2014

ACCESS TO THERAPY FOR CHILDREN WITH AUTISM: A POPULATION-BASED ANALYSIS

Teal W. Benevides
Virginia Commonwealth University

ACCESS TO THERAPY FOR CHILDREN WITH AUTISM: A POPULATION-BASED ANALYSIS

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

by

Teal Wisniewski Benevides

Bachelors of Science in Psychology, The College of William and Mary, 2002
Masters of Science in Occupational Therapy, Thomas Jefferson University, 2004

Dissertation Chair: Shelly J. Lane, PhD, OTR/L, FAOTA
Professor, Department of Occupational Therapy

Virginia Commonwealth University
Richmond, Virginia
March 21, 2014

Acknowledgement

The completion of this work represents the selfless dedication and steadfast support of many people, to whom I am eternally grateful. To my husband, my rock, I cannot express how much your love, encouragement, and patience has meant to me when I needed strength. To my daughter, Eliana Grace, your pure happiness in all things reminded me to be joyful, and your unconditional hugs and kisses were a blessing. To my parents and my parents-in-law, your flexibility, love, and willingness to help manage the homefront in my stead was an incredible gift. I would also like to recognize the incredible contributions of my dissertation chair, Dr. Shelly Lane. Your perspicacious guidance during the entire process was invaluable, and for all that is unsaid, thank you. Along the way, many other wise and pioneering mentors have also supported and guided me through the years, and most especially I am grateful for the vision and encouragement of Dr. Roseann Schaaf. My colleagues in the Department of Occupational Therapy and in the SIRC research group also are sources of collegial support for whom I am thankful. Last but not least are the contributions and time invested by all of my other committee members, including Dr. Henry Carretta, Dr. James Cotter, and Dr. Carole Ivey. A random acknowledgement is in order, namely to the coffeeshops who provided a power supply for my computer and an inviting and tasty place to think and write. To Artisan's Café in Phoenixville, PA and Café Cattura in Richmond, VA, your coffee, food and creative ambiance were sometimes the only thing that I looked forward to when working on the weekends.

Table of Contents

List of Tables

List of Figures

Abstract

ACCESS TO THERAPY FOR CHILDREN WITH AUTISM: A POPULATION-BASED ANALYSIS

By Teal Wisniewski Benevides, MS, OTR/L

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2014.

Dissertation Chair: Shelly J. Lane, PhD, OTR/L, FAOTA
Professor, Department of Occupational Therapy

Children with autism spectrum disorder (ASD) represent a growing category of children who have special health care needs. Recent Centers for Disease Control and Prevention (CDC) estimates suggest that 1 in 88 children in the United States have an ASD (CDC, 2012). Due to difficulty with communication, social skills, and restricted and/or repetitive behaviors that comprise current diagnostic criteria (APA, 2013), children with ASD require significant medical, mental health, and therapeutic supports that contribute to greater heath care utilization costs than persons without ASD (e.g., Shimabukuro, Grosse, & Rice, 2008). Therapies such as occupational, physical, and speech therapy are among recommended services provided to remediate functional or behavioral needs (Johnson & Myer, 2007). Studies investigating access to healthcare services such as diagnostic and genetic screening or primary care are frequently published in the literature; however, few studies examine access to needed therapy services. The purpose of this study was to examine population-based trends in therapy service access in children with ASD compared to children with attention deficit hyperactivity disorder (ADHD) and cerebral palsy (CP) using two waves of the National Survey for Children with Special Health Care Needs (NS-CSHCN). Additionally, this study aimed to identify predisposing, enabling, and need characteristics that predicted lack of access to therapy across the two cross-sectional points in time. Parent-reported contextual characteristics that potentially limited access to needed therapy services were compared between survey time periods (2005-06 and 2009-10). Results of this study suggest that children with ASD are significantly more likely to not receive needed therapy services than children with attention-deficit hyperactivity disorder (ADHD), but are similar in their unmet need for therapy compared to children with cerebral palsy (CP). Significant predictors of an unmet need for therapy were having a current ASD diagnosis, age, uninsured status, greater functional limitation, and having a reported behavior problem. The only access problem that differentiated children from ASD from ADHD and CP was “difficulty finding a provider accepting insurance”. Implications of these results are discussed in the context of Andersen’s Behavioral Model of Health Service Use and recommendations for future research are presented.

Chapter 1: Introduction

Children with autism spectrum disorders (ASD) challenge health care system resources (e.g., Shimabukuro, Grosse, & Rice, 2008) and healthcare provider's efforts to provide best practice care because they often present with changing medical, mental health, and educational needs that must be met over their lifetime by multiple service providers (e.g., Kogan et al., 2008). Access to appropriate and timely care represents an area of significant stress and burden to parents of children with ASD (Carbone, Behl, Azor, & Murphy, 2010; Shimabukuro, Grosse, & Rice, 2008). The identified pathways to recommended care for a child with ASD includes screening/diagnostic evaluations, evaluation for functional limitations, and referral to appropriate health care practitioners such as occupational therapists, physical therapists, and speech therapists that can address identified needs (Johnson & Myer, 2007). Studies investigating access to healthcare services such as diagnostic and genetic screening or primary care are frequently published in the literature; however, few studies examine access to therapy services. Since therapy services are considered an important component of care for persons with ASD, this study proposed to examine population-based trends in therapy service access in children with ASD. Additionally, this study aimed to identify predisposing, enabling, and need characteristics of children with ASD that predicted lack of access to therapy at two cross-sectional points in time. In addition, parent-reported contextual characteristics that potentially limited access to needed therapy services were compared between survey time periods. The results of this study could be used to develop future system-wide interventions to reduce inequitable access to therapy services, as recommended by the Institute of Medicine's Committee report on reducing health care disparities (Smedley, Stith, & Nelson, 2003).

Importance of the Problem

Needs of children with ASD. Children with ASD represent a growing category of children who have special health care needs. Recent Centers for Disease Control and Prevention (CDC) estimates suggest that 1 in 88 children in the United States have an ASD (CDC, 2012). Due to deficits in communication, social skills, and restricted and/or repetitive behaviors that comprise current diagnostic criteria of the American Psychiatric Association (APA, 2013), children with ASD require significant medical, mental health, and therapeutic supports that contribute to greater heath care utilization costs than persons without ASD (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Shimabukuro, Grosse, & Rice, 2008). Among the recommended services identified by the American Academy of Pediatrics (AAP) for children with ASD are therapy services provided to remediate functional or behavioral needs (AAP, 2010; Johnson & Myer, 2007).

Occupational therapy (OT), physical therapy (PT), and speech-language (ST) therapy are among the most frequently used services for children with ASD (Thomas, Ellis, McLaurin, Daniels, & Morissey, 2007). Children with ASD are significantly more likely than non-ASD children to need therapy services (Odds Ratio, *OR*=44.4, Confidence Interval, 95% CI=31.9, 61.8) (Gurney, McPheeters, & Davis, 2006). Additionally, according to findings from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), OT, PT, and ST are needed by children with ASD significantly more than other children with special health care needs (CSHCN), with 76.2% of children with ASD requiring therapy compared to 18.1% of other CSCHN (Montes, Halterman, & Magyar, 2009). Furthermore, OT and ST are among the most frequently requested services by parents of children with ASD (Green et al., 2006).

Access to medical and therapy services. Although children with ASD need and utilize more health care services than non-ASD children, disparities in access to health care services are recognized as a problem which has cascading effects on family financial stability and caregiver quality of life (e.g., Kogan et al., 2008). Disparities are defined in the literature as differences in health outcomes or health care use that affect specific populations and are not explained by appropriate clinical factors (such as illness severity) or patient preferences for care (Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006; Smedley et al., 2003). Access is defined as actual use of health services and studies of access encompass examining those things that prevent or facilitate the use of health services (Andersen, Davidson, & Baumeister, 2013). Advancing knowledge regarding disparities in access to health care services are important objectives of the U.S. Department of Health and Human Services (DHHS) Healthy People 2020 (DHHS, n.d.) and the National Institutes of Health (NIH; Dankwa-Mullan et al., 2010). The first steps in understanding and reducing access problems in our health care system are detecting and describing access problems and disparities (Kilbourne et al., 2006) for specific populations such as children with ASD.

Previous research has attempted to identify factors related to utilization and access to specific health care services for children with ASD. Reduced access to medical care for this population has been well documented in the literature. Studies have demonstrated reduced access to diagnostic services (e.g., Liptak et al., 2008; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell, Novak, & Zubritsky, 2005), genetic screening (e.g., McGrath, Laflamme, Schwartz, Stransky, & Moeschler, 2009), family-centered health care (e.g., Montes &

Halterman, 2011), and specialty care (e.g., Krauss, Gulley, Sciegaj, & Wells, 2003) as well as factors that contribute to increased utilization or costs. At this time, however, only five studies were identified that investigated access to therapy services in children with ASD (Chiri & Warfield, 2012; Irvin, McBee, Boyd, Hume, & Odom, 2012; Kohler, 1999; Montes et al., 2009; Thomas et al., 2007).

Montes and colleagues (2009) examined access to community and school services solely, which include early intervention and special education. While their study does not explicitly define community and school services as including therapy such as OT, PT or ST, traditionally these services are provided for children with ASD in these environments, and therefore this study is included in this review of the literature. In their examination of school and community health resources by families of children with ASD, Montes and colleagues (2009) found that individual characteristics of the child and family contributed to significantly reduced access for children with ASD in comparison to other CSHCN. Specifically, the child's predisposing characteristics such as age and ethnicity, and the family's enabling characteristics such as geographical location (urban), reduced family income, and lack of insurance contributed significantly to problems accessing school and community health services for families of children with ASD. Parents of children with ASD were also significantly more likely to be dissatisfied with community health care and school services than parents of other CSHCN. Factors that influenced a child's lack of access in the ASD group included both provider and contextual enabling characteristics within the community. Specifically, parents of children with ASD were significantly more likely to report that providers did not have the skills needed to treat their child with ASD; that needed services were not available in their community; or were limited in accessing needed school and community services due to long waiting lists (Montes et al., 2009).

Four of the studies examined and described the factors contributing to the lack of access to OT, PT, and ST services specifically, which will collectively be referred to as “therapy services”. These studies document differing conclusions regarding access to therapy services and the factors that may be related to reduced access. In the only population-based study to examine access to therapy services for children with ASD, Chiri and Warfield (2012) found significant differences in access to therapy services when comparing children with ASD to other CSHCN and other children with emotional, developmental and behavioral problems (CSHCH with EDB). In this study, significant predictors of having an unmet therapy need (reflecting limited access) included the child being female, being uninsured, and having limited functional abilities (2012).

The remaining three articles describing access to therapy services for children with ASD utilized small, non-representative samples. These articles found different results than those of other studies utilizing larger, more representative datasets, thus these findings presented below are less easily applied to understanding access to therapy services. For example, Irvin and researchers (2012) found in their parent survey of children with ASD in four states that children with ASD of Hispanic ethnicity or Asian race were less likely to access OT services than other non-minority children with ASD, and that children of Hispanic ethnicity were also less likely to receive ST services than non-Hispanic children with ASD. Thomas et al. (2007) similarly determined that children with ASD of minority race or ethnicity were less likely to receive occupational therapy using a sensory integrative approach in their small parent survey conducted in North Carolina. No other factors were found to contribute to lack of access to OT or ST services, although they did examine insurance status, geographical location, and child characteristics such as mental retardation (currently referred to as intellectual disability). These findings regarding race and ethnicity are different than those reported by Chiri and Warfield (2012) and Montes et al., (2009). Chiri and Warfield (2012) did not find that Hispanic ethnicity or race was a factor contributing to unmet need for therapy services, and Montes et al. (2009) only found that Hispanic ethnicity, and not race, was predictive of reduced access to school and community services. In a small study of early intervention and school-based service use by 25 families of children with ASD living in Pennsylvania, Kohler (1999) reports that while ST, OT, and PT therapy services were frequently used (88%, 48%, and 8% respectively) by children with ASD, parents reported that provider-related problems (e.g., provider did not know how to treat the child or provider did not communicate effectively with other providers) prevented effective service delivery.

Based on current available literature, questions exist regarding whether variables such as race, urbanicity (geographical location), family income, child gender, or functional status are related to decreased access to therapy services. The use of a comparison group of other CSHCN in two of these studies (Chiri & Warfield, 2012; Montes et al., 2009) allowed for examination of relative access between two groups of children with clear therapy and health care need, but overall, dissimilarities in the samples and comparison groups may have contributed to discrepant results in examining factors contributing to reduced access.

In addition to the lack of consistent results between the studies described above, these studies utilized samples collected in the early or mid-2000's. Since that time, economic and health care policy changes have occurred that could impact therapy service provision and access to these services for children with ASD. Health care policy for children with ASD changed drastically since the most recent 2005-2006 NS-CSHCN with the passage of the Combating Autism Act of 2006 (S.843, 109th Cong., P.L. 11–148). This law had the explicit goals of increasing awareness of ASD, reducing barriers to needed screening/diagnostic services, improving evidence-based research, and increasing training of professionals to provide screening and intervention for persons with ASD. This law authorized the use of nearly one-billion dollars in accomplishing these aims, and therefore, had the potential to both increase access and improve provider-related problems reported in the early therapy access literature described above.

In addition to the potential policy impact noted above in access to care, the U.S. national economy underwent a recession, formally declared to have begun in December 2007 (Borbely, 2009). While the economic impacts of this recession are still being felt today, the immediate impact on access to therapy and other health care services was being felt by families since the last published results on access were available (2005-06). Therefore, access to therapy services, and factors contributing to reduced access, were likely to have changed due to the economic recession. Thus, there is a significant need to examine therapy service access by children with ASD in a more recent sample in comparison to previous samples. Due to the multifaceted influences on therapy service access, the use of a well-developed theoretical model for understanding access to therapy will contextualize results using clearly defined constructs in order to lead to potential solutions for improving access in this population.

Introduction to Andersen's Behavioral Model of Access

The Andersen Behavioral Model is one predominating theoretical sociocultural model for understanding health care access within a population and has a long history of use in health care access surveys (Andersen, 2008). Although the Andersen Behavioral Model has undergone multiple versions, the most recent model is the 2013 version (Andersen et al., 2013). This version was utilized in this study; however, explication of constructs in earlier Andersen Behavioral Model versions were utilized when these provide additional clarity to constructs of interest. Andersen's Behavioral Model is depicted below illustrating the constructs of interest in Figure 1. This model proposes that the ability to access or use health services (called Health Behaviors) are impacted by other constructs, identified in the model's feedback loops, such as Individual Characteristics or the Contextual Characteristics in which the health care occurs. Realized access will be used as the measure of access and is defined as whether all recommended therapy services were received by the child. Individual Characteristics include predisposing, enabling, and need factors of the child and family in which they live. Contextual Characteristics also include predisposing, enabling, and need factors, but these are characteristics of the community and health care environment and not the individual. A list of important constructs from this model and their definitions is included in Appendix B and is described more thoroughly in Chapter 2.

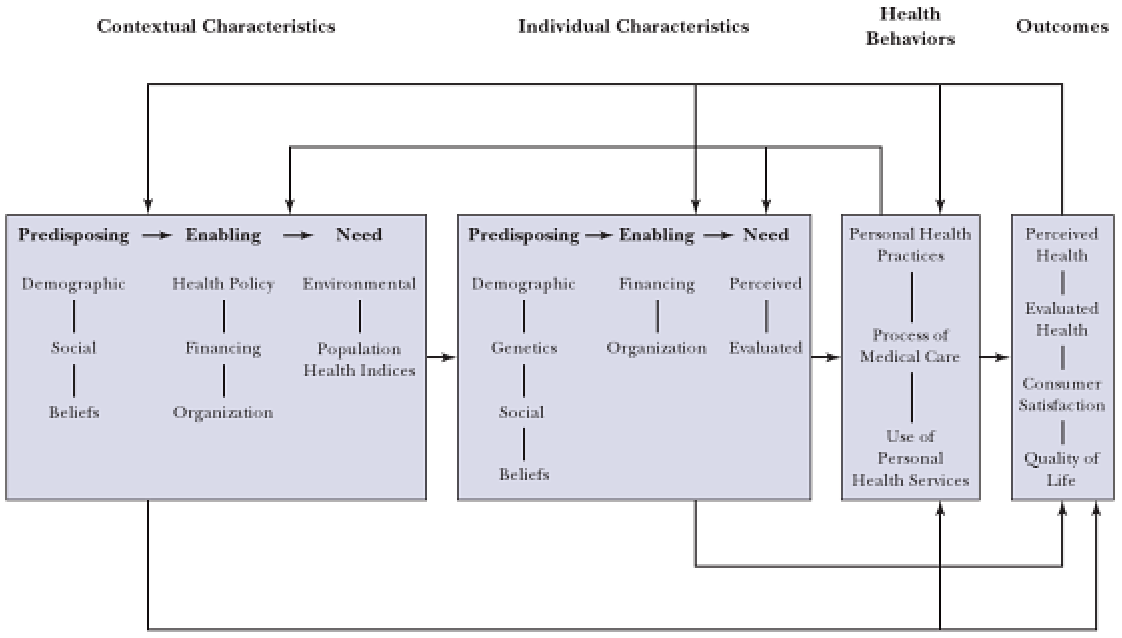

Figure 1. A Behavioral Model of Health Services Use, 6th ed. Figure and caption from Andersen et al. (2013). In Kominski *Changing the U.S. Health Care System,* p.35. Copyright © 2013 John Wiley and Sons. Reprinted with permission from John Wiley and Sons, Inc.

According to this model, both contextual characteristics of the environment that a person lives in and the individual characteristics of the person needing services can influence their use of healthcare. Equitable access is that in which need characteristics of the individual explain health service use (Andersen et al., 2013). Examining constructs such as Health Behaviors (e.g., access/use), Individual Characteristics (e.g., predisposing, enabling, need characteristics), and the Contextual Characteristics in which health care occurs (e.g., enabling variables of the environment, provider variables) will provide a strong theoretical basis for drawing conclusions regarding factors that impact access to therapy care.

Justification and Purpose of the Study

Minimizing health disparities and improving access to services is a current focus of Healthy People 2020, with specific Maternal, Infant, and Child Health objectives (e.g., MICH–29) targeting improved diagnosis and access to appropriate intervention for children with ASDs (DHHS, n.d.). The 2012 NIH Interagency Autism Coordinating Committee (IACC, 2012) recently identified that disparities in quality care for persons with ASD are problematic and recommended continued research into service access. Although significant literature exists on diagnostic disparities for children with ASD and access to specific medical services, very few studies have investigated access to therapy services in children with ASD (Chiri & Warfield, 2012; Irvin et al., 2012; Kohler, 1999; Thomas et al., 2007). Moreover, these studies utilize data from the early/mid-2000s and primarily utilize small datasets limited by geographic location. Access to therapy services represents an understudied but important health care equity issue given that these services are deemed necessary and important for improving functional outcomes in children with ASD. Current literature suggests that children with ASD need more therapy services than other CSHCN (e.g., Gurney et al., 2006; Montes et al., 2009). However, access to these therapy services and factors contributing to lack of access are less frequently examined and results suggest inconsistency in potential limiting factors.

Current research on the nature of therapy service access limitations are outdated and provide conflicting results that hamper efforts to detect, understand, and improve access. In order for federal and state programs to improve access to appropriate interventions, including therapies such as OT, PT, and ST, policymakers require more recent data on factors that limit such access. Without a clear, comprehensive understanding of the factors that restrict therapy access, such problems cannot be ameliorated. Given the age of the existing literature and discrepancies in factors limiting therapy service access in children with ASD, a greater understanding of individual characteristics and contextual aspects of the community and health care environment related to the utilization and access to therapy services for children with ASD is warranted. Therefore, examination of current factors impacting access to therapy in children with ASD will clarify existing knowledge on factors that contribute to reduced access. Additionally, the use of a well-developed model for understanding access to therapy will contextualize results using clearly defined constructs.

Purpose statement, research questions, and hypotheses. The purpose of this study was to examine access to therapy services in children with ASD compared to other CSHCN before and after major policy and economic changes to identify if differences in access exist between time points. A secondary purpose was to describe factors related to reduced access, such as individual and contextual characteristics that contribute to poor access to therapy services in children with ASD compared to other CSHCN at both time points. Individual Characteristics hypothesized to impact therapy access included predisposing, enabling, and need characteristics of children and the households in which they live. Additionally, Contextual Characteristics such as enabling factors and provider-related factors were hypothesized to contribute to decreased access. The research questions that guided this investigation were:

1. What is the difference in the percentage of children with ASD who demonstrate need for therapy services compared to children with other selected health care needs in the 2005-2006 and 2009-2010 NS-CHCSN?
2. What is the difference in the percentage of children with ASD who demonstrate reduced realized access to services compared to children with other selected health care needs at both survey time points?
3. To what extent are Individual Characteristics and Contextual Characteristics associated with realized access problems in children with ASD as compared to other children with selected special health care needs at both survey time points?

Significance of the Research

Quality health care increases the likelihood of positive health outcomes. Quality can be measured in domains of effectiveness, efficiency of care, and equity (Beal et al., 2004). Effective care suggests that the care is appropriate, evidence-based, safe, patient-centered, and timely. Efficient care utilizes resources efficiently. Finally, care must be equitable, or fairly distributed (Aday et al., 2004). Access to services is a measure of equity (Arah, Westert, Hurst, & Klazinga, 2006; Beal et al., 2004). When parents are unable to access appropriate care for their children with ASD, quality of care may be negatively impacted, which in turn impacts a child's health outcomes. It is important, therefore, to understand the factors that reduce or improve access to recommended services for children with ASD, including therapy services such as OT, PT, and ST. A clear understanding of the individual and contextual characteristics contributing to lack of realized access will pave the way for future studies designed to reduce such therapy access disparities for persons with ASD.

Identification of individual and contextual characteristics related to lack of realized access will be useful for developing potential future systems-based interventions designed to ameliorate access problems. The National Institute of Medicine report on Racial and Ethnic Disparities in Health care (Smedley et al., 2003) makes multiple recommendations based on available evidence to address disparities in health care. For example, if access problems are related to predisposing individual characteristics such as race or ethnicity, and parents report problems finding an appropriate provider (a Contextual Characteristic construct), then interventions targeting educational settings can be implemented to improve access using these two constructs as a guide (finding appropriate providers for minority families). Minority health care workers are more likely to deliver care to underserved populations (Moy & Bartman, 1995; Saha & Shipman, 2008). Therefore, an example of an educational intervention is the recruitment and training of diverse therapy providers to the workforce, and is one such potential approach emphasized by the Institute of Medicine (Recommendation 5-3, p. 186). In contrast, if access problems are not related to any particular predisposing characteristic of the family or child, but rather are related to the child's functional limitations, and lack of provider skills/knowledge to treat problems are also reported more frequently for children with ASD than other CSHCN, a clinical intervention could be implemented in therapy education settings to increase the knowledge, skills, and tools that therapy providers need to have when working in settings with children specifically with ASD (Betancourt, Green, Carrillo, & Aneneh-Firempong, 2003).

Summary

Children with ASD represent a growing population who are in need of multiple medical and therapy services due to limitations in social, communication, and restricted/repetitive behaviors. These needs contribute to greater health care utilization in the United States and negatively impact caregiver health and family wellbeing. Although therapy services are recommended as part of best-practice interventions for children with ASD, it is not well understood whether disparities in therapy access exist and current literature on factors limiting therapy service access remains inconclusive and represent a gap in the literature. Elucidating the factors that contribute to lack of access to therapy services in two recent population-based surveys will contribute to a firmer foundation from which to make recommendations for improving access for this vulnerable group of children if such disparities exist.

Chapter 2: Review of the Literature

Children with ASD experience a myriad of health care needs. These include a greater need for therapy services such as occupational therapy, physical therapy, and speech-language therapy than other children with special health care needs (Chiri & Warfield, 2012; Montes et al., 2009). Additionally, children with ASD utilize more outpatient services, mental health services, and specialty care services (e.g., neurology) than other children without ASD (Croen et al., 2006; Liptak et al., 2008; Liptak, Stuart, & Auinger, 2006). Previous research has found that access to health care services, including access to physicians and specialty care, has been restricted due to specific predisposing, enabling, and need characteristics of the child, family and community; although fewer studies have investigated the relationship of these characteristics to therapy access. This chapter describes the theoretical approach used to frame the study of access to these services. Additionally, a summary of medical and therapeutic needs of children with ASD for the reader unfamiliar with this population is provided with a focus on pathways to appropriate care including therapy services. Finally, the literature examining access to health care services in children with ASD as well as factors that may contribute to limited access for this population, particularly therapy services, is synthesized in relation to the theoretical constructs.

Theoretical Basis for Understanding Access Problems in Children with ASD

The Andersen Behavioral Model was used to frame this study of access to therapy services in children with autism spectrum disorders (Andersen, 1995; Andersen et al., 2013). The purpose of the Andersen Behavioral Model is to hypothesize relationships between constructs that contribute to health care service use and explain factors that contribute to equitable access to such services. This Model has been modified to reflect therapy access variables of interest as indicated in red font. Relationships are indicated by arrows in Figure 2, and support for the inclusion of specific variables is described in the subsequent literature review.

The Andersen Behavioral Model was originally derived from a sociological perspective to explain how people use health care services and has been used by policy makers and those seeking to explore outcomes such as equity of health service use and equity-related variables of potential access, realized access, and equitable/inequitable access. Recently, the Model has been expanded to focus on the contextual characteristic variables (e.g., the environment in which health care is delivered, provider-related factors) that affect health care use which have become important with the advent of health care reform (Andersen et al., 2013; Phillips, Morrison, Andersen, & Aday, 1998). The Andersen Behavioral Model has great utility due to its ability to explain and predict how people will use and access health care. The Andersen Behavioral Model also has been broadly examined by researchers using population-based health surveys (Andersen, 2008) due to the ease of statistical modeling to predict both community and individual-based factors related to access or use of health care services. For this study specifically, these population-based databases yielded variables that documented parent-reported problems that potentially could affect access to therapy services, and these variables were theoretically linked to Andersen's Behavioral Model.

