support Services***: 4.3% (n = 1,467)</td>
<td></td>
</tr>
<tr>
<td>Age of child (mean = 10.2 years old)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>19.8% (n = 1,298)</td>
<td>M: 2.8% (n = 174)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 7.3% (n = 486)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 3.6% (n = 234)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 1.6% (n = 102)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8.0% (n = 593)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.0% (n = 262)</td>
</tr>
<tr>
<td>6-11 years</td>
<td>23.5% (n = 3,175)</td>
<td>M: 2.8% (n = 425)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 8.3% (n = 1,070)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 3.9% (n = 524)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 4.9% (n = 584)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11.4% (n = 1,592)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.5% (n = 607)</td>
</tr>
<tr>
<td>12-17 years</td>
<td>25.7% (n = 3,601)</td>
<td>M: 3.2% (n = 429)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 10.4% (n = 1,403)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 5.1% (n = 662)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 7.9% (n = 1,012)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10.9% (n = 1,579)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.6% (n = 645)</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>23.0% (n = 4,852)</td>
<td>M: 3.0% (n = 610)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 9.1% (n = 1,792)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 4.0% (n = 833)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 4.9% (n = 980)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11.2% (n = 2,397)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.6% (n = 970)</td>
</tr>
<tr>
<td>Female</td>
<td>24.6% (n = 3,211)</td>
<td>M: 2.9% (n = 417)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 8.8% (n = 1,165)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 4.9% (n = 585)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 6.2% (n = 715)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10.7% (n = 1,368)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.4% (n = 574)</td>
</tr>
<tr>
<td>Race/Ethnicity of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>20.7% (n = 5,065)</td>
<td>M: 2.1% (n = 579)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 7.2% (n = 397)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 3.7% (n = 870)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 4.5% (n = 1,004)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10.4% (n = 2,442)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.1% (n = 579)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>28.4% (n = 1,032)</td>
<td>M: 3.8% (n = 130)</td>
</tr>
<tr>
<td>Black, non-Hispanic (cont.)</td>
<td></td>
<td>D: 12.5% (n = 449)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 5.5% (n = 175)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 6.4% (n = 257)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11.3% (n = 406)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.7% (n = 180)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>28.4% (n = 1,121)</td>
<td>M: 5.1% (n = 208)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 10.4% (n = 397)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 5.5% (n = 202)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 7.4% (n = 255)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12.1% (n = 483)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5.1% (n = 208)</td>
</tr>
<tr>
<td>Other minority, non-Hispanic</td>
<td>26.1% (n = 859)</td>
<td>M: 3.0% (n = 111)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 11.5% (n = 349)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M: 4.7% (n = 173)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D: 5.9% (n = 182)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12.5% (n = 437)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5.8% (n = 199)</td>
</tr>
</tbody>
</table>

Table 16. Study 2b Summary Statistics – Percentage of CSHCN with Any Unmet Need or Unmet Need for Specific Services
Table 16 continued

<table>
<thead>
<tr>
<th>Variable</th>
<th>Overall %</th>
<th>% of CSHCN with unmet needs for specific health services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family structure</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother-only</td>
<td>31.5% (n = 2,202)</td>
<td>M: 3.7% (n = 268) D: 12.9% (n = 895)</td>
</tr>
<tr>
<td>All other</td>
<td>22.5% (n = 5,872)</td>
<td>M: 3.0% (n = 246) D: 9.2% (n = 2,097)</td>
</tr>
<tr>
<td><strong>Parental education (highest education of adult in household)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school</td>
<td>28.3% (n = 2,010)</td>
<td>M: 4.7% (n = 168) D: 12.1% (n = 868)</td>
</tr>
<tr>
<td>&gt; High school</td>
<td>21.8% (n = 6,067)</td>
<td>M: 2.4% (n = 692) D: 7.6% (n = 2,091)</td>
</tr>
<tr>
<td><strong>Household income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 300% FPL</td>
<td>42.6% (n = 5,367)</td>
<td>M: 3.7% (n = 292) D: 10.1% (n = 2,165)</td>
</tr>
<tr>
<td>At or above 300% FPL</td>
<td>23.9% (n = 2,710)</td>
<td>M: 1.7% (n = 207) D: 3.6% (n = 794)</td>
</tr>
</tbody>
</table>

Key: For Preventive Services, M = preventive medical care and D = preventive dental care. *Preventive Services = well-child check-up and prescription medications. ^ For Specialty Care, M = specialist medical care and D = other dental care (includes specialty dental care such as orthodontia). **Therapeutic Services = physical, occupational, or speech therapy; mental health care/counseling; and substance abuse treatment/counseling. ***Support Services = home health care; eyeglasses/vision care; hearing aids/hearing care; durable medical equipment; communication aids/devices; and family support services. See Appendix B for specific survey items used to operationalize categories of unmet need for Study 2b and for specific percentages of unmet need for each item within a particular category (e.g., unmet need for substance abuse treatment and counseling)
Figure 8. Study 2b Results – Venn Diagram of Unmet Need for Services*

*Additional overlap for unmet needs, not shown in Figure 8:
  • Unmet need for preventive, specialty, and therapy services: 15.1% (N = 5,142)
  • Unmet need for preventive, specialty, and support services: 12.1% (N = 4,127)
  • Unmet need for preventive, therapy, and support services: 12.9% (N = 4,416)
  • Unmet need for specialty, therapy, and support services: 10.8% (N = 3,681)
  • Unmet need for ALL (preventive, specialty, therapy, AND support services): 1.8% (N = 604)

Care Coordination and Unmet Need (Study 2b), continued:

As summarized in Table 17, the odds of having any unmet need among those who received ineffective care coordination were 3.16 times the odds of having any unmet need among those who did receive effective care coordination. Ineffective care coordination was defined as (1) not receiving help with CC when needed; (2) not being satisfied with communication among child’s doctors or other health care providers when needed for CC; or (3) not being satisfied with communication among child’s doctors and school/other special
education programs when needed for CC. This result for the relationship between ineffective care coordination and any unmet need was statistically significant at $p < 0.001$.

For preventive services, the odds of having an unmet need among those who received ineffective CC were 2.45 times the odds of having an unmet need among those who did receive effective CC. This association between receiving ineffective CC and having an unmet need for preventive services was statistically significant at $p < 0.001$. Preventive services included both preventive medical and dental care, with preventive medical care including the well-child check-up and prescription medications.

For specialty services, the odds of having an unmet need among those who received ineffective CC were 2.64 times the odds of having an unmet need among those who did receive effective CC. This relationship between receiving ineffective CC and having an unmet need for specialty services was statistically significant at $p < 0.001$. Specialty care included specialist medical care and other dental care, including specialty dental care such as orthodontia. Appendix B includes details on survey items used to operationalize categories of unmet need for Study 2b, as well as percentages of unmet need for an item within a category, such as unmet need for well-child check-ups only.

For therapy services, the odds of having an unmet need among those who received ineffective CC were 3.01 times the odds of having an unmet need among those who did receive effective CC. This relationship between receiving ineffective CC and having an unmet need for therapy services was statistically significant at $p < 0.001$. Therapy services included (1) physical, occupational, or speech therapy; (2) mental health care/counseling; and (3) substance abuse treatment/counseling. Substance abuse treatment/counseling was applicable only for CSHCN between 8-17 years of age. Mental health care or counseling was most commonly reported as being needed but not received (overall unmet need of 5.6% for this group of CSHCN).
For support services, the odds of having an unmet need among those who received ineffective CC were 2.67 times the odds of having an unmet need among those who did receive effective CC. Although this relationship was not statistically significant at p < 0.001, it was statistically significant at p < 0.01. Support services encompassed all other categories of service needs for CSHCN, including home health care, eyeglasses/vision care, hearing aids/hearing care, durable medical equipment, communication aids/devices, and family support services.

Lastly, the relationships between effective CC and unmet need with respect to the four condition-specific characteristics are shown in the last four rows of Table 17, for (1) condition complexity (Rx medication use only or other), (2) condition severity (low vs. moderate or high), (3) number of health conditions (one vs. more than one), and (4) number of functional difficulties (split into two comparisons: any functional difficulty vs. no functional difficulties; and more than one functional difficulty vs. only one functional difficulty). As shown in Table 17, the odds of having any unmet need or an unmet need for preventive, specialty, therapeutic, or support services were either not significantly different or not statistically significant at p < 0.001 when comparing between these groups of CSHCN with varying degrees of condition complexity, condition severity, number of health conditions and number of functional difficulties. In other words, for CSHCN who did receive effective care coordination, there was not a statistically significant difference in the odds of having any unmet need for CSHCN who qualified as special needs based on prescription medication usage versus any other usage. For this reason, none of the odds shown in the last four rows of Table 17 are marked with *** to denote significance at the p < 0.001 level.
<table>
<thead>
<tr>
<th>Measure of Care Coordination</th>
<th>Any Unmet Need</th>
<th>Unmet Need for Preventive Services</th>
<th>Unmet Need for Specialty Care</th>
<th>Unmet Need for Therapeutic Services+</th>
<th>Unmet Need for Support Services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ineffective CC (NO to any of the 3 CC components below)</strong></td>
<td>3.16***</td>
<td>2.45***</td>
<td>2.64***</td>
<td>3.01***</td>
<td>2.67</td>
</tr>
<tr>
<td></td>
<td>(2.25-4.43)</td>
<td>(1.78-3.37)</td>
<td>(1.98-3.52)</td>
<td>(2.03-4.46)</td>
<td>(1.40-3.09)</td>
</tr>
<tr>
<td><strong>Effective CC</strong> and condition-specific characteristic below:**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rx meds only (vs. other reason)</td>
<td>0.81</td>
<td>0.69</td>
<td>0.76</td>
<td>0.81</td>
<td>0.63</td>
</tr>
<tr>
<td></td>
<td>(0.60-1.19)</td>
<td>(0.37-1.09)</td>
<td>(0.51-1.16)</td>
<td>(0.59-1.11)</td>
<td>(0.38-1.05)</td>
</tr>
<tr>
<td>Low severity (3-5) [vs. moderate or high severity (6 and up)]</td>
<td>1.00</td>
<td>1.06</td>
<td>1.09</td>
<td>1.02</td>
<td>0.91</td>
</tr>
<tr>
<td></td>
<td>(0.83-1.21)</td>
<td>(0.88-1.26)</td>
<td>(0.93-1.28)</td>
<td>(0.83-1.26)</td>
<td>(0.66-1.24)</td>
</tr>
<tr>
<td>1 health condition [vs. &gt;1 health conditions]</td>
<td>0.99</td>
<td>1.21</td>
<td>1.34</td>
<td>0.98</td>
<td>1.43</td>
</tr>
<tr>
<td></td>
<td>(0.73-1.35)</td>
<td>(0.95-1.57)</td>
<td>(1.08-1.70)</td>
<td>(0.71-1.37)</td>
<td>(0.76-2.70)</td>
</tr>
<tr>
<td>Any functional difficulty [vs. no functional difficulties]</td>
<td>1.26</td>
<td>1.23</td>
<td>1.32</td>
<td>1.22</td>
<td>2.05</td>
</tr>
<tr>
<td></td>
<td>(0.95-1.68)</td>
<td>(0.87-1.59)</td>
<td>(0.96-1.76)</td>
<td>(0.88-1.68)</td>
<td>(1.29-3.27)</td>
</tr>
<tr>
<td>&gt;1 functional difficulty [vs. only 1 difficulty]</td>
<td>1.35</td>
<td>1.04</td>
<td>1.13</td>
<td>0.96</td>
<td>1.84</td>
</tr>
<tr>
<td></td>
<td>(0.85-2.15)</td>
<td>(0.79-1.43)</td>
<td>(0.77-1.62)</td>
<td>(0.59-1.56)</td>
<td>(1.06-3.18)</td>
</tr>
</tbody>
</table>

*Adjusted for age, gender, race/ethnicity, family structure, parental education, income and insurance status (identified as potential confounders for Study 2).

**Components of effective care coordination: (1) received help with care coordination when needed; (2) satisfied with communication among child’s doctors and other health care providers when needed for care coordination; and (3) satisfied with communication among child’s doctors and school/other special ed. programs when needed for care coordination. *Includes any time when survey respondent or other family members received care coordination assistance through the following individuals or offices: doctor’s office, case manager, another parent, social worker, therapist, other family member, friend, guardian, nurse, or hospital discharge planner. **For details on how unmet needs for specific health services were categorized into the four groups: (1) unmet need for preventive care; (2) unmet need for specialty care; (3) unmet need for therapeutic services; and (4) unmet need for support services – see Appendix B.

The service that was most commonly reported as being needed but not received was mental health care or counseling (unmet need for 5.6% of CSHCN)

*** p-level: p < 0.001. Due to the large sample size for Study 2b, a p-value < 0.001 was used for the significance level for each aim and sub-aim despite the number of comparisons involved. This p-value was deemed to be appropriate because, even if up to 50 comparisons were conducted, 0.001 would still be a conservative estimate (standard p-value < 0.05/50 = 0.001).