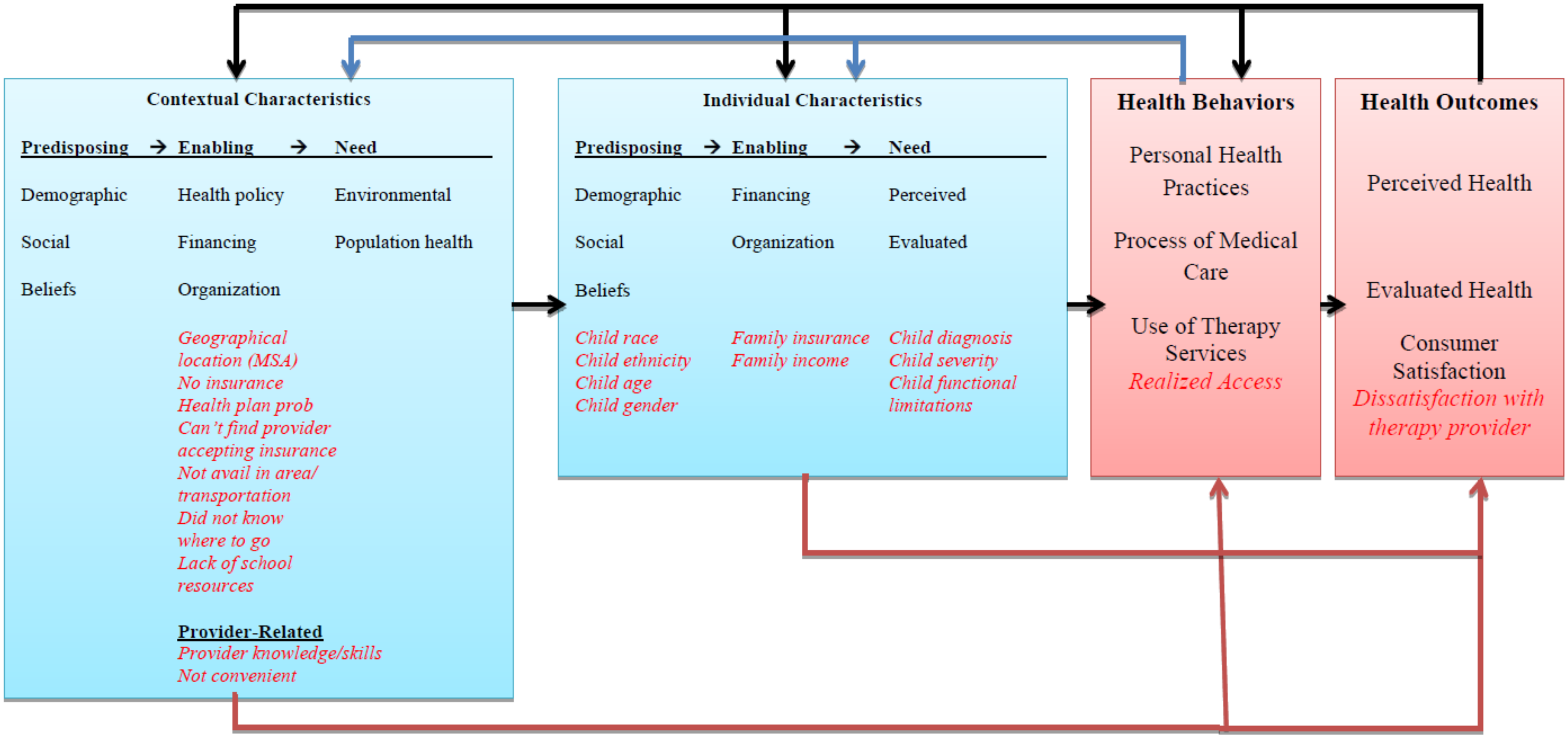

Figure 2. Revised Andersen's Behavioral Model of Access to Therapy Services. Adapted from Andersen (1995), p 8; Andersen, Davidson & Baumeister, p 35 in Kominski (2013).

The Andersen Behavioral Model, with its extensive historical use to predict access and utilization factors and its clearly defined constructs, was used to frame this study of access for children with ASD. Two constructs from the Andersen Behavioral Model that were proposed to affect use of therapy services (a Health Behavior) were *the context in which health care is provided* (Contextual Characteristics) and *characteristics of the population in need* (Individual Characteristics; Andersen et al., 2013).

Definition of primary constructs. The Andersen Behavioral Model has undergone various revisions in the past several decades. Therefore, a table documenting the primary construct, operational definition, and source of the original theoretical definition is provided in Appendix B. Additionally, the measurement of each construct is discussed below.

Use of therapy services. Health behaviors were defined as those behaviors that impact one's health (Andersen et al., 2013). Andersen and colleagues proposed several ways to measure health behaviors, including the actual use of health services measured in visits to a provider. The NS-CSHCN does not measure actual utilization of therapy services (visits); however, the survey inquires about *therapy need* (In the past year, has your child been needed OT/PT/ST services?), and whether the child received the needed therapy services (In the past year, has your child received all needed OT/PT/ST services?). Therefore, *realized access* was defined as the actual use of needed therapy (Andersen, 1995; Andersen et al., 2013); in this study, this was operationalized as those children who were referred for therapy services and received all necessary therapy during the past year as reported by parents. Children lacking realized access were those children who were referred for therapy services, but who did not receive all needed therapy.

Characteristics of the individual. In concordance with Andersen's Behavioral Model for understanding health care access (Andersen et al., 2013), characteristics of the individual may be related to decreased access to therapy services. *Predisposing characteristics* were defined as sociodemographic characteristics that are inherent to an individual (cannot be changed) but affect a person's tendency to use health services or manage a health problem. Predisposing characteristics of the individual included variables such as age, gender, race, or ethnicity. *Enabling characteristics* of the individual were defined as those variables that support an individual's ability to pay for, travel to, and use services (Andersen, 1995; Andersen et al., 2013). These included things such as insurance status and family income represented by federal poverty level. *Need characteristics* have also been described as affecting access to services for children with ASD, and were defined as those perceived or evaluated factors that are influenced by the illness or diagnosis that result in the need for care (Andersen, 1995; Andersen et al., 2013). For children with ASD, these included variables such as a child's functional abilities, parent reported extent of the disorder's impact on function, and any co-morbid conditions that the child might have.

Contextual characteristics impacting access. The Andersen Behavioral Model suggests that the context of the health care system and community in which a person lives can influence access and utilization of health care services. Similar to Individual Characteristics, the Contextual Characteristics also include predisposing, enabling, and need characteristics of the community at large. Additionally, Phillips and colleagues (1998) include *provider problems* as being a contextual characteristic that influences use and access to health care. Andersen and colleagues (2013) define the predisposing, enabling, and need contextual characteristics similarly to those of the individual, except they represent characteristics that are provided by a community rather than a person. For example, predisposing contextual characteristics were defined as those demographic, social or prevailing beliefs of a community or health care system that affect a person's use of healthcare (e.g., race or ethnic composition of a community, mean age of the community being studied). *Contextual enabling characteristics* were defined as those community, organizational, or policy factors that affect the financing, and also include factors that impact one's ability to receive care in a particular community such as availability of providers in a geographic area and health care policies that support or inhibit health care use. Examples included whether providers in the community accepted insurance to cover the necessary care, the cost of treatment, or the lack of providers in an area. *Contextual need characteristics* are those that represent the quality of the surrounding environment that influence or suggest the health of the community, such as quality of water supply, morbidity and mortality rates, etc. *Provider characteristics* are variables that interact with the population of need (Phillips, Morrison, Andersen, & Aday, 1998), such as the convenience of seeing a particular health care provider or whether the provider was perceived to have enough knowledge/skill to treat the condition. In this study, only *contextual enabling characteristics* and *provider problems* were utilized in predicting realized access to therapy services for children with ASD because they were represented by variables in the datasets of interest. Predisposing contextual characteristics such as the ethnic make-up of a family's community were not available in the NS-CSHCN. Similarly, contextual need characteristics such as morbidity and mortality of a given family's community, were not available in the NS-CSHCN, nor are expected to influence access to therapy services.

Assumptions and Limitations of the Andersen Behavioral Model. The Andersen Behavioral Model focuses on access to health care services specifically. It was not constructed to describe access to community services, such as school-based services or early intervention services that commonly include therapy practitioners such as school-based OT, PT or ST. However, the NS-CSHCN asks whether a child has needed OT, PT, or ST services in the past year, and does not distinguish between those therapy services that are received privately and which are typically funded by insurance versus those that were received through early intervention or educational systems. It is likely that parent responses to the Therapy Need variable and Realized Access variable reflects parent's thinking of therapy needed both at school and through therapy providers in the healthcare system.

Additionally, the original Andersen Behavioral Model included Contextual Characteristics that were measured at the community (aggregate) level, such as age of a particular community (e.g., median age in the area a child lives). These variables were not available in the NS-CSHCN and therefore were not included in the research questions posed for this study. However, it was not anticipated that their absence specifically impacted the understanding of therapy access.

Needs of Children with Autism Spectrum Disorder

In order to map constructs of the theory to those of the population of interest, children with ASD, a detailed description of the needs of this population, as well as anticipated pathways to care is delineated below.

Diagnosis of ASD. Appropriate surveillance and screening of all children under the age of three for symptoms of ASD is recommended by the AAP (AAP, 2010; Johnson & Myers, 2007), and is the first step in receiving necessary therapeutic services. In 2004, prevalence estimates were at 1 in 125 U.S. children diagnosed with an ASD; in 2006 the prevalence rose to 1 in 110 children, and most recent estimates from data collected in 2008 suggest that 1 in 88 children in the U.S. are diagnosed with an ASD (CDC, 2012, 2006). Children with ASD are diagnosed if they meet criteria in four critical areas, recently revised by the American Psychiatric Association (APA, 2013). First, symptoms of ASD must be present in early childhood and second, must limit functional abilities. Additionally, symptoms are considered to be indicative of ASD if the child displays:

a. Three main deficits in social-communication and social-interaction skills, encompassing social-emotional reciprocity, nonverbal behaviors used to communicate, and beginning/maintaining social relationships with others.

b. At least two deficits in restricted, repetitive behavior or interests including stereotypy in speech or motor actions, routines or patterns of behavior that are excessively maintained, intensive and unusual interests, or hyper- or hypo-reactivity to sensation and/or sensory interests.

Autism spectrum disorders remain identifiable only through behavioral signs and symptoms, and thus diagnosis of ASD typically requires administration of gold standard measures, including the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview-Revised. These assessments allow confirmation of autism diagnostic features through parent interview and observation of the child’s behaviors. Diagnosis is limited by skill and training of the interviewer or examiner on these tools, and diagnosis based on best clinical judgment also varies widely (Lord et al., 2012). Additionally, parent’s cultural and other beliefs about their child’s skills impact decisions to seek diagnoses, and thus children with ASD are often not identified until after the age of 3 years (Mandell et al., 2005).

Educational, therapeutic, and medical needs of children with ASD. Persons with ASD have complex medical, cognitive, mental health, and behavioral symptoms requiring frequent interactions with physicians and other members of the health care team. Frequently, children and adolescents with ASD also display co-morbid medical or psychiatric diagnoses not part of their ASD diagnosis (Levy et al., 2010). These conditions impact the appropriate care that is recommended for children, and thus have an impact on what kinds of referred therapeutic and education services are provided.

Medical and psychiatric diagnoses associated with ASD. Co-morbid diagnoses often blur the distinction between autism-specific problems and problems associated with other psychiatric conditions. For example, approximately 30-70% of children with ASD also have an intellectual disability (Fombonne, 2002; Mandell et al., 2005; Nicholas at al., 2008). Similarly, research demonstrates that nearly 75% of children with ASD display at least one other co-morbid mental health condition (Leyfer et al., 2006). Commonly diagnosed mental health conditions seen in children with ASD include attention-deficit hyperactivity disorder (ADHD), anxiety disorder, and depression (Leyfer et al., 2006; MacNeil, Lopes, & Minnes, 2009; Mayes, Calhoun, Murray, Ahuja, & Smith, 2011). In addition to the co-morbid psychiatric diagnoses noted above, children with ASD often develop or are diagnosed with genetic, developmental, gastrointestinal, or neurological disorders such as constipation, gastroesophageal reflux disease, seizure disorder, Fragile X, tuberous sclerosis, and others (Levy et al., 2010; Wang, Tancredi, & Thomas, 2011). These conditions complicate the medical and therapeutic care that is required of this special population.

Additional limitations associated with ASD diagnosis. In addition to the primary diagnostic symptoms comprising ASD diagnosis, and the potential medical and psychiatric diagnoses that might impact function, additional challenges are reported in the literature for this population. Notably, researchers have found that a large percentage of children with ASD display fine and gross motor delays (e.g., Jansiewicz et al., 2006; Provost, Lopez, & Heimerl, 2007; Siaperas, et al., 2012) that are not part of their core diagnostic features. Provost and colleagues (2007) recently found in their sample of young children (21-41 months) that all children with ASD (*n*=18) displayed some degree of fine or gross motor delay, with 60% of their ASD group being eligible for early intervention services based solely on their motor delays. Thus, while psychiatric symptoms related to both core symptoms and co-morbid diagnoses result in social-communication, sensory, behavioral, attentional, and emotional difficulties, children with ASD also frequently display physical symptoms related to their diagnosis such as fine motor and gross motor delays that also require treatment from therapy providers.

Recommended treatments to meet the needs of children with ASD. Due to the nature of their condition, children with an ASD are likely to require long-term educational, therapeutic, medical, and pharmacological treatments that seek to improve cognitive functioning, ameliorate social communication skills, reduce restricted behaviors or sensory atypicalities, and expand functional capacities needed to participate in daily life (Johnson & Myers, 2007). The AAP suggests that pediatricians manage the care of young patients with ASD by referring parents to primary treatments utilized *outside* of the medical field. Specifically, in a clinical report by the AAP, recommended non-pharmacological services include intensive educational interventions (e.g., Denver model, TEACCH program), applied behavior analysis (ABA), speech and language therapy, social skills instruction, occupational therapy and sensory integration therapy (Johnson & Myers, 2007).

Therapy services, including occupational, physical, and speech-language services, are considered to be important in managing the functional limitations that accompany symptoms related to ASD diagnosis; however, mixed research is available to support ST and OT (Miller, Schreck, Mulick, & Butter, 2012). In a survey of parent reported treatments used by their children, Green et al. (2006) found that speech services were the most frequently reported service used, followed by visual schedules, sensory integration (an approach mainly used by occupational therapists), and ABA. Parents also report improvements from occupational therapy and speech-language therapy. Goin-Kochel and colleagues (2009) found that 72% of parents using occupational therapy services reported that OT was effective at improving functional problems “somewhat” or “dramatically” in their child with ASD, and that occupational therapy was the least likely service to cause the child to get worse, compared to ABA or other therapies. Similarly, these authors also found that speech language services resulted in 71% of parents endorsing that their child improved “somewhat” or “dramatically”. In a non-random survey of approximately 8,000 parents accessing the website of Autism Speaks, an advocacy group, parents reported that occupational therapy and speech therapy services were the top two treatments that were effective for their child with ASD (Accessed 11/10/12 at: http://www.autismspeaks.org/blog/2012/09/25/top-8-autism-therapies-%E2%80%93-reported-parents). Therefore, while effectiveness studies are lacking for therapy services for children with ASD, preliminary evidence suggests that these therapies do not cause harm, are utilized frequently by parents for their children, and are felt to be effective at ameliorating functional limitations (Goin-Kochel et al., 2009; Green et al., 2006; Gurney et al., 2006; Montes et al., 2009). Further, respected medical professionals treating children with ASD also recommend these therapies as part of a comprehensive treatment for meeting the complex needs of this population (Johnson & Myers, 2007).

A Review of Disparities in Access to Health Care Services for Children with ASD

In the United States, there are no universally recognized recommendations on pathways to care for children with ASD that specify which providers should be involved in diagnosis and treatment. The AAP provides recommendations for pediatricians which suggests that therapists including ST and OT be involved in contributing to diagnostic and functional evaluations and treatment of identified needs (Johnson & Myers, 2007). However, as discussed below, research suggests that access to diagnostic services is limited and this therefore will impact appropriate referral to therapy providers by physicians. Other countries with national healthcare services such as the United Kingdom (UK), however, have identified protocols that suggest how therapists should be involved in care for children with ASD. In the UK, local pathways for recognizing and referring children with ASD include use of a multidisciplinary autism team including a pediatrician, speech therapist, and psychologist with access to a neurologist, occupational therapist, and psychiatrist when indicated (National Collaborating Centre for Women's and Children's Health, 2011). Since access to physicians for diagnosis and care appears to be the most recommended pathway for receipt of therapy services, a brief review of access to other healthcare services for children with ASD is described below.

Access to health care services. Several studies published in the past ten years have examined access problems to health care services for children with ASD. Research has sought to understand whether children with ASD coming from underserved populations experience disparities in rate of diagnosis, whether having a medical home (a patient-centered approach to providing consistent and comprehensive health care for an individual) or receiving family-centered health care were different in families with ASD of different backgrounds.

Research has identified disparities in pathways to care for children with ASD, beginning with access to diagnostic services. Importantly, disparities in diagnosis occur, in which certain characteristics of the family and children predict increased time to ASD diagnosis. Mandell and colleagues (2005) show that characteristics of the child, the family, and the context in which health care occur relate to diagnostic access problems. Certain characteristics of the child were related to earlier diagnosis in this sample. Specifically, children with ASD and severe communication delays, hand mannerisms (e.g., flapping), toe walking, and sustained unusual play were diagnosed sooner. However, children with ASD and hearing delays were diagnosed nearly one year later on average than children without hearing delays (Mandell et al., 2005). Additionally, family enabling characteristics, including children living in 'near-poor' families were diagnosed nearly one year later than children from 'non-poor' families. These researchers also found that children living in rural areas were diagnosed 0.4 years later than children from more urban areas, and suggest that these factors relate to primary and specialty care access problems. Liptak et al. (2008) more recently confirmed that the prevalence of children with ASD was much lower in Latino families and young children from poor families, and these authors suggest that disparities in diagnosis contributed to the decreased prevalence of ASD diagnosis in younger children (but not older children) from these ethnic and socioeconomic groups. From a process of care perspective, the lack of diagnostic equity could contribute to lack of access to other health care services for families of children with ASD, including therapy services.

Additionally, some studies have sought to determine what factors contributed to reduced access to genetic or specialty health care services. These studies collectively suggest that certain *predisposing characteristics* such as race predicted lack of access (Montes et al., 2011), that *enabling characteristics* such as lack of insurance, lack of a medical home, and family income below the federal poverty level contributed to reduced ability to access health care services in general (Thomas, Parish, Rose, & Kilany, 2011), and are related to reduced access to genetic services (McGrath, et al., 2009). Additionally, the child's *need characteristics*, such as severity of autism symptoms or unstable health care needs, contributed to reduced access for a variety of health care services (Thomas et al., 2011), to specialty care services (Krauss, et al., 2003), and genetic counseling services (McGrath et al., 2009).

Access to therapy services. There has been some interest in determining access to therapy services for children with ASD in the past ten years. Five studies have examined national or small state level data on access to therapies such as OT, PT, or ST. Summary tables of evidence supporting factors contributing to reduced access are provided.

Studies that examine *predisposing characteristics* of the child including age, gender, race, and ethnicity report conflicting findings whether certain factors contribute to reduced access of therapy services in children with ASD. Table 1 describes predisposing characteristics that influence access to therapy services. Being of Hispanic ethnicity was found to predict lack of access to therapy services in a small state-based survey of 137 parents living in Colorado, Florida, Minnesota, and North Carolina (Irvin et al., 2012) and in the 2005-06 NS-CSHCN (Montes et al., 2009). However, Chiri and Warfield (2012) did not find that Hispanic ethnicity contributed to difficulty accessing OT, PT or ST services in their large population-based dataset. Therefore, ethnicity is a variable that requires exploration in a large, more recent dataset.

Table 1

Predisposing Individual Characteristics Related to Reduced Therapy Access

	Chiri & Warfield (2012)	Montes et al. (2009)	Irvin et al. (2012)	Thomas et al. (2007)	Kohler (1999)
Minority Race	0	0	✓- Asian – school OT	✓-	
Hispanic Ethnicity	0	✓-	✓- School OT and ST	✓- Non-white for OT/SI	
Gender	✓- Female	0	0		
Age	0	✓- Older	✓+ Older and higher cog private OT	✓+ Younger ST ✓- Older SI	
Language spoken	0				

✓- suggests that the variable was found to be predictive of an access problem. ✓+ suggests that the variable positively influences access. 0 indicates that the variable was not found to be predictive of an access problem. Blank cells indicate that the author did not examine the variable of interest. OT= Occupational Therapy, ST= Speech Therapy, SI=Sensory Integration.

Being of racial minority status has also been found to predict lack of access to school-based therapy services in small state-based data (Irvin et al., 2012). Irvin and colleagues found in their sample of 137 caregivers living in four states that children of Asian caregivers were less likely than children of White caregivers to receive school-based OT. Similarly, children of Hispanic caregivers were less likely to receive school-based OT and ST than children of non-Hispanic caregivers. However, these authors did not find the same results for access to private ST or OT services. Similarly, Chiri and Warfield did not find that race was predictive of lack of access to therapy services for children with ASD in the 2005-06 NS-CSHCN. Inconclusive evidence exists on whether being of a racial minority impacts therapy access for children with ASD.

Of the two remaining studies that examined access to therapy services, Kohler (1999) did not examine the impact of race or ethnicity on service use and Thomas and colleagues (2007) combined race and ethnicity into one variable. Thomas et al. (2007), who examined service access and use in 383 caregivers of children with ASD living in North Carolina, found that being of a racial or ethnic minority reduced the odds that children used sensory integration therapy, an intervention frequently used by occupational therapists. Although these authors did not find that race/ethnicity limited use of other services including private OT or ST, the use of a combined race and ethnicity variable considerably reduces the interpretability of these findings.

The two large-population based studies also found inconclusive results for the impact of age, gender, and home language on access to therapy services. The only predisposing characteristic found by Chiri and Warfield (2012) to predict access problems in their examination of the 2005-06 NS-CSHCN was being of female gender contributed to reduced therapy access. Other predisposing characteristics of child's age, child's ethnicity and race, language spoken at home, and family structure did not significantly predict unmet need for therapy services in the data used by Chiri and Warfield. However, in a small study examining the use of multiple services living in North Carolina, Thomas et al. (2007) found that older children (9-11 years old) were less likely than younger children (5-8 years old) to utilize sensory integration. Similarly, age influenced the probability of using ST services in this study; younger children under the age of 4 years were significantly more likely to utilize ST than children aged 5 to 8 years. Irvin and researchers (2012), however, did not find that age alone impacted the probability of receiving ST or OT, but did find that older children with better cognitive skills were significantly more likely to receive private OT than younger children with lower cognitive levels. This interaction between age and cognitive level is not one that has been examined by other authors, making the interpretation of this finding difficult. Overall, these studies provide conflicting evidence that race or ethnicity contributes to reduced therapy access. Additionally, inconclusive evidence exists on the role of gender and age on access to therapy services. Although both Montes et al. (2009) and Chiri and Warfield (2012) used the same database to examine access to services for children with ASD, these studies differed in their comparison groups and in their dependent variable of interest (therapy services specifically versus community/school services typically including therapies), thus potentially contributing to differences noted in predictors to therapy access. Similarly, the use of small samples by Thomas et al. (2007) and Irvin et al. (2012) may have contributed to differences reported in the literature on predisposing characteristics contributing to therapy access problems.

Enabling characteristics of the child's family such as insurance status and income also predict reduced access to therapies, although some inconsistencies exist in the literature, as shown in Table 2.

Table 2

Enabling Individual Characteristics Related to Reduced Therapy Access

	Chiri & Warfield (2012)	Montes et al. (2009)	Irvin et al. (2012)	Thomas et al. (2007)	Kohler (1999)
Insurance	✓- Uninsured	✓- Uninsured		✓+ Medicaid ST	
Income	✓- Below FPL	✓- Below FPL	✓+ Private OT*	Income > $50,000 ✓+ ST	

✓- suggests that the variable was found to be predictive of an access problem. ✓+ suggests that the variable positively influences access. 0 indicates that the variable was not found to be predictive of an access problem. Blank cells indicate that the author did not examine the variable of interest. OT= Occupational Therapy, ST= Speech Therapy.

* Irvin et al.(2012) did not examine income alone; rather they used a combined SES metric including parent education and family income.

Both Chiri and Warfield (2012) and Montes et al. (2009) found in the 2005-06 NS-CSHCN that being uninsured predicted reduced access to school/community and OT/PT/ST therapy services. However, Thomas and colleagues (2007) found in their small state-based survey that utilizing Medicaid for a child's health care predicted greater ST use, as did having a family income of greater than $50,000. This counter-intuitive finding was explained that those families that lacked private insurance were utilizing Medicaid case managers, and these case managers were facilitating the families' ability to receive necessary services. These discrepancies in the literature regarding the role of insurance status may be due to differences in sample size or geographic region; however, insurance status poses an area for additional inquiry in more recent data. Another enabling characteristic, family poverty, has been examined in large population based surveys. Both Montes and colleagues (2009) and Chiri and Warfield (2012) found that families living at or below 200% of the federal poverty level reported significantly greater problems accessing community/school services and OT/PT/ST services. On the other extreme, Irvin and colleagues (2012) found that families of children with ASD with high socioeconomic status (SES) were significantly more likely to use more private OT services than families with low SES. However, SES was not predictive of ST use (private or school based) or predictive of school-based OT use (Irvin et al., 2012).

Overall across these studies, family income, family poverty level, and SES represent different variables but a similar construct of family resources available to pay for therapy; in these studies, having less income appears to be predictive of therapy access problems. The role of insurance status and its impact on therapy service access is confounded in the literature by different types of insurance being investigated, and the dichotomies of no insurance versus private versus public (e.g., Medicaid). Children with no insurance at all may be different than children with public insurance such as Medicaid due to family resources to seek out publically funded resources. These differences in type of insurance need to be further investigated in a more recent dataset.

Need characteristics of the child such as ASD diagnosis, other co-morbid diagnosis (e.g., intellectual disability), severity of autism symptoms, and functional limitations have also been found to predict problems with access or utilization of therapy services, as shown in Table 3. Differences in the operationalization of these variables in the studies discussed previously limits interpretation of the results. Findings from studies that included need characteristics are discussed below.

Table 3

Need Individual Characteristics Related to Reduced Therapy Use and Access

	Chiri & Warfield (2012)	Montes et al. (2009)	Irvin et al. (2012)	Thomas et al. (2007)	Kohler (1999)
ASD Diagnosis	✓-	✓-		0	
Intellectual Disability or Cognitive Level				✓+ SI use	
Greater ASD Severity			✓+ School based OT use		
Greater functional limitation	✓-		✓+ School based ST use		

✓- suggests that the variable was found to be predictive of an access problem. ✓+ suggests that the variable positively influences access. 0 indicates that the variable was not found to be predictive of an access problem. Blank cells indicate that the author did not examine the variable of interest. OT= Occupational Therapy, ST= Speech Therapy, SI=Sensory Integration.

Thomas and colleagues (2007) classified child age[1], co-morbid mental retardation (currently referred to as intellectual disability), and ASD diagnosis (Asperger's Syndrome, "classical" autism, Pervasive Developmental Disability-Not Otherwise Specified, or PDD-NOS) as need characteristics. Type of ASD diagnosis was not found to predict use of ST, OT, or sensory integration treatment (Thomas et al., 2007). No other study distinguished type of ASD diagnosis, although both Chiri and Warfield (2012) and Montes et al. (2009) found that children with a diagnosis of an ASD (including Aspergers Syndrome, autistic disorder, PDD-NOS) were significantly more likely to experience reduced access to therapy services and school/community services typically provided by therapists, compared to other CSHCN (Chiri & Warfield, 2012; Montes et al., 2009) and compared to other children with EDB difficulty (Chiri & Warfield, 2012).

As discussed previously, co-morbid intellectual disability affects a significant percent of children with ASD and is classified under the Andersen model as a need characteristic due to the likelihood that this factor may influence the type or need for therapy services. Only one study examined the influence of co-morbid intellectual disability on access to therapy services. Thomas et al. (2007) found in their North Carolina sample that children with ASD and co-morbid mental retardation had nearly double the odds of using sensory integration than children with ASD and no mental retardation. MR status did not influence use of ST or OT services.

Another need characteristic potentially influencing the type or need for therapy services is the severity of autism symptoms. Irvin and colleagues (2012), the only researchers to examine this construct, found that having a high ADOS severity score (indicative of greater severity of autism symptoms) was related to increased use of school-based OT services, but was not related

---

[1] It should be noted that Thomas et al. (2007) classified age as a need characteristic. Since age is typically classified as a predisposing characteristic in the literature, it was discussed in relation to other predisposing variables, above.

to greater probability of receiving either school-based ST or private ST or OT. No other study has examined severity of autism symptoms specifically. Related to severity of ASD symptoms, but operationalized differently, is functional limitation. Irvin and colleagues operationalized functional limitations by using the Mullen Scales of Early Learning, a measure of motor, language, and visual perceptual skills. These authors found that although children with ASD and greater functional limitations received *more* school-based ST services than children with ASD and fewer functional limitations, functional limitations alone did not increase the probability of receiving ST or OT, either in school or privately. Chiri and Warfield (2012) operationalized functional limitation through use of the NS-CSHCN question, "How often have your child's problems affected his/her ability to do things?". Contrary to Irvin et al. (2007), these authors suggest that children with ASD and greater parent-reported functional problems have significantly greater problems receiving needed therapy services compared to other CSHCN and other children with EDB (Chiri & Warfield, 2012).

Overall, very few studies examine similarly defined individual need characteristics that influence therapy service access. It is clear that children with a diagnosis of ASD, in general, are significantly less likely than other CSHCN to receive all needed therapy. However, evidence supporting other need characteristics as influencing access to therapy is inconclusive. Future studies should utilize constructs such as co-morbid intellectual disability (MR), severity of autism symptoms, and functional limitations.

Contextual Characteristics that impact therapy service access are infrequently discussed in the literature. One contextual enabling characteristic that is discussed is the geographical location in which a child lives. This variable, typically dichotomized as rural and urban, can be utilized as a proxy for provider availability in a given area (R. Andersen, personal communication, February 2, 2013). Four studies have examined the use of this variable in relation to access to therapy services, which are summarized in Table 4. Chiri and Warfield (2012), in the only population-based study of therapy access specifically, did not find that geographical location predicted reduced therapy access for children with ASD compared to other CSHCN or other CSHCN and EDB. Similarly, Thomas and colleagues (2009) did not find that geographical location of the family predicted likelihood of therapy service use. Montes et al. (2009), however, found that children with ASD living in urban areas were significantly more likely to experience difficulty accessing school and community services compared to other CSHCN. The discrepancies in these findings may be due to the difference in type of service (therapy services specifically versus non-specific school/community services which typically include OT/PT/ST).

Table 4

Contextual Characteristics Related to Reduced Therapy Access

	Chiri & Warfield (2012)	Montes et al. (2009)	Irvin et al. (2012)	Thomas et al. (2007)	Kohler (1999)
Geography	0	✓- Urban		0	
Provider Problems	✓- Provider skill	✓- Provider skill			✓- Provider skill Coordination w/family
Community Problems	0	✓- Service not avail Long waiting lists			✓- Delayed dx Delay in service Collaboration btwn providers Lack info Payment

✓- suggests that the variable was found to be predictive of an access problem. ✓+ suggests that the variable positively influences access. 0 indicates that the variable was not found to be predictive of an access problem. Blank cells indicate that the author did not examine the variable of interest.

Other enabling contextual characteristics include those that include policy, financing, and organization of therapy service provision. Few studies specifically describe these characteristics in relation to therapy access. In a small study of 25 families participating in a variety of therapies, Kohler (1999) describes parent reported frequency of problems with obtaining needed early intervention and school-based services, with contextual enabling characteristics reported by few parents as limiting access. Contextual enabling characteristics endorsed most frequently by parents of children with ASD included delay or inaccuracy in child's diagnosis (44%), delay or difficulty in accessing services (40%), lack of collaboration between agencies and providers when providing services (32%), lack of information on how to identify or access services (28%), and problems with payment for services (8%). These findings mirror those of Montes and colleagues (2009), in which parents of children with ASD were significantly more likely than parents of other CSHCN to report long waiting lists (55% v. 45% respectively) and that the needed school/community service was not available in the area (56% v. 39%). In contrast to the findings of Kohler (1999) and Montes et al. (2009), problems with community/health plan problems were not reported by Chiri and Warfield (2012) as being significantly different between children with ASD and other CSHCN or CSHCN with EDB problems. Chiri and Warfield (2012) did not find that differences in cost of therapy, lack of insurance to pay for therapy, a health plan problem impacting therapy, lack of referral for therapy, or providers not accepting insurance for therapy impacted access for children with ASD differentially compared to these other comparison groups (Chiri & Warfield, 2012). At this time, the literature on contextual enabling characteristics paints a discrepant picture of factors that limit access to therapy services.

Provider-related characteristics, another type of contextual characteristic that can influence therapy access, are described frequently in the literature by parents of children with ASD. Kohler (1999) reported that the most prevalent reason for service delivery receipt problems were lack of provider effectiveness (64% of parents endorsing), poor communication between the provider and family (60%), or providers that miss or shorten scheduled therapy sessions (28%) (Kohler, 1999). Montes and colleagues (2009) examined reasons for lack of access to community/school services, and similarly found that parents of children with ASD were significantly more likely to report the provider-related problem of “no providers with necessary skills to treat” than parents of other CSHCN. Chiri and Warfield (2012) specifically found that the therapy provider-related problem of “provider did not know how to treat” was reported significantly more by parents of children with ASD compared to other CSHCN and CSHCN with EDB problems, although no other provider-related problems were found to be different between the groups (such as whether a provider was available in the area/transportation problem, care was provided at an inconvenient time, or dissatisfaction with provider). Within the variables reflecting provider-related contextual characteristics, researchers consistently have found that the therapy provider’s lack of skill in treating the child with ASD was the greatest barrier to receiving needed therapy services. This is a conclusion that was explored further in this study.

The findings of these five studies (Chiri & Warfield, 2012; Irvin et al., 2012; Kohler, 1999; Montes et al., 2009; Thomas et al., 2007) suggest that certain individual characteristics may be predictive of therapy service access limitations. Inconclusive or discrepant results in the literature on the variables of child age, gender, ethnicity, race, co-morbid intellectual disability, severity of autism symptoms, family insurance status, and income/poverty level are important to explore in a more recent dataset. Contextual characteristics that limit therapy access are more regularly described in the literature, with provider-related variables appearing to impact receipt of therapy services most consistently. More recent data is needed to clarify discrepancies in the literature to inform policies for improving therapy service access in today's health care environment.

Summary

Children with ASD require significant health care and therapy services to improve functional abilities and promote participation in everyday activities. Current literature suggests that access to needed therapy services may be restricted in children with ASD but the findings of these studies are inconclusive in regard to which individual characteristics predict lack of access to therapy services. Additionally, the need to more fully understand other potential contextual factors that contribute to reduced access to therapy services for families of children with ASD is warranted. The purpose of this study was to examine these individual and contextual factors that contribute to access problems for children with ASD, compared to other diagnostic groups that require therapy services in two recent, population-based databases.

Chapter 3: Methods

Research Design

The purpose of this study was to examine individual predisposing, enabling, and need characteristics of children with ASD over two cross-sectional data collection time points, and determine if need for therapy and access to therapy differs in ASD compared to children with ADHD and CP. Additionally, contextual characteristics that could be related to reduced access were examined and compared between these groups. A retrospective, population-based cohort design was used to answer the research questions, with secondary data sets from the CDC serving as the primary data for analysis. Previous research on this topic has been constrained by small samples (i.e., state-based data) and data from the early to mid-2000's (e.g., data collected earlier than 2005). In this study, a population-based approach was appropriate to assure generalizability of the results and ensure findings were applicable to federal policymakers. Between the two data collection points of 2005 and 2009, several notable changes occurred within health care, as well as in autism spectrum disorder research. First, a steady increase in prevalence estimates in the U.S. population of children with ASD contributed to more children needing services. Second, health care policy changed significantly. Finally, the economic impacts of the U.S. recession of 2009 impacted many families. These factors all were considered as having had an impact on access to therapy services in children with ASD and justify a study design comparing the two most recent national population-based surveys on children's therapy service need and access.

Choice of Comparison Group. There has been little consistency in the therapy access literature regarding comparison groups against which to evaluate similarities and differences. This has led to inconsistent results with limited application to potential solutions. Several of the studies above utilized comparison groups of other CSHCN, which are defined as "those [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, p. 138). Unfortunately, there are often CSHCN who experience a health care problem, but who are not frequently referred for therapy services (e.g., children with depression, children with deafness). Some studies compare children with ASD to other children, including typically developing children without ASD (e.g., Gurney et al., 2006). However, in order to identify factors that are inherent to ASD specifically that impact therapy access, a chosen comparison group must include children with similar need characteristics and include children who typically require therapy services. Therefore, since children with ASD experience both physical symptoms (e.g., limited fine and gross motor skills), as well as mental health symptoms that relate to emotional or behavioral needs that are addressed by therapy services, a comparison group of children with representative needs in each of these areas was used in this study.

Children identified as having attention deficit hyperactivity disorder (ADHD) with no associated ASD or physical disability served to control for access limitations frequently experienced by children with mental health diagnoses. On the 2005-2006 NS-CSHCN, approximately 20.2% of children with ADHD required therapy services. In addition, a sample of children with physical disabilities (PD), represented by children with cerebral palsy and no associated ASD or ADHD, were included to compare children requiring therapy services addressing chronic physical symptoms related to their functional limitations. In the 2005-06 NS-CSHCN, approximately 83.3% of children with CP required therapy services. These comparison groups were included to control for children with similar needs as children with ASD (children with physical and mental health concerns) who required therapy. Of interest is determining whether these children with physical or mental health symptoms experienced similar access problems, and whether similar Individual and Contextual Characteristics predicted access problems in these populations compared to children with ASD.

Research Questions and Hypotheses

Children with ASD were compared to children with other complex needs as described above. Based on the previously reviewed literature, the following research questions and associated hypotheses were tested.

1. What is the percentage of children with ASD who demonstrate need for therapy services compared to children with other selected health care needs in the 2005-2006 and 2009-2010 NS-CHCSN?

   H1: Children with ASD will demonstrate greater need for therapy than children with ADHD but similar need for therapy than children with CP at both survey time points.

   Justification**:** Studies using two population-based surveys have documented greater need for therapy services for children with ASD compared to other CSHCN in the 2005-06 NS-CSHCN (Gurney et al., 2006; Montes et al., 2009), thus the proportion of needed services is known from previous data. No recent studies have specifically examined prevalence of therapy service need in comparison to a matched physical disability group (e.g., CP) or a matched mental health disorder (e.g., ADHD); however, 2005-06 NS-CSHCN data suggest that a similar percent of children with CP need therapy compared to children with ASD, and fewer children with ADHD need therapy compared with ASD. Similar findings were anticipated in the 2009-10 NS-CSHCN.

2. What is the difference in the percentage of children with ASD who demonstrate reduced realized access to services compared to children with other selected health care needs at both survey time points?

   H2.1: Children with ASD will demonstrate less realized access than either ADHD or CP groups at both time points.

   H2.2: Among children with ASD alone, children sampled in 2009-10 will demonstrate greater realized access than children sampled in 2005-06.

   Justification: The only existing population-based study of realized access to therapy in children with ASD demonstrated that children with ASD were significantly more likely to have a therapy access problem compared to other CSHCN in the 2006-06 NS-CSHCN (Chiri & Warfield, 2012). Although policy changes sought to improve organizational and financing problems related to reduced access for children with ASD since that study, it was anticipated that other factors specific to the ASD population continued to result in disparities in access to therapy services compared to other CSHCN. Therefore, it was hypothesized (H2.1) that this finding of lower realized access compared to other CSHCN will be replicated in the 2009-10 NS-CSHCN.

   However, within the sample of children with ASD alone, it was expected (H2.2) that realized access to therapy services was greater in the 2009-10 survey than in the 2005-06 survey year. This was due to anticipated effects of legislation from federal and state levels which have contributed to better awareness of disparities in ASD diagnosis and treatment. The Combating Autism Act of 2006 (CAA) legislated funding to improve access and use of evidence-based /interventions to improve care for persons with ASD. Additionally, between the two time points in this study, nine state legislatures enacted laws to improve coverage for autism-related services (http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx).

3. To what extent are Individual Characteristics and Contextual Characteristics associated with realized access problems in children with ASD as compared to other children with selected special health care needs in the 2005-2006 and 2009-2010 NS- CHCSN?

   H3.1: Individual Predisposing, Enabling, and Need Characteristics will predict realized access problems in ASD and CP and ADHD comparison groups.

   Justification: For children with ASD, recent literature suggested that various predisposing, enabling, and need characteristics were related to access and use of therapy services, although the literature was inconsistent regarding the impact and significance of these characteristics in relation to other populations (Chiri & Warfield, 2012; Irvin et al., 2012; Thomas et al., 2007). This study explored the significance of these characteristics related to realized access after controlling for group and year of survey.

   H3.2: For children with a reported realized access problem, children with ASD, ADHD, and CP will report a similar proportion of Contextual Enabling variable access problems.

   Justification: Few studies have described contextual characteristics that contribute to therapy access problems. Only Montes and colleagues (2009) found that "service not available in my area" was reported more frequently than parents of children with ASD than other CSHCN. Chiri and Warfield (2012) reported that the prevalence of health plan-based problems (in this study, considered contextual enabling characteristics) was similar among children with ASD, other children with CSHCN, and children with

Emotional, Developmental, and Behavioral problems, based on 2005-06 NS-CSHCN data. Thus, because limited data exists on contextual characteristics, a null hypothesis of no differences in frequency of access problems was proposed.

H3.3: Children with ASD will have a greater proportion of provider-related problems than other CSHCN across both survey years; but within the ASD sample at both points, parents will report community-related problems more frequently than provider problems.

Justification: Existing studies using data from the early/mid 2000's suggest that lack of provider skill in treating children was reported more frequently by parents of children with ASD compared to parents of other CSHCN (Chiri & Warfield, 2012; Kohler, 1999; Montes et al., 2009). These studies also implied that lack of ability to treat the child resulted in disparities in service receipt.

Data Sources and Sampling

Data sources. Two databases were utilized: 1) the 2005-2006 NS-CSHCN and 2) the 2009-2010 NS-CSHCN. Both surveys were designed to collect information about access to health care services. Sufficiently similar wording of question allowed for comparison between the two datasets, and question phrasing for each survey year and variable of interest is provided in Appendix C. Some questions changed slightly, either in the question wording, or the response options available to respondents. Variable differences and management of differences are provided in Appendix D. The following summary of data sources and weighting is based on information contained in the CDC's *Design and Operation of the NS-CSHCN, 2005-2006* guide (Blumberg et al., 2008) and the *2009-2010 NS-CSHCN Frequently Asked Questions* guide (CDC, 2011). At each time point (05-06, 09-10), four different survey datasets were available:

1. A *screening dataset*, which included demographic information about each child under the age of 18 in a particular household and whether any have a special health care need based on the screening questions;
2. A *household dataset,* which included information about the demographic characteristics of the household such as total number of children in each household, household income, and geographical location;
3. A *main interview dataset*, which included information on one randomly selected child with special health care needs per household, such a services used by the child, as well as satisfaction and problems with accessing needed health care for that child; and
4. A *referent dataset*, in which a smaller sample of children without special health care needs was surveyed using a different sampling frame to obtain a comparison group.

For the purposes of this research, only the *screening, household,* and *main interview* datasets were utilized. The remaining description of the sampling plan refers to sampling conducted for these datasets only.

Complex sampling design. The sampling plan for both the 2005-2006 and 2009-2010 NS-CSHCN utilized a complex sampling design with stratified and cluster sampling methods in order to obtain a nationally representative sample of children with special health care needs. The sampling was conducted through the National Center for Health Statistics (NCHS) via the State and Local Area Integrated Telephone Survey (SLAITS) program (http://www.cdc.gov/nchs/slaits.htm). Methods used by SLAITS are more fully described in Blumberg et al. (2008) pages 1-44 and are summarized here. A pictorial representation of the sampling strata, clusters, and sample size for each survey year is provided in Figure 3.

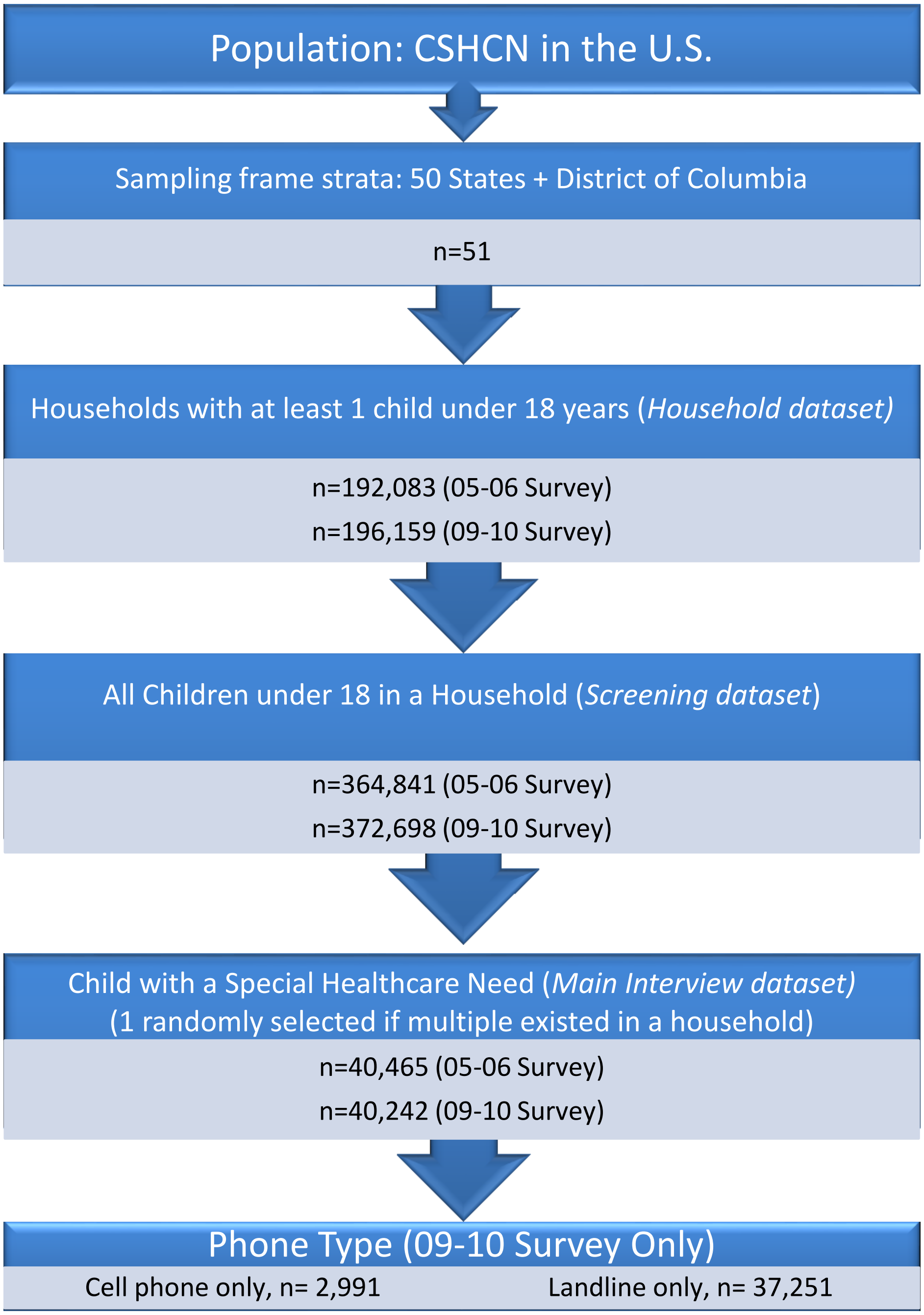

Figure 3. Sampling Frame and Associated Sample for 2005-06 and 2009-10 NS-CSHCN

Data from Blumberg et al., (2008), p. 10; Data from CDC (2011), p. 3-4.

First, each state and the District of Columbia were identified as the strata from which random households would be contacted. A random sample of telephone numbers in each geographic area was selected, with the goal of including a minimum of 750 eligible households with a CSHCN under the age of 18 years per strata (state). A *household sampling weight* was developed for use with the *household* dataset, and was based on the probability that any telephone number would be selected in a given geographic area, the frequency of nonresponse, and whether a household reported having more than one residential phone line. A *child screener weight* was developed for use with child-level data within each household such as demographic characteristics that were collected in the *screening* dataset. This weight was developed and adjusted to control for multiple socio-demographic characteristics such as gender, race, ethnicity, income, and education using census population estimates in each state. Finally, a *child interview weight* was created for use with the *main interview* dataset that includes information about CSHCN. The child interview weight includes the child screener weight, but also includes an adjustment for the total number of children with a SHCN in the household, and for nonresponse.

Sampling methods. Both the 2005-2006 and 2009-2010 surveys used primarily households from the National Immunization Survey (NIS) sample frame (http://www.cdc.gov/nchs/nis.htm), and in cases in which the NIS did not contain enough eligible households to allow for random selection to meet the goal of 750 per state, a larger state sample was drawn using random-digit dialing to obtain required numbers of households with a CSHCN in each state. Both the 2005-2006 and 2009-2010 survey for CSHCN were integrated within the State and Local Area Integrated Telephone Survey (SLAITS) program, which uses random-digit dialing sampling of households. The sampling and data collection were conducted with rigorous quality controls by the National Center for Health Statistics, including supervisory monitoring of phone interviews by trained staff, use of a computer-assisted telephone interview, which corrects and alerts for out-of-range codes, and data cleaning to ensure validity of data (Blumberg et al., 2008).

Differences in the telephone sampling processes existed at both time points: in 2005-2006, only households with landline (non-cellular) customers were included, whereas the 2009-2010 survey included both landline and cell-phone customers. Although potential sampling bias existed in the 2005-2006 survey due to inclusion of only landline customers, research suggests that persons in the mid-2000s who solely had cell-phones were more likely than customers with a landline to be not married, be a non-Hispanic male, or be a student (Link, Battaglia, Frankel, Osborn, & Mokdad, 2007). Therefore, it was less likely that these groups would have a child with ASD who would have been eligible at the time of the 2005-2006 CSHCN survey. Sampling bias based on the type of phone (landline versus cell phone) was controlled for through the use of a special sampling weight for only the 2009-2010 datasets in the regression analyses (CDC, 2011).

Additionally, the sample size for certain cell-phone strata collected in 2009-10 were either non-existent or too low to calculate standard errors and confidence intervals for some analyses. These problematic 2009 cell-phone strata included: South Dakota, Hawaii, North Dakota, Delaware, Nebraska, New Mexico, Colorado, Indiana, Massachusetts, New Jersey, South Carolina, and Michigan. CDC recommendations for managing this analytic issue included collapsing cell-phone strata with similar sampling weights to ensure a large enough sample in the problematic cell-phone strata (S. Blumberg, personal communication November 19, 2013). Appendix E illustrates each 2009 strata with the mean sampling weight, as well as the demonstration of how these problematic strata were combined with strata with similar sampling weights.

Subjects

As described above, the 2005-2006 sampling techniques produced a total of 364,841 screening interviews from households with children under the age of 18, and the 2009-2010 sampling techniques produced 372,698 screening interviews. Demographic questions and items eliciting CSHCN status are contained in the screening dataset, and were merged with the main interview dataset to ensure that Individual Characteristics such as child's race, ethnicity, age, and gender were included in the analyses.

In order to be included in the main interview dataset, children with special health care needs under the age of 18 years at the time of the NS-CSHCN screening were defined as, "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138), and had to meet three criteria, derived from a Bethell et al. (2002) screening tool, summarized in Table 5.

Table 5

Inclusion Criteria for Children with Special Health Care Needs

1. Must answer YES to one of the following questions:
    - Does your child currently need or use medicine prescribed by a doctor, other than vitamins?
    - Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?
    - Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
    - Does your child need or get special therapy, such as physical, occupational, or speech therapy?
    - Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling?
2. Must answer YES to follow up questions asking whether the child's limitation or need was due to any medical, behavioral, or other health condition.
3. Must answer YES to follow up questions asking whether the condition is expected to last 12 months or longer.

Criteria from McPherson et al. (1998), p. 138.

Children assessed as having a special health care need upon screening were invited to participate in the longer survey assessing child needs, utilization of health care services, satisfaction with services, and insurance information. On both surveys, specific questions elicited respondent-reported diagnoses in a yes/no format. The total number of detailed surveys eliciting information about one randomly selected CSHCN in each household is detailed in Figure 3.

Identification of children with ASD, ADHD, and CP. The main interview dataset for each survey year contains reference to a variety of diagnosis that any one child might have. Children with ASD were identified by respondents as having a diagnosis made by a physician, and answered affirmatively to the dichotomous question, "To the best of your knowledge, does (child) *currently* have autism or autism spectrum disorder, that is, an ASD?" (2005-06 survey, n=2125) or "Does (child) *currently* have Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder?" (2009-10 survey, n=3055). For the ASD sample, approximately 50% of had a diagnosis of comorbid ADHD (n=2215) and approximately 2% had comorbid CP (n=130). In order to understand if children with ASD specifically had access limitations that were different than other children who had health care needs and who also were reported to need therapy services. Two comparison groups were selected: children with ADHD (no ASD or CP, n_{2005}=10511, n_{2009}=10055) and children with CP (no ASD, n_{2005}=607, n_{2009}=576), of which approximately 15% (n= 188) were diagnosed with comorbid ADHD.

Children with ADHD were included as a comparison group of children who required therapy to address mental health symptoms that affect functional performance difficulties treated by OT, PT, or ST. Children with ADHD who were not reported to have co-morbid ASD or CP were included in this group. Similarly, children with a chronic physical disability, CP, without

ASD, who commonly require therapeutic services to improve function, were included as a second comparison group. Children with ASD with comorbid ADHD were included in the ASD group for two reasons: first, because eliminating children with ASD and comorbid ADHD would decrease the available sample by half, and second, because children with ASD frequently display symptoms of ADHD (e.g., distractibility, inattention), and thus, it was not felt that the comorbid diagnoses *per se* of ADHD would significantly confound results for the ASD (e.g., Simonoff, Pickles, Charman, Chandler, Loucas, Baird, 2008).

Power Analysis

Power for large random samples takes several values into consideration. First, the size of the population from which the sample will be selected is needed, the expected likelihood of the outcome variable (in this case, realized access), the expected confidence interval for the expected outcome variable of interest, usually estimated for either 95% or 99% (http://bphc.hrsa.gov/policiesregulations/performancemeasures/patientsurvey/calculating.html). For this survey, the sample size of children with ASD (*n*=2123 in the 2005-06 survey; *n*=3055 in the 2009-10 NS-CSHCN) was large enough to exceed a 99% confidence level with dichotomous responses (has realized access, does not have realized access) as close as 48% while having a 2.8% confidence interval for estimates.

Variables

Over 400 variables were available for analysis in the main interview dataset from both the 2005-2006 and 2009-2010 survey. Variables included in this study were chosen based on Andersen's Behavioral Model (Andersen, 1995; Andersen et al., 2013) and that were available in the dataset. Variables and their relationship to the theoretical model are pictured in Figures 1 and 2 (See Chapter 1 and Chapter 2).

Table 6 illustrates the planned variables of interest and their relationship to the study design and research questions. Appendix C provides verbatim wording for each variable utilized from the 2005-06 and 2009-10 NS-CSHCN.