Table 17. Study 2b Results – Adjusted* Odds of Unmet Need Among Those Receiving Care Coordination
7.5 Study 2 Discussion

Prior studies have demonstrated that care coordination is a necessary and beneficial mechanism in health services delivery, as it allows for continuity of care beyond the level of specific episodes of illness or disease (Haggerty et al, 2003). For CSHCN, who have a complex array of health conditions, functional limitations, and other needs, care coordination offers the opportunity to access and manage a myriad of health and related service needs in a more efficient, effective and organized manner (AAP, 1999). For these reasons, Study 2 examined condition-specific characteristics and their impact on care coordination, to add to the current health services literature for CSHCN. Overall, findings from this study support the added emphasis that the Patient Protection and Affordable Care Act places on the importance and need to improve care coordination for all children, including CSHCN, in order to meet their health needs and reduce racial/ethnic and socioeconomic disparities in health care (Toomey et al., 2013). However, further research is needed to more comprehensively understand the precise barriers to care coordination that CSHCN experience and to inform the development or restructuring of health policies with respect to enhancing care coordination.

Study 2b specifically analyzed the association between care coordination and unmet need, to discern whether or not coordination of care alone might have a beneficial relationship in terms of reductions in unmet need for CSHCN. Although results were not statistically significant, results did show a relationship between ineffective CC and the likelihood of having unmet need. The overarching findings from both studies also demonstrate that there are important differences between CSHCN depending on insurance status (private versus public) and between CSHCN depending on demographics, health needs, and condition-specific characteristics. In particular, privately insured CSHCN were more likely to have received care
coordination help when needed. Privately insured CSHCN were also more likely to be satisfied with communication between doctors and other health care providers, as well as more likely to be satisfied with communication between doctors and school/special education programs, when needed for care coordination.

Previous research indicates that greater care coordination and integration can lead to higher-quality care and more efficient care (Devers, 1995; Seigel, 1996; Van Achterberg, 1996; Bennett, 1997; Watson, 1997; Hughes, 1999; Ronder, 1999). Study 2 demonstrates that certain care coordination aspects alone may not be effective due to differences in insurance status, since all insurance plans do not incentivize or reimburse the extra time providers need to effectively coordinate care with family or caregivers, other providers, schools or therapists (Antonelli et al., 2008; Bodenheimer, 2008).

With respect to CSHCN who did receive effective care coordination, CSHCN with less complex conditions (i.e., those who qualified based on prescription medication usage alone), lower severity conditions, only one health condition, and no functional difficulties were less likely to have any unmet need than those with more complex conditions, higher severity conditions, more than one health condition, or more than one functional difficulty. Conversely, this aligns with the hypotheses that greater complexity and severity are associated with a greater likelihood of having unmet needs.

7.5.1 Limitations

Since the respondents of the NS-CSHCN are parents/guardians, and not the health care providers or CSHCN themselves, the integrity of the data provided by the NS-CSHCN may be impacted by recall bias and the subjectivity of the respondents, by virtue of the study design of the survey. Additionally, the results from the survey were weighted to reflect the population of
CSHCN ages 0-17, at the state and national level. Therefore, further sub-setting of the survey data to a specific population subgroup, such as a particular racial/ethnic group or poverty level, could lead to incorrect standard error estimation. For this reason, conclusions cannot be drawn at a subpopulation level, aside from generalizations for an entire state or nationally.

Secondly, a major limitation of the cross-sectional data derived from the NS-CSHCN is that it does not allow for causal inferences, since measurements were taken only at one point in time. Therefore, all results from the three studies are presented solely as associations, because causal relationships cannot be substantiated. Thirdly, as is the case with many other national surveys of this scale, only non-institutionalized CSHCN and those who have permanent residences were interviewed for the NS-CSCHN. For this reason, families with CSHCN living in institutions or families who are homeless or migrants are underrepresented in the survey data. Results from the studies are representative only of non-institutionalized CSHCN 0-17 years old.

With respect to care coordination, the inclusion criteria for whether or not CSHCN needed care coordination and received effective care coordination was subjective, rather than objective, in nature. For this reason, the way in which care coordination variables were measured could have influenced the results of Study 2. Perceptions of quality may have differed depending on how parents or guardians of CSHCN defined effectiveness of, and satisfaction with, care coordination. Further assessment of the validity of existing measures of care coordination would aid in determining how extensive of a problem ineffective care coordination is for CSHCN overall and for specific subgroups of CSHCN.
Chapter 8. Study 3: The Medical Home

8.1 Study 3 Aims

**Aim 3a:** Determine the likelihood of CSHCN in medical homes experiencing the following parent/guardian-reported outcomes of care, as compared to CSHCN who are not in a medical home: (1) decreased caregiver burden, (2) increased satisfaction with care, and (3) receipt of transition planning to adult care, taking into account functional status, insurance status, and demographics such as the age of the child, the gender of the child, the race/ethnicity of the child, and household income.

**Hypothesis 3a(1) – Caregiver Burden:** Parents/guardians of CSHCN who are part of a medical home will be more likely to report decreased caregiver burden than parents/guardians of CSHCN who are not part of a medical home.

**Hypothesis 3a(2) – Satisfaction with Care:** Parents/guardians of CSHCN who are part of a medical home will be more likely to report increased satisfaction with care than parents/guardians of CSHCN who are not part of a medical home.

**Hypothesis 3a(3) – Transition Planning:** Parents/guardians of CSHCN who are part of a medical home will be more likely to report receiving transition planning to adult care than parents/guardians of CSHCN who are not part of a medical home.

**Aim 3b:** Determine if the following parent/guardian-reported outcomes of care differ between groups of CSHCN who are not in a medical home but who experience individual components of
the medical home in the following combinations: (1) care that is accessible and comprehensive; (2) care that is family-centered and culturally sensitive; and (3) care that is coordinated. The outcomes analyzed include (1) decreased caregiver burden, (2) increased satisfaction with care, and (3) receipt of transition planning to adult care.

**Hypothesis 3b(1) – Accessible & Comprehensive Care:** Parents/guardians of CSHCN who are not part of a medical home but receive care that is accessible and comprehensive will be more likely to report (1) decreased caregiver burden, (2) increased satisfaction with care, and (3) receipt of transition planning to adult care than parents/guardians of CSHCN who are not part of a medical home and do not receive care that is accessible and comprehensive.

**Hypothesis 3b(2) – Family-Centered and Culturally Effective Care:** Parents/guardians of CSHCN who are not part of a medical home but receive care that is family-centered and culturally effective/sensitive will be more likely to report (1) decreased caregiver burden, (2) increased satisfaction with care, and (3) receipt of transition planning to adult care than parents/guardians of CSHCN who are not part of a medical home and do not receive care that is family-centered and culturally effective/sensitive.

**Hypothesis 3b(3) – Coordinated Care:** Parents/guardians of CSHCN who are not part of a medical home but receive coordinated care will be more likely to report (1) decreased caregiver burden, (2) increased satisfaction with care, and (3) receipt of transition planning to adult care than parents/guardians of CSHCN who are not part of a medical home and do not receive coordinated care.

**8.2 Study 3 Background and Significance**

The medical home is a model of care delivery shown to be beneficial with respect to improving care coordination and providing more comprehensive care for patients, particularly
with respect to CSHCN. Although some researchers have examined clinical outcomes for CSHCN in medical homes, no published studies have investigated the association between medical homes and non-clinical outcomes, such as caregiver burden. Nor have any studies looked at the relationship between components of the medical home, such as family-centered care, and non-clinical outcomes.

A more in-depth analysis of the potential benefits of the medical home would therefore significantly contribute to the current literature on CSHCN. In particular, an whether the presence of a medical home is associated with unmet need, improved satisfaction with care, and reduced caregiver burden are of interest, as identified by the existing literature. Additionally, assessing whether the presence or absence of particular components of the medical home, either individually or in groups, may identify which components have a differential and positive impact on CSHCN, even when delivered in a care setting that is not formally classified as a medical home.

8.3 Study 3 Research Methods

8.3.1 Participants

The overall study population for this dissertation included children with special health care needs (CSHCN) from 0 to 17 years of age whose parents or caregivers were surveyed in the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN). Of the 372,698 children screened, 59,941 were identified with special health care needs, and in-depth interviews were subsequently completed for a total of 40,242 CSHCN. This total included approximately 750 interviews per state and the District of Columbia, with a range of 751 in the District of Columbia to 878 in Texas.
Study 3a consisted of the entire study population of NS-CSHCN, in order to compare between CSHCN who were classified by the 2009-10 NS-CSHCN as being part of a medical home and those CSHCN who were not classified as being part of a medical home. For Study 3b, only CSHCN who were not classified as being part of a medical home in the 2009-10 NS-CSHCN were part of the analyses, since Study 3b compared individual non-clinical outcomes of care between CSHCN who were not in a medical home but experience some components of care of the medical home. Lastly, since Study 3 involved CSHCN who experienced the non-clinical outcomes of care (caregiver burden, satisfaction with care, and transition planning to adult care), only CSHCN who had some type of response for those survey indicators were included in the study sample.

8.3.2 Data Source

All data for this study was obtained from the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN), sponsored by the Maternal and Child Health Bureau, the U.S. Department of Health and Human Services, and the Health Resources and Services Administration. The NS-CSHCN is a national telephone survey that was conducted for the third time in 2009-10. Previous administrations of the survey took place in 2000-2001 and 2005-2006. Independent random samples are taken in all 50 states and the District of Columbia, with at least 750 interviews conducted in each state and the District of Columbia. Its primary goal was to assess the prevalence and impact of special health care needs among children under age 18 in all 50 states and the District of Columbia.

A SLAITS approach, developed by the National Center for Health Statistics to quickly and consistently collect information on a variety of health topics at the state and local levels, is used for sampling and data collection for the NS-CSHCN. This mechanism is also used for sampling
and data collection for the National Survey of Children’s Health (NSCH), the National Survey of Early Childhood Health, the National Asthma Survey, and the National Survey of Adoptive Parents. The SLAITS study design involves random-digit dialing (RDD) and computer-assisted telephone interviewing (CATI) to annually contact and identify children between ages 0-17. Only landline phone numbers have been included in the study design in previous years; however, for the 2009/10 NS-CSHCN, the sample of landline telephone numbers was supplemented by an independent RDD sample of cell phone numbers. This cell phone sampling was a new feature of the NS-CSHCN, and information is included on whether the respondent was interviewed via landline or cell phone number. SLAITS surveys use the sampling frame from the National Immunization Survey (NIS) for purposes of efficiency and economy.

The following sections are included in the NS-CSHCN interview:

- Section 1: NIS/SLAITS (qualifying question on household having a child less than 18 years old)
- Section 2: Initial Screening (to determine if child has special health care needs)
- Section 3: Health and Functional Status
- Section 4: Access to Care – Use of Services and Unmet Needs
- Section 5: Care Coordination
- Section 6A: Family Centered Care and Shared Decision Making
- Section 6B: Transition Issues
- Section 6C: Developmental Screening
- Section 7: Health Insurance
- Section 8: Adequacy of Health Care Coverage
- Section 9: Impact on the Family
- Section 9.5: ADD/ADHD Questions
- Section 10: Demographics
- Section 11: Household Income
- Section 11A: Telephone Line and Household Information (questions not released due to confidentiality)

Data from the NS-CSHCN was publicly available, at no cost, from the Data Resource Center of the CDC. This data was provided in SAS and SPSS formats, and the original SAS version of the data set (without constructed indicators) was also downloadable at no cost from the
8.3.3 Variables

A complete list of all variables in Study 3, as well as their detailed descriptions, is provided in Table 18. The outcomes of interest, or dependent variables, in Study 3 were (1) caregiver burden, (2) satisfaction with care, and (3) transition planning to adult care. Tables 16, 17, and 18 show the NS-CSHCN survey items that were used to assess the outcomes of caregiver burden, satisfaction with care, and transition planning to adult care, respectively. The independent variable for Study 3a is the medical home, and information on whether or not CSHCN belong to a medical home was provided by the 2009-10 NS-CSHCN. The independent variables for Study 3b included individual components of the medical home, analyzed separately or in dyads, as follows: (1) accessible care and comprehensive care, (2) family-centered care and culturally effective/culturally sensitive care, and (3) coordinated care.

Table 18 also shows demographic characteristics, such as the age of the child, gender of the child, race/ethnicity, parental education, family structure, and residence, which were included in analyses as control variables and as potential confounders. These demographics have been shown in the literature to be related to the independent variable (the medical home and its components) and the dependent variables (the three non-clinical outcomes of care). Additionally, since the transition planning to adult care outcome variable was only relevant for
CSHCN from 15-17 years of age, age was operationalized as follows for Study 3: age 0-5, 6-11, 12-14 and 15-17 years old.

Financial characteristics – specifically, household income and insurance status (public only, private only, or both public and private) – were also part of the analyses in Study 3 as control variables and are shown in Table 18. Household income was considered a potential confounder, since the literature indicated that income influences the likelihood of CSHCN of being in a medical home or receiving components of care that are part of a medical home (the independent variables). Income may also influence non-clinical outcomes of care, such as satisfaction with care (a dependent variable).