Table 6

Constructs, Variables, Measurement and Relationship to Study Design

Construct	**Variable**	**Measurement**	**Relationship to Study Design**
Diagnosis	Diagnosis per NS-CSHCN	Categorical (ASD, ADHD, CP)	Grouping variable, RQ1-3
Time	Survey Year	Dichotomous (2005-06, 2009-10)	Grouping variable, RQ1-3
Individual Characteristics			
Predisposing Characteristics	Age	Continuous	Independent variable RQ3
	Gender	Dichotomous (Male/Female)	
	Race	Categorical	
	Ethnicity	Dichotomous (Hispanic/non-Hispanic)	
Enabling Characteristics	Income (Federal Poverty Level)	Categorical	
	Insurance status	Dichotomous (Insured/Not Insured)	
Need Characteristics	Extent of functional limitations	Categorical	
	Intellectual disability status (MR)	Dichotomous (Co-morbid intellectual disability-yes/no)	
	Self-care difficulty	Dichotomous (Yes/no)	
	Gross motor difficulty	Dichotomous (Yes/no)	
	Fine motor difficulty	Dichotomous (Yes/no)	
	Communication difficulty	Dichotomous (Yes/no)	
	Problem behaviors	Dichotomous (Yes/no)	
Contextual Characteristics			
Provider Problems	Provider did not know how to treat	Dichotomous (Yes/no)	Independent Variable, RQ3
	Inconvenient times	Dichotomous (Yes/no)	
	Dissatisfaction with provider	Dichotomous (Yes/no)	
Enabling Variables	Family Geographic Region (MSA)	Dichotomous (urban/rural)	
	Lack of resources at school	Dichotomous (Yes/no)	
	Can't find a provider who accepts insurance	Dichotomous (Yes/no)	
	Therapy cost too much	Dichotomous (Yes/no)	
	Health plan problems	Dichotomous (Yes/no)	
	No referral	Dichotomous (Yes/no)	
	Did not know where to go	Dichotomous (Yes/no)	
	Therapy not available in area	Dichotomous (Yes/no)	
Health Behaviors			
Need for therapy	Parent reported referral for OT/PT/ST services for child within past 12 months	Dichotomous(Yes/no)	Dependent Variable, RQ1
Realized Access	Child did not receive all of referred OT/PT/ST services within the past 12 months	Dichotomous (Yes/no whether child received all needed therapy services)	Dependent Variable, RQ2, RQ3

Variables that did not relate to either the Individual Characteristics or Contextual Characteristics that impacted therapy service access were not included in the planned analyses. For example, many excluded variables related to access to non-therapy health care services (i.e., primary care, specialty care such as genetic counseling, dental services). Independent variables that were chosen focused on a) hypothesized parent-reported characteristics of the individual and b) contextual characteristics that contributed to lack of realized access, based on Andersen's Behavioral Model and a review of the literature that yielded information regarding their potential relationship to other variables. Additionally, Survey Year and Diagnosis served as independent variables. The dependent variables of interest were Therapy Need and Realized Access.

Data Analysis

Missing values. The CDC reports that nonresponse rates for specific predisposing and enabling characteristics (e.g., income, race, ethnicity) were greater in the 2009-2010 survey than in the previous survey conducted in 2005-2006 (CDC, NCHS, SLAITS, 2011). The CDC provides databases which have estimated the values for missing data from individual respondents; these multiple imputation databases produced by the CDC were utilized to control for nonresponse bias in analyses requiring these variables (poverty level, race, ethnicity), as opposed to excluding cases listwise with missing data. Additionally, some parents responded with "Don't Know" or "Refused" in some analytic variables. These responses were identified and re-coded as missing. One variable that is automatically coded as missing in the original CDC datasets for multiple cases is geographical location (MSA status). Geographical location is a dichotomous variable of Urban (living in metropolitan statistical area, or MSA) or Not Urban (not living in a MSA). In states that have few non-urban locations, or states with few urban locations, the variable is suppressed to protect the confidentiality of the respondent. Therefore, to include all possible cases in the analysis, the following procedures will be used, in accordance with recommendations of the CDC as described in Dusing, Skinner, and Mayer (2004). Cases living in states with few MSAs (Alaska, Idaho, Maine, Montana, North Dakota, South Dakota, Vermont, and Wyoming) were classified as not living in an MSA. Cases living in states (Connecticut, Delaware, Hawaii, Massachusetts, Maryland, New Hampshire, Nevada, and Rhode Island) with large numbers of MSAs were classified as living in an MSA. These procedures are considered to be valid and appropriate for maximum inclusion of all potential children in the study (Dusing et al., 2004).

Data cleaning. Each of the three databases for each year (Screener, Household, Main Interview, and any related imputed files) were downloaded and imported into SAS ® version 9.3 (SAS Analytics, 2011, Cary, NIC) from the CDC website. For the 2009-10 survey, additional data were available on the U.S. Virgin Islands in a separate dataset. The U.S. Virgin Islands data were not included in this analysis, in order to retain comparability to the 2005-06 sample which came from the 50 states and Washington D.C. Prior to analysis of the main research questions, imputed and non-imputed databases for each year were merged to ensure that all required variables exist in one database for each year. In order to retain original values prior to imputing within years, original cases with missing data and imputed variables for cases with missingness were interleaved into the existing data using appropriate procedures. Imputed data were produced by the CDC and included five estimates for each case with a missing variable (CDC, NCHS, SLAITS, 2012). Preliminary analyses of frequency counts of non-imputed data were performed and compared with CDC frequency counts published in Blumberg et al. (2008) and CDC (2011) in order to confirm accuracy in the merging process within each year for variables of interest. Then, each variable of interest was renamed and coded with an easy-to-identify label to reduce syntax errors during analyses (e.g., CDC variable name for Therapy Need is C4Q05_X05 will be relabeled 'txneed'). Specific variables with coding differences between years (e.g., MSA status, see Appendix D) were re-coded to ensure valid merge across years. Additionally, case identification number was modified to include a .05 or .09 to ensure unique identification of cases from the 2005-06 and 2009-10 datasets respectively. Finally, concatenation of each dataset occurred through a process which merges each of the two survey year databases by layering the datasets, with a new variable created to establish the survey year in which data were collected (2005-2006 or 2009-2010).

Finally, the large multi-year dataset, which contained over 400 variables originally, was reduced to include only the variables of interest in this study to reduce errors in analysis. All observations (cases) were retained to assure appropriate application of variance estimation procedures. For analyses (H1, H2.1, H2.2, H3.2, H3.3) which did not include variables with imputed values (poverty level, race, ethnicity), a non-imputed dataset was created to eliminate the need for analyses specific to multiple imputation. Thus, only one case existed for each record of analyses. For analyses requiring the use of variables that were imputed in either 2005 or 2009 (H3.1), the full concatenated, multiply imputed dataset was utilized to produce regressions accounting for multiply imputed data. Thus, one original case (m=0) and five imputed cases (m=1…5) existed for all records of analysis.

Controlling for complex sampling design. The CDC includes sampling weights that are available for researchers to account for the complex sampling design. Each survey has its own sampling weights; therefore these sampling weights were applied separately to the data when examining the hypotheses. This was handled through creation of a written syntax program (H. Carretta, personal communication, March 28, 2012). Because SAS does not easily allow for new syntaxes to be applied within their programming, Stata SE 12.1 (College Station, Texas) was used for examination of hypotheses that require sampling weights using `svy` features. Additionally, for analyses using multiply imputed data (H3.1), `mi estimate` and `svy estimate` features were used concurrently to examine the hypothesis. A summary description of hypotheses and related statistical analysis is presented in Table 7.

Table 7

Research Questions, Hypotheses, and Statistical Analyses

Research Question 1: What is the percentage of children with ASD who demonstrate need for therapy services compared to children with other selected health care needs in the 2005-2006 and 2009-2010 NS-CHCSN?	
Hypothesis	**Statistical Analysis Summary**
H1: Children with ASD will demonstrate greater need for therapy than children with ADHD but similar need for therapy than children with CP at both survey time points.	Binomial logistic regression was used to predict need for therapy (outcome variable) based on three predictors: group, year, and a group x year interaction term.
Research Question 2: What is the difference in the percentage of children with ASD who demonstrate reduced realized access to services compared to children with other selected health care needs at both survey time points?	
H2.1: Children with ASD will demonstrate less realized access than either ADHD or CP groups at both time points.	Binomial logistic regression was used to predict realized access to therapy (outcome variable) based on three predictors: group, year, and a group x year interaction term.
H2.2: Among children with ASD alone, children sampled in 2009-10 will demonstrate greater realized access than children sampled in 2005-06.	Binomial logistic regression was used to predict realized access to therapy (outcome variable) based on year for an ASD group only.
Research Question 3: To what extent are Individual Characteristics and Contextual Characteristics associated with realized access problems in children with ASD as compared to other children with selected special health care needs in the 2005-2006 and 2009-2010 NS- CHCSN?	
H3.1: Individual Predisposing, Enabling and Need Characteristics will predict realized access problems in ASD and CP and ADHD comparison groups	A separate binomial logistic regression was used to examine the relationship between the independent variables of interest (Individual predisposing, enabling, and need characteristic variables) and the dependent variable of interest (realized access) for each group, while controlling for time of data collection (2005-2006 vs. 2009-2010).
H3.2: For children with a reported realized access problem, children with ASD, ADHD, and CP will report similar proportion of Contextual Enabling variable access problems.	Chi-square tests was used to independently test for difference in frequency of children in each group (ASD, ADHD, CP) who report each Contextual Enabling variable. Due to the large sample, the significance level will be set to $p<.01$.
H3.3: Children with ASD will report greater proportion of provider-related problems than other CSHCN across both survey years.	Chi-square tests was used to independently test for difference in frequency of children in each group (ASD, ADHD, CP) who report each Provider Problem variable. Due to the large sample, the significance level will be set to $p<.01$.

Research Question 1. *What is the percentage of children with ASD who demonstrate need for therapy services compared to children with other selected health care needs in the 2005-2006 and 2009-2010 NS-CHCSN?*

Hypotheses: Children with ASD will demonstrate greater need for therapy than children with ADHD but similar need for therapy than children with CP at both survey time points.

Statistical Test: The following binomial logistic regression equation was used to test this hypothesis.

$$\text{H1: } TxNeed = \beta_0 + \beta_1(Group) + \beta_2(Year) + \beta_3(Group * Year) + \mu$$

Where β_0 is the constant and μ is the error term. Wald chi-square was used to determine the significance of each predictor to the model, and odds ratios and confidence intervals are reported for each variable. A p-value of <.01 was set to reduce Type I error. In this analysis, the variable of interest was the Group*Year interaction term (categorical by categorical interaction), and represents a difference-in-difference model. Potential combinations of the interaction term were identified as follows:

	2005-06 (h=0)	2009-10 (h=1)
ADHD (f=0)	0 0	0 1
ASD (f=1)	1 0	1 1
CP (f=2)	2 0	2 1

In this analyses, none of the interaction terms were significant, and the interaction was removed from the analyses to examine the independent contribution of predictors to therapy access. Specification error was examined with the `linktest` in Stata. Specification errors occur when the predictor variables that are included in the model are either not linearly related to the outcome, or if the model does not include all relevant predictors (Chen, Ender, Mitchell, & Wells, n.d). In this analysis, a significant `_hat` suggested that meaningful, linear predictors were included in the model, β=1.00, SE=.0124, p<.001. A significant `_hatsq` value, on the other hand, suggests that other non-model variables may contribute to predicting the outcome; for this model, `_hatsq` was not significant, meaning that even with the limited predictors, they were appropriate for predicting therapy need, β=.005, SE=.099, p=.96. Model fit was assessed with an F-adjusted mean residual test, which has been demonstrated to be better than the Hosmer-Lemeshow statistic for population based surveys (Archer, Lemeshow, & Hosmer, 2007). A non-significant goodness of fit test is indicative of good model fit; in this analysis the model demonstrated good fit, $F(4,80769)=0.042$, p=.997. Point estimates of therapy need and corresponding confidence intervals were calculated for each group by survey year to understand directional relationships between access and group.

Research Question 2. *What is the difference in the percentage of children with ASD who demonstrate reduced realized access to services compared to children with other selected health care needs at both survey time points?*

H2.1: Children with ASD will demonstrate less realized access than either ADHD or CP groups at both time points.

H2.2: Among children with ASD alone, children sampled in 2009-10 will demonstrate greater realized access than children sampled in 2005-06.

Statistical Tests: The following binomial logistic regression equations were used to test these hypotheses:

H2.1: $$RealAcc = \beta_0 + \beta_1(Group) + \beta_2(Year) + \beta_3(Group * Year) + \mu$$

Where β_0 is the constant and μ is the error term. The impact of three predictors, Group (ASD, CP, ADHD), Year (05-06, 09-10) and a Group x Year interaction, were used to examine the effect of these on Realized Access after controlling for appropriate survey sampling weights. Predictors were evaluated for their significance using Wald chi-square. A p-value of <.01 was set to control for the large sample size. In this analysis, the variable of interest was the Group*Year interaction term (categorical by categorical interaction). Non-significant interaction terms resulted in the use of binary predictor-only model without an interaction term to examine the independent effect of the predictors on realized access. Examination of specification error revealed that _hat was not significant, indicating that the predictors were linearly related to the outcome (β=.1.76, SE=1.575, p=.265), but that _hatsq was not significant, suggesting other predictors were missing from the model (β=.248, SE=.508, p=.626). This model represents the base model of access, and thus analyses for Research Question 3 specifically examine the inclusion of other variables contributing to therapy access that might improve the specification of the model.

H2.2: (Children with ASD only)

$$RealAcc = \beta_0 + \beta_1(Year) + \mu$$

Where β_0 is the constant and μ is the error term.

Wald chi-square was used to reveal whether Year contributed significantly to Realized Access within the ASD group alone. A p-value of <.01 was set to reduce type I error. Odds ratios and confidence intervals are provided to give information regarding the direction of prediction. Additionally, point estimates of therapy need and corresponding confidence intervals were calculated for each group by survey year to understand directional relationships between access and group.

Research Question 3. *To what extent are Individual Characteristics and Contextual Characteristics associated with realized access problems in children with ASD as compared to other children with selected special health care needs in the 2005-2006 and 2009-2010 NS-CHCSN?*

H3.1: Individual Predisposing, Enabling and Need Characteristics will predict realized access problems in ASD and CP and ADHD comparison groups.

Statistical Test:

$H3.1$:

$$RealAcc = \beta_0 + \beta_1(Year) + \beta_2(Group * Year) +$$

$$\beta_3[Individual\ Characteristics] + \beta_4[Enabling\ Characteristicss] + \beta_5[Need\ Characteristics] + \mu$$

Where $\underline{\beta_0}$ is the constant and $\underline{\mu}$ is the error term. Four sequential binomial logistic regression models were used to examine the contribution of each set of variables to realized access. Sequential entry of grouped variables allowed for comparison between grouped Individual Predisposing, Enabling, and Need Characteristic variables after controlling for Year and Group*Year interaction. Potential combinations of the interaction term were:

	2005-06 (h=0)	2009-10 (h=1)
ADHD (f=0)	0 0	0 1
ASD (f=1)	1 0	1 1
CP (f=2)	2 0	2 1

The interaction term was dropped from models due to lack of significance in order to preserve degrees of freedom. Examination of the coefficient change on individual variables between the full model and reduced models (model with predisposing characteristics only, model with enabling characteristics only, and a model with need characteristics only) and the constant-only model and the constant plus covariates allowed for determining which model most reliably predicts realized access. Specification error in inclusion of model predictors was used to identify whether all relevant predictors were included, whether included variables were sufficient for predicting the outcome variable, and for identifying whether the predictors were linearly related to the outcome (UCLA Regression Diagnostics, available from: http://www.ats.ucla.edu/stat/stata/webbooks/logistic/chapter3/statalog3.htm). Using the `linktest` in Stata produced `_hat` and `_hatsq`, which revealed different types of specification errors in the regression model. A significant `_hat` suggests that meaningful predictors were included in the model, thus, it was expected the best model would have a significant p-value for `_hat`. However, a significant `_hatsq` suggests that not all relevant or appropriate variables were included in the model. Thus, models with a significant `_hatsq` were identified as incomplete models. Goodness of fit was evaluated with an F-adjusted mean residual test, which has been demonstrated to be better than the Hosmer-Lemeshow statistic for population based surveys (Archer, Lemeshow, & Hosmer, 2007). Additionally, multicollinearity of included predictors was evaluated with the `collin` command in Stata. Predictors with greater collinearity are observed to have a tolerance closer to 0, whereas predictors without collinearity with other variables are observed to have a tolerance of closer to 1. Observed decreases in collinearity diagnostics resulted in the use of correlation coefficients using `tetrachoric` command for dichotomous variables in Stata. Correlation coefficients of .7 or greater resulted in removal from the model to observe for improved model fit, represented by changes in the coefficients and standard errors, improved link test and improved goodness of fit statistics. Wald chi-square was used to determine the significance of each variable to the equation, and odds ratios, coefficients and 95% confidence intervals are reported for each variable.

H3.2: For children with a reported realized access problem, children with ASD, ADHD, and CP will report a similar proportion of Contextual Enabling variable access problems.

Statistical Test: Chi-square tests of independence were planned to evaluate the difference in reported prevalence of each access problem variable between three groups (ASD, ADHD, and CP) within 2005-06, with an F-adjusted test used to determine the significance of models using the complex sampling design. However, when the test was repeated for the 2009-10 data, errors occurred in producing standard errors of point estimates for group comparisons. Due to the nature of two samples in the 2009 dataset (landline vs. cell-phone samples), the sample size for certain cell-phone strata were either non-existent or too low to calculate standard errors and confidence intervals. These problematic 2009 cell-phone strata included: South Dakota, Hawaii, North Dakota, Delaware, Nebraska, New Mexico, Colorado, Indiana, Massachusetts, New Jersey, South Carolina, and Michigan. Appendix E illustrates each 2009 strata with the mean sampling weight, as well as the demonstration of how these problematic strata were combined with strata with similar sampling weights. CDC recommendations for managing this included collapsing cell-phone strata with similar sampling weights to ensure a large enough sample in the problematic cell-phone strata (S. Blumberg, personal communication November 19, 2013). Due to the nature of the sample size for each strata, analyses focused on comparing children with ASD to ADHD and CP children as a combined group. This was done to ensure large enough cell sizes for comparison.

Chi-square distributions in large samples have been reported to overestimate the effect (Diaconis & Efron, 1985), and thus, due to the large sample size the significance level was set to $p<.01$. A significant p-value indicates that the observed frequency of access problem across all groups is different, but does not provide information regarding which groups are different from each other. Likelihood of a particular problem (percent of children in a group reporting an access problem divided by the total number of children in that group) and 95% confidence interval of that estimate were used to descriptively evaluate which group was reported to have a particular access problem. Non-overlapping confidence intervals between groups indicate that there are differences between the groups. Similarly, comparison of between-year estimates of confidence intervals will allow for descriptive analysis of whether the likelihood of a particular problem changed from one survey to the next.

H3.3: Children with ASD will have a greater proportion of provider-related problems than other CSHCN across both survey years.

Statistical Test: Similar to the test evaluating differences in contextual characteristics affecting access, chi-square tests of independence were planned to evaluate the difference in reported proportion of each provider-related access problem variable between three groups (ASD, ADHD, and CP) within each survey year (2005-06 and 2009-10). Due to the nature of the sample size for each strata in the 2009 cell-phone sample, analyses focused on comparing children with ASD to children with ADHD and CP as a combined group. This was done to ensure large enough cell sizes for comparison in the 2009 year.

Chi-square distributions in large samples have been reported to overestimate the effect (Diaconis & Efron, 1985), and thus, due to the large sample size the significance level was set to $p<.01$. A significant *p*-value suggests that the observed frequency of therapy need across all groups was different, but did not provide information regarding which groups were different from each other. Prevalence of a particular problem (percent of children in a group reporting an access problem divided by the total number of children in that group) and 95% confidence interval of that estimate was used to descriptively evaluate which group is reported to have greater provider-related problems than another. Non-overlapping confidence intervals between groups suggested differences between the groups. Similarly, comparison of between-year prevalence estimates of confidence intervals allowed for descriptive analysis of whether the likelihood of a particular problem changed from one survey to the next.

Protection of Human Subjects

This study was submitted to the Virginia Commonwealth University Institutional Review Board for exempt review, and received confirmation of exempt status and approval to conduct the research in the approved manner. A copy of the approval letter is attached in Appendix F.

Chapter 4: Results

Child and Family Characteristics

Table 8 displays percent and 95% confidence intervals (CI) for all child predisposing, need and family enabling characteristics across survey years. In both the 2005 and 2009 surveys, there were significantly more male than female children with ASD, and the percentage of males with ASD was significantly greater than males with ADHD or CP groups. For all study groups, there were significantly more children reporting white race than any other race. In 2009, there were fewer children with ASD reporting black race compared to the other study groups. In 2009, there were significantly fewer children with ASD living below 200% of the Federal Poverty Level (FPL) compared to children with ADHD, and correspondingly, there were significantly greater children with ASD living between 200-400% FPL compared to children with ADHD. In both survey years, significantly more children with ASD than those with ADHD or CP were reported that their condition "Usually" impacted their ability to do things, however, a significantly more children with CP reported that their condition "Always" impacted their function compared to other groups. There were significantly more children with ASD who reported an intellectual disability and communication difficulty than either other study group at both time points. Children with CP were significantly more likely at both time points to report a gross motor, fine motor, or self-care difficulty than either children with ASD or ADHD, although children with ASD were more likely than children with ADHD to report these need-related problems.

Table 8

Child and Family Characteristics

	2005-06 National Survey for Children with Special Health Care Needs					2009-10 National Survey for Children with Special Health Care Needs				
	ASD (n=2,123)	ADHD (n=10,511)	CP (n=607)	F	*p*	ASD (n=3,055)	ADHD (n=10,055)	CP (n=576)	F	*p*
	% [95% CI]	% [95% CI]	% [95% CI]			% [95% CI]	% [95% CI]	% [95% CI]		
Predisposing Characteristics										
Age, mean y	9.7 [9.4, 10.0]	11.6 [11.5, 11.7]	10.1 [9.4, 10.7]			9.8 [9.5, 10.0]	11.7 [11.5, 11.8]	9.8 [9.0, 10.5]		
Gender				31.6	<.001				37.0	<.001
Male	79.1 [76.1, 81.7]	70.1 [68.7, 71.6]	52.3 [45.6, 58.9]			80.6 [78.0, 82.9]	67.9 [66.2, 69.5]	57.3 [50.2, 64.2]		
Female	20.9 [18.3, 23.9]	29.9 [28.4, 31.3]	47.7 [41.1, 54.4]			19.4 [17.1, 22.0]	32.1 [30.5, 33.8]	42.7 [35.8, 49.8]		
Race				4.2	<.001				6.3	<.001
White	73.5 [70.3, 76.4]	72.3 [70.7, 73.8]	64.0 [57.0, 70.4]			70.8 [67.4, 74.0]	72.7 [71.0, 74.3]	67.9 [60.3, 74.6]		
Black	15.2 [12.9, 17.9]	17.7 [16.3, 19.2]	19.4 [14.5, 25.5]			11.3 [9.4, 13.6]	15.4 [14.1, 16.9]	16.4 [11.8, 22.5]		
Multiple[a] (avail in 2005-06 dataset only)	3.3 [2.4, 4.4]	3.9 [3.4, 4.5]	3.0 [1.5, 5.9]			--	--	--		
Other	8.0 [6.2, 10.2]	6.1 [5.3, 7.1]	13.6 [9.0, 20.0]			17.9 [15.0, 21.2]	11.9 [10.7, 13.1]	15.7 [10.5, 22.8]		
Ethnicity				2.6	.072				3.0	.051
Non-Hispanic	87.7 [85.0, 90.0]	90.3 [89.1, 91.3]	86.2 [79.6, 90.9]			83.8 [81.1, 86.1]	86.9 [85.4, 88.3]	83.4 [76.9, 88.4]		
Hispanic	12.3 [10.0, 15.0]	9.7 [8.7, 10.9]	13.8 [9.1, 20.5]			16.2 [13.9, 18.9]	13.1 [11.7, 14.6]	16.6 [11.6, 23.1]		

Table 8. Continued

	2005-06 National Survey for Children with Special Health Care Needs					2009-10 National Survey for Children with Special Health Care Needs				
	ASD (n=2,123)	ADHD (n=10,511)	CP (n=607)	F	*p*	ASD (n=3,055)	ADHD (n=10,055)	CP (n=576)	F	*p*
	% [95% CI]	% [95% CI]	% [95% CI]			% [95% CI]	% [95% CI]	% [95% CI]		
Enabling Characteristics										
Poverty Level				2.0	.089				4.6	.001
<200% FPL	44.2 [40.6, 47.9]	47.5 [45.9, 49.2]	54.7 [47.8, 61.4]			40.0 [36.8, 43.2]	48.3 [46.5, 50.1]	46.3 [38.6, 54.1]		
201-400% FPL	30.1 [26.6, 33.8]	27.5 [26.1, 28.9]	23.5 [18.7, 29.1]			32.8 [29.6, 36.2]	27.7 [26.1, 29.3]	29.3 [23.3, 36.2]		
>400% FPL	25.7 [22.9, 28.7]	25.0 [23.7, 26.4]	21.8 [16.7, 27.9]			27.3 [24.4, 30.3]	24.1 [22.7, 25.5]	24.4 [17.8, 32.6]		
Insurance Status				0.2	.801				0.9	.406
Insured	96.6 [95.3, 97.6]	96.5 [95.9, 97.0]	95.6 [88.6, 98.4]			97.3 [96.4, 98.0]	96.8 [96.1, 97.4]	97.9 [95.5, 99.0]		
Uninsured	3.4 [2.4, 4.7]	3.5 [3.0, 4.1]	4.4 [1.6, 11.4]			2.7 [2.0, 3.7]	3.2 [2.6, 4.0]	2.1 [1.0, 4.5]		
MSA Status				1.5	.228				1.2	.307
Non, urban	16.2 [14.2, 18.5]	18.3 [17.3, 19.4]	16.5 [12.7, 21.2]			16.7 [14.6, 19.1]	18.8 [17.6, 20.0]	18.4 13.7, 24.3]		
Urban	83.8 [81.5-85.8]	81.7 80.6-82.7]	83.5 [78.8-87.3]			83.3 [81.0-85.4]	81.3 [80.0-82.5]	81.6 [75.7-86.3]		
Need Characteristics										
Condition Impact on Function				118.4	<.001				136.8	<.001
Never	5.4 [4.1-7.0]	28.3 [26.9-29.7]	6.2 [3.8-9.9]			6.1 [4.8-7.7]	28.3 [26.8-29.8]	4.1 [2.3-7.2]		
Sometimes	30.3 [27.0-33.7]	42.0 [40.4-43.6]	18.4 [13.9-23.8]			26.8 [24.3-29.5]	41.5 [39.9-43.2]	16.0 [11.9-21.3]		
Usually	16.7 [14.4-19.3]	12.7 [11.7-13.8]	8.6 [5.8-12.5]			19.2 [16.9-21.7]	12.9 [11.7-14.1]	8.3 [5.5-12.3]		
Always	47.6 [44.1-51.1]	17.1 [15.8-18.4]	66.9 [60.6-72.6]			48.0 [44.7-51.2]	17.3 [15.9-18.9]	71.7 [65.4-77.2]		

Table 8. Continued

	2005-06 National Survey for Children with Special Health Care Needs					2009-10 National Survey for Children with Special Health Care Needs				
	ASD (n=2,123)	ADHD (n=10,511)	CP (n=607)	F	*p*	ASD (n=3,055)	ADHD (n=10,055)	CP (n=576)	F	*p*
	% [95% CI]	% [95% CI]	% [95% CI]			% [95% CI]	% [95% CI]	% [95% CI]		
Problem Behavior				40.34	<.001				39.44	<.001
No	42.4	46.2	76.0			32.6	36.2	66.5		
	[39.0,45.8]	[44.6,47.8]	[69.6,81.4]			[29.8,35.5]	[34.6,37.9]	[59.4,72.9]		
Yes	57.6	53.8	24.0			67.5	63.8	33.5		
	[54.2,61.0]	[52.2,55.4]	[18.6,30.4]			[64.5,70.2]	[62.1,65.4]	[27.1,40.6]		
Comorbid intellectual disability/mental retardation				440.7	<.001				211.8	<.001
No	46.6	88.0	32.5			76.4	95.3	55.3		
	[43.1, 50.1]	[86.8, 89.1]	[26.5, 39.3]			[73.0, 79.5]	[94.4, 96.0]	[47.7, 62.7]		
Yes	53.4	12.0	67.5			23.6	4.7	44.7		
	[50.0, 56.9]	[10.9, 13.2]	[60.8, 73.5]			[20.5, 27.0]	[4.0, 5.6]	[37.3, 52.3]		
Gross Motor Difficulty				507.8	<.001				534.2	<.001
No	55.4	88.8	11.3			49.9	85.3	5.5		
	[51.8, 58.9]	[87.7, 89.8]	[7.5, 16.6]			[46.7, 53.1]	[84.1, 86.4]	[3.2, 9.2]		
Yes	44.6	11.23	88.7			50.1	14.7	94.5		
	[41.1, 48.2]	[10.2, 12.3]	[83.5, 92.5]			[47.0, 53.3]	[13.6, 16.0]	[90.8, 96.8]		
Fine Motor Difficulty				484.1	<.001				588.6	<.001
No	51.0	89.9	25.8			44.6	86.9	15.4		
	[47.5, 54.5]	[88.9, 90.8]	[20.1, 32.6]			[41.5, 47.9]	[85.6, 88.0]	[11.5, 20.4]		
Yes	49.0	10.1	74.2			55.4	13.1	84.6		
	[45.5, 52.5]	[9.2, 11.1]	[67.4, 79.9]			[52.1, 58.6]	[12.0, 14.4]	[79.6, 88.6]		
Self Care Difficulty				428.6	<.001				413.2	<.001
No	44.5	87.6	33.7			33.0	79.3	21.2		
	[41.1, 48.0]	[86.5, 88.7]	[27.2, 40.8]			[30.2, 35.9]	[77.8, 80.7]	[15.3, 28.7]		
Yes	55.5	12.4	66.3			67.1	20.7	78.8		
	[52.0, 58.9]	[11.3, 13.6]	[59.2, 72.8]			[64.1, 69.9]	[19.3, 22.2]	[71.3, 84.7]		
Communication/Speaking Difficulty				420.1	<.001				405.1	<.001
No	20.1	72.2	35.6			15.8	61.9	25.9		
	[17.7, 22.7]	[70.7, 73.7]	[29.5, 42.2]			[13.8, 18.0]	[60.2, 63.6]	[20.6, 31.9]		
Yes	79.9	27.8	64.4			84.2	38.1	74.2		
	[77.3, 82.4]	[26.3, 29.3]	[57.8, 70.5]			[82.0, 86.2]	[36.4, 39.8]	[68.1, 79.4]		

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.

Research Question 1: Need for Therapy Services

Need for therapy services for all comparison groups at both survey time points are displayed in Table 9. It was hypothesized that children with ASD would demonstrate greater need for therapy than children with ADHD, but similar need for therapy than children with CP at both survey time points. The hypothesis was partially supported. Children with ASD were reported to have significantly greater need for therapy services than children with ADHD across both the 2005 and 2009 time points, *Odds Ratio (OR)*=11.27, 95% Confidence Interval (CI) [10.01, 12.70], $p<.001$. However, children with ASD were reported to have a significantly lesser need for therapy than children with CP in both 2005 and 2009, *OR*=.62, 95% CI [0.47, 0.81], $p=.001$.

Research Question 2: Access to Therapy Services

Two hypotheses were proposed: 2.1) Children with ASD will demonstrate poorer realized access than either ADHD or CP groups at both time points, and 2.2) among children with ASD alone, children sampled in 2009-10 will demonstrate greater realized access than children sampled in 2005-06. Hypothesis 2.1 was partially supported, and Hypothesis 2.2 was not supported. Percent of children reporting receipt of therapy services in each group for each survey year is displayed in Table 10. Logistic regression results comparing ASD and CP groups to the ADHD indicator group suggest that overall, children with ASD across both time points had significantly greater odds of having a realized access problem compared to ADHD, *OR*=1.66, 95% CI [1.36, 2.03], $p< .001$. Children with CP did not differ from children with ADHD in access to therapy services, *OR*=1.28, 95% CI [.95, 1.72], $p= .11$. Across both time points, children with ASD did not demonstrate differences in realized access compared to children with CP, *OR*=1.30, 95% CI [0.97, 1.74], $p=.08$.

Table 9

Need for Therapy Services by Group and Year

	2005-06 National Survey for Children with Special Health Care Needs					2009-10 National Survey for Children with Special Health Care Needs				
	ASD (n=2,121)	ADHD (n=10,491)	CP (n=605)	F [a]	*p*	ASD (n=3,051)	ADHD (n=10,043)	CP (n=576)	F [b]	*p*
	% 95% CI	% 95% CI	% 95% CI			% 95% CI	% 95% CI	% 95% CI		
Needed therapy services in past year				531.11	<.001				697.19	<.001
Yes	75.39 [72.43, 78.14]	21.29 [19.98, 22.66]	80.69 [74.66, 85.57]			75.77 [73.14, 78.22]	21.77 [20.35, 23.25]	86.15 [81.34, 89.87]		
No	24.61 [21.86, 27.57]	78.71 [77.34, 80.02]	19.31 [14.43, 25.34]			24.23 [21.78, 26.86]	78.23 [76.75, 79.65]	13.85 [10.13, 18.66]		

Note. Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.

[a] Design-based F (1.97, 80150.99). Strata=51, PSU=40699, Subpopulation obs=13217.

[b] Design-based F (1.97, 78891.93). Strata=102, PSU=40226, Subpopulation obs=13670.

Table 10

Access to Therapy Services by Group and Year

	2005-06 National Survey for Children with Special Health Care Needs					2009-10 National Survey for Children with Special Health Care Needs				
	ASD (n=1,538)	ADHD (n=2,111)	CP (n=489)	F [a]	*p*	ASD (n=2,216)	ADHD (n=2,029)	CP (n=492)	F [b]	*p*
	% [95% CI]	% [95% CI]	% [95% CI]			% [95% CI]	% [95% CI]	% [95% CI]		
Received all needed therapy services				4.88	.008				9.73	<.001
Yes	82.14 [78.83, 85.03]	87.25 [84.84, 89.31]	88.22 [83.70, 91.61]			75.56 [72.34, 78.52]	84.64 [81.62, 87.25]	77.45 [70.74, 82.99]		
No	17.86 [14.97, 21.17]	12.75 [10.69, 15.16]	11.78 [8.39, 16.30]			24.44 [21.48, 27.66]	15.36 [12.75, 18.38]	22.55 [17.01, 29.26]		

Note. Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.

[a] Design-based F (1.97,62255.53). Strata=51, PSU=31620, Subpopulation obs=4138.

[b] Design-based F (1.98,61824.90). Strata=102, PSU=31293, Subpopulation obs=4737.

Additionally, for all diagnostic groups (ASD, ADHD, CP), realized access was significantly poorer for children sampled in 2009 than for children sampled in 2005, *OR*=1.41, 95% CI [1.17, 1.70], *p* < .001.

Hypothesis 2.2 was in reference to the sample of children with ASD only. Children with ASD sampled in 2009 were nearly 1.5 times more likely to not receive all needed therapy services compared to children with ASD sampled in 2005, *OR*=1.47, 95% CI [1.12, 1.93], *p*= .006. Nearly 25% of children with ASD did not receive therapy services in 2009 compared to 17.86% of children with ASD sampled in 2005.

Research Question 3: Factors Contributing to Lack of Therapy Service Receipt

It was hypothesized that individual predisposing, enabling and need characteristics would predict lack of realized access in all diagnostic groups. Table 11 displays the results of the multivariate logistic regression analyses using the imputed concatenated dataset predicting lack of therapy services with ADHD as the indicator group. Due to the lack of significant group by year interaction in the base model, the interaction term was removed from subsequent models. A base model with diagnosis, year, and sample was compared to predisposing, enabling, need characteristic, and a full model. Comparison of non-imputed models (base, predisposing, enabling, need, and full) were conducted first to examine model specification errors, goodness of fit, and multicollinearity prior to running models using the imputed dataset. Variable coefficients for each non-imputed model are provided in Appendix G. Several need characteristics had poor tolerance and examination of correlation coefficients using tetrachoric commands demonstrated strong relationships between several need characteristic variables. These variables were dropped from the model (intellectual disability/ mental retardation comorbidity, gross motor problem, fine motor problem, self-care problem, communication problem) and subsequent analyses of the need model produced adequate fit and specification. The final need characteristic model included frequency of a conditions' impact on function and problem behaviors. Following analysis of non-imputed data, the models were run using imputed data. Results of the full imputed model are presented in Table 11 and are described below.

Table 11

Imputed Multivariate Logistic Regression Results Predicting Unmet Need for Therapy

	Did not receive therapy services			
	Odds Ratio	*β* Coefficient	95% CI of *β*	*p*
Current ADHD	Reference			
Current ASD	1.330	0.284	.066, .503	.01**
Current CP	1.050	-0.049	-.402, .304	.79
Year--2005	Reference			
Year--2009	1.474	0.388	.179, .596	<.001**
Landline sample	Reference			
Cell-phone sample	1.150	0.140	-.320, .610	.56
Predisposing Characteristics				
Age (continuous)	0.968	-0.033	-.058, -.008	.01**
Male	Reference			
Female	1.278	0.241	.021, .462	.03*
White race	Reference			
Black race	1.112	0.107	-.210, .423	.52
Multiple race	1.342	0.294	-.238, .826	.29
Other race	0.912	-0.092	-.450, .266	.61
Non-Hispanic ethnicity	Reference			
Hispanic ethnicity	1.189	0.174	-.140, .487	.26
Enabling Characteristics				
≤200% FPL	0.824	-0.193	-.463, .078	.17
200-400% FPL	1.051	0.050	-.220, .320	.74
> 400% FPL	Reference			
Non-urban	Reference			
Urban	1.115	0.109	-.131, .349	.35
Insured	Reference			
Uninsured	3.260	1.181	.699, 1.665	<.001**
Need Characteristics				
How often condition affected ability to do things—Never	Reference			
How often condition affected ability to do things—Sometimes	1.406	0.341	-.125, .807	.15
How often condition affected ability to do things—Usually	2.433	0.889	.410, 1.367	<.001**
How often condition affected ability to do things—Always	3.108	1.134	.675, 1.593	<.001**
Problem behaviors--No	Reference			
Problem behaviors--Yes	1.305	0.266	.059, .473	.01**

Note. Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.

Overall model: Linearized F-test (18, 61268)=7.28, *p*<.001. Strata=153, PSU=62042, Subpopulation obs=8004, Imputations=5

* *p*≤.05, ***p*≤.01

Having a current ASD was a significant predictor of lack of realized access when compared to children with a current ADHD after controlling for year, sample, predisposing, enabling, and need characteristics, *OR*=1.33, 95% CI: [1.07, 1.65], *p*=.01. The only predisposing characteristic that predicted poor realized access was child's age, with younger children being significantly more likely to not receive needed therapy services than older children, *OR*=.97, [.94, .99], *p*=.01. One enabling characteristic, uninsured status, predicted lack of realized access to therapy services, with uninsured children three times more likely to have an access problem compared to insured children, *OR*=3.26, [2.0, 5.3], *p*<.001. Need characteristics of the child significantly predicted difficulty obtaining needed therapy services, with increasing frequency of functional difficulty predicting lack of therapy service access. Children who "usually" had more difficulty performing functional activities were two times more likely to have difficulty obtaining needed therapy services than children who "never" had functional difficulties, *OR*=2.43, [1.5, 3.9], *p*<.001. Children who "always" had more difficulty performing functional activities were three times more likely to have difficulty obtaining needed therapy services, *OR*=3.11, [1.96, 4.92], *p*<.001. Lastly, children reported to have problem behaviors were significantly more likely to report lack of realized access, *OR*=1.31, [1.06, 1.60], *p*=.01.

The full model with CP group as indicator diagnostic group produced similar results as Research Question 2 (Appendix H), in which children with ASD did not demonstrate poorer access to therapy than children with CP, even after controlling for predisposing, enabling, and need characteristics, *OR*= 1.40, 95% CI: [1.00, 1.96], *p*= .05.

Research Question 3: Frequency of Reported Access Problems

Hypotheses 3.2 and 3.3 examined the extent to which certain access problems were reported among children who had a realized access problem. Low cell sample sizes prevented analysis of group differences between ASD, ADHD, and CP groups in frequency of reported access problems, therefore comparisons between children with ASD and children with ADHD and CP as the comparison group were conducted using chi-square statistics and reporting of design-based F-statistics to control for survey design characteristics. Contextual enabling problems were compared between the two groups for each survey year and affirmative response to a particular problem are reported in Tables 12 and 13. Provider-related problems were compared between the two groups for each survey year and affirmative response to a provider-related problem are reported in Table 14.

It was hypothesized that children with ASD would demonstrate similar contextualizing enabling access problems compared to other groups. This hypothesis was mostly supported. Of the eight contextual enabling characteristics examined, only one was different between children with ASD and children with other special health care needs (Tables 12 and 13). Children with ASD in 2009 were significantly more likely than other CSHCN to report that ‘can’t find a provider accepting insurance’ prevented therapy access, $p<.001$.

It was also hypothesized that children with ASD would demonstrate more provider-related problems than other children not receiving needed therapy services. This hypothesis was not supported. There were three provider-related variables compared across groups and years. Children with ASD were significantly more likely than the ADHD/CP comparison group to report that the ‘provider did not know how to treat’ ($p=.018$) as a problem in 2005, but no provider-related problems were found to be different between the groups in 2009.

Table 12

Prevalence of Contextual Enabling Variables by Group and Year

	Cost too much			Not available in area/ no transportation			Did not know where to go for therapy			Lack of school resources		
	% [95% CI]	F	*p*	% [95% CI]	F	*p*	% [95% CI]	F	*p*	% [95% CI]	F	*p*
2005-06 NS-CSHCN [a]		0.24	.62		1.85	.17		0.15	.69		.17	.68
ASD	17.05 [11.61, 24.33]			19.20 [12.70, 27.97]			5.46 [2.83, 10.28]			25.47 [18.22, 34.39]		
ADHD & CP	19.42 [13.28, 27.5]			12.81 [8.22, 19.42]			4.43 [1.92, 9.88]			27.79 [21.07, 35.69]		
2009-10 NS-CSHCN [b]		1.62	.20		0.85	.36		1.60	.21		1.65	.20
ASD	24.78 [19.09, 31.52]			15.20 [11.01, 20.63]			4.53 [1.98, 10.03]			19.78 [14.64, 26.17]		
ADHD & CP	19.09 [13.75, 25.89]			11.8 [7.50, 18.09]			2.05 [0.77, 5.30]			14.64 [10.12, 20.72]		

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.

[a] Number of observations= 28084, Subpop number of observations= 602, Strata= 51, PSUs= 28084

[b] Number of observations= 27485, Subpop number of observations= 929, Strata= 72, PSUs= 27485

Table 13

Prevalence of Contextual Enabling Variables Related to Insurance by Group and Year

	No insurance			Health plan problem			No referral			Can't find a provider accepting insurance		
	% 95% CI	F	*p*	% 95% CI	F	*p*	% 95% CI	F	*p*	% 95% CI	F	*p*
2005-06 NS-CSHCN [a]		0.62	.43		0.05	.82		3.94	.05		1.38	.24
ASD	5.89 [2.75, 12.15]			15.82 [10.85, 22.5]			1.20 [0.45, 3.17]			6.57 [3.31,12.62]		
ADHD & CP	8.72 [4.52, 16.16]			16.78 [10.85, 22.5]			4.13 [1.75, 9.44]			3.05 [0.97, 9.18]		
2009-10 NS-CSHCN [b]		.002	.97		0.44	.51		.38	.54			
ASD	6.74 [3.62, 12.23]			16.17 [11.60, 22.10]			2.01 [0.51, 7.64]			7.55 [3.92, 14.07]	11.34	<.001
ADHD & CP	6.62 [3.41, 12.48]			13.56 [8.89, 20.15]			3.32 [1.39, 7.73]			1.63 [0.78, 3.38]		

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.

[a] Number of observations= 28084, Subpop number of observations= 602, Strata= 51, PSUs= 28084

[b] Number of observations= 27485, Subpop number of observations= 929, Strata= 72, PSUs= 27485

Table 14

Prevalence of Reported Provider Problems by Group and Year

	Not convenient times			Provider did not know how to treat			Dissatisfaction with provider		
	% 95% CI	F	*p*	% 95% CI	F	*p*	% 95% CI	F	*p*
2005-06 NS-CHSCN [a]		0.01	.94		5.58	.02		0.12	.72
ASD	5.79			5.72			5.28		
	[2.98, 10.98]			[2.92, 10.9]			[1.90, 13.86]		
ADHD & CP	6.00			1.84			4.29		
	[3.22, 10.91]			[0.88, 3.82]			[2.41, 7.52]		
2009-10 NS-CSHCN [b]		0.17	.68		0.29	.59		0.26	.61
ASD	10.63			3.60			2.62		
	[7.25, 15.33]			[1.58, 7.99]			[1.38, 4.91]		
ADHD & CP	12.25			2.60			3.64		
	[6.92, 20.79]			[1.08, 6.11]			[1.18, 10.74]		

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.

[a] Number of observations= 28084, Subpop number of observations= 602, Strata= 51, PSUs= 28084

[b] Number of observations= 27485, Subpop number of observations= 929, Strata= 72, PSUs= 27485

It should be noted that the confidence intervals were wide, and the sample sizes small, thus statistical conclusion validity supporting these results must be considered. Additionally, these results should be interpreted with caution due to the need to collapse the strata in 2009 because of insufficient sample size in each strata.

CHAPTER 5: DISCUSSION

This is the first study to examine population-based need for and access to therapy services by children with ASD across two cross-sectional survey years. The statistical approaches used in the current study rigorously controlled for missing data (race, ethnicity, and poverty level) through use of imputed datatsets. This represents work that has not been previously published.

Across both survey time points approximately 75% of children with ASD were reported to need therapy services. As hypothesized, children with ASD reported a significantly greater need for therapy compared to children with ADHD at both time points, which likely represents the greater functional difficulties displayed by children with ASD compared to children with ADHD. However, across both time points children with ASD were significantly less likely to need therapy compared to children with CP, again possibly reflecting the greater functional limitations reported by children with CP compared to children with ASD. Comparison of point estimates of therapy need across the two survey years revealed, however, that children with ASD's need for therapy remained stable across the two time points, suggesting that this group of children are being identified as needing these therapy services consistently. These findings are similar to published reports of therapy need (Farmer et al., 2013; Gurney et al., 2006; Montes et al., 2009).

The findings of this study generally support those of other published literature regarding access to services; namely, that children with ASD experience significantly poorer access to therapy services than other CHSCN (Chiri & Warfield; Thomas et al., 2007). This study specifically compared children with ASD to a comparison group with mental health and behavioral difficulties (ADHD) and a comparison group with physical limitations (CP). These specific comparison groups were included because of the heterogeneity of autism symptoms that may contribute to therapy need, including mental health and attentional symptoms, and physical/motor symptoms that impact participation in gross motor, fine motor, and self-care activities.

Children with ASD had significantly poorer access than children with ADHD, but did not differ in access from children with CP in regression models including diagnostic group and year as predictors, even after controlling for predisposing, enabling, and need characteristics. It is interesting that children with CP did not demonstrate poorer access than children with ADHD, even though they were reported to be more severely impacted by their condition than both ASD and ADHD. These findings together lend support for the conclusion that having an ASD diagnosis represents a unique constellation of factors which make it difficult to access therapy services, above and beyond any particular predisposing, enabling or need characteristic. The concept of equal access for equal need (Oliver & Mossialos, 2004) implies that if two groups have similar needs, they should display the same access to needed services. Children with CP, who have *greater* need than ASD, did not display an access problem compared to ADHD, but children with ASD *did* display a therapy access problem compared to ADHD. Based on the current findings, it is important to identify actions by which children with ASD can access appropriate services based on need. Although outside the scope of this study, the literature suggests two areas for action: influence the supply side and demand side reasons for lack of access (Oliver & Mossialos, 2004). Supply side reasons would include availability of appropriately trained providers in the geographic area serving children with ASD, availability of providers who accept insurance, or who provide services at the service level that is required to treat the needed symptoms. Using Andersen's model, these are contextual enabling characteristics. It is well-known that parents of children with ASD report that finding appropriate providers to address their child's extensive needs is difficult, time consuming, and costly (e.g., Vohra, Madhavan, Sambamoorthi, & St Peter, 2013) implying that supply side reasons may influence access to therapy services. Additionally, the current study found that "can't find a provider that accepts insurance" was reported significantly more by the ASD group than the ADHD/CP group in 2009. This variable represents one potential area for future investigation, especially given that the vast majority of children with ASD are insured by private and/or public insurance. If, as these data suggest, children with ASD cannot find a provider accepting insurance, then access problems persist despite public policies aimed at improving health care coverage. Recent research aimed at this phenomenon has occurred in studies investigating access to mental health services. Specifically, psychiatrists are significantly less likely than other medical doctors to accept insurance and have been hypothesized as one barrier to mental health services (Bishop, Press, Keyhani, & Pincus, 2014). Future research should investigate whether therapy providers also limit access by refusing to accept insurance for children with ASD. Additionally, factors related to how insurance coverage dictates payment are of interest. Little work has been done that investigates the impact of autism insurance mandates that either support or limit coverage based on age of the child, number of visits, or type of treatment. Future studies should conduct policy analysis aimed at understanding state-level variation in ASD access and receipt of services based on state autism mandates and autism parity laws that may cap autism or therapy-related expenditures, or that limit coverage based on age.

Demand side reasons for lack of access in the ASD group specifically may be due to the increase in incidence and prevalence of ASD (there are more children with ASD needing services, and the numbers are increasing each year), and/or the cultural or social factors that influence a family or child with ASDs' predisposition to seek out services (Mandell & Novak, 2005; Oliver & Mossialos, 2004). In Andersen's Behavioral Model, these are contextual predisposing or contextual need characteristics. Future research should control for prevalence of the disorder when examining access to services, and should consider the use of propensity score matching to create equivalent groups of children with ASD and children with other diagnoses matched on identified need characteristics.

A surprising finding was that access to therapy services, for all diagnostic groups, was poorer in 2009-2010 than in 2005-2006. This may be explained in part by historic effects of the U.S. national recession, which impacted families' financial status (Borbely, 2009). However, results from this study do not completely support this reason, since regression results did not demonstrate that federal poverty level contributed to access to therapy. However, although poverty level may not have been a factor contributing to poor access, caregivers in 2009 may not have reported that their child received *all* needed therapy due to reduction in private therapy services. These private services are those that low-income families would not have likely accessed at either time point due to high out-of-pocket expenses spent on private OT, PT, or ST. However, the recession did contribute to reduced disposable income for many families, and thus, for parents previously paying for out-of-pocket expenses on private therapy, an indirect impact of the recession may have contributed to overall unmet need for therapy in 2009 for all diagnostic groups compared to 2005. An examination of parent-reported cost as a problem impeding access ("cost too much") show that 19-24% percent of caregivers of children with

ASD and ADHD/CP reported this as a reason for reduced access to therapy. Greater investigation is warranted to examine the effect of provider level factors (e.g., acceptance of private insurance, hourly rate for private services) on access to therapy services.

Results of the imputed regression analyses point to age as a significant predictor of therapy access. It should be noted that this finding applies to all diagnostic groups, and thus does not reflect children with ASD alone. Although Chiri & Warfield (2012) did not find that age contributed to lack of access, Montes and colleagues (2009) did find that older children had poorer access to school and community services than younger children. Thus, the findings of this study stand in some contrast to existing literature, and suggest that younger children are more likely to have an unmet need for therapy services than older children. Additional inquiry is needed to explore the relationship between age and access.

Of interest is that no other predisposing characteristics of the child, such as gender, race, or ethnicity, predicted lack of therapy access. Inequitable access and disparity occurs when immutable factors contribute to not receiving the services that are needed. In this study, no inequitable disparities based on gender, race, or ethnicity were found, even after controlling for missing responses using multiply imputed data for both 2005 and 2009. Among studies investigating therapy access, the current finding supports those of Chiri and Warfield (2012), but is dissimilar than smaller, non-population based studies that have reported racial or ethnic disparities in therapy service access (Irvin et al., 2012; Thomas et al., 2007). One potential explanation is that most other research on access by children with ASD consider access to services provided solely in the healthcare system (e.g., specialty physician visits, genetic screening, primary care visits), and access to these services has been reported to be impacted by racial or ethnic disparities. However, therapy services are often provided in the school or community, in addition to healthcare settings, and it is unclear how respondents to the survey were answering the question regarding therapy service need and receipt; thus, in these survey data, it remains unclear whether the findings are applicable to therapy services provided in a healthcare system or therapy services provided in an educational setting, or both. Future research should identify factors contributing to therapy access in both healthcare and educational systems, where respondents clearly identify where services are received (e.g., private practice, school, home). Additionally, research should explore whether access to therapy provided in an educational system is different than access to therapy provided in the healthcare system, due to the differences in pathways by which children come to receive those services and pay for those services. Another line of inquiry could investigate the interaction of family’s cultural beliefs about appropriate care, racial/ethnic status and access to services, as was done by Mandell & Novak (2005).

Lack of child health insurance predicted lack of access to therapy services in the full regression model, which is a finding consistent with most access studies including those examining access to other healthcare providers (e.g., Chiri & Warfield, 2012; Kogan et al., 2008; McGrath et al., 2009; Montes et al., 2009). Unreported regression models included the a priori specified categorical insurance variable with private, public, private and public, and no insurance; the only category to predict lack of access was no insurance, thus other categories were collapsed to improve model fit. This finding was unexpected, given that a recent study by Wang, Mandell, and colleagues found that OT/PT services were provided significantly less frequently for children with private insurance than for those with public Medicaid (Wang et al., 2013). Further investigation is warranted.

Lastly, the imputed regression analyses suggest that the predominant predictors of poor access are functional needs of the child. Children who were reported to "Usually" or "Always" be impacted by their condition (regardless of diagnosis), had greater odds of not receiving needed therapy services, and similarly, children with a reported behavior problem were significantly more likely to not receive therapy compared to children without problem behaviors. This is consistent with other literature, which suggests that having greater functional limitation, or having greater multi-morbidity, results in greater problems accessing needed services (Kogan et al., 2008; McGrath et al., 2011; Thomas et al., 2011). However, causal predictions cannot be assumed from these data, as it is unclear whether the lack of therapy receipt contributed to greater reported functional limitations, or whether increased functional limitation contributed to greater report of poor therapy access.