<table>
<thead>
<tr>
<th>Variable/Survey Item(s)</th>
<th>Description</th>
<th>Role(s) in Study*</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE_X</td>
<td>Age of child</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>C2Q03_X</td>
<td>Gender of child</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>HISPANIC C10Q32_X</td>
<td>Race/ethnicity of child</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>EDUCR_IMP</td>
<td>Highest education level attained by any parent in household</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>FAMSTRUCT (*derived from responses to C11Q01_A through C10Q05)</td>
<td>Family structure (biological or adopted child, step-family, mother-only, other)</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>C10Q41</td>
<td>Residence</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>POVLEVEL_IMP C11Q11 C11Q12 C11Q13</td>
<td>Household income (by FPL) Receipt of welfare Receipt of SSI SSI for disability</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>TYPEINS (*derived from Section 7 survey questions)</td>
<td>Insured status (uninsured, private and/or public coverage)</td>
<td>Control variable; confounder</td>
</tr>
<tr>
<td>Summary measure</td>
<td>Medical home**</td>
<td>Independent variable (Study 3a only)</td>
</tr>
<tr>
<td>C4Q02A</td>
<td>Accessible care</td>
<td>Independent variable (Study 3b only)</td>
</tr>
<tr>
<td>C4Q0A-C4Q0D, K4Q20; skip to C5Q01, C5Q11, C4Q07 depends on K4Q20 total</td>
<td>Comprehensive care (includes usual source of care)</td>
<td>Independent variable (Study 3b only)</td>
</tr>
</tbody>
</table>

Table 18. Study 3 Variables
Table 18 continued

<table>
<thead>
<tr>
<th>Variable/Survey Item(s)</th>
<th>Description</th>
<th>Role(s) in Study*</th>
</tr>
</thead>
<tbody>
<tr>
<td>C6Q02 through C6Q06; C6Q11, C6Q12</td>
<td>Family-centered care; culturally-sensitive care</td>
<td>Independent variables (Study 3b only)</td>
</tr>
<tr>
<td>C5Q01; C5Q05-C5Q07; C5Q09-C5Q13; C5Q15-C5Q17</td>
<td>Coordinated care</td>
<td>Independent variable (Study 3b only)</td>
</tr>
<tr>
<td>C9Q02-4; C9Q06; C9Q10</td>
<td>Caregiver burden</td>
<td>Dependent variable</td>
</tr>
<tr>
<td>C6Q0C</td>
<td>Satisfaction with care</td>
<td>Dependent variable</td>
</tr>
<tr>
<td>C6Q07; C6Q0A, C6Q0A_B-F; C6Q08</td>
<td>Transition planning to adult care</td>
<td>Dependent variable</td>
</tr>
</tbody>
</table>

*Unless otherwise noted, all study variables were used in both Study 3a and Study 3b.

**The medical home variable is a summary measure compiled by the NS-CSHCN, based on multiple indicators/survey questions. See Appendix C for details on how the medical home variable and its components were operationalized.

Tables 19, 20 and 21 list survey items for caregiver burden, satisfaction with care, and transition planning to adult care, the three dependent variables in Study 3. As noted in the footnotes for Table 20 (NS-CSHCN Survey Items for Satisfaction with Care), operationalization of the satisfaction with care variable was as follows: “Very satisfied” and “somewhat satisfied” were coded as 1 (satisfied with care), while “Somewhat dissatisfied” and “Very dissatisfied” were coded as 0 (dissatisfied with care). Responses of “Don’t Know” or respondents who did not answer the question did not have their responses included in the analyses.

**Table 19. NS-CSHCN Survey Items for Caregiver Burden**

<table>
<thead>
<tr>
<th>Survey Item Description</th>
<th>Survey Item</th>
<th>Survey Response*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you or any other family members provide health care at home for [CHILD’S NAME]?:</td>
<td>C9Q02</td>
<td>Yes</td>
</tr>
<tr>
<td>How many hours per week?</td>
<td>C9Q03</td>
<td>N/A</td>
</tr>
<tr>
<td>How many hours per week do you or other family members spend arranging or coordinating [CHILD’S NAME]’s care?</td>
<td>C9Q04</td>
<td>N/A</td>
</tr>
<tr>
<td>Have you or other family members stopped working because of [CHILD’S NAME]’s health conditions?</td>
<td>C9Q10</td>
<td>Yes</td>
</tr>
<tr>
<td>Have you or other family members cut down on the hours you work because of [CHILD’S NAME]’s health?</td>
<td>C9Q06</td>
<td>Yes</td>
</tr>
</tbody>
</table>

*Indicates a survey response of interest. If ≥ 1 of these survey responses above is true in addition to a response of “Yes” to the qualifying question, excluding responses to survey items about how many hours per week care is provided, then the parent/guardian has experienced caregiver burden.
Table 20. NS-CSHCN Survey Items for Satisfaction with Care
*Indicates a survey response of interest/that parent is satisfied with the care. Operationalization of the satisfaction with care variable was as follows: “Very satisfied” and “somewhat satisfied” were coded as 1 (satisfied with care), while “Somewhat dissatisfied” and “Very dissatisfied” were coded as 0 (dissatisfied with care). Responses of “Don’t Know” or respondents who did not answer the question did not have their responses included in the analyses.

Table 21. NS-CSHCN Survey Items for Transition Planning to Adult Care
*Indicates a survey response of interest/that transition planning occurred, unless N/A.
**Operationalization of variables: in all instances where the question asked elicits a Yes/No response, the variable was coded as 1 if the response was “Yes” and 0 if the response was “No.” For a question with response choices of “Sometimes,” “often,” or “always,” “Sometimes” were coded as 0 and the remaining options were coded as 1.

8.3.4 Statistical Methods

Prior to determining any associations, univariate analyses were performed to obtain descriptive statistics for the sample of CSHCN who receive care in a medical home and those
who do not, in addition to summary statistics for the sample with respect to important
covariates such as insurance status and household income.

Statistical analyses for Study 3 encompassed a number of formal comparisons, and
when multiple statistical tests or comparisons are being performed simultaneously on a single
data set, this increases the chances of obtaining false-positive results (Type I errors). This
problem of multiple comparisons is commonly compensated for through the use of the
Bonferroni method or correction, which is an adjustment made to the p-values to mitigate this
risk of false positives when a large number of significance tests are involved in a study. However,
due to the large sample size for Study 3, a p-value < 0.001 was used for the significance level for
each aim and sub-aim despite the number of comparisons involved. This p-value was deemed to
be appropriate because, even if up to 50 comparisons were conducted, 0.001 would still be a
conservative estimate (standard p-value < 0.05/50 = 0.001).

In Study 3a and Study 3b, logistic regression was used to examine associations between
the independent variable and the various outcomes of care (the dependent variables). An
alternative model is a linear probability model (ordinary least squares approach). This approach
is less desirable because it would (1) not have addressed issues of heteroskedasticity, (2) would
have resulted in a non-normal distribution of errors, and (3) would have yielded predicted
probabilities that could be greater than 1 or less than 0. Logistic regression is employed when
the dependent variable (Y) is dichotomous, rather than continuous and approximately normal
with respect to its distribution. Logistic regression models are a form of generalized linear
models \[g(E(y|x) = B_0 + B_1x + ...], \] where the link function, \(g(\mu),\) is defined as the logit.

Multiple logistic regression was also used to examine if two or more independent
variables in the model for Study 3 were predictors for the dependent variable, the non-clinical
outcomes of care. Additionally, collinearity between two predictor variables and
multicollinearity between more than two predictor variables was determined by whether there was a non-zero correlation between the variables by examining the following two diagnostic factors as part of the collinearity statistics: tolerance and Variance Inflation Factor (VIF). Specifically, a tolerance statistic (1-R²) below 0.20 was the threshold used to determine if further investigation would be warranted. This value is interpreted as indicating that at least 80% of the variance of the independent variable is being shared with other independent variables.

Typically, situations in which the tolerance value is low and accompanied by large standard errors and non-significance indicate an almost perfect linear combination of the independent variables in the model and imply that the independent variable should not be added to the regression equation. However, neither low tolerance statistics nor large standard errors were found to be significant issues for the independent variables included in the multiple regression models for Study 3. The VIF (1/Tolerance) measures the impact of collinearity in a regression model and is always greater than or equal to one. Although there is no formal VIF value for determining the presence of multicollinearity, the literature generally assumes values of VIF above 10 may indicate multicollinearity (Regression with SPSS, Chapter 2). When compared to the individual R² values (separate from the overall R² of the model) for Study 3, neither the R² nor VIF values for any of the independent variables were higher than the threshold of 10. This indicated that multicollinearity was present to a small degree (as is to be expected for a multiple regression model), but was not a serious cause for concern.

In particular, the analyses for Study 3a involved comparing outcomes between CSHCN in a medical home and CSHCN who were not receiving care from a medical home. However, since CSHCN who were not classified as receiving care from a medical home could vary with respect to the type of care they received – e.g., they may have either received no characteristics of care from a medical home or may still have received some components of care that are part of a
medical home – Study 3a also consisted of analyses between CSHCN who received particular components of a medical home. This allowed for more equivalent comparisons to be made between CSHCN in a medical home and CSHCN who were not part of a medical home.

Study 3b consisted of three separate analyses of non-clinical outcomes: (1) odds of experiencing caregiver burden, (2) odds of being satisfied with care, and (3) odds of receiving transition planning to adult care. These odds were reported for CSHCN who were not part of a medical home (non-MH CSHCN), but who experienced individual components or dyads of medical home components: care that was (1) accessible and comprehensive, (2) family-centered and culturally effective/sensitive, and (3) coordinated. Because these categories are not mutually exclusive (e.g., a non-MH CSHCN who received accessible care may also have received coordinated care), separate effects were reported for each dyad or individual component of the medical home that non-MH CSHCN experienced.

The weighting variable, WEIGHT_I, was included in the Interview File and adjusts survey responses to reflect the population of CSHCN age 0-17 years in each state and the District of Columbia. As recommended by CAHMI, this weight variable was applied to all analyses using the Interview File. Survey weights were used rather than using unweighted data since the 2009/10 NS-CSHCN oversampled based on multiple demographics and preliminary data analyses demonstrated that estimates were not equivalent when using survey weights versus unweighted data. Another rationale for utilizing survey weights was that the study sample was not large enough to provide estimates specific to the U.S. population, so conclusions could be drawn about the general population of CSHCN based on study results.

The initial model that was tested for each non-clinical outcome of care (caregiver burden, satisfaction with care, and transition planning to adult care) for all CSHCN in a medical
home or not in a medical home in Study 3a is presented below. It includes all aforementioned independent variables, demographics, and financial characteristics described for CSHCN.

\[ g(E(\text{outcome})) = \beta_0 + \beta_1(\text{medical home}) + \beta_2(\text{age}) + \beta_3(\text{gender}) + \beta_4(\text{parental education}) + \beta_5(\text{family structure}) + \beta_6(\text{residence}) + \beta_7(\text{household income}) + \beta_8(\text{insurance status}) + \beta_9(\text{welfare recipient}) + \beta_{10}(\text{SSI recipient}) \]

The initial model tested for each non-clinical outcome of care (caregiver burden, satisfaction with care, and transition planning to adult care) in Study 3b for CSHCN who are not part of a medical home is below. It includes independent variables, demographics, and financial characteristics, and was used to evaluate each component of a medical home or grouped components of a medical home as follows: (1) accessible care and comprehensive care, (2) family-centered and culturally effective/sensitive care, and (3) coordinated care.

\[ g(E(\text{outcome})) = \beta_0 + \beta_1(\text{non-MH component 1-3}) + \beta_2(\text{age}) + \beta_3(\text{gender}) + \beta_4(\text{parental education}) + \beta_5(\text{family structure}) + \beta_6(\text{residence}) + \beta_7(\text{household income}) + \beta_8(\text{insurance type}) + \beta_9(\text{welfare recipient}) + \beta_{10}(\text{SSI recipient}) \]

Each parameter (beta) is presented as exp(beta) or odds ratio (OR), since odds ratios provide an estimate of the likelihood of a given outcome relative to a reference category for the independent variable. The results are presented in terms of odds ratios (exponential coefficient), 95% confidence intervals and p-values. Associations were classified as strong if the odds ratio was greater than 3.0, moderate if the odds ratio was between 1.6-3.0, and weak if the odds ratio fell between 1.1-1.5.

8.4 Study 3 Results

Descriptive and Summary Statistics
Table 22 shows descriptive statistics for Study 3, including financial characteristics such as insurance type and demographics such as age, gender, and parental education. Table 22 also lists the percentage of CSHCN in the 2009/10 NS-CSHCN who belonged to a medical home (43.0%) and the percentages of CSHCN in the survey who received specific components of care, such as coordinated care.