This study yields important information that may be relevant to policy makers. Specifically, the findings that a significant majority of children with ASD require therapy services, and that many children with ASD display extensive functional limitation suggest that state and federal policies, including autism insurance mandates, should cover such services that serve to improve or remediate functional challenges. Second, the only enabling predictor of unmet need for therapy, lack of health insurance, is a concern given that there are already available services for children living in families lacking financial resources, such as S-CHIP and Medicaid. Although a very small percentage of children reported lack of health insurance, this predictor significantly contributed to lack of therapy service receipt, suggesting that improved access to insurance may improve therapy service receipt. Since the 2009-2010 NS-CSHCN, the Affordable Care Act (Patient Protection and Affordable Care Act, H.R. Act 3590, 2010) also legislated insurance coverage for all Americans. The influence of this policy on future therapy access will be of interest. Lastly, and most importantly, children with ASD experienced greater access problems than children with ADHD even after controlling for predisposing, enabling, and need characteristics. Access was poorer in 2009 than in 2005, although reasons for this finding are unclear and need to be explored further. Due to the myriad of factors present, the impact of the Combating Autism Act on access was unable to be determined. Study designs with greater control over policy or community level factors (such as provider density, provider acceptance of insurance, state insurance mandates, federal funding for ASD related services, etc) should be used to better examine the impact of such broad policies on access to therapy.

Interpretation of Findings in Relation to Andersen's Behavioral Model

The results of this study suggest that the majority of children with ASD are identified as needing services, but approximately 20% of these children do not receive their needed therapy services. The most significant predictors of lack of service receipt were need characteristics of the child. Figure 4 displays the revised Andersen Behavioral Model with significant predictors indicated. According to Andersen and colleagues (2013), equitable access occurs when need characteristics, rather than predisposing or enabling characteristics, explain most of the variation in access, which is what was found in the current study. Andersen's Behavioral Model implies that need characteristics, as well as child predisposing and family enabling characteristics, interact to influence how people seek out and utilize healthcare services. Given the findings of this study, two important questions might be posed: 1) Considering the literature supporting racial, ethnic, and poverty level disparities among access to other healthcare services for children with ASD, what factors contributed to equitable access to therapy services in this study? Andersen's model points to policies and social level factors that may influence access that were not examined in the current study. Therapy services can be provided in both an educational and

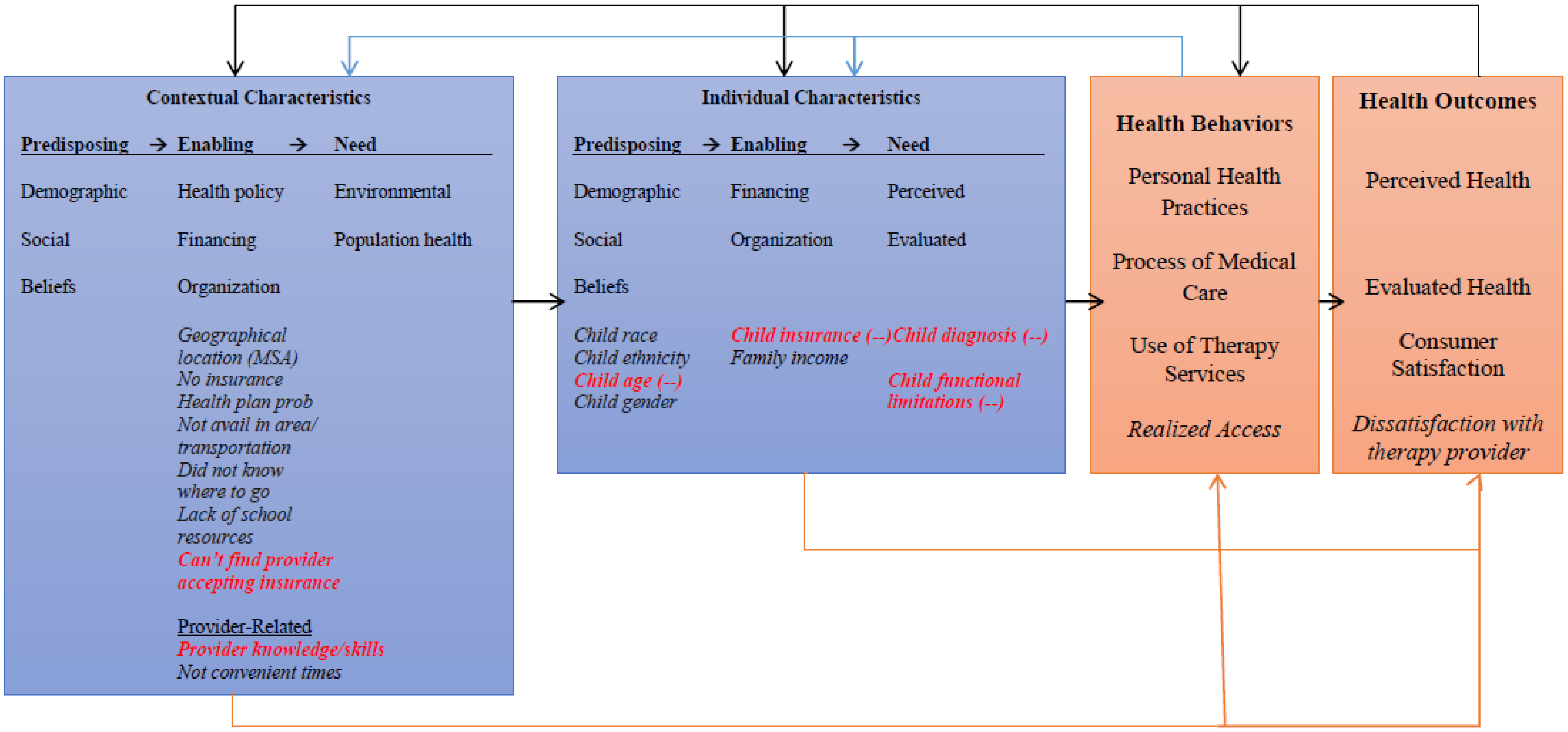

Figure 4. Revised Andersen's Behavioral Model of Access to Therapy with Significant Predictors. Significant predictors of therapy access are italicized in bold, red font. Negative predictors are indicated by (--).Adapted from Andersen (1995), p 8; Andersen, Davidson & Baumeister, p 35 in Kominski (2013).

in a healthcare setting. It may be that disparities exist for access to therapy provided by private practitioners, but that these are masked or hidden by children who are consistently receiving services in school. This leads to the second question: 2) What are the pathways by which children with ASD are receiving their therapy services? If access to therapy services are truly equitable via the healthcare system (as opposed to access via the educational system), then gatekeeper factors, such as access to a primary care provider or having a medical home should not predict lack of access to therapy services. It is unfortunate that the most recent NS-CSHCN eliminated the only variable related to receipt of school and community services, thus limiting the ability to fully understand these two pathways to therapy service provision. Future research should investigate how children with ASD are referred to therapy providers and participate in therapy services. Additionally, future research should explore the contribution of state and federal policy on referral patterns and access to therapy services, variables that were not available for investigation in this study, but are potential factors in Andersen’s Behavioral Model (Andersen et al., 2013).

The use of Andersen’s Behavioral Model was useful in understanding the influence or predictive value of certain constructs on health behavior (reported access to therapy). For example, taken together, predisposing variables including those immutable factors such as age, gender, race and ethnicity, could potentially influence health behaviors. The predictive value of these variables on access is typically large for most minority and underserved groups; however, .model is useful in explaining other constructs that might influence access besides these typical variables. It should be noted that the full explanatory power of this model was not examined in this study, since policy and other system-level variation was not included (e.g., autism insurance mandates, provider density, etc). But, knowing that these unexplored variables are potentially important helps contextualize the current results in light of what other research needs to be done to fully understand the problem.

Limitations

Controlling for threats to internal validity. There are several potential threats that need to be discussed that may have influenced study results: selection factors, instrumentation, and history. First, the present study proposed to examine therapy-service access limitations in children with ASD compared to children with ADHD and CP. The original data were based on caregiver-reported diagnosis. According to the NS-CSHCN Design and Operation Manual (Blumberg et al., 2008; CDC, 2011), children with autism spectrum disorder were selected as those with any of the ASDs, including Asperger's Disorder, Autistic Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified. While parent reports can be fraught with recall bias, a diagnosis of ASD is an impactful life event that results in significant coping challenges for parents (Twoy, Connolly, & Novak, 2007), and therefore it was expected that parents experiencing this diagnosis are reporting their child's diagnosis correctly. The survey was designed to minimize biased reporting with confirmation of parent answers and repeat questions built into the structure to check previous answers. Additionally, parents who engage in survey research practices that require parent-reported confirmation of ASD diagnosis have been found to be reliable and accurate in corroborating actual diagnosis results (Daniels et al., 2012). Limitations to using caregiver reported diagnosis for assessing ASD status is acknowledged, but was unable to be controlled for beyond reporting this limitation. Additionally, assumption of ADHD diagnosis is also based on caregiver report; thus this reflects another potential limitation in the results.

Instrumentation threats arise when the tool used to measure the variables of interest is not valid and reliable. The NS-CSHCN publishes its survey questions, and the face validity of the questions has been established. Additionally, the constructs of access and use of therapy services have been validated in several previously published studies using the NS-CSHCN, including Chiri and Warfield (2012) and Montes et al. (2009). Therefore, the tool has established construct validity. The use of definitions from the Andersen Behavioral Model further strengthen the construct validity of this tool to measure variables of interest in the current study.

The threat of history arises when events occurring during the study period potentially affect the ability to draw conclusions from the results. In this study, health policy factors, prevalence of autism spectrum disorders, and family socio-demographics related to a national recession changed between the two study periods of 2005-06 and 2010-11. These changes are of interest in the interpretation of the results, and therefore contribute to drawing conclusions about potential differences between the two samples.

Controlling for threats to statistical conclusion validity. The comparison of two separate population-based surveys raises questions about the ability to draw appropriate conclusions, considering that findings from each survey year do not represent longitudinal data (following the same families over two time points) but rather cross-sectional inclusion of different families at each time point. None-the-less, discussion with Stephen J Blumberg (Senior Scientist, Division of Health Interview Statistics, Centers for Disease Control and Prevention, personal communication, April 2, 2012) lead to the conclusion that comparison of two cross-sectional NS-CSHCN databases was appropriate and feasible. Both sampling techniques for the two survey years were done using valid and reliable methods for obtaining appropriate population based parameters, and demographic characteristics between the two ASD samples were compared using descriptive statistics to ensure comparability.

Conclusion

This is the first population-based study to examine cross-sectional changes in reported need for and access to therapy services for children with autism spectrum disorder and other populations. This study used a well-accepted model of healthcare access to understand constructs related to outcome variables of interest, and also included appropriate modelling using survey-design weights to conduct primary analyses. The results of this study suggest that children with ASD are at risk for having greater access problems than other children with similar mental health and behavioral needs, but that access problems are similar to those experienced by children with similar or greater physical limitations. Factors that may significantly impact access to therapy services include child diagnosis, child age, child insurance status, and child need characteristics. Additionally, the results of this study suggest that access to therapy worsened for all children studied over the time period that data were available (2005-06 and 2009-10). Future study is needed to identify if these findings are supported by additional data, and to identify additional factors influencing therapy access that were not examined in the current investigation.

References

Aday, L.A. and Andersen, R. (1974). A framework for the study of access to medical care. *Health Services Research,* 208-220.

Aday, L, Begley, C., Lairson, D. & Slater, C. (2004). *Evaluating the health care system: Effectiveness, efficiency and equity* (3rd ed). Ann Arbor, MI: Health Administration Press.

American Academy of Pediatrics (2010). AAP publications retired and reaffirmed. *Pediatrics, 126,* e1622. doi: 10.1542/peds.2010-2549

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed). Arlington, VA: Author. Retrieved from http://dsm.psychiatryonline.org

Andersen, R.M. (1995). Revisiting the Behavioral Model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36,* 1-10.

Andersen, R.M. (2008). National health surveys and the Behavioral Model of health service use. *Medical Care, 46,* 647-653.

Andersen, R.M. Davidson, P.L. & Baumeister, S.E. (2014). Chapter 2: Improving access to care, pp. 33-70. In G.F. Kominski (Ed). *Changing the U.S. health care system: Key issues in health services policy and management* (4th ed). San Francisco, CA: John Wiley & Sons, Inc.

Anderson, L.M., Scrimshaw, S.C., Fullilove, M.T., Fielding, J.E., Normand, J., and the Task Force on Community Preventive Services (2003). Culturally competent health care systems: A systematic review. *American Journal of Preventive Medicine, 24,* 68-79.

Arah, O.A., Westert, G.P., Hurst, J. & Klazinga (2006). A conceptual framework for the OECD Health Care Quality Indicators Project. *International Journal for Quality in Health Care, September edition*, 5-13. doi: 10.1093/intqhc/mzl024

Babitsch, B., Gohl, D. & von Lengerke, T. (2012). Re-visiting Andersen's Behavioral Model of Health Services Use: A systematic review of studies from 1998-2011. *GMS Psycho-Social Medicine, 9,* 1-15. doi: 10.3205/psm000089, URN: urn:nbn:de:0183-psm0000891

Beal, A.C., Co, J.P.T., Dougherty, D., Jorsling, T., Kam, J., Perrin, J., & Palmer, R.H. (2004). Quality measures for children's health care. *Pediatrics, 113,* 199-209. Accessed online at: http://pediatrics.aappublications.org/content/113/Supplement_1/199.full.html

Betancourt, J.R., Green, A.R., Carrillo, J.E., & Ananeh-Firempong, O. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports, 118,* 293-302.

Bethell, C.D., Read, D., Stein, R.E., Blumberg, S.J., Wells, N., Newacheck, P.W. (2002). Identifying children with special health care needs: Development and evaluation of a short screening tool. *Ambulatory Pediatrics, 2,* 38–48.

Blumberg, S.J., Welch, E.M., Chowdhury, S.R., Upchurch, H.L., Parker, E.K., Skalland, B.J. (2008). Design and operation of the National Survey of Children with Special Health Care Needs, 2005–2006. National Center for Health Statistics. *Vital Health Statistics*, *1*(45).

Bishop, T.F., Press, M.J., Keyhani, S., & Pincus, H.A., (2014). Acceptance of insurance by psychiatrists and implications for access to mental health care. *JAMA Psychiatry, 71,* 176-181. doi:10.1001/jamapsychiatry.2013.2862

Borbely, J.M. (2009, March). U.S. labor market in 2008: Economy in recession. *Monthly Labor Review,* 3-19.

Boulet, S.L., Boyle, C.A. & Schieve, L.A. (2009). Health care use and health and functional impact of developmental disabilities among U.S. children, 1997-2005. *Archives of Pediatric and Adolescent Medicine, 163,* 19-26.

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

Centers for Disease Control and Prevention (2012, March 30). Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2008. *MMWR Surveillance Summaries, 61*. Accessed 3/31/12 at: http://www.cdc.gov/mmwr/pdf/ss/ss6103.pdf

Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey (2011, December). 2009-2010 National Survey of Children with Special Health Care Needs Frequently Asked Questions. Available from URL: http://www.cdc.gov/nchs/slaits/cshcn.htm

Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey (2012, March). 2009-2010 National Survey of CSHCN Frequently Asked Questions: Missing Data and Multiple Imputation. Available from URL: http://www.cdc.gov/nchs/slaits/cshcn.htm

Centers for Disease Control and Prevention (2009). Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2006. *MMWR Surveillance Summaries, 58*, SS-10.

Chen, X., Ender, P., Mitchell, M., & Wells, C. (n.d). UCLA: Statistical Consulting Group. Logistic Regression Chapter 3: Regression Diagnostics. Accessed 11/20/13 at: http://www.ats.ucla.edu/stat/stata/webbooks/logistic/chapter3/statalog3.htm

Chiri, G., & Warfield, M.E. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal, 16,* 1081-1091. doi: 10.1007/s10995-011-0833-6

Combating Autism Act of 2006, S. 843, 109th Congress (2006) (enacted).

Coury, D. (2010). Medical treatment of autism spectrum disorders. *Current Opinion in Neurology, 23,* 131-136. doi: 10.1097/WCO.0b013e32833722fa

Croen, L.A., Najjar, D.V., Ray, G.T., Lotspeich, L., & Bernal, P. (2006). A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics, 118*(4), e1203-e1211. doi: 10.1542/peds.2006-0127

Daniels, A.M. & Mandell, D.S. (2013). Children's compliance with American Academy of Pediatrics' well-child care visit guidelines and the early detection of autism. *Journal of Autism and Developmental Disorders, 43,* 2844-2854. doi: 10.1007/s10803-013-1831-x

Daniels, A.M., Rosenberg, R.E., Anderson, C., Law, J.K., Marvin, A.R., & Law, P.A. (2012). Verification of parent-report of child autism spectrum disorder diagnosis to a web-based autism registry. *Journal of Autism and Developmental Disorders, 42,* 257-265. doi: 10.1007/s10803-011-1236-7

Dankwa-Mullan, I., Rhee, K.B., Williams, K., Sanchez, I., Sy, F.S., Stinson, N., & Ruffin, J. (2010). The science of eliminating health disparities: Summary and analysis of the NIH

Summit recommendations. *American Journal of Public Health, 100,* S12-18. doi:10.2105/AJPH.2010.191619

Diaconis, P. & Efron, B. (1985). Testing for independence in a two-way table: New interpretations of the chi-square statistic. *The Annals of Statistics, 13,* 845-874.

Dusing, S.C., Skinner, A.C., & Mayer, M.L. (2004). Unmet need for therapy services, assistive devices, and related services: Data from the National Survey of Children with Special Health Care Needs. *Ambulatory Pediatrics, 4*, 448-454. doi: 10.1367/A03-202R1.1

Farmer, J.E., Clark, M.J., Mayfield, W.A., Cheak-Zamora, N., Marvin, A.R. Law, J.K, Law, P.A. (2013). The relationship between the medical home and unmet needs for children with autism spectrum disorder. *Maternal and Child Health, Online First (June 23, 2013).* doi: 10.1007/s10995-013-1292-z

Fombonne, E. (2002). Epidemiological trends in rates of autism. *Molecular Psychology, 7,* S4-6.

Green, V.A., Pituch, K.A., Itchon, J., Choi, A., O'Reilly, M., & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities, 27,* 70-84. doi:10.1016/j.ridd.2004.12.002

Goin-Kochel, R.P., Mackintosh, V.H., & Myers, B.J. (2009). Parental reports on the efficacy of treatments and therapies for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3,* 528-537. doi:10.1016/j.rasd.2008.11.001

Gurney, J.G., McPheeters, M.L., & Davis, M.M. (2006). Parental report of health conditions and health care use among children with and without autism. *Archives of Pediatric and Adolescent Medicine, 160,* 825-830.

Interagency Autism Coordinating Committee (IACC). *IACC Strategic Plan for Autism Spectrum Disorder Research—2012 Update.* December 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/strategic-plan/2012/index.shtml.

Irvin, D.W., McBee, M., Boyd, B.A., Hume, K., Odom, S.L. (2012). Child and family factors associated with the use of services for preschoolers with autism spectrum disorder. *Research in Autism Spectrum Disorders, 6,* 565-572. doi:10.1016/j.rasd.2011.07.018

Jansiewicz, E.M., Goldberg, M.C., Newschaffer, C.J., Denckla, M.B., Landa, R., & Mostofsky, S.H. (2006). Motor signs distinguish children with high functioning autism and Asperger's Syndrome from controls. *Journal of Autism and Developmental Disorders, 36,* 613-621. 10.1007/s10803-006-0109-y

Johnson, C.P. and Myers, S.M. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics, 120,* 1183-1215. doi: 10.1542/peds.2007-2361

Kilbourne, A.M., Switzer, G., Hyman, K., Crowley-Matoka, M., & Fine, M.J. (2006). Advancing health disparities research within the health care system: A conceptual framework. *American Journal of Public Health, 96,* 2113-2121. doi: 10.2105/AJPH.2005.077628

Kohler, F.W. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities, 14,* 150-158. doi: 10.1177/108835769901400304

Kogan, M.D, Strickland, B.B, Blumberg, S.J., Singh, G.K, Perrin, J.M., van Dyck, P.C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics, 122,* e1149-1158. doi: 10.1542/peds.2008-1057

Kominski, G.F. (Ed) .(2013). *Changing the U.S. Health Care System: Key Issues in Health Services Policy and Management, 4th ed.* San Francisco, CA: John Wiley and Sons, Inc.

Krauss, M.W., Gulley, S. Sciegaj, M. & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation, 41,* 329-339.

Levy, S.E., Giarelli, E., Lee, L., Schieve, L.A., Kirby, R.S., Cunniff, C., Nicholas, J., Reaven, J., & Rice, C.E. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental and Behavioral Pediatrics, 31,* 267-275.

Leyfer, O.T, Folstein, S.E., Bacalman, S., Davis, N.O, Dinh, E., Morgan, J., Tager-Flusberg, H., & Lainhart, J.E. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. *Journal of Autism and Developmental Disorders, 36,* 849-861. doi: 10.1007/s10803-006-0123-0

Link, M.W., Battaglia, M.P., Frankel, M.R., Osborn, L. & Mokdad, A.H. (2007). Reaching the U.S. cell phone generation: Comparison of cell phone survey results with an ongoing landline telephone survey. *Public Opinion Quarterly, 71,* 814-839. doi:10.1093/poq/nfm051

Liptak, G.S., Benzoni, L.B., Mruzek, D.W., Nolan, K.W., Thingvoll, M.A., Wade, C.M., Fryer, G.E. (2008). Disparities in diagnosis in access to health services for children with autism: Data from the National Survey of Children's Health. *Journal of Developmental and Behavioral Pediatrics, 29,* 152-160.

Liptak, G.S., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders, 36,* 871-879. doi: 10.1007/s10803-006-0119-9

Lord, C., Petkova, E., Hus, V., Gan, W., Lu, F., Martin, D.M., Ousley, O., Guy, L…Risi, S. (2012). A multisite study of the clinical diagnosis of different autism spectrum disorders. *Archives of General Psychiatry, 69,* 306-313. doi: *10.1001/archgenpsychiatry.2011.148*

MacNeil, B.M., Lopes, V.A., & Minnes, P.M. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3,* 1-21. doi:10.1016/j.rasd.2008.06.001

Mandell, D.S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11,* 110-115.

Mandell, D.S., Novak, M.M., & Zubritsky, C.D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116,* 1480-1486. doi: 10.1542/peds.2005-0185

Mandell, D.S., Ittenbach, R.F., Levy, S.E., Pinto-Martin, J.A. (2007). Disparities in diagnosis received prior to diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37,* 1795-1802. doi: 10.1007/s10803-006-0314-8

Mayes, S.D., Calhoun, S.L., Murray, M.J., Morrow, J.D., Yurich, K.K.L, Mahr, F., Cothren, S., Purichia, H., Bouder, J.N., Petersen, C. (2009). Comparison of scores on the Checklist for Autism Spectrum Disorder, Childhood Autism rating Scale, and Gilliam Asperger's Disorder Scale for children with low functioning autism, high functioning autism

Asperger's Disorder, ADHD, and typical development. *Journal of Autism and Developmental Disorders, 39,* 1682-1693. doi: 10.1007/s10803-009-0812-6

McGrath, R.J., Laflamme, D.J., Schwartz, A.P., Stransky, M., & Moeschler, J.B. (2009). Access to genetic counseling for children with autism, Down syndrome, and intellectual disabilities. *Pediatrics, 124,* S443-S449. doi: 10.1542/peds.2009-1255Q

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M. Newacheck, P.W., Perrin, J.M., Shonkoff, J.P., Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics, 102*, 137–140.

Miller, V.A., Schreck, K.A., Mulick, J.A., & Butter, E. (2012). Factors related to parents' choices of treatments for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6,* 87-95. doi:10.1016/j.rasd.2011.03.008

Montes, G., Halterman, J.S., & Magyar, C.I. (2009). Access to and satisfaction with school and community health services for US children with ASD. *Pediatrics, 124,* S407-S413. doi: 10.1542/peds.2009-1255L

Montes, G.& Halterman, J.S. (2011). White-Black disparities in family-centered care among children with autism in the United States: Evidence from the NS-CSHCN 2005-2006. *Academic Pediatrics,11,* 297-304.

Moy, E.M., & Bartman, B.A. (1995). Physician race and care of minority indigent patients. *Journal of the American Medical Association, 273,* 1515-1520. doi:10.1001/jama.1995.03520430051038

National Collaborating Centre for Women's and Children's Health (2011, September). National Institute for Health and Clinical Excellence Clinical Guideline for Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum. London: Royal College of Obstetricians and Gynaecologists Press.

Nicholas, J.S., Charles, J.M., Carpenter, L.A., King, L.B., Jenner, W., & Spratt, E.G. (2008). Prevalence and characteristics of children with autism-spectrum disorders. *Annals of Epidemiology, 18,* 130-136. doi:10.1016/j.annepidem.2007.10.013

Oliver, A., & Mossialos, E. (2003). Equity of access to health care: outlining the foundations for action. *Journal of Epidemiology in Community Health, 58,* 655-658. doi: 10.1136/jech.2003.017731

Patient Protection and Affordable Care Act. HR. Act 3590, 111th Cong. (2010) (enacted).

Phillips, K.A., Morrison, K.R., Andersen, R. & Aday, L.A. (1998). Understanding the context of health care utilization: Assessing environmental and provider-related variables in the Behavioral Model of utilization. *Health Services Research, 33,* 571-596.

Polit, D.F. & Beck, C.T. (2008). *Nursing Research: Generating and assessing evidence for nursing practice* (8th ed). Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins.

Provost, B., Lopez, B.R., and Heimerl, S. (2007). A comparison of motor delays in young children: Autism spectrum disorder, developmental delay, and developmental concerns. *Journal of Autism and Developmental Disorders, 37,* 321-328. doi: 10.1007/s10803-006-0170-6

Saha, S. and Shipman, S.A. (2008). Race-neutral versus race-conscious workforce policy to improve access to care. *Health Affairs, 27,* 234-245. doi: 10.1377/hlthaff.27.1.234

Shimabukuro, T.T., Grosse, S.D. & Rice, C. (2008). Medical expenditures for children with autism spectrum disorder in a privately insured population. *Journal of Autism and Developmental Disorders, 38,* 546-552. doi: 10.1007/s10803-007-0424-y

Siaperas, P., Ring, H.A., McAllister, C.J., Henderson, S., Barnett, A., Watson, P. and Holland, A.J. (2012). Atypical movement performance and sensory integration in Asperger's Syndrome. *Journal of Autism and Developmental Disorders, 42,* 718-725. 10.1007/s10803-011-1301-2

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample. *Child and Adolescent Psychiatry, 47,* 921-929.

Smedley, B.D., Stith, A.Y. & Nelson, A.R. (Eds.) for the National Institute of Medicine's Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care (2003). *Unequal Treatment: Confronting racial and ethnic disparities in health care.* Washington, D.C.: National Academies Press. Retrieved from http://www.nap.edu/catalog/12875.html

StataCorp, LP. Stata Statistics, Version 12.1, SE [computer software]. College Station, TX.

Taylor, J.L., McPheeters, M.L., Sathe, N.A., Dove, D., Veenstra-Vanderweele, J., Warren, Z. (2012). A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics, 130,* 531-538.