Table 23 shows summary statistics for MH CSHCN and non-MH CSHCN. Overall, 43.0% of CSHCN belonged to a medical home (n = 18,279), while 57.0% of CSHCN did not belong to a medical home but received at least one individual component of care that was included in a medical home (n = 21,963). These individual components of care for CSHCN who did not belong to a medical home included receiving accessible care, comprehensive care, family-centered care and coordinated care. A given non-MH CSHCN may have received more than one of these individual components of care, e.g., a child may have coordinated care and accessible care, but not be part of a medical home. Due to this overlap in receiving more than one individual component of care, summing all four components of care for a particular subgroup will not result in the total number of CSHCN in that particular subgroup. These summary statistics are further broken down by demographics such as age, gender, race/ethnicity, family structure, parental education, insurance type, and household income in Table 23.
<table>
<thead>
<tr>
<th>Survey Item</th>
<th>% CSHCN in survey</th>
<th>n**</th>
<th>Pop. Est.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total CSHCN in survey</td>
<td>100%</td>
<td>40,242</td>
<td>11,081,774</td>
</tr>
<tr>
<td>Type of health insurance coverage – private insurance only*</td>
<td>52.4%</td>
<td>23,315</td>
<td>5,621,137</td>
</tr>
<tr>
<td>Type of health insurance coverage – public insurance only*</td>
<td>35.9%</td>
<td>11,362</td>
<td>3,848,567</td>
</tr>
<tr>
<td>Both public and private health insurance*</td>
<td>8.2%</td>
<td>2,910</td>
<td>880,494</td>
</tr>
<tr>
<td>Uninsured*</td>
<td>3.6%</td>
<td>1,149</td>
<td>384,698</td>
</tr>
<tr>
<td>Financial - income level: 0-99% FPL</td>
<td>22.2%</td>
<td>6,899</td>
<td>2,469,569</td>
</tr>
<tr>
<td>Financial - income level: 100-199% FPL</td>
<td>21.9%</td>
<td>7,722</td>
<td>2,425,959</td>
</tr>
<tr>
<td>Financial - income level: 200-399% FPL</td>
<td>28.5%</td>
<td>12,572</td>
<td>3,163,784</td>
</tr>
<tr>
<td>Financial - income level: 400% FPL or more</td>
<td>27.4%</td>
<td>13,049</td>
<td>3,042,439</td>
</tr>
<tr>
<td>Demographic – age of child: 0-5 years</td>
<td>20.8%</td>
<td>7,294</td>
<td>2,307,940</td>
</tr>
<tr>
<td>Demographic – age of child: 6-11 years</td>
<td>38.7%</td>
<td>15,834</td>
<td>4,292,126</td>
</tr>
<tr>
<td>Demographic – age of child: 12-14 years</td>
<td>20.8%</td>
<td>7,705</td>
<td>2,086,522</td>
</tr>
<tr>
<td>Demographic – age of child: 15-17 years</td>
<td>20.9%</td>
<td>7,742</td>
<td>2,096,553</td>
</tr>
<tr>
<td>Demographic – gender of child: male</td>
<td>59.3%</td>
<td>24,139</td>
<td>6,572,740</td>
</tr>
<tr>
<td>Demographic – gender of child: female</td>
<td>40.7%</td>
<td>16,033</td>
<td>4,509,034</td>
</tr>
<tr>
<td>Demographic – race/ethnicity of child: White, non-Hispanic</td>
<td>59.3%</td>
<td>27,989</td>
<td>6,579,873</td>
</tr>
<tr>
<td>Demographic – race/ethnicity of child: Black, non-Hispanic</td>
<td>16.1%</td>
<td>4,010</td>
<td>1,790,890</td>
</tr>
<tr>
<td>Demographic – race/ethnicity of child: Hispanic</td>
<td>16.8%</td>
<td>4,479</td>
<td>1,859,879</td>
</tr>
<tr>
<td>Demographic – race/ethnicity of child: Other minority, non-Hispanic</td>
<td>7.8%</td>
<td>3,764</td>
<td>871,109</td>
</tr>
<tr>
<td>Demographic – family structure: mother-only</td>
<td>25.7%</td>
<td>7,803</td>
<td>2,811,253</td>
</tr>
<tr>
<td>Demographic – family structure: all other households</td>
<td>74.3%</td>
<td>31,857</td>
<td>8,117,649</td>
</tr>
<tr>
<td>Demographic – parental education: ≤ high school</td>
<td>31.0%</td>
<td>8,152</td>
<td>3,442,765</td>
</tr>
<tr>
<td>Demographic – parental education: &gt; high school</td>
<td>69.0%</td>
<td>32,090</td>
<td>7,658,986</td>
</tr>
<tr>
<td>Medical home (yes)~</td>
<td>43.0%</td>
<td>18,279</td>
<td>4,613,661</td>
</tr>
<tr>
<td>Accessible Care: 1 or more personal doctor or nurse (PDN)</td>
<td>93.1%</td>
<td>37,735</td>
<td>10,325,867</td>
</tr>
<tr>
<td>Comprehensive Care: Usual source of care for both sick and well care</td>
<td>89.3%</td>
<td>36,407</td>
<td>9,881,507</td>
</tr>
<tr>
<td>Comprehensive Care: Did not need any referrals in past 12 months</td>
<td>66.3%</td>
<td>26,774</td>
<td>7,331,050</td>
</tr>
</tbody>
</table>

Table 22. Study 3 Descriptive Statistics

Continued
<table>
<thead>
<tr>
<th>Survey Item</th>
<th>% CSHCN in survey</th>
<th>n**</th>
<th>Pop. Est.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehensive Care: No problems obtaining referrals when needed</td>
<td>76.6%</td>
<td>10,649</td>
<td>2,854,120</td>
</tr>
<tr>
<td>Comprehensive Care: Problem obtaining referrals when needed</td>
<td>23.4%</td>
<td>2,625</td>
<td>870,885</td>
</tr>
<tr>
<td>Family-Centered Care &amp; Culturally Sensitive Care (combined measure): Family receives family-centered care from health providers</td>
<td>64.6%</td>
<td>27,106</td>
<td>7,073,553</td>
</tr>
<tr>
<td>Coordinated Care: Did not need care coordination</td>
<td>24.4%</td>
<td>9,815</td>
<td>2,666,191</td>
</tr>
<tr>
<td>Coordinated Care †: Met all needed components of effective care coordination if needed (among CSHCN who needed care coordination)</td>
<td>56.0%</td>
<td>17,390</td>
<td>4,618,391</td>
</tr>
</tbody>
</table>

Note: *Survey weights were utilized to derive all calculations of n. Unweighted calculations were not equivalent to weighted calculations, partly due to the fact that the survey oversampled based on particular demographic characteristics. Percentages reported are weighted to population characteristics.

Yellow = Predictor/independent variable

Gray = not of interest; included as a reference

*Insurance coverage status AT TIME OF SURVEY — “both” indicates public & private at same time

**Total n = 40,242 (entire CSHCN population included in 2009/10 NS-CSHCN). Totals may not always sum to 40,242 since unknown values (responses coded as “refused”, “don’t know”, or system missing) were not included in the denominator count. Missing data counts for each variable were found to be less than 2% of the overall value for each variable; multiple imputation will therefore be unnecessary.

Additional note: The American Academy of Pediatrics’ (AAP) description of a “medical home” lists 7 defining components: (1) accessible, (2) continuous, (3) comprehensive, (4) family-centered, (5) coordinated, (6) compassionate, and (7) culturally effective. 5 of these 7 medical home components and the presence of a personal doctor or nurse are assessed by the 2009/10 NS-CSCHN. The overall medical home measure is a composite score derived from 5 different subparts based on 19 different individual survey items. To qualify as having a medical home, a child must (a) have a personal doctor or nurse and (b) meet the criteria for adequate care on each of the 5 needed components.

Family-centered care and culturally sensitive care were part of the same group when components of the medical home are being assessed in Study 3b. Responses of “always” or “usually” were coded as 1 and responses of “sometimes” or “never” were coded as 0.

† Additional details on individual care coordination components and survey items used to measure care coordination are listed in Table 11 of Study 2, under the “Variables” section of the Methods. Responses of “very satisfied” or “somewhat satisfied” were coded as 1 (satisfied with care coordination), while responses of “somewhat dissatisfied” and “very dissatisfied” were coded as 0 (dissatisfied with care coordination).
Table 23. Study 3a Summary Statistics – for CSCHN in a medical home vs. CSHCN not in medical home

<table>
<thead>
<tr>
<th>Variable</th>
<th>% of CSHCN in a medical home</th>
<th>% of CSHCN not in a medical home, but receiving at least one individual component of care that is included in a medical home: Total = 21,963 (57.0% of all CSHCN)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>43.0% (n = 18,279)</td>
<td>Accessible Care 74.5% (n = 16,366) Comprehensive Care 69.2% (n = 15,193) Family-Centered Care^ 63.2% (n = 13,890) Coordinated Care 40.9% (n = 8,987) All non-MH 57.0% (n = 21,963)</td>
</tr>
<tr>
<td>Age of child (mean = 10.2 years old)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>44.2% (n = 3,224)</td>
<td>94.9% (n = 3,060)</td>
</tr>
<tr>
<td>6-11 years</td>
<td>42.1% (n = 6,666)</td>
<td>93.9% (n = 5,914)</td>
</tr>
<tr>
<td>12-14 years</td>
<td>43.1% (n = 3,321)</td>
<td>94.0% (n = 3,122)</td>
</tr>
<tr>
<td>15-17 years</td>
<td>46.4% (n = 3,592)</td>
<td>94.6% (n = 3,926)</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>45.2% (n = 10,911)</td>
<td>74.1% (n = 9,802)</td>
</tr>
<tr>
<td>Female</td>
<td>45.9% (n = 7,359)</td>
<td>75.7% (n = 6,566)</td>
</tr>
<tr>
<td>Race/Ethnicity of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>50.1% (n = 14,022)</td>
<td>89.6% (n = 12,564)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>33.6% (n = 1,347)</td>
<td>76.0% (n = 1,024)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>32.2% (n = 1,442)</td>
<td>73.9% (n = 1,066)</td>
</tr>
<tr>
<td>Other minority, non-Hispanic</td>
<td>39.1% (n = 1,472)</td>
<td>74.6% (n = 1,710)</td>
</tr>
</tbody>
</table>

Table 23. Study 3a Summary Statistics – for CSCHN in a medical home vs. CSHCN not in medical home

Continued
<table>
<thead>
<tr>
<th>Variable</th>
<th>% CSHCN in a MH</th>
<th>% of CSHCN not in a medical home, but receiving individual components of medical home care: Total = 21,963 (57.0% of all CSHCN)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>% of CSHCN in a MH</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
<td>43.0% (n = 18,279)</td>
</tr>
<tr>
<td>Family structure Mother-only</td>
<td></td>
<td>34.9% (n = 2,723)</td>
</tr>
<tr>
<td>Family structure All other</td>
<td>48.8% (n = 15,556)</td>
<td>80.1% (n = 12,169)</td>
</tr>
<tr>
<td>Parental education ≤ High school</td>
<td>33.9% (n = 2,767)</td>
<td>61.7% (n = 3,323)</td>
</tr>
<tr>
<td>Parental education &gt; High school</td>
<td>48.3% (n = 15,512)</td>
<td>76.8% (n = 12,732)</td>
</tr>
<tr>
<td>Type of Insurance</td>
<td></td>
<td>51.2% (n = 11,937)</td>
</tr>
<tr>
<td>Type of Insurance Private insurance only</td>
<td></td>
<td>41.7% (n = 4,735)</td>
</tr>
<tr>
<td>Type of Insurance Public insurance only</td>
<td></td>
<td>49.6% (n = 1,443)</td>
</tr>
<tr>
<td>Type of Insurance Both public and private</td>
<td></td>
<td>14.2% (n = 163)</td>
</tr>
<tr>
<td>Household income At or above 300% FPL</td>
<td></td>
<td>54.8% (n = 10,312)</td>
</tr>
<tr>
<td>Household income &lt; 300% FPL</td>
<td></td>
<td>39.6% (n = 7,965)</td>
</tr>
</tbody>
</table>
Study 3a: Caregiver Burden, Satisfaction with Care, and Transition Planning

Table 24 shows the odds of experiencing non-clinical outcomes of care for CSHCN in a medical home (MH CSHCN), versus CSHCN not in a medical home (non-MH CSHCN). The three non-clinical outcomes were caregiver burden, satisfaction with care, and transition planning to adult care. The statistically significant odds ratio less than one for caregiver burden indicates lower odds of experiencing caregiver burden for MH CSHCN versus non-MH CSHCN. The odds of caregiver burden for MH CSHCN are 0.42 times those of non-MH CSHCN; this is a 58% lower odds of caregiver burden for CSHCN who are in a medical home versus CSHCN who are not.

Secondly, a statistically significant odds ratio of greater than one for satisfaction with care indicates strong, higher odds of being satisfied with care for MH CSHCN, versus non-MH CSHCN. Specifically, the odds of MH CSHCN being satisfied with care is 6.16 times that of non-MH CSHCN; MH CSHCN thus had 516% higher odds of being satisfied with care than non-MH CSHCN. Similarly, the odds ratio for transition planning was also statistically significant and greater than one, indicating moderately higher odds of receiving transition planning for adult care for MH CSHCN, versus non-MH CSHCN. MH CSHCN had 183% higher odds of receiving transition planning to adult care (odds ratio of 2.83) than non-MH CSHCN.

<table>
<thead>
<tr>
<th>Variable</th>
<th>CSHCN in Medical Home?^</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MH (43.0%, n = 18,279) vs. non-MH (57.0%, n = 21,963)</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>0.42**</td>
</tr>
<tr>
<td>Satisfaction with Care</td>
<td>6.16**</td>
</tr>
<tr>
<td>Transition Planning to Adult Care*</td>
<td>2.83**</td>
</tr>
</tbody>
</table>

Table 24. Study 3a Results: Unadjusted Odds of Experiencing Specific Non-Clinical Outcomes of Care for CSHCN in a Medical Home vs. CSHCN not in a Medical Home (Odds Ratios)

^CSHCN were classified as being “in” a medical home if they received coordinated, ongoing, comprehensive care within a medical home, as determined by the AAP definition of a medical home and the relevant summary measures and related subparts included in the 2009/10 NS-CSHCN section on the medical home. *Only CSHCN between the ages of 15-17 years old were asked about transition to adult care questions. For this reason, the denominator or total population studied for transition planning to adult care was the 4,346 CSHCN in this age group that were part of a medical home (and not the total CSHCN in a medical home, n = 18,279).

**p-value < 0.001 for these odds ratios.
Table 25 shows the odds of experiencing each of the non-clinical outcomes of care based on specific covariates. Results for CSHCN who were not part of a medical home but received: (1) accessible and comprehensive care, (2) family-centered/compassionate care, and (3) coordinated care are shown in Tables 26 and 27.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Non-Clinical Outcome of Care for CSHCN in Medical Home vs. CSHCN not in MH***</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caregiver Burden</td>
</tr>
<tr>
<td>Age of child (mean = 10.2 years old)</td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>2.03**</td>
</tr>
<tr>
<td>6-11 years</td>
<td>1.49**</td>
</tr>
<tr>
<td>12-14 years</td>
<td>1.27**</td>
</tr>
<tr>
<td>15-17 years</td>
<td>Referent</td>
</tr>
<tr>
<td>Gender of child (results omitted; no significant difference)</td>
<td></td>
</tr>
<tr>
<td>Race/Ethnicity of child</td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>Referent</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>0.96</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.28**</td>
</tr>
<tr>
<td>Other, non-Hispanic</td>
<td>1.01</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
</tr>
<tr>
<td>Mother-only</td>
<td>1.07</td>
</tr>
<tr>
<td>Biological parents</td>
<td>Referent</td>
</tr>
<tr>
<td>All Other</td>
<td>0.96*</td>
</tr>
<tr>
<td>Parental education</td>
<td></td>
</tr>
<tr>
<td>&lt; High school</td>
<td>0.97</td>
</tr>
<tr>
<td>High school education</td>
<td>0.97</td>
</tr>
<tr>
<td>&gt; High school</td>
<td>Referent</td>
</tr>
<tr>
<td>Type of Insurance</td>
<td></td>
</tr>
<tr>
<td>Private insurance only</td>
<td>Referent</td>
</tr>
<tr>
<td>Public insurance only</td>
<td>2.13**</td>
</tr>
<tr>
<td>Both public and private</td>
<td>3.08**</td>
</tr>
<tr>
<td>Uninsured</td>
<td>1.86**</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
</tr>
<tr>
<td>At or above 300% FPL</td>
<td>0.90**</td>
</tr>
<tr>
<td>100-299% FPL</td>
<td>1.01</td>
</tr>
<tr>
<td>0-99% FPL</td>
<td>Referent</td>
</tr>
</tbody>
</table>

Table 25. Study 3a Results: Odds of Experiencing Non-Clinical Outcomes of Care, Based on Specific Covariates

^Only CSHCN 15-17 years old were asked about transition to adult care questions. *p-value < 0.01
**p-value < 0.001 ***Each covariate is adjusted for the other covariates in the table
### Table 26. Study 3b Summary Statistics – Combinations of Care Experienced by CSHCN Not in Medical Homes

<table>
<thead>
<tr>
<th>Variable</th>
<th>Combinations of Care (non-MH CSHCN only, n = 21,963)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Categories of care are not mutually exclusive. The total is thus greater than n = 21,963 non-MH CSHCN.</td>
<td>Accessible &amp; Comprehensive Care 61.4% (n = 13,485)</td>
</tr>
<tr>
<td>Age of Child: 0-5 years</td>
<td>67.4% (n = 2,741)</td>
</tr>
<tr>
<td>Age of Child: 6-11 years</td>
<td>62.3% (n = 5,708)</td>
</tr>
<tr>
<td>Age of Child: 12-14 years</td>
<td>62.5% (n = 2,753)</td>
</tr>
<tr>
<td>Age of Child: 15-17 years</td>
<td>55.2% (n = 2,283)</td>
</tr>
<tr>
<td>Gender: Male</td>
<td>62.3% (n = 8,020)</td>
</tr>
<tr>
<td>Gender: Female</td>
<td>60.7% (n = 5,465)</td>
</tr>
<tr>
<td>Race/Ethnicity: White, non-Hispanic</td>
<td>66.8% (n = 9,323)</td>
</tr>
<tr>
<td>Race/Ethnicity: Black, non-Hispanic</td>
<td>53.0% (n = 1,412)</td>
</tr>
<tr>
<td>Race/Ethnicity: Hispanic</td>
<td>50.1% (n = 1,521)</td>
</tr>
<tr>
<td>Race/Ethnicity: Other, non-Hispanic</td>
<td>53.6% (n = 1,229)</td>
</tr>
<tr>
<td>Family Structure: Mother-only</td>
<td>54.5% (n = 2,767)</td>
</tr>
<tr>
<td>Family Structure: All Other</td>
<td>65.7% (n = 10,718)</td>
</tr>
<tr>
<td>Parental Education: ≤ High school</td>
<td>46.8% (n = 2,523)</td>
</tr>
<tr>
<td>Parental Education: &gt; High school</td>
<td>66.2% (n = 10,962)</td>
</tr>
<tr>
<td>Private insurance only</td>
<td>72.6% (n = 8,262)</td>
</tr>
<tr>
<td>Public insurance only</td>
<td>57.8% (n = 3,826)</td>
</tr>
<tr>
<td>Both public and private</td>
<td>70.2% (n = 1,029)</td>
</tr>
<tr>
<td>Uninsured</td>
<td>37.4% (n = 368)</td>
</tr>
<tr>
<td>Income at or above 300% FPL</td>
<td>72.5% (n = 6,168)</td>
</tr>
<tr>
<td>Income &lt; 300% FPL</td>
<td>60.2% (n = 7,317)</td>
</tr>
</tbody>
</table>
**Study 3b: Non-Clinical Outcomes of Care for Non-MH CSHCN**

Table 27 shows Study 3b results, which include the odds of reporting caregiver burden, satisfaction with care, and receipt of transition planning for non-MH CSHCN who experience one of the following dyadic or individual components of a medical home: (a) accessible and comprehensive care, (b) family-centered and culturally-sensitive care, and (c) coordinated care. The reported odds ratios for the odds of caregiver burden, satisfaction with care, and receipt of transition planning are for the following three groups of non-MH CSHCN: (1) any CSHCN who received coordinated care, (2) any CSHCN who received both accessible and comprehensive care and (3) any CSHCN who received both family-centered and culturally-sensitive care.

With respect to caregiver burden, all odds were less than one, indicating a lower odds of experiencing caregiver burden for (a) non-MH CSHCN who had both accessible and comprehensive care (versus non-MH CSHCN who did not); (b) non-MH CSHCN who had family-centered care (versus non-MH CSHCN who did not); and (c) any non-MH CSHCN who had coordinated care (versus non-MH CSHCN who did not). The odds of caregiver burden for non-MH who received coordinated care were 0.70 times those of non-MH CSHCN who did not receive coordinated care; this is a 30% lower odds of experiencing caregiver burden for non-MH CSHCN who received coordinated care versus those who did not and it is statistically significant at p < 0.001. Although the odds of caregiver burden for non-MH CSHCN who received family-centered care (versus those who did not) was not statistically significant, the odds of caregiver burden for non-MH CSHCN who received both accessible and comprehensive care (versus those who did not) was statistically significant. Namely, non-MH who received both accessible and comprehensive care had 21% lower odds of experiencing caregiver burden versus non-MH CSHCN who did not receive accessible and comprehensive care (OR = 0.79).
Secondly, the odds of non-MH CSHCN who received coordinated care being satisfied with care was 1.86 times that of non-MH CSHCN who did not receive coordinated care; non-MH CSHCN who received care coordination thus had an 86% higher odds of being satisfied with care than non-MH CSHCN who did not receive care coordination. This result was statistically significant at \( p < 0.001 \), as was the result for non-MH CSHCN who received accessible and comprehensive care versus those who did not. The odds of non-MH CSHCN who received accessible and comprehensive care being satisfied with care was 1.23 times that of non-MH CSHCN who did not receive both accessible and comprehensive care. Specifically, non-MH CSHCN who received both accessible and comprehensive care had 23% higher odds of being satisfied with care versus non-MH CSHCN who did not.

For transition planning to adult care, none of the results were statistically significant. Non-MH CSHCN who received accessible and comprehensive care had a 9% higher odds (OR = 1.09) of receiving transition planning to adult care versus non-MH CSHCN who did not, but this result was not statistically significant at \( p < 0.001 \). Similarly, non-MH CSHCN who received family-centered care had a 6% higher odds (OR = 1.06) of receiving transition planning to adult care versus non-MH CSHCN who did not receive family-centered care, and this result was not significant at \( p < 0.001 \). Lastly, non-MH CSHCN who received care coordination had 44% higher odds of receiving transition planning to adult care versus non-MH CSHCN who did not receive care coordination, and this result also was not significant at \( p < 0.001 \).
<table>
<thead>
<tr>
<th>Variable</th>
<th>Non-Clinical Outcome</th>
<th>Non-MH CSHCN receiving individual components of care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CSHCN in MH</td>
<td>(a) Accessible &amp; Comprehensive</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(b) Family-Centered^</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(c) Coordinated</td>
</tr>
<tr>
<td>(1) Caregiver Burden</td>
<td>0.42*** (CI: 0.40-0.44)</td>
<td>0.79*** (CI: 0.66-0.95)</td>
</tr>
<tr>
<td>(2) Satisfaction with Care</td>
<td>6.16*** (CI: 5.86-6.47)</td>
<td>1.23*** (CI: 1.12-1.34)</td>
</tr>
<tr>
<td>(3) Transition Planning to Adult Care*</td>
<td>2.83*** (CI: 2.26-3.54)</td>
<td>1.09 (CI: 0.65-1.83)</td>
</tr>
</tbody>
</table>

Table 27. Study 3b Results: Adjusted* Odds of CSHCN in Medical Homes Experiencing Non-Clinical Outcomes, vs. CSHCN Not in Medical Homes Receiving Individual Components of Care

Notes: (1) CSHCN in MH column (Column 1) presents the weighted odds ratios of CSHCN belonging to a medical home experiencing a particular non-clinical outcome (e.g., caregiver burden, satisfaction with care, or transition planning to adult care), as outlined in additional detail in Table 25: Study 3a Results. (2) The following columns [(a)-(c)] present the weighted odds ratios of outcomes for CSHCN who were not part of a medical home (non-MH CSHCN) who only received care coordination (the reference group/referent). (3) All confidence intervals for weighted odds ratios are reported at the 95% level.

*Adjusted for age, gender, race/ethnicity, family structure, parental education, income and insurance status (identified as potential confounders for Study 3)

**Only CSHCN between the ages of 15-17 years old were asked about transition to adult care questions. For this reason, the denominator or total population studied for transition planning to adult care was the 4,346 CSHCN in this age group that were part of a medical home (and not the total CSHCN in a medical home, n = 18,279)

***p-value < 0.001 for these odds ratios

^CSHCN were classified as being “in” a medical home if they received coordinated, ongoing, comprehensive care within a medical home, as determined by the AAP definition of a medical home and the relevant summary measures and related subparts included in the 2009/10 NS-CSHCN section on the medical home. 24.1% of CSHCN in a medical home (n = 4,405) reported experiencing caregiver burden; 39.5% of CSHCN in a medical home (n = 7,220) reported experiencing satisfaction with care; and 35.3% of CSHCN in a medical home (n = 1,535) reported receiving transition planning to adult care*. 
8.5 Study 3 Discussion

Although the medical home has been proposed as an improved model of care for individuals and children with chronic conditions, previous studies have not thoroughly examined the data on the medical home and its effect on patients, particularly those with special and complex health care needs. Additionally, no prior study has investigated the impact of individual components of care experienced by CSHCN and how these might be associated with non-clinical outcomes of care for CSHCN. This is important because improvements in clinical outcomes, while crucial in decreasing hospitalizations and emergency department visits for CSHCN, are not the sole measure of health care outcomes and quality for CSHCN and their families. Often, non-clinical outcomes, such as decreased caregiver burden, are as important, if not more important than clinical improvements, since physical impairments for CSHCN with severe conditions may be permanent and less facile to alleviate or treat in comparison.

To assess the association between non-clinical outcomes of care for CSHCN, Study 3a therefore examined the likelihood of CSHCN in medical homes experiencing three parent/guardian-reported non-clinical outcomes of care: (1) caregiver burden, (2) satisfaction with care, and (3) receipt of transition planning to adult care. And in order to identify which components of a medical home might have a differential or particularly positive impact on non-clinical outcomes for CSHCN, Study 3b investigated whether CSHCN who were not in a medical home, but experienced specific components of a medical home, also had better non-clinical outcomes. These specific medical home components included the following dyads of variables, which were grouped together based on their co-occurrence/coincidence in health services (1) accessible and comprehensive care, (2) family-centered and culturally effective/sensitive care, and (3) coordinated care.
Study 3a: Caregiver Burden, Satisfaction with Care, and Transition Planning

Previous literature indicates that the issue of caregiver burden is heightened for CSHCN whose families are not part of a medical home (AAP, 2005; Drummond et al., 2012). In particular, those who are publicly insured or uninsured and living at greater than the 300% FPL are at much higher odds of reporting caregiver burden, which was also demonstrated in the preliminary results for Study 3. This indicates that improving access to medical homes, especially by targeting the most vulnerable populations of CSHCN (non-privately insured, lower income families) could better address the needs of the overall CSHCN population, a recommendation that the American Academy of Pediatrics has made in the past (AAP, 2002).