Thomas, K.C., Ellis, A.R., McLaurin, C., Daniels, J., & Morrissey, J.P. (2007). Access to care for autism-related services. *Journal of Autism and Developmental Disorders, 37,* 1902-1912. doi: 10.1007/s10803-006-0323-7

Thomas, K.C., Parish, S.L., Rose, R.A., Kilany, M. (2011). Access to care for children with autism in the context of state Medicaid reimbursement. *Maternal and Children Health Journal, online first.*

Twoy, R., Connolly, P.M., & Novak, J.M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners, 19,* 251-260. doi: 10.1111/j.1745-7599.2007.00222.x

U.S. Department of Health and Human Services (n.d.) Healthy People 2020: Summary of Objectives: Maternal, Child, Infant Health. Accessed 2/24/12 at: http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=26

Vohra, R., Madhavan, S., Sambamoorthi, U. & St Peter, C. (2013). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism, Online First* (Dec 18, 2013). doi: 10.1177/1362361313512902

Wang, L., Mandell, D.S., Lawer, L., Cidav, Z, & Leslie, D.L. (2013). Healthcare service use and costs for autism spectrum disorder: A comparison between Medicaid and private insurance. *Journal of Autism and Developmental Disorders, 43,* 1057-1064. doi: 10.1007/s10803-012-1649-y

Wang, L.W., Tancredi, D.J., & Thomas, D.W. (2011). The prevalence of gastrointestinal problems in children across the United States with autism spectrum disorders from families with multiple affected members. *Journal of Developmental and Behavioral Pediatrics, 32, 35*1-360.

Warren, Z. McPheeters, M.L, Sathe, N. Foss-Feig, J.H., Glasser, A., & Veenstra-VanderWeele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics, 127,* e1303. doi: 10.1542/peds.2011-0426

Appendix A

Acronyms Used

AAP	American Academy of Pediatrics
ABA	Applied Behavior Analysis
ADHD	Attention-deficit hyperactivity disorder
ASD	Children with autism spectrum disorder
CDC	Centers for Disease Control & Prevention
CP	Cerebral palsy
CSHCN	Children with a Special Health Care Need
EDB	Children with emotional, developmental or behavioral conditions
MR	Mental retardation (more recently known as Intellectual Disability)
MSA	Metropolitan statistical area, a variable for geographical location
NIS	National Immunization Survey
NS-CSHCN	National Survey for Children with Special Health Care Needs
OT	Occupational therapy
PT	Physical therapy
SLAITS	State and Local Area Integrated Telephone Survey
ST	Speech/language therapy

Appendix B

Important Constructs from the Andersen Behavioral Model and Definitions

Construct	Operational Definition	Variable(s)	Source
Health Behavior—process of care, use of therapy services (Andersen et al., 2013)			
Need for therapy services	Parent-reported need for therapy services in the past year, coded as a Yes or No	Therapy Need	Blumberg et al. (2008), p78
Realized access	Actual use of therapy services Calculated as the number of children who have a Therapy Need and who receive all needed therapy. Conversely, lack of realized access are children who have a Therapy Need but who do not receive all needed therapy	Realized access	Andersen et al., 2013
Individual Characteristics—characteristics of the individual that can explain or predict health service use (Andersen, 1995, p1)			
Predisposing Characteristics	Socio-demographic characteristics that represent a biological or social chance of needing or using services, and which represent the person's ability to manage health problems	• Child age • Child gender • Child race • Child ethnicity	Andersen et al., 2013 Andersen (1995), p2
Enabling Characteristics	Characteristics of the household or individual that support the financing of care, and the means of getting to and using care	• Family insurance • Household poverty level	Andersen et al., 2013
Need Characteristics	Characteristics of the individual that support their view of health needs (perceived need); can also include evaluated need from a professional	• Co-morbid mental retardation • Parent-reported extent of functional limitations • Swallowing-eating problem • Self-care problem • Gross motor problem • Fine motor problem • Learning/attention problem • Communication problem	Andersen et al., 2013

Construct	Operational Definition	Variable(s)	Source
		• Anxious/depressed • Behavior problem • Social skill problem	
Contextual Characteristics—characteristics of the health care delivery system and community environment that predispose, enable or suggest a community need for services measured at a level higher than the individual (Andersen et al., 2013)			
Predisposing Characteristics	Demographic, social or prevailing beliefs of a community or health care system	• *None will be utilized in this study.* • *Can include: age or ethnic characteristics of a community*	Andersen et al., 2013
Enabling Characteristics	Financing, cost, and organization of health services in a community and health policy that impact care in that community	• Family Geographical location Reasons why parents report not receiving therapy including: • Cost too much • Health plan problem • Can't find provider who accepts insurance • Therapy not available in area • Did not know where to go for therapy • No referral • Lack of resources *Secondary analysis of Education Enabling Characteristic in 2005-06 NS-CSHCN* • *Lack of school resources*	Andersen et al., 2013 Blumberg et al. (2008), p78
Need Characteristics	Quality of the surrounding environment that influence or suggest the health of the community	• *None will be utilized in this study* • *Can include: quality of housing, air, water, death rate, morbidity, mortality*	
Provider Characteristics	Contextual characteristics of the provider that may influence a person or community's ability to obtain or use services	• Provider did not know how to treat • Dissatisfaction with provider • Inconvenient times	Phillips, Morrison, Andersen, & Aday, 1998, p576

Appendix C

Survey Questions from the 2005-06 and 2009-10 NS-CSHCN for Variables of Interest

Construct	Variable	2005-06 Survey Question [a]	2009-10 Survey Question [b]
Health Behaviors			
Need for therapy	Parent reported referral for OT/PT/ST services for child within past 12 months	During the past 12 months, was there any time when (your child) needed physical, occupational or speech therapy?	During the past 12 months, was there any time when (your child) needed physical, occupational or speech therapy?
Realized Access	Child did not receive all of referred OT/PT/ST services within the past 12 months	*For parents who said "yes" to Need for Therapy, above, they were asked:* Did (your child) receive all the therapy that (he/she) needed?	*For parents who said "yes" to Need for Therapy, above, they were asked:* Did (your child) receive all the therapy that (he/she) needed?
Diagnosis	Diagnosis per NS-CSHCN	**To the best of your knowledge, does [child's name] have…** ■ Asthma ■ Attention Deficit Disorder or Attention Deficit Hyperactive Disorder *(sic)* ■ Autism or Autism Spectrum Disorder ■ Down Syndrome ■ Mental retardation or developmental delay ■ Depression, anxiety, an eating disorder, or other emotional problem ■ Diabetes ■ A heart problem, including congenital heart disease ■ Blood problems such as anemia or sickle cell disease ■ Cystic fibrosis ■ Cerebral palsy ■ Muscular Dystrophy ■ Epilepsy or other seizure disorder ■ Migraine or frequent headaches ■ Arthritis or other joint problems ■ Allergies	**Has a doctor or other health care provider *ever* told you that X child had…** If respondent responded positively, they were asked, **Does X *currently* have ….** ■ Asthma ■ Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder ■ Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder ■ Down Syndrome ■ Intellectual disability or mental retardation ■ Developmental delay that affects X's ability to learn ■ Depression ■ Anxiety problems ■ Behavioral or conduct problems, such as oppositional defiant disorder or conduct disorder ■ Diabetes ■ A heart problem, including congenital heart disease ■ Blood problems such as anemia or sickle cell disease ■ Cystic Fibrosis ■ Cerebral Palsy ■ Muscular Dystrophy ■ Epilepsy or seizure disorder ■ Migraines or frequent headaches ■ Arthritis or other joint problems ■ Allergies ■ A head injury, concussion, or traumatic brain injury
Individual Characteristics			
Predisposing Characteristics	Age	What is the age of [your child]?	Please tell me the age of your children who are less than 18 years old living in this household.
	Gender	Is [your child] male or female?	Is [your child] male or female?
	Race	Please choose one or more of the following categories to describe [your child's] race. Is [your child] White, Black or African American, American Indian, Alaska native, Asian, Native Hawaiian or other Pacific Islander?	Please choose one or more of the following categories to describe [your child's] race. Is [your child] White, Black or African American, American Indian, Alaska native, Asian, Native Hawaiian or other Pacific Islander?
	Ethnicity	Is [your child] of Hispanic or Latino	Is [your child] of Hispanic, Latino, or Spanish

Construct	Variable	2005-06 Survey Question ^{a}	2009-10 Survey Question ^{b}
		origin?	origin?
Enabling Characteristics	Poverty level *Household dataset*	Poverty level of household *Derived based on DHHS guidelines* *1—At or below 50% FPL* *2- Above 50% to at or below 100% FPL* ….	What was the total combined income of your household in [year], including income from all sources such as wages, salaries, unemployment payments, public assistance, Social Security or retirement benefits, help from relatives and so forth? Can you tell me that amount before taxes?
	Insurance status (TYPEINS) *Interview dataset*	*Derived from multiple variables in NS-CSHCN* *--Private* *-- Public* *--Both private and public* *-- Other comprehensive ins* *--Uninsured*	*Derived from multiple variables in NS-CSHCN* *--Private* *-- Public* *--Both private and public* *-- Other comprehensive ins* *--Uninsured*
	Regular source of preventive care (C4Q02A) *Interview dataset*	A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as [S.C.]'s personal doctor or nurse?	A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as **(S.C.)**'s personal doctor or nurse?
Need Characteristics	Extent of functional limitations *Interview dataset*	[During the past 12 months / Since [his/her] birth], how often have [S.C.]'s [medical, behavioral, or other health conditions/ emotional, developmental, or behavioral problems] affected [his/her] ability to do things other children [his/her] age do? *--Never, Sometimes, Frequently, Always*	[During the past 12 months / Since [his/her] birth], how often have [S.C.]'s [medical, behavioral, or other health conditions/ emotional, developmental, or behavioral problems] affected [his/her] ability to do things other children [his/her] age do? *--Never, Sometimes, Frequently, Always*
	Intellectual disability status (MR) *Interview dataset*	*Derived from diagnosis question, above, when parent reports "yes" to mental retardation or intellectual disability*	*Derived from diagnosis question, above, when parent reports "yes" to mental retardation or intellectual disability*
	Self-care difficulty *Interview dataset*	Compared to other [child's age]-year-old children, would you say (he/she) experiences any difficulty taking care of (himself/herself), for example, doing things like eating, dressing and bathing?	Compared to other [child's age] year-old children, would you say [he/she] experiences a lot, a little, or no difficulty taking care of [himself/herself], for example, doing things like eating, dressing and bathing?
	Gross motor difficulty *Interview dataset*	Compared to other [child's age]-year-old children would you say (he/she) experiences any difficulty with coordination or moving around, such as walking or running?	Compared to other [child's age] year-old children, would you say [he/she] experiences a lot, a little, or no difficulty with coordination or moving around such as walking or running?
	Fine motor difficulty *Interview dataset*	Compared other [child's age]--year-old children would you say (he/she) experiences any difficulty using (his/her) hands such as such as using scissors, a pencil, or a fork?	Compared to other [child's age] year-old children, would you say [he/she] experiences a lot, a little, or no difficulty using (his or her) hands such as using scissors, a pencil or a fork?
	Attention-Learning *Interview dataset*	Compared to other [child's age]-year-old children, would you say (he/she)experiences any difficulty learning, understanding, or paying attention?	Compared to other [child's age] year-old children, would you say [he/she] experiences a lot, a little, or no difficulty learning, understanding, or paying attention?
	Problem behaviors *Interview dataset*	Compared to other[child's age]--year-old children, would you say (he/she) experiences any difficulty with behavior	Compared to other [child's age] year-old children, would you say [he/she] experiences a lot, a little, or no difficulty with behavior

Construct	Variable	2005-06 Survey Question [a]	2009-10 Survey Question [b]
		problems, such as acting out, fighting, bullying, or arguing?	problems, such as acting out, fighting, bullying, or arguing?
	Communicating *Interview dataset*	Compared to other[child's age]--year-old children, would you say (he/she) experiences any difficulty speaking, communicating, or being understood?	Compared to other [child's age] year-old children, would you say [he/she] experiences a lot, a little, or no difficulty speaking, communicating, or being understood?
	Socialization *Interview dataset*	Compared to other[child's age]--year-old children, would you say (he/she) experiences any difficulty making and keeping friends?	Compared to other [child's age] year-old children, would you say [he/she] experiences a lot, a little, or no difficulty making and keeping friends?
	Anxiety-Depression *Interview dataset*	Compared to other[child's age]--year-old children, would you say (he/she) experiences any difficulty with feeling anxious or depressed?	Compared to other [child's age] year-old children, would you say [he/she] experiences a lot, a little, or no difficulty with feeling anxious or depressed?

Construct	**Variable**	**2005-06 Survey Question** [a]	**2009-10 Survey Question** [b]
Contextual Characteristics			
Enabling	Geographic Region (MSASTATR) *Interview dataset*	Please tell me your zip code. *Metropolitan status (MSA) derived* *--HH within an MSA* *--HH located outside of an MSA*	Please tell me your zip code. *Metropolitan status (MSA) derived* *--HH within an MSA* *--HH located outside of an MSA*
Provider Problems	Provider did not know how to treat Inconvenient times Dissatisfaction with provider	Why did (your child) not get the [therapy]{he/she} needed? 01 COST TOO MUCH 02 NO INSURANCE 03 HEALTH PLAN PROBLEM 04 CAN'T FIND PROVIDER WHO ACCEPTS CHILD'S INSURANCE 05 NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS 06 NOT CONVENIENT TIMES/COULD NOT GET APPOINTMENT 07 PROVIDER DID NOT KNOW HOW TO TREAT OR PROVIDE CARE 08 DISSATISFACTION WITH PROVIDER 09 DID NOT KNOW WHERE TO GO FOR TREATMENT 10 CHILD REFUSED TO GO 11 TREATMENT IS ONGOING 12 VACCINE SHORTAGE 13 NO REFERRAL 14 LACK OF RESOURCES AT SCHOOL 15 DID NOT GO TO APPT/NEGLECTED APPT/FORGOT APPT 16 OTHER (SKIP TO C4Q0505OE)	Why did [your child] not get *all* the therapy [he/she] needed? (1) COST WAS TOO MUCH (2) NO INSURANCE (3) HEALTH PLAN PROBLEM (4) CAN'T FIND PROVIDER WHO ACCEPTS CHILD'S INSURANCE (5) NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS (6) NOT CONVENIENT TIMES/COULD NOT GET APPOINTMENT (7) PROVIDER DID NOT KNOW HOW TO TREAT OR PROVIDE CARE (8) DISSATISFACTION WITH PROVIDER (9) DID NOT KNOW WHERE TO GO FOR TREATMENT (10) CHILD REFUSED TO GO (11) TREATMENT IS ONGOING (13) NO REFERRAL (14) LACK OF RESOURCES AT SCHOOL (15) DID NOT GO TO APPT/NEGLECTED APPT/FORGOT APPT (16) OTHER (77) DON'T KNOW (99) REFUSED
Enabling Variables	Lack of resources at school Can't find a provider who accepts insurance Therapy cost too much Health plan problems No referral Did not know where to go Therapy not available in area		

---

[a] Survey Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 interview questions. Available at: http://www.cdc.gov/nchs/slaits/cshcn.htm

[b] Survey Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2009-2010 interview questions. Available at: http://www.cdc.gov/nchs/slaits/cshcn.htm

Appendix D

Variable Differences by Survey Year and Management Solutions

Data set	0506 Original Name	0910 Original Name	New Variable Name	Variable Format	Issue	Solution
Screener	AGE	AGE	age	AGE.		
	CSHCN1	CSHCN1	cshcn1	YNDKRFF.		
	CSHCN2	CSHCN2	cshcn2	YNDKRFF.		
	CSHCN3	CSHCN3	cshcn3	YNDKRFF.		
	CSHCN4	CSHCN4	cshcn4	YNDKRFF.		
	CSHCN5	CSHCN5	cshcn5	YNDKRFF.		
	CSHCN1_A	CSHCN1_A	cshcn1a	YNDKRFF.		
	CSHCN1_B	CSHCN1_B	cshcn1b	YNDKRFF.		
		CSHCN1_C	cshcn1c	YNDKRFF.		
	CSHCN2_A	CSHCN2_A	cshcn2a	YNDKRFF.		
	CSHCN2_B	CSHCN2_B	cshcn2b	YNDKRFF.		
		CSHCN2_C	cshcn2c	YNDKRFF.		
	CSHCN3_A	CSHCN3_A	cshcn3a	YNDKRFF.		
	CSHCN3_B	CSHCN3_B	cshcn3b	YNDKRFF.		
		CSHCN3_C	cshcn3c	YNDKRFF.		
	CSHCN4_A	CSHCN4_A	cshcn4a	YNDKRFF.		
	CSHCN4_B	CSHCN4_B	cshcn4b	YNDKRFF.		
		CSHCN4_C	cshcn4c	YNDKRFF.		
	CSHCN5_A	CSHCN5_A	cshcn5a	YNDKRFF.		
	HISPANIC	HISPANIC	hispanic	YNDKRFF.		
	IDNUMR	IDNUMR	idnumr	NUMVR.		
	IDNUMXR	IDNUMXR	idnumxr	NUMVR.		
	INTVIEW	INTVIEW	intview	INTVIEW.		
	NEEDTYPE	NEEDTYPE	needtype	NEEDTYPE.		
	RACEASIA	RACEASIA	raceasia	RACEASN.		
	RACENAAN	RACENAAN	racenaan	RACENAAN.		
	RACER	RACER	racer	RACER.	0506 1=white only, 2=black only,3= multiple, 4=other, 96=DK, 97-R; 0910 1=white only, 2=black only, 3= other	recode 0910 “3” to “4” prior to merge
	RACE_HI	RACE_HI	racehi	RACEHI.		
		SAMPLE	sample	CELLF.		
	SEX	SEX	sex	SEX.		
	STATE	STATE	state	STATE.		
	WEIGHT_S	WEIGHT_S	weight_s	NUMVR.		
Ho	C11Q11	C11Q11	welfare	YNDKRFF.		

C2Q05R	PLANGUAGE	lang	PLANGF.		
EDUCR	EDUCR	educr	EDUCR.	0506 refers to education of anyone in HH, 0910 refers to education of parents in HH	
HHSTATUS	HHSTATUS	hhstatus	HHSTATUSF.		
IDNUMR	IDNUMR	idnumr	NUMVR.		
MSASTATR	MSASTATR	msa	MSAF.	Codes are different. 0506, 1=In MSA, 2=Outside MSA; 0910, 0=Outside MSA, 1=In MSA. Also, need to recode cases that are missing due to suppression with appropriate code per Dusing et al	In 0506 Recode 2 as 0 prior to merge. For both datasets, if STATE= 1, 14, 22, 27, 29, 42, 47, or 51, recode MSA to 0. If STATE= 7,9,12,20,21,31,34,40 recode MSA to 1.
NM_NSPFR	NM_NSPFR				
NM_NSPMR	NM_NSPMR				
NM_NSPR	NM_NSPR				
NM_SPFR	NM_SPFR				
NM_SPMR	NM_SPMR				
NM_SPR	NM_SPR				
OTH_LANGR	OTH_LANGR				
POVLEVEL	POVLEVEL	povlevel	POVERTY_LEVELF.		
STATE	STATE	state	STATE.		
TOTADULTR	TOTADULTR				
TOTKIDFR	TOTKIDSFR			Name is different in 0506.	Rename 0506 TOTKIDFR to TOTKIDSFR
TOTKIDMR	TOTKIDSMR			Name is different in 0506.	Rename 0506 TOTKIDMR to TOTKIDSMR
TOTKIDSR	TOTKIDSR				
WEIGHT_H	WEIGHT_H	weight_h	NUMVR.		
	SAMPLE	sample			

Main Interview	AGE	AGE	age	AGE.		
	STATE	STATE	state	STATE.		
	TYPEINS	TYPEINS	typeins	INSTYPE.		
	UNINS	UNINS	unins	UNINS.		
	UNINS_YR	UNINS_YR	uninsyr	UNINSYR.		
	WEIGHT_I	WEIGHT_I	weight_i	NUMVR.		
	YS_UNINS	YS_UNINS	ysunin	UNINSY.		
		SAMPLE	sample	CELLF.	0506 did not have a cell phone sample. But, this needs to be included in stratification	Dr. Blumberg from CDC indicates that all 0506 "sample" codes be designated as "landline".
	C11Q12	C11Q12	ssi	YNDKRFF.		
	C11Q13	C11Q13	ssidis	YNDKRFF.		
	C3Q02	C3Q02	freqdis	HOWOFTE.		
	C3Q03	C3Q03	affected	C3Q03F.		
	C3Q10		severe	SEVERIT.	In 0910 asked severity only for certain conditions.	Recode the single variable from 0506 (C3Q10) and the few variables from 0910 (K2Q31C, etc) into one new variable (severe). If a child does not have this data, it will be marked as missing.
		K2Q31C	severe			
		K2Q32C	severe			
		K2Q33C	severe			
		K2Q34C	severe			
		K2Q35C	severe			
		K2Q36C	severe			
		K2Q42C	severe			
		K2Q37C	severe			
		K2Q44C	severe			
	C3Q11	C3Q11	needstbl	C3Q11F.		
	C3Q12	C3Q12	earlyint	YNDKRFF.		
	C3Q13	C3Q13	speced	YNDKRFF.		
		C3Q13A	C3Q13A	DKRFF.		
		C3Q13AA	C3Q13AA	K2Q35DA.		
		C3Q13B	C3Q13B	YNDKRFF.		

C3Q14R	C3Q14R	schlmiss	C3Q14R.
	C3Q15	C3Q15	YNDKRFF.
	C3Q40	C3Q40	YNDKRFF.
	C3Q41	C3Q41	YNDKRFF.
	C3Q42	C3Q42	YNDKRFF.
	C3Q43	C3Q43	YNDKRFF.
	C3Q50	C3Q50	YNDKRFF.
C40501BR01	C4Q05_1BR01	wellcost	YNDKRFF.
C40501BR02	C4Q05_1BR02	wellunins	YNDKRFF.
C40501BR03	C4Q05_1BR03	wellplan	YNDKRFF.
C40501BR04	C4Q05_1BR04	wellinsur	YNDKRFF.
C40501BR05	C4Q05_1BR05	welltrans	YNDKRFF.
C40501BR06	C4Q05_1BR06	welltime	YNDKRFF.
C40501BR07	C4Q05_1BR07	wellknow	YNDKRFF.
C40501BR08	C4Q05_1BR08	wellsatis	YNDKRFF.
C40501BR09	C4Q05_1BR09	wellwhere	YNDKRFF.
C40501BR10	C4Q05_1BR10	wellrefus	YNDKRFF.
C40501BR11	C4Q05_1BR11	wellongoing	YNDKRFF.
C40501BR12		wellvacc	YNDKRFF.
C40501BR13	C4Q05_1BR13	wellrefer	YNDKRFF.
C40501BR14	C4Q05_1BR14	wellschool	YNDKRFF.
C40501BR15	C4Q05_1BR15	wellforgot	YNDKRFF.
C40501BR16	C4Q05_1BR16	wellother	YNDKRFF.
C40501BR17	C4Q05_1BR17	wellsick	YNDKRFF.
C40501BR18		C40501BR18	YNDKRFF.
C40501BR19		C40501BR19	YNDKRFF.
	C4Q05_1BR18	welldiff	YNDKRFF.
C40502BR01	C4Q05_2BR01	speccost	YNDKRFF.
C40502BR02	C4Q05_2BR02	specunins	YNDKRFF.
C40502BR03	C4Q05_2BR03	specplan	YNDKRFF.
C40502BR04	C4Q05_2BR04	specinsur	YNDKRFF.
C40502BR05	C4Q05_2BR05	spectrans	YNDKRFF.
C40502BR06	C4Q05_2BR06	spectime	YNDKRFF.
C40502BR07	C4Q05_2BR07	specknow	YNDKRFF.
C40502BR08	C4Q05_2BR08	specsatis	YNDKRFF.
C40502BR09	C4Q05_2BR09	specwhere	YNDKRFF.
C40502BR10	C4Q05_2BR10	soecrefus	YNDKRFF.
C40502BR11	C4Q05_2BR11	specongoing	YNDKRFF.

C40502BR12		specvacc	YNDKRFF.
C40502BR13	C4Q05_2BR13	specrefer	YNDKRFF.
C40502BR14	C4Q05_2BR14	specschool	YNDKRFF.
C40502BR15	C4Q05_2BR15	specforgot	YNDKRFF.
C40502BR16	C4Q05_2BR16	specother	YNDKRFF.
	C4Q05_2BR17	specsick	YNDKRFF.
	C4Q05_2BR18	specdiff	YNDKRFF.
C405031BR01	C4Q05_31BR01	C405031BR01	YNDKRFF.
C405031BR02	C4Q05_31BR02	C405031BR02	YNDKRFF.
C405031BR03	C4Q05_31BR03	C405031BR03	YNDKRFF.
C405031BR04	C4Q05_31BR04	C405031BR04	YNDKRFF.
C405031BR05	C4Q05_31BR05	C405031BR05	YNDKRFF.
C405031BR06	C4Q05_31BR06	C405031BR06	YNDKRFF.
C405031BR07	C4Q05_31BR07	C405031BR07	YNDKRFF.
C405031BR08	C4Q05_31BR08	C405031BR08	YNDKRFF.
C405031BR09	C4Q05_31BR09	C405031BR09	YNDKRFF.
C405031BR10	C4Q05_31BR10	C405031BR10	YNDKRFF.
C405031BR11	C4Q05_31BR11	C405031BR11	YNDKRFF.
C405031BR12		C405031BR12	YNDKRFF.
C405031BR13	C4Q05_31BR13	C405031BR13	YNDKRFF.
C405031BR14	C4Q05_31BR14	C405031BR14	YNDKRFF.
C405031BR15	C4Q05_31BR15	C405031BR15	YNDKRFF.

C405031BR16	C4Q05_31BR16	C405031BR16	YNDKRFF.
C405031BR17	C4Q05_31BR17	C405031BR17	YNDKRFF.
C405031BR18	C4Q05_31BR18	C405031BR18	YNDKRFF.
C405031BR19		C405031BR19	YNDKRFF.
C405031BR20		C405031BR20	YNDKRFF.
C405032BR01	C4Q05_32BR01	C405032BR01	YNDKRFF.
C405032BR02	C4Q05_32BR02	C405032BR02	YNDKRFF.
C405032BR03	C4Q05_32BR03	C405032BR03	YNDKRFF.
C405032BR04	C4Q05_32BR04	C405032BR04	YNDKRFF.
C405032BR05	C4Q05_32BR05	C405032BR05	YNDKRFF.
C405032BR06	C4Q05_32BR06	C405032BR06	YNDKRFF.
C405032BR07	C4Q05_32BR07	C405032BR07	YNDKRFF.
C405032BR08	C4Q05_32BR08	C405032BR08	YNDKRFF.
C405032BR09	C4Q05_32BR09	C405032BR09	YNDKRFF.
C405032BR10	C4Q05_32BR10	C405032BR10	YNDKRFF.
C405032BR11	C4Q05_32BR11	C405032BR11	YNDKRFF.
C405032BR12		C405032BR12	YNDKRFF.
C405032BR13	C4Q05_32BR13	C405032BR13	YNDKRFF.
C405032BR14	C4Q05_32BR1		YNDKRFF.