The literature has also shown that an improved model of health services delivery that incorporates more family-centered care can reduce patient dissatisfaction with care, primarily since CSHCN who are more satisfied with their care are usually non-minority, privately insured, and living in a household with both biological parents (Ngui and Flores, 2006). Results from this study indicate that CSHCN in a medical home are more likely to be satisfied with their care than non-MH CSHCN, which corroborates the existing research on family-centered care being beneficial in improving care satisfaction, since family-centered care is a component of the medical home. Additionally, the results for receipt of transition planning to adult care demonstrate that CSHCN in medical homes were more likely to discuss this topic.

Family-centered care encompasses aspects such as parents partnering with providers to be part of their child’s care, and makes it more likely for parents and providers to have effective conversations about how a child’s care will be managed once they surpass a certain age. The disparity in receipt of transition planning to adult care was also consistent with disparities in caregiver burden and satisfaction with care, in that CSHCN of minority race/ethnicity were less likely to report receiving transition planning to adult care. Therefore, when examining
overarching trends in the results for Study 3a, it is clear that being part of a medical home is associated with an increased likelihood of experiencing improved non-clinical outcomes that would benefit both CSHCH and their families.

Overall, the preliminary results from Study 3b demonstrate that CSHCN who are not part of a medical home are still likely to experience positive, non-clinical outcomes of care, although these results show associations as opposed to causation. The main finding is that an increased emphasis on improving care coordination could have benefits for CSHCN, since care coordination was consistently found to be more strongly associated with beneficial non-clinical outcomes of care for non-MH CSHCN, when compared to other components of a medical home, such as family-centered care. Future research may be able to better identify causal relationships between the medical home or between components of the medical home and non-clinical outcomes of care, and thus more strongly inform policy discussions when comparing outcomes between CSHCN in medical homes to those who are not part of medical homes. Additional studies need to be done before a more thorough understanding of medical homes and their causal impact on non-clinical outcomes can be clearly ascertained.

8.5.1 Limitations

Since the respondents of the CSHCN are parents/guardians, and not the health care providers of CSHCN or CSHCN themselves, the integrity of the data provided by the NS-CSHCN may be impacted by recall bias and the subjectivity of the respondents, by virtue of the study design of the survey. Additionally, the results from the survey are weighted to reflect the population of CSHCN ages 0-17, at the state and national level. Therefore, further subsetting of the survey data to a specific population subgroup, such as a particular racial/ethnic group or...
poverty level, would lead to incorrect standard error estimation. For this reason, conclusions cannot be drawn at a subpopulation level, aside from generalizations for a state or nationally.

Secondly, a major limitation of the cross-sectional data derived from the NS-CSHCN is that it is does not allow for causal inferences, since measurements were taken only at one point in time. Therefore, all results from the three studies are presented solely as associations, because causal relationships cannot be substantiated. Thirdly, as is the case with many other national surveys of this scale, only non-institutionalized CSHCN and those who have permanent residences were interviewed for the NS-CSCHN. For this reason, families with CSHCN living in institutions or families who are homeless or migrants are underrepresented in the survey data. Results from the studies are representative only of non-institutionalized CSHCN 0-17 years old.
Chapter 9. Dissemination

Upon completion of the proposed studies, dissemination of this dissertation will be to committee members at The Ohio State University and potentially to relevant peer-reviewed journals with the intent of publication. Scholarly, peer-reviewed journals that focus on public health, pediatric/child health, or developmental disabilities research would be the primary targets for submitting modified versions of all three studies individually. Target journals may possibly include, but are not limited to, the following journals: Academic Pediatrics (formerly Ambulatory Pediatrics); BMC Health Services Research; Health Services Research; Journal of Adolescent Health; Maternal and Child Health Journal; Pediatrics; Pediatric Clinics of North America; and Research in Developmental Disabilities. Committee members will receive the complete dissertation, including findings from all three studies, in both written and presentation form for the final defense.
Works Cited


American Academy of Pediatrics (AAP) (2003). Family-Centered Care and the Pediatrician’s Role: Committee on Hospital Care. *Pediatrics* 112(3):691-696. (*Statement of reaffirmation for this policy was published on 120(3):683 and this policy has also been partly revised by the policy on 129(2):394-404*).


Hughes, W. C. (1999). Managed care, meet community support: ten reasons to include direct support services in every behavioral health plan. *Health & social work, 24*(2), 103–111.


National Center for Medical Home Implementation, A. A. of P. (2011a). Building Your Care
Notebook. Retrieved from
http://www.medicalhomeinfo.org/for_families/care_notebook


Ziring, P. R., Brazdziunas, D., Cooley, W. C., Kastner, T. A., Kummer, M. E., Gonzalez de Pijem, L.,
### Appendix A: Study 1 Survey Items

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Percentage of Missing Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private insurance only*</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Public insurance only*</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Both public and private insurance*</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Other insurance*</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Income level: At or below 300% FPL</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Income level: Below 300% FPL</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Age of child: 0-3 years</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Age of child: 4-7 years</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Age of child: 8-11 years</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Age of child: 12-14 years</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Age of child: 15-17 years</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Gender of child: Male</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Gender of child: Female</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Race/ethnicity of child: White, non-Hispanic</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Race/ethnicity of child: Black, non-Hispanic</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Race/ethnicity of child: Hispanic</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Race/ethnicity of child: Other minority, non-Hispanic</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Family structure: Mother-only</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Family structure: All other households</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Parental education: ≤ High school</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Parental education: &gt; High school</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Condition complexity: Rx medication usage only</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Condition complexity: Other reason§</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Condition severity: Low (3-5) (based on summary score*)</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Condition severity: Moderate (6-9) (based on summary score*)</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>Condition severity: High (≥ 10) (based on summary score*)</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>No. of health conditions reported: None</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>No. of health conditions reported: 1</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>No. of health conditions reported: 2</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>No. of health conditions reported: 3</td>
<td>&lt;1.3%</td>
</tr>
<tr>
<td>No. of health conditions reported: ≥ 4 (up to 14)</td>
<td>&lt;1.3%</td>
</tr>
</tbody>
</table>

Note: Only CSHCN who were continuously insured for 12 months were included in these descriptive statistics. Total n = 40,242 (entire CSHCN population included in 2009/10 NS-CSHCN). Totals may not always sum to 40,242 since unknown values (responses coded as “refused”, “don’t know”, or system missing) are not included in the denominator count.
Table 28 continued

*Insurance coverage status AT TIME OF SURVEY

§ Other reasons could include (1) elevated service use or needs; (2) functional limitations; (3) use of special therapies; or (4) ongoing emotional, developmental, or behavioral conditions. Children may have qualified under multiple reasons, so totals (if reported separately) do not add up to 100%.

†Based on preliminary analyses, less than 2% of respondents had missing data with respect to each of the variables of interest.

^ The summary score is a combination of the following three variables: (1) the amount of time the child is affected by the condition, (2) the severity rating of the difficulties caused by the condition, and (3) the pervasiveness of the condition (pervasiveness is defined by the number of qualifying reasons the child had for being included in the survey). See Appendix A for details on measurement of the summary score.

Percent of Missing Data for Each Survey Item

The percentage of missing data for each survey item from Study 1 is listed in Table 28. The missing data count for each variable was found to be less than 5% of the overall value for each variable, and multiple imputation was therefore deemed to be unnecessary.

Summary Score for Condition Severity

The mean summary score for condition severity was calculated based on the following three variables, which are used in the literature as indicators for the severity of a child’s condition. The mean summary score for condition severity was 5.63 and the mode or most frequently occurring summary score was 4. Summary scores for condition severity were operationalized as “low” (3-5), “moderate” (6-9), or “high” (10-13).

(1) The amount of time the child is affected by the condition: 0 = Never, 1 = Sometimes, 2 = Usually, 3 = Always;

(2) The severity rating of the difficulties caused by the condition: 1 = Minor, 2 = Moderate, 3 = Severe;

(3) The pervasiveness of the condition, where pervasiveness is defined by the number of qualifying reasons the child had for being included in the survey: from 1 = 1 qualifying response to 5 = 5 qualifying responses.
The numerical values of these three variables were summed to create the summary score for condition severity and the summary score range was from 3-12. For example, if a child was sometimes affected by his/her condition (amount of time = 1), if his/her condition caused minor difficulty (severity rating = 1), and if he/she had one qualifying reason for being included in the survey (pervasiveness = 1), then that child’s summary score would be equivalent to 3. “Sometimes” was the most frequently occurring amount of time that a child was affected by his/her condition, and “Minor” was the most frequently occurring severity rating of the difficulties caused by his/her condition. The mean pervasiveness was 1.84 qualifying reasons, with 1 qualifying reason being the most frequently occurring (the mode).

The percentages of CSHCN in the survey with each summary score for condition severity are provided in Table 29. Table 30 presents percentages of CSHCN in the survey that were never, sometimes, usually, or always affected by his/her condition. Table 31 presents percentages of CSHCN in the survey that had difficulties caused by the condition with severity ratings of minor, moderate, or severe. Table 32 presents percentages of CSHCN in the survey that qualified based on 1 to 5 responses, a measure of health condition pervasiveness.

<table>
<thead>
<tr>
<th>Summary Score for Condition Severity</th>
<th>% CSHCN in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>19.1%</td>
</tr>
<tr>
<td>4</td>
<td>23.5%</td>
</tr>
<tr>
<td>5</td>
<td>15.4%</td>
</tr>
<tr>
<td>6</td>
<td>11.5%</td>
</tr>
<tr>
<td>7</td>
<td>9.3%</td>
</tr>
<tr>
<td>8</td>
<td>6.7%</td>
</tr>
<tr>
<td>9</td>
<td>4.9%</td>
</tr>
<tr>
<td>10</td>
<td>4.3%</td>
</tr>
<tr>
<td>11</td>
<td>3.5%</td>
</tr>
<tr>
<td>12</td>
<td>1.8%</td>
</tr>
</tbody>
</table>

Table 29. Summary Score for Condition Severity
<table>
<thead>
<tr>
<th>Amount of time</th>
<th>% CSHCN in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>38.8%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>40.1%</td>
</tr>
<tr>
<td>Usually</td>
<td>8.0%</td>
</tr>
<tr>
<td>Always</td>
<td>13.1%</td>
</tr>
</tbody>
</table>

Table 30. Amount of Time Child Affected by Condition

<table>
<thead>
<tr>
<th>Amount of time</th>
<th>% CSHCN in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minor</td>
<td>52.0%</td>
</tr>
<tr>
<td>Moderate</td>
<td>38.3%</td>
</tr>
<tr>
<td>Severe</td>
<td>9.7%</td>
</tr>
</tbody>
</table>

Table 31. Severity Rating of Difficulties Caused by Condition

<table>
<thead>
<tr>
<th>No. of qualifying responses</th>
<th>% CSHCN in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>55.4%</td>
</tr>
<tr>
<td>2</td>
<td>20.5%</td>
</tr>
<tr>
<td>3</td>
<td>12.6%</td>
</tr>
<tr>
<td>4</td>
<td>7.6%</td>
</tr>
<tr>
<td>5</td>
<td>3.9%</td>
</tr>
</tbody>
</table>

Table 32. Pervasiveness Based on Qualifying Responses
<table>
<thead>
<tr>
<th>Variable</th>
<th>% CSHCN Insured (n = 37,043)</th>
<th>% CSHCN Insured by Type* (p-value &lt; 0.001 for all)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(62.9%; n = 23,315)</td>
<td>(27.6%; n = 10,224)</td>
</tr>
<tr>
<td><strong>Age of child (mean = 10.2)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-3 years (coded as 1)</td>
<td>11.0% (n = 4,075)</td>
<td>44.0% (n = 1,793)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8.3% (n = 338)</td>
</tr>
<tr>
<td>4-7 years (coded as 2)</td>
<td>21.6% (n = 8,001)</td>
<td>46.1% (n = 3,688)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9.7% (n = 776)</td>
</tr>
<tr>
<td>8-11 years (coded as 3)</td>
<td>25.7% (n = 9,520)</td>
<td>51.4% (n = 4,893)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8.4% (n = 800)</td>
</tr>
<tr>
<td>12-14 years (coded as 4)</td>
<td>20.8% (n = 7,705)</td>
<td>56.1% (n = 4,322)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6.5% (n = 501)</td>
</tr>
<tr>
<td>15-17 years (coded as 5)</td>
<td>20.9% (n = 7,742)</td>
<td>56.6% (n = 4,382)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7.2% (n = 557)</td>
</tr>
<tr>
<td><strong>Gender of child (coding from survey)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (coded as 1)</td>
<td>59.3% (n = 21,966)</td>
<td>51.9% (n = 11,400)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8.4% (n = 1,845)</td>
</tr>
<tr>
<td>Female (coded as 2)</td>
<td>40.7% (n = 15,077)</td>
<td>53.0% (n = 7991)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7.8% (n = 1,176)</td>
</tr>
<tr>
<td><strong>Race/Ethnicity of child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic (ref)</td>
<td>66.3% (n = 24,560)</td>
<td>76.7% (n = 17,871)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>54.8% (n = 1,522)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>15.7% (n = 5,816)</td>
<td>8.7% (n = 2,001)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>26.4% (n = 733)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>10.9% (n = 4,038)</td>
<td>7.8% (n = 1,817)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11.1% (n = 308)</td>
</tr>
<tr>
<td>Other, non-Hispanic</td>
<td>6.6% (n = 2,445)</td>
<td>6.8% (n = 1,585)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7.7% (n = 214)</td>
</tr>
<tr>
<td><strong>Family structure</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother-only (coded as 1)</td>
<td>20.9% (n = 7,742)</td>
<td>9.6% (n = 2,439)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13.9% (n = 385)</td>
</tr>
<tr>
<td>All other (coded as 2)**</td>
<td>79.1% (n = 29,301)</td>
<td>90.4% (n = 21,077)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>86.1% (n = 2,393)</td>
</tr>
<tr>
<td><strong>Parental education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school (coded as 1)</td>
<td>21.1% (n = 7,816)</td>
<td>15.7% (n = 3,658)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>40.2% (n = 1,117)</td>
</tr>
<tr>
<td>&gt; High school (coded as 2)</td>
<td>71.4% (n = 26,449)</td>
<td>84.3% (n = 19,642)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>59.8% (n = 1,661)</td>
</tr>
<tr>
<td><strong>Household income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 300% FPL (coded as 1)</td>
<td>55.0% (n = 20,374)</td>
<td>31.9% (n = 7,426)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>70.2% (n = 1,951)</td>
</tr>
<tr>
<td>≥ 300% FPL (coded 2)</td>
<td>45.0% (n = 16,669)</td>
<td>68.1% (n = 15,867)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>29.8% (n = 828)</td>
</tr>
</tbody>
</table>

Table 33. Financial Characteristics for Insured CSHCN, by Insurance Type (Bivariate Analysis)
Table 33 continued

<table>
<thead>
<tr>
<th>Variable</th>
<th>% CSHCN Insured (n)</th>
<th>% CSHCN Insured by Type* (p-value &lt; 0.001 for all)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Private Only</td>
<td>Public Only</td>
</tr>
<tr>
<td>Condition complexity (qualification reason from screener)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rx med usage only (1)</td>
<td>44.6% (n = 16,521)</td>
<td>49.2% (n = 11,453)</td>
</tr>
<tr>
<td>Other (0 if not Rx only)</td>
<td>55.4% (n = 20,522)</td>
<td>50.8% (n = 11,836)</td>
</tr>
<tr>
<td>Condition severity (mode = 4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low severity (3-5)</td>
<td>52.0% (n = 19,262)</td>
<td>63.2% (n = 14,726)</td>
</tr>
<tr>
<td>Moderate severity (6-9)</td>
<td>38.3% (n = 14,187)</td>
<td>27.6% (n = 6,431)</td>
</tr>
<tr>
<td>High severity (≥ 10)</td>
<td>9.7% (n = 3,593)</td>
<td>9.2% (n = 2,144)</td>
</tr>
<tr>
<td>No. of health conditions (mode = 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>12.3% (n = 4,556)</td>
<td>13.2% (n = 3,078)</td>
</tr>
<tr>
<td>1</td>
<td>30.6% (n = 11,335)</td>
<td>35.6% (n = 8,300)</td>
</tr>
<tr>
<td>2</td>
<td>28.0% (n = 10,372)</td>
<td>30.4% (n = 7,088)</td>
</tr>
<tr>
<td>3</td>
<td>12.5% (n = 4,630)</td>
<td>11.0% (n = 2,565)</td>
</tr>
<tr>
<td>≥ 4 (up to 20)</td>
<td>16.6% (n = 6,149)</td>
<td>9.9% (n = 2,308)</td>
</tr>
<tr>
<td>No. of functional difficulties (mode = 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>9.9% (n = 3,670)</td>
<td>12.6% (n = 2,929)</td>
</tr>
<tr>
<td>1</td>
<td>21.3% (n = 7,896)</td>
<td>26.3% (n = 6,140)</td>
</tr>
<tr>
<td>2</td>
<td>15.3% (n = 5,668)</td>
<td>17.1% (n = 3,976)</td>
</tr>
<tr>
<td>3</td>
<td>12.3% (n = 4,569)</td>
<td>12.0% (n = 2,793)</td>
</tr>
<tr>
<td>≥ 4 (up to 14)</td>
<td>41.2% (n = 15,261)</td>
<td>32.1% (n = 7,477)</td>
</tr>
</tbody>
</table>

*2.0% of CSHCN who were continuously insured during the 12 months prior to the survey were classified as having “other comprehensive insurance” and were not included in study analyses. As a result, totals do not sum to 100% or the total CSHCN in a particular comparison group.

**CSHCN insured by type was determined primarily for demographics and independent variables of interest – condition complexity, severity, health conditions, and functional difficulties.

***Two parent biological/adoptive families (68.8% with private insurance) and two parent families with at least one step-parent (45.5% with private insurance) comprised the majority of non-single mother households.
Appendix B: Study 2 Survey Items

Summary Score for Condition Severity

The mean summary score for condition severity was calculated based on the following three variables, which are used in the literature as indicators for the severity of a child’s condition. The mean summary score for condition severity was 5.63 and the mode or most frequently occurring summary score was 4. Summary scores for condition severity were operationalized as “low” (3-5), “moderate” (6-9), or “high” (10-13).

1. The amount of time the child is affected by the condition: 0 = Never, 1 = Sometimes, 2 = Usually, 3 = Always;

2. The severity rating of the difficulties caused by the condition: 1 = Minor, 2 = Moderate, 3 = Severe;

3. The pervasiveness of the condition, where pervasiveness is defined by the number of qualifying reasons the child had for being included in the survey: from 1 = 1 qualifying response to 5 = 5 qualifying responses.

The numerical values of these three variables were summed to create the summary score for condition severity and the summary score range was from 3-12. For example, if a child was sometimes affected by his/her condition (amount of time = 1), if his/her condition caused minor difficulty (severity rating = 1), and if he/she had one qualifying reason for being included in the survey (pervasiveness = 1), then that child’s summary score would be equivalent to 3. “Sometimes” was the most frequently occurring amount of time that a child was affected by
his/her condition, and “Minor” was the most frequently occurring severity rating of the difficulties caused by his/her condition. The mean pervasiveness was 1.84 qualifying reasons, with 1 qualifying reason being the most frequently occurring (the mode).

The percentages of CSHCN in the survey with each summary score for condition severity are provided in Table 34. Table 35 presents percentages of CSHCN that were never, sometimes, usually, or always affected by their condition. Table 36 presents percentages of CSHCN who experienced difficulties caused by their condition with ratings of minor, moderate, or severe. Table 37 presents percentages of CSHCN in the survey that qualified based on 1 to 5 responses, an indicator that was used to measure the pervasiveness of the child’s special health condition.

<table>
<thead>
<tr>
<th>Summary Score for Condition Severity</th>
<th>% CSHCN in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>19.1%</td>
</tr>
<tr>
<td>4</td>
<td>23.5%</td>
</tr>
<tr>
<td>5</td>
<td>15.4%</td>
</tr>
<tr>
<td>6</td>
<td>11.5%</td>
</tr>
<tr>
<td>7</td>
<td>9.3%</td>
</tr>
<tr>
<td>8</td>
<td>6.7%</td>
</tr>
<tr>
<td>9</td>
<td>4.9%</td>
</tr>
<tr>
<td>10</td>
<td>4.3%</td>
</tr>
<tr>
<td>11</td>
<td>3.5%</td>
</tr>
<tr>
<td>12</td>
<td>1.8%</td>
</tr>
</tbody>
</table>

Table 34. Summary Score for Condition Severity

<table>
<thead>
<tr>
<th>Amount of time</th>
<th>% CSHCN in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>38.8%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>40.1%</td>
</tr>
<tr>
<td>Usually</td>
<td>8.0%</td>
</tr>
<tr>
<td>Always</td>
<td>13.1%</td>
</tr>
</tbody>
</table>

Table 35. Amount of Time Child Affected by Condition

<table>
<thead>
<tr>
<th>Amount of time</th>
<th>% CSHCN in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minor</td>
<td>52.0%</td>
</tr>
<tr>
<td>Moderate</td>
<td>38.3%</td>
</tr>
<tr>
<td>Severe</td>
<td>9.7%</td>
</tr>
</tbody>
</table>

Table 36. Severity Rating of Difficulties Caused by Condition
Table 37. Pervasiveness Based on Qualifying Responses

<table>
<thead>
<tr>
<th>Health Care Service or Equipment</th>
<th>Did not need care % (n)</th>
<th>Received all needed care % (n)</th>
<th>Did not receive all care (unmet need)* % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Preventive care (well-child)</td>
<td>7.7% (3,627)</td>
<td>89.3% (35,439)</td>
<td>3.0% (1,028)</td>
</tr>
<tr>
<td>(2) Specialist care</td>
<td>52.6% (20,703)</td>
<td>5.4% (18,026)</td>
<td>3.7% (1,420)</td>
</tr>
<tr>
<td>(3) Preventive dental care</td>
<td>10.4% (3,493)</td>
<td>80.7% (33,684)</td>
<td>5.4% (n = 2,959)</td>
</tr>
<tr>
<td>(4) Other dental care</td>
<td>73.3% (29,049)</td>
<td>21.3% (9,403)</td>
<td>5.4% (1,698)</td>
</tr>
<tr>
<td>(5) Prescription medications</td>
<td>14.0% (5,116)</td>
<td>83.4% (34,284)</td>
<td>2.6% (791)</td>
</tr>
<tr>
<td>(6) Physical, occupational, or speech therapy</td>
<td>73.5% (29,942)</td>
<td>21.8% (8,475)</td>
<td>4.7% (1,749)</td>
</tr>
<tr>
<td>(7) Mental health care</td>
<td>72.4% (29,570)</td>
<td>21.9% (8,703)</td>
<td>5.6% (1,859)</td>
</tr>
<tr>
<td>(8) Substance abuse treatment (ages 8-17)</td>
<td>97.3% (27,685)</td>
<td>2.0% (537)</td>
<td>0.6% (160)</td>
</tr>
<tr>
<td>(9) Home health care</td>
<td>95.7% (n = 38,661)</td>
<td>3.8% (1,352)</td>
<td>0.5% (184)</td>
</tr>
<tr>
<td>(10) Eyeglasses/vision care</td>
<td>64.7% (25,700)</td>
<td>33.3% (13,838)</td>
<td>2.1% (643)</td>
</tr>
<tr>
<td>(11) Hearing aids/hearing care</td>
<td>94.8% (38,268)</td>
<td>5.5% (1,765)</td>
<td>0.6% (182)</td>
</tr>
<tr>
<td>(12) Mobility aids/devices (ages 3-17)</td>
<td>95.4% (36,335)</td>
<td>4.3% (1,565)</td>
<td>0.3% (116)</td>
</tr>
<tr>
<td>(13) Communication aids/devices (ages 3-17)</td>
<td>97.5% (37,007)</td>
<td>1.9% (746)</td>
<td>0.6% (239)</td>
</tr>
<tr>
<td>(14) Durable medical equipment</td>
<td>88.7% (36,058)</td>
<td>10.8% (3,978)</td>
<td>0.5% (193)</td>
</tr>
</tbody>
</table>

*CSHCN who did not receive all needed care and had unmet needs for a particular health care service or equipment are primarily of interest for determining CSHCN with any unmet need, one unmet need, or two or unmet needs for the purposes of Study 2b analyses.

Table 38: Level of Unmet Need for Specific Health Care Services or Equipment, Past 12 Months

Operationalization of Unmet Need

Overall unmet need (any unmet need) is a combined measure of the level of unmet need for 14 specific health care services or equipment in the past 12 months. These are listed above in Table 38. Due to the low percentages of CSHCN who had unmet needs for particular services or equipment.
health care services, unmet need was analyzed as four different categories that combine unmet needs for specific health services: (1) preventive care; (2) specialty care; (3) therapeutic services; and (4) support services. These are listed below in Table 39.

<table>
<thead>
<tr>
<th>Category of Unmet Need</th>
<th>Specific Health Service or Equipment Need</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Preventive care</td>
<td>Preventive care (well-child check ups); preventive dental care; and prescription medications [Items 1, 3, and 5]</td>
</tr>
<tr>
<td>(2) Specialty care</td>
<td>Specialist care; other dental care [Items 2 and 4]</td>
</tr>
<tr>
<td>(3) Therapeutic services</td>
<td>Physical, occupational, or speech therapy; mental health care/counseling; substance abuse treatment/counseling [Items 6, 7, and 8]</td>
</tr>
<tr>
<td>(4) Support Services</td>
<td>Home health care; eyeglasses/vision care; hearing aids/hearing care; durable medical equipment; communication aids/devices; family support services* [Items 9-14]</td>
</tr>
</tbody>
</table>

* Family support services include respite care, genetic counseling, and mental health care/counseling – see Table 12 for a description of survey items for unmet need in Study 2b.

Table 39. Categories of Unmet Need for Study 2b

All cell sizes for the level of unmet need for specific services are larger than 50, and these sample sizes are large enough for sufficient statistical power to detect differences in analyses. Totals for levels of unmet need for specific services or equipment, which include CSHCN who did not need care, received all needed care, and had unmet needs (did not receive all needed care), sum to 100% in all instances. CSHCN whose families have any unmet need for support services, such as respite care or genetic counseling, also had cell sizes larger than 50 and thus sample sizes with sufficient statistical power to detect differences in analyses for Study 2b.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Unmet Need for Preventive Services – Well-Child Check-Up: 3.0% (n = 1,028)</th>
<th>Unmet Need for Preventive Services – Rx Medications: 2.6% (n = 791)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child (mean = 10.2 years old)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>2.8% (n = 174)</td>
<td>2.0% (n = 107)</td>
</tr>
<tr>
<td>6-11 years</td>
<td>2.8% (n = 425)</td>
<td>2.5% (n = 309)</td>
</tr>
<tr>
<td>12-17 years</td>
<td>3.2% (n = 429)</td>
<td>3.0% (n = 375)</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.0% (n = 610)</td>
<td>2.4% (n = 455)</td>
</tr>
<tr>
<td>Female</td>
<td>2.9% (n = 417)</td>
<td>2.9% (n = 334)</td>
</tr>
<tr>
<td>Race/Ethnicity of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>2.1% (n = 579)</td>
<td>2.3% (n = 467)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>3.8% (n = 130)</td>
<td>3.1% (n = 115)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5.1% (n = 208)</td>
<td>3.4% (n = 125)</td>
</tr>
<tr>
<td>Other minority, non-Hispanic</td>
<td>3.0% (n = 111)</td>
<td>2.3% (n = 84)</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother-only</td>
<td>3.7% (n = 268)</td>
<td>3.9% (n = 277)</td>
</tr>
<tr>
<td>All other</td>
<td>3.0% (n = 246)</td>
<td>2.5% (n = 168)</td>
</tr>
<tr>
<td>Parental education (highest education of adult in household)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school</td>
<td>4.7% (n = 168)</td>
<td>3.3% (n = 102)</td>
</tr>
<tr>
<td>&gt; High school</td>
<td>2.4% (n = 692)</td>
<td>2.4% (n = 587)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 300% FPL</td>
<td>3.7% (n = 292)</td>
<td>3.3% (n = 234)</td>
</tr>
<tr>
<td>At or above 300% FPL</td>
<td>1.7% (n = 207)</td>
<td>1.5% (n = 152)</td>
</tr>
</tbody>
</table>

Table 40: Unmet Need for Well-Child Check-Ups and Prescription Medications (Preventive Services) for Study 2b
<table>
<thead>
<tr>
<th>Variable</th>
<th>Unmet Need for PT/OT/Speech: 4.7% (n = 1,749)</th>
<th>Unmet Need for Mental Health: 5.6% (n = 1,859)</th>
<th>Unmet Need for Substance Abuse*: 0.6% (n = 160)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child (mean = 10.2 years old)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>6.8% (n = 454)</td>
<td>2.2% (n = 143)</td>
<td>n/a</td>
</tr>
<tr>
<td>6-11 years</td>
<td>5.2% (n = 784)</td>
<td>5.8% (n = 747)</td>
<td>*8-11: 0.4% (n = 61)</td>
</tr>
<tr>
<td>12-17 years</td>
<td>3.1% (n = 511)</td>
<td>7.2% (n = 969)</td>
<td>0.6% (n = 99)</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5.1% (n = 1,163)</td>
<td>5.5% (n = 1,140)</td>
<td>0.6% (n = 94)</td>
</tr>
<tr>
<td>Female</td>
<td>4.2% (n = 585)</td>
<td>5.8% (n = 717)</td>
<td>0.7% (n = 66)</td>
</tr>
<tr>
<td>Race/Ethnicity of child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>4.4% (n = 1,150)</td>
<td>5.4% (n = 1,194)</td>
<td>0.6% (n = 98)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>4.7% (n = 180)</td>
<td>6.0% (n = 206)</td>
<td>0.8% (n = 20)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5.4% (n = 220)</td>
<td>6.1% (n = 244)</td>
<td>0.6% (n = 19)</td>
</tr>
<tr>
<td>Other minority, non-Hispanic</td>
<td>5.8% (n = 199)</td>
<td>5.9% (n = 215)</td>
<td>0.8% (n = 23)</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother-only</td>
<td>4.8% (n = 356)</td>
<td>8.1% (n = 596)</td>
<td>0.7% (n = 48)</td>
</tr>
<tr>
<td>All other</td>
<td>4.5% (n = 457)</td>
<td>4.2% (n = 412)</td>
<td>0.9% (n = 37)</td>
</tr>
<tr>
<td>Parental education (highest education of adult in household)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school</td>
<td>4.3% (n = 162)</td>
<td>6.2% (n = 208)</td>
<td>0.9% (n = 22)</td>
</tr>
<tr>
<td>&gt; High school</td>
<td>4.9% (n = 1,425)</td>
<td>5.5% (n = 1,444)</td>
<td>0.6% (n = 115)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 300% FPL</td>
<td>4.8% (n = 433)</td>
<td>6.5% (n = 506)</td>
<td>1.3% (n = 45)</td>
</tr>
<tr>
<td>At or above 300% FPL</td>
<td>4.5% (n = 517)</td>
<td>4.6% (n = 455)</td>
<td>0.5% (n = 36)</td>
</tr>
</tbody>
</table>

Table 41: Unmet Need for Physical, Occupational or Speech Therapy; Mental Health Care/Counseling; and Substance Abuse Treatment/Counseling (Therapeutic Services) for Study 2b - *Substance Abuse: CSHCN age 8-17 years only
<table>
<thead>
<tr>
<th>Variable</th>
<th>Unmet Need for Home HC: 4.7% (n = 1,749)</th>
<th>Unmet Need for Vision Care: 5.6% (n = 1,859)</th>
<th>Unmet Need for Hearing Care: 0.6% (n = 160)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child (mean = 10.2 years old)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>6.8% (n = 454)</td>
<td>2.2% (n = 143)</td>
<td>n/a</td>
</tr>
<tr>
<td>6-11 years</td>
<td>5.2% (n = 784)</td>
<td>5.8% (n = 747)</td>
<td>0.4% (n = 61)</td>
</tr>
<tr>
<td>12-17 years</td>
<td>3.1% (n = 511)</td>
<td>7.2% (n = 969)</td>
<td>0.6% (n = 99)</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5.1% (n = 1,163)</td>
<td>5.5% (n = 1,140)</td>
<td>0.6% (n = 94)</td>
</tr>
<tr>
<td>Female</td>
<td>4.2% (n = 585)</td>
<td>5.8% (n = 717)</td>
<td>0.7% (n = 66)</td>
</tr>
<tr>
<td>Race/Ethnicity of child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>4.4% (n = 1,150)</td>
<td>5.4% (n = 1,194)</td>
<td>0.6% (n = 98)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>4.7% (n = 180)</td>
<td>6.0% (n = 206)</td>
<td>0.8% (n = 20)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5.4% (n = 220)</td>
<td>6.1% (n = 244)</td>
<td>0.6% (n = 19)</td>
</tr>
<tr>
<td>Other minority, non-Hispanic</td>
<td>5.8% (n = 199)</td>
<td>5.9% (n = 215)</td>
<td>0.8% (n = 23)</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother-only</td>
<td>4.8% (n = 356)</td>
<td>8.1% (n = 596)</td>
<td>0.7% (n = 48)</td>
</tr>
<tr>
<td>All other</td>
<td>4.5% (n = 457)</td>
<td>4.2% (n = 412)</td>
<td>0.9% (n = 37)</td>
</tr>
<tr>
<td>Parental education (highest education of adult in household)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school</td>
<td>4.3% (n = 162)</td>
<td>6.2% (n = 208)</td>
<td>0.9% (n = 22)</td>
</tr>
<tr>
<td>&gt; High school</td>
<td>4.9% (n = 1,425)</td>
<td>5.5% (n = 1,444)</td>
<td>0.6% (n = 115)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 300% FPL</td>
<td>4.8% (n = 433)</td>
<td>6.5% (n = 506)</td>
<td>1.3% (n = 45)</td>
</tr>
<tr>
<td>At or above 300% FPL</td>
<td>4.5% (n = 517)</td>
<td>4.6% (n = 455)</td>
<td>0.5% (n = 36)</td>
</tr>
</tbody>
</table>

**Unmet needs for 1 or more specific family support services, such as respite care, mental health counseling and/or genetic counseling for families of CSHCN, were also included in the overall category of “Unmet Need for Support Services” in Study 2b.

Table 42: Unmet Need for home health care; eyeglasses/vision care; hearing aids/hearing care; communication aids/devices (*ages 3-17 only); and durable medical equipment (DME) (Support Services**) for Study 2b
<table>
<thead>
<tr>
<th>Variable</th>
<th>Unmet Need for Family Support Services:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>36.9%</td>
</tr>
<tr>
<td>Age of child (mean = 10.2 years old)</td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>2.8% (n = 174)</td>
</tr>
<tr>
<td>6-11 years</td>
<td>2.8% (n = 425)</td>
</tr>
<tr>
<td>12-17 years</td>
<td>3.2% (n = 429)</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.0% (n = 610)</td>
</tr>
<tr>
<td>Female</td>
<td>2.9% (n = 417)</td>
</tr>
<tr>
<td>Race/Ethnicity of child</td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>2.1% (n = 579)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>3.8% (n = 130)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5.1% (n = 208)</td>
</tr>
<tr>
<td>Other minority, non-Hispanic</td>
<td>3.0% (n = 111)</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
</tr>
<tr>
<td>Mother-only</td>
<td>3.7% (n = 268)</td>
</tr>
<tr>
<td>All other</td>
<td>3.0% (n = 246)</td>
</tr>
<tr>
<td>Parental education (highest education of adult in household)</td>
<td></td>
</tr>
<tr>
<td>≤ High school</td>
<td>4.7% (n = 168)</td>
</tr>
<tr>
<td>&gt; High school</td>
<td>2.4% (n = 692)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
</tr>
<tr>
<td>&lt; 300% FPL</td>
<td>3.7% (n = 292)</td>
</tr>
<tr>
<td>At or above 300% FPL</td>
<td>1.7% (n = 207)</td>
</tr>
</tbody>
</table>

Table 43: Unmet Need for Family Support Services (Respite Care, Mental Health Counseling, and/or Genetic Counseling) (Support Services**) for Study 2b
### Appendix C: Study 3 Survey Items

<table>
<thead>
<tr>
<th>Medical Home Component</th>
<th>Specific Survey Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receipt of coordinated, ongoing, comprehensive care in a medical home (summary measure)</td>
<td>A total of 19 different survey questions from 5 different sections* used to develop the overall composite score</td>
</tr>
<tr>
<td>(1) Accessible Care</td>
<td>CSHCN has 1 or more personal doctor(s) or nurse(s) (PDN) (C4Q02A)</td>
</tr>
<tr>
<td>(2) Comprehensive Care</td>
<td>Usual source of care for sick and well care (Medical Home Part A; C4Q0BR, C4Q0A, C4Q0D, C4Q01, and C4Q02R)</td>
</tr>
<tr>
<td>(3) Family-Centered Care</td>
<td>C6Q02, C6Q03, C6Q05, C6Q06</td>
</tr>
<tr>
<td>(4) Culturally Sensitive Care</td>
<td>C6Q04</td>
</tr>
<tr>
<td>(5) Coordinated Care</td>
<td>C5Q01; C5Q05-C5Q07; C5Q09-C5Q13; C5Q15-C5Q17</td>
</tr>
</tbody>
</table>

*Additional note: The American Academy of Pediatrics’ (AAP) description of a “medical home” lists 7 defining components: (1) accessible, (2) continuous, (3) comprehensive, (4) family-centered, (5) coordinated, (6) compassionate, and (7) culturally effective. 5 of these 7 medical home components and the presence of a personal doctor or nurse are assessed by the 2009/10 NS-CSCHN. The overall medical home measure is a composite score derived from 5 different subparts based on 19 different individual survey items. To qualify as having a medical home, a child must (a) have a personal doctor or nurse and (b) meet the criteria for adequate care on each of the 5 needed components.

* Family-centered care and culturally sensitive care were part of the same group when components of the medical home are being assessed in Study 3b. Responses of “always” or “usually” were coded as 1 and responses of “sometimes” or “never” will be coded as 0.

† Additional details on individual care coordination components and survey items used to measure care coordination are listed in Table 8 of Study 2, under the “Variables” section of the Methods. Responses of “very satisfied” or “somewhat satisfied” were coded as 1 (satisfied with care coordination), while responses of “somewhat dissatisfied” and “very dissatisfied” were coded as 0 (dissatisfied with care coordination).

Table 44. Operationalization of the Medical Home and Medical Home Components (Independent Variables) for Study 3a and Study 3b