	4	C405032BR14	
C405032BR15	C4Q05_32BR15	C405032BR15	YNDKRFF.
C405032BR16	C4Q05_32BR16	C405032BR16	YNDKRFF.
	C4Q05_32BR17	C405032BR17	YNDKRFF.
	C4Q05_32BR18	C405032BR18	YNDKRFF.
C40504BR01	C4Q05_4BR01	C40504BR01	YNDKRFF.
C40504BR02	C4Q05_4BR02	C40504BR02	YNDKRFF.
C40504BR03	C4Q05_4BR03	C40504BR03	YNDKRFF.
C40504BR04	C4Q05_4BR04	C40504BR04	YNDKRFF.
C40504BR05	C4Q05_4BR05	C40504BR05	YNDKRFF.
C40504BR06	C4Q05_4BR06	C40504BR06	YNDKRFF.
C40504BR07	C4Q05_4BR07	C40504BR07	YNDKRFF.
C40504BR08	C4Q05_4BR08	C40504BR08	YNDKRFF.
C40504BR09	C4Q05_4BR09	C40504BR09	YNDKRFF.
C40504BR10	C4Q05_4BR10	C40504BR10	YNDKRFF.
C40504BR11	C4Q05_4BR11	C40504BR11	YNDKRFF.
C40504BR12		C40504BR12	YNDKRFF.
C40504BR13	C4Q05_4BR13	C40504BR13	YNDKRFF.
C40504BR14	C4Q05_4BR14	C40504B	YNDKRFF.

		R14			
C40504BR15	C4Q05_4BR15	C40504BR15	YNDKRFF.		
C40504BR16	C4Q05_4BR16	C40504BR16	YNDKRFF.		
	C4Q05_4BR17	C40504BR17	YNDKRFF.		
	C4Q05_4BR18	C40504BR18	YNDKRFF.		
C40505BR01	C4Q05_5BR01	txcost	YNDKRFF.		
C40505BR02	C4Q05_5BR02	txunins	YNDKRFF.		
C40505BR03	C4Q05_5BR03	txplan	YNDKRFF.		
C40505BR04	C4Q05_5BR04	txinsur	YNDKRFF.		
C40505BR05	C4Q05_5BR05	txtrans	YNDKRFF.		
C40505BR06	C4Q05_5BR06	txtime	YNDKRFF.		
C40505BR07	C4Q05_5BR07	txknow	YNDKRFF.		
C40505BR08	C4Q05_5BR08	txsatis	YNDKRFF.		
C40505BR09	C4Q05_5BR09	txwhere	YNDKRFF.		
C40505BR10	C4Q05_5BR10	txrefus	YNDKRFF.		
C40505BR11	C4Q05_5BR11	txongoing	YNDKRFF.		
C40505BR12		txvacc	YNDKRFF.		
C40505BR13	C4Q05_5BR13	txrefer	YNDKRFF.		
C40505BR14	C4Q05_5BR14	txschool	YNDKRFF.		
C40505BR15	C4Q05_5BR15	txforgot	YNDKRFF.		
C40505BR16	C4Q05_5BR16	txother	YNDKRFF.		
C40505BR17	C4Q05_5BR17	txsick	YNDKRFF.		
C40505BR18		txabs	YNDKRFF.	there is a similar variable in 0910, but the question/content is different.	need to carefully rename the 0506 variable and be sure it didn't recode the similar 0910 variable
C40505BR19		txnoscl	YNDKRFF.		
	C4Q05_5BR18	txdiff	YNDKRFF.	there is a similar variable in 0910, but the question/content is different.	
C40506BR01	C4Q05_6BR01	mhcost	YNDKRFF.		
C40506BR02	C4Q05_6BR02	mhunins	YNDKRFF.		
C40506BR03	C4Q05_6BR03	mhplan	YNDKRFF.		

C40506BR04	C4Q05_6BR04	mhinsur	YNDKRFF.
C40506BR05	C4Q05_6BR05	mhtrans	YNDKRFF.
C40506BR06	C4Q05_6BR06	mhtime	YNDKRFF.
C40506BR07	C4Q05_6BR07	mhknow	YNDKRFF.
C40506BR08	C4Q05_6BR08	mhsatis	YNDKRFF.
C40506BR09	C4Q05_6BR09	mhwhere	YNDKRFF.
C40506BR10	C4Q05_6BR10	mhrefus	YNDKRFF.
C40506BR11	C4Q05_6BR11	mhongoing	YNDKRFF.
C40506BR12		mhvacc	YNDKRFF.
C40506BR13	C4Q05_6BR13	mhrefer	YNDKRFF.
C40506BR14	C4Q05_6BR14	mhschool	YNDKRFF.
C40506BR15	C4Q05_6BR15	mhforgot	YNDKRFF.
C40506BR16	C4Q05_6BR16	mhother	YNDKRFF.
	C4Q05_6BR17	mhsick	YNDKRFF.
	C4Q05_6BR18	mhdiff	YNDKRFF.
C40507BR01	C4Q05_7BR01	C40507BR01	YNDKRFF.
C40507BR02	C4Q05_7BR02	C40507BR02	YNDKRFF.
C40507BR03	C4Q05_7BR03	C40507BR03	YNDKRFF.
C40507BR04	C4Q05_7BR04	C40507BR04	YNDKRFF.
C40507BR05	C4Q05_7BR05	C40507BR05	YNDKRFF.
C40507BR06	C4Q05_7BR06	C40507BR06	YNDKRFF.
C40507BR07	C4Q05_7BR07	C40507BR07	YNDKRFF.
C40507BR08	C4Q05_7BR08	C40507BR08	YNDKRFF.
C40507BR09	C4Q05_7BR09	C40507BR09	YNDKRFF.
C40507BR10	C4Q05_7BR10	C40507BR10	YNDKRFF.
C40507BR11	C4Q05_7BR11	C40507BR11	YNDKRFF.
C40507BR12			YNDKRFF.

		C40507BR12	
C40507BR13	C4Q05_7BR13	C40507BR13	YNDKRFF.
C40507BR14	C4Q05_7BR14	C40507BR14	YNDKRFF.
C40507BR15	C4Q05_7BR15	C40507BR15	YNDKRFF.
C40507BR16	C4Q05_7BR16	C40507BR16	YNDKRFF.
	C4Q05_7BR17	C4Q05_7BR17	YNDKRFF.
	C4Q05_7BR18	C4Q05_7BR18	YNDKRFF.
C40601BR01	C4Q06_1BR01	respcost	YNDKRFF.
C40601BR02	C4Q06_1BR02	respunins	YNDKRFF.
C40601BR03	C4Q06_1BR03	respplan	YNDKRFF.
C40601BR04	C4Q06_1BR04	respinsur	YNDKRFF.
C40601BR05	C4Q06_1BR05	resptrans	YNDKRFF.
C40601BR06	C4Q06_1BR06	resptime	YNDKRFF.
C40601BR07	C4Q06_1BR07	respknow	YNDKRFF.
C40601BR08	C4Q06_1BR08	respsatis	YNDKRFF.
C40601BR09	C4Q06_1BR09	respwhere	YNDKRFF.
C40601BR10	C4Q06_1BR10	resprefus	YNDKRFF.
C40601BR11	C4Q06_1BR11	respongoing	YNDKRFF.
C40601BR12		respvacc	YNDKRFF.
C40601BR13	C4Q06_1BR13	resprefer	YNDKRFF.
C40601BR14	C4Q06_1BR14	respschool	YNDKRFF.
C40601BR15	C4Q06_1BR15	respforgot	YNDKRFF.
C40601BR16	C4Q06_1BR16	respother	YNDKRFF.
C40601BR17		C40601BR17	YNDKRFF.
C40601BR18		C40601BR18	YNDKRFF.
C40601BR19		C40601BR19	YNDKRFF.
C40601BR20		C40601BR20	YNDKRFF.

	C4Q06_1BR17	respsick	YNDKRFF.	There is a similar variable in 0910, but the question/content is different.	Rename variable in 0910 prior to merge.
	C4Q06_1BR18	respdiff	YNDKRFF.	There is a similar variable in 0910, but the question/content is different.	Rename variable in 0910 prior to merge.
C40602BR01	C4Q06_2BR01	C40602BR01	YNDKRFF.		
C40602BR02	C4Q06_2BR02	C40602BR02	YNDKRFF.		
C40602BR03	C4Q06_2BR03	C40602BR03	YNDKRFF.		
C40602BR04	C4Q06_2BR04	C40602BR04	YNDKRFF.		
C40602BR05	C4Q06_2BR05	C40602BR05	YNDKRFF.		
C40602BR06	C4Q06_2BR06	C40602BR06	YNDKRFF.		
C40602BR07	C4Q06_2BR07	C40602BR07	YNDKRFF.		
C40602BR08	C4Q06_2BR08	C40602BR08	YNDKRFF.		
C40602BR09	C4Q06_2BR09	C40602BR09	YNDKRFF.		
C40602BR10	C4Q06_2BR10	C40602BR10	YNDKRFF.		
C40602BR11	C4Q06_2BR11	C40602BR11	YNDKRFF.		
C40602BR12		C40602BR12	YNDKRFF.		
C40602BR13	C4Q06_2BR13	C40602BR13	YNDKRFF.		
C40602BR14	C4Q06_2BR14	C40602B	YNDKRFF.		

		R14	
C40602BR15	C4Q06_2BR15	C40602BR15	YNDKRFF.
C40602BR16	C4Q06_2BR16	C40602BR16	YNDKRFF.
	C4Q06_2BR17	C40602BR17	YNDKRFF.
	C4Q06_2BR18	C40602BR18	YNDKRFF.
C40603BR01	C4Q06_3BR01	C40603BR01	YNDKRFF.
C40603BR02	C4Q06_3BR02	C40603BR02	YNDKRFF.
C40603BR03	C4Q06_3BR03	C40603BR03	YNDKRFF.
C40603BR04	C4Q06_3BR04	C40603BR04	YNDKRFF.
C40603BR05	C4Q06_3BR05	C40603BR05	YNDKRFF.
C40603BR06	C4Q06_3BR06	C40603BR06	YNDKRFF.
C40603BR07	C4Q06_3BR07	C40603BR07	YNDKRFF.
C40603BR08	C4Q06_3BR08	C40603BR08	YNDKRFF.
C40603BR09	C4Q06_3BR09	C40603BR09	YNDKRFF.
C40603BR10	C4Q06_3BR10	C40603BR10	YNDKRFF.
C40603BR11	C4Q06_3BR11	C40603BR11	YNDKRFF.
C40603BR12		C40603BR12	YNDKRFF.
C40603BR13	C4Q06_3BR13	C40603BR13	YNDKRFF.
C40603BR14	C4Q06_3BR14	C40603BR14	YNDKRFF.

C40603BR15	C4Q06_3BR15	C40603BR15	YNDKRFF.
C40603BR16	C4Q06_3BR16	C40603BR16	YNDKRFF.
	C4Q06_3BR17	C4Q06_3BR17	YNDKRFF.
	C4Q06_3BR18	C4Q06_3BR18	YNDKRFF.
C4Q01	C4Q01	placecare	YNDKRFF.
C4Q03		C4Q03	YNDKRFF.
	C4Q04	frustrat	HOWOFTE.
C4Q07	C4Q07	referralprob	C4Q07F.
C4Q02A	C4Q02A	hasdoctor	C4Q02AF.
C4Q02BR01	C4Q02BR01	typedoc	YNDKRFF.
C4Q02BR02	C4Q02BR02	typeped	YNDKRFF.
C4Q02BR03	C4Q02BR03	typespec	YNDKRFF.
C4Q02BR04	C4Q02BR04	typenp	YNDKRFF.
C4Q02BR05	C4Q02BR05	typepa	YNDKRFF.
C4Q02BR06	C4Q02BR06	typerel	YNDKRFF.
C4Q02BR07	C4Q02BR07	typeoth	YNDKRFF.
	C4Q02BR08	typemh	YNDKRFF.
C4Q02R	C4Q02R	placedr	C4Q0B_BC.
C4Q04_A		C4Q04_A	YNDKRFF.
C4Q04_B		C4Q04_B	YNDKRFF.
C4Q04_C		C4Q04_C	YNDKRFF.
C4Q04_D		C4Q04_D	YNDKRFF.
C4Q04_E		C4Q04_E	YNDKRFF.
C4Q04_F		C4Q04_F	YNDKRFF.
C4Q04_G		C4Q04_G	YNDKRFF.
C4Q04_H		C4Q04_H	YNDKRFF.
C4Q04_I		C4Q04_I	YNDKRFF.
C4Q04_J		C4Q04_J	YNDKRFF.
C4Q04_K		C4Q04_K	YNDKRFF.
C4Q04_L		C4Q04_L	YNDKRFF.
	C4Q03_A	C4Q03_A	YNDKRFF.
	C4Q03_B	C4Q03_B	YNDKRFF.

	C4Q03_C	C4Q03_C	YNDKRFF.
	C4Q03_D	C4Q03_D	YNDKRFF.
	C4Q03_E	C4Q03_E	YNDKRFF.
	C4Q03_F	C4Q03_F	YNDKRFF.
C4Q05X01A	C4Q05_1A	allwell	YNDKRFF.
C4Q05X01C		anywell	YNDKRFF.
C4Q05X02A	C4Q05_2A	allspec	YNDKRFF.
C4Q05X02AAR	C4Q05_2AAR	numspec	C4Q05_2AAR.
C4Q05X02C	C4Q05_2C	anyspec	YNDKRFF.
C4Q05X031A	C4Q05_31A	alldental	YNDKRFF.
C4Q05X031C		C4Q05X031C	YNDKRFF.
C4Q05X032A	C4Q05_32A	alldental2	YNDKRFF.
C4Q05X032C	C4Q05_32C	anydental2	YNDKRFF.
C4Q05X04A	C4Q05_4A	allmeds	YNDKRFF.
C4Q05X04C	C4Q05_4C	anymeds	YNDKRFF.
C4Q05X05A	C4Q05_5A	alltx	YNDKRFF.
C4Q05X05C	C4Q05_5C	anytx	YNDKRFF.
C4Q05X06A	C4Q05_6A	allmh	YNDKRFF.
C4Q05X06C	C4Q05_6C	anymh	YNDKRFF.
C4Q05X07A	C4Q05_7A	allabuse	YNDKRFF.
C4Q05X07C	C4Q05_7C	anyabuse	YNDKRFF.
C4Q05X08A	C4Q05_8A	allhomecare	YNDKRFF.
C4Q05X08C	C4Q05_8C	anyhomecare	YNDKRFF.
C4Q05X09A	C4Q05_9A	allglasses	YNDKRFF.
C4Q05X09C	C4Q05_9C	anyglasses	YNDKRFF.
C4Q05X10A	C4Q05_10A	allhearing	YNDKRFF.
C4Q05X10C	C4Q05_10C	anyhearing	YNDKRFF.
C4Q05X11A	C4Q05_11A	alldevice	YNDKRFF.
C4Q05X11C	C4Q05_11C	anydevice	YNDKRFF.
C4Q05X12A	C4Q05_12A	allcomm	YNDKRFF.
C4Q05X12C	C4Q05_12C	anycomm	YNDKRFF.
C4Q05X13A		C4Q05X13A	YNDKRFF.
C4Q05X13C		C4Q05X13C	YNDKRFF.
C4Q05X14A	C4Q05_14A	alldme	YNDKRFF.
C4Q05X14C	C4Q05_14C	anydme	YNDKRFF.
C4Q05_X01	C4Q05_1	wellneed	YNDKRFF.

C4Q05_X02	C4Q05_2	specneed	YNDKRFF.
C4Q05_X04	C4Q05_4	medneed	YNDKRFF.
C4Q05_X05	C4Q05_5	txneed	YNDKRFF.
C4Q05_X06	C4Q05_6	mhneed	YNDKRFF.
C4Q05_X07	C4Q05_7	abuseneed	YNDKRFF.
C4Q05_X08	C4Q05_8	homecareneed	YNDKRFF.
C4Q05_X09	C4Q05_9	visionneed	YNDKRFF.
C4Q05_X10	C4Q05_10	hearneed	YNDKRFF.
C4Q05_X11	C4Q05_11	deviceneed	YNDKRFF.
C4Q05_X12	C4Q05_12	commneed	YNDKRFF.
C4Q05_X13		C4Q05_X13	YNDKRFF.
C4Q05_X14	C4Q05_14	dmneed	YNDKRFF.
C4Q05_X031	C4Q05_31	dentalneed	YNDKRFF.
C4Q05_X032	C4Q05_32	dental2need	YNDKRFF.
C4Q06X01A	C4Q06_1A	allrespite	YNDKRFF.
C4Q06X01C	C4Q06_1C	anyrespite	YNDKRFF.
C4Q06X02A	C4Q06_2A	allgenetic	YNDKRFF.
C4Q06X02C	C4Q06_2C	anygenetic	YNDKRFF.
C4Q06X03A	C4Q06_3A	allmh	YNDKRFF.
C4Q06X03C	C4Q06_3C	anymh	YNDKRFF.
C4Q06_X01	C4Q06_1	respiteneed	YNDKRFF.
C4Q06_X02	C4Q06_2	geneticneed	YNDKRFF.
C4Q06_X03	C4Q06_3	fammhneed	YNDKRFF.
C4Q0A	C4Q0A	C4Q0A	C4Q0AF.
C4Q0BR	C4Q0BR	C4Q0BR	C4Q0B_BC.
C4Q0D	C4Q0D	C4Q0D	C4Q0AF.
C5Q01	C5Q01	C5Q01	YNDKRFF.
C5Q05	C5Q05	C5Q05	YNDKRFF.
C5Q06	C5Q06	C5Q06	SATISFI.
C5Q09	C5Q09	C5Q09	C5Q09F.
C5Q10	C5Q10	C5Q10	C5Q10F.
C5Q11	C5Q11	C5Q11	YNDKRFF.
C5Q12	C5Q12	C5Q12	YNDKRFF.
C5Q13	C5Q13	C5Q13	YNDKRFF.
C5Q15	C5Q15	C5Q15	YNDKRFF.
C5Q17	C5Q17	C5Q17	YNDKRFF.
C5Q14R01			YNDKRFF.

		C5Q14R01	
C5Q14R02		C5Q14R02	YNDKRFF.
C5Q14R03		C5Q14R03	YNDKRFF.
C5Q14R04		C5Q14R04	YNDKRFF.
C5Q14R05		C5Q14R05	YNDKRFF.
C5Q14R06		C5Q14R06	YNDKRFF.
C5Q14R07		C5Q14R07	YNDKRFF.
C5Q14R08		C5Q14R08	YNDKRFF.
C5Q14R09		C5Q14R09	YNDKRFF.
C5Q14R10		C5Q14R10	YNDKRFF.
C5Q14R11		C5Q14R11	YNDKRFF.
C5Q14R12		C5Q14R12	YNDKRFF.
C5Q14R13		C5Q14R13	YNDKRFF.
C5Q14R14		C5Q14R14	YNDKRFF.
C5Q14R15		C5Q14R15	YNDKRFF.
C5Q14R16		C5Q14R16	YNDKRFF.
C5Q16R01	C5Q16R01	parentcoor	YNDKRFF.
C5Q16R02	C5Q16R02	guardcoor	YNDKRFF.
C5Q16R03	C5Q16R03	famcoor	YNDKRFF.
C5Q16R04	C5Q16R04	frindcoor	YNDKRFF.
C5Q16R05	C5Q16R05	nursecoor	YNDKRFF.
C5Q16R06	C5Q16R06	thercoor	YNDKRFF.

C5Q16R07	C5Q16R07	socworcoor	YNDKRFF.		
C5Q16R08	C5Q16R08	hospcoor	YNDKRFF.		
C5Q16R09	C5Q16R09	casecoor	YNDKRFF.		
C5Q16R10	C5Q16R11	othercoor	YNDKRFF.	variable name from 0506 is same as 0910, but content of variable question is different	Recode the 0910 variable prior to merging 0506 data
	C5Q16R10	schlcoor	YNDKRFF.		
	C6Q01	C6Q01	YNDKRFF.		
C6Q02	C6Q02	C6Q02	HOWOFTE.		
C6Q03	C6Q03	C6Q03	HOWOFTE.		
C6Q04	C6Q04	C6Q04	HOWOFTE.		
C6Q05	C6Q05	C6Q05	HOWOFTE.		
C6Q06	C6Q06	C6Q06	HOWOFTE.		
C6Q07	C6Q07	C6Q07	YNDKRFF.		
C6Q08	C6Q08	C6Q08	HOWOFTE.		
C6Q00R	C6Q00R	C6Q00R	C6Q00R.		
C6Q01R		C6Q01R	C6Q01R.	Format is from 0506 formats	
C6Q01_A		C6Q01_A	C6Q01_A	Format is from 0506 formats	
C6Q0A	C6Q0A	C6Q0A	YNDKRFF.		
C6Q0A_B	C6Q0A_B	C6Q0A_B	YNDKRFF.		
C6Q0A_C	C6Q0A_C	C6Q0A_C	YNDKRFF.		
C6Q0A_D	C6Q0A_D	C6Q0A_D	YNDKRFF.		
C6Q0A_E	C6Q0A_E	C6Q0A_E	YNDKRFF.		
C6Q0A_F	C6Q0A_F	C6Q0A_F	YNDKRFF.		
C6Q0C		C6Q0C	C6Q0C	Format is from 0506 formats	
C6Q0D		C6Q0D	YNDKRFF.		
C6Q0E_A		C6Q0E_A	YNDKRFF.		
C6Q0E_B		C6Q0E_B	YNDKRFF.		
C6Q0E_C		C6Q0E_C	YNDKRFF.		
C6Q0E_D		C6Q0E_D	YNDKRFF.		
C6Q0E_E		C6Q0E_E	YNDKRFF.		
C6Q0E_E1		C6Q0E_E	YNDKRFF.		

		1	
C6Q0E_F		C6Q0E_F	YNDKRFF.
C6Q0E_G		C6Q0E_G	YNDKRFF.
C6Q0E_H		C6Q0E_H	YNDKRFF.
C6Q0E_I		C6Q0E_I	YNDKRFF.
C6Q0E_J		C6Q0E_J	YNDKRFF.
C6Q0E_K		C6Q0E_K	YNDKRFF.
C6Q0E_L		C6Q0E_L	YNDKRFF.
	C6Q21	C6Q21	C6Q21F.
	C6Q22	C6Q22	HOWOFTE.
	C6Q23	C6Q23	HOWOFTE.
	C6Q24	C6Q24	HOWOFTE.
	C6Q30	C6Q30	YNDKRFF.
	C6Q31A	C6Q31A	YNDKRFF.
	C6Q31B	C6Q31B	YNDKRFF.
	C6Q32A	C6Q32A	YNDKRFF.
	C6Q32B	C6Q32B	YNDKRFF.
C7Q01	C7Q01	C7Q01	YNDKRFF.
C7Q02	C7Q02	C7Q02	YNDKRFF.
C7Q03	C7Q03	C7Q03	YNDKRFF.
C7Q04	C7Q04	C7Q04	YNDKRFF.
C7Q05	C7Q05	C7Q05	YNDKRFF.
C7Q07	C7Q07	C7Q07	YNDKRFF.
C7Q09	C7Q09	C7Q09	YNDKRFF.
C7Q03A	C7Q03A	C7Q03A	YNDKRFF.
C7Q08A	C7Q08A	C7Q08A	YNDKRFF.
C7Q08B	C7Q08B	C7Q08B	YNDKRFF.
	C7Q08C	C7Q08C	YNDKRFF.
	C7Q15B	C7Q15B	YNDKRFF.
C7Q15R01	C7Q15R01	C7Q15R01	YNDKRFF.
C7Q15R02	C7Q15R02	C7Q15R02	YNDKRFF.
C7Q15R04	C7Q15R03	C7Q15R03	YNDKRFF.
C7Q15R05	C7Q15R04	C7Q15R04	YNDKRFF.
C7Q15R06	C7Q15R05	C7Q15R05	YNDKRFF.
C7Q15R07	C7Q15R06	C7Q15R06	YNDKRFF.
C7Q15R08	C7Q15R07	C7Q15R0	YNDKRFF.

		7			
C7Q15R09	C7Q15R08	C7Q15R08	YNDKRFF.		
C7Q15R10	C7Q15R09	C7Q15R09	YNDKRFF.		
C8Q01_A	C8Q01_A	C8Q01_A	HOWOFTE.		
C8Q01_B	C8Q01_B	C8Q01_B	C8Q01BF.		
C8Q01_C	C8Q01_C	C8Q01_C	HOWOFTE.		
C9Q01	C9Q01	C9Q01	C9Q01F.		
C9Q02	C9Q02	C9Q02	YNDKRFF.		
C9Q05	C9Q05	C9Q05	YNDKRFF.		
C9Q06	C9Q06	C9Q06	YNDKRFF.		
C9Q07		C9Q07	YNDKRFF.		
C9Q10	C9Q10	C9Q10	YNDKRFF.		
	C9Q11	C9Q11	YNDKRFF.		
C9Q01_A	C9Q01_A	C9Q01_A	C9Q01AF.		
C9Q03R	C9Q03R	C9Q03R	C9Q03R.		
C9Q03_A		DO NOT KEEP			
C9Q04R	C9Q04R	C9Q04R	C9Q03R.		
C9Q04_A		DO NOT KEEP			
FAMSTRUCT	FAMSTRUCT	FAMSTRUCT	FAMSTRUC.		
IDNUMR	IDNUMR	IDNUMR	NUMVR.		
IDNUMXR	IDNUMXR	IDNUMXR	NUMVR.		
MSASTATR	MSASTATR	MSASTATR	MSAF.		
MS_UNINS	MS_UNINS	MS_UNINS	UNINSM.		
NEEDTYPE	NEEDTYPE	NEEDTYPE	NEEDTYPE.		
RELATIONR	RELATIONR	RELATIONR	REL.		
S3Q01B	C3Q21	diffsee	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q02B	C3Q22	diffhear	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be

					recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q03	C3Q23	diffbreath	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q04	C3Q24	diffswal	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q05	C3Q25	diffcirc	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q06	C3Q26	diffpain	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q07	C3Q27	diffcare	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.

S3Q08	C3Q28	diffgross	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q09	C3Q29	difffine	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q10	C3Q30	diffatt	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q11	C3Q31	diffspk	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q12	C3Q32	diffanx	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q13	C3Q33	diffbeh	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0";

					0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q14	C3Q34	diffsoc	DO NOT USE 0910	0506 was y/no, 0910 ordinal response	Recode 0910 prior to merging variables. 0910 code of "3" should be recoded to "0"; 0910 code of "2" recoded to "1". The labeling will be YNDKRFF.
S3Q15	C3Q35	noprob	YNDKRFF.		
S3Q16	K2Q40B	asthma	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q40A	everasthma09	YNDKRFF.		
S3Q17	K2Q31B	adhd	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q31A	everadhd09	YNDKRFF.		
S3Q18	K2Q35B	autism	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q35A	everaut09	YNDKRFF.		
S3Q19	K2Q50B	downs	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked	No solution.

				whether the child "currently" had XYZ issue.	
	K2Q50A	everdown09	YNDKRFF.		
S3Q20	K2Q37B	idmr	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue. Additionally, 0506 asked whether the child had MR or developmental delay, and in 0910, they asked about DD separately.	No solution.
	K2Q37A	evermr09	YNDKRFF.		
S3Q21		emotiondx05	YNDKRFF.		
S3Q22	K2Q41B	diabetes	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q41A	everdiabet09	YNDKRFF.		
S3Q23	K2Q45B	cardiac	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q45A	everheart09	YNDKRFF.		

S3Q25	K2Q46B	blood	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q46A	everblood 09	YNDKRFF.		
S3Q26	K2Q47B	cystic	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q47A	evercf09	YNDKRFF.		
S3Q27	K2Q48B	cerebral	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q48A	evercp09	YNDKRFF.		
S3Q28	K2Q49B	mdyst	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q49A	evermdyst 09	YNDKRFF.		
S3Q29	K2Q42B	seizure	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ	No solution.

				issue.	
	K2Q42A	everseiz09	YNDKRFF.		
S3Q30	K2Q43B	migraine	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q43A	evermig09	YNDKRFF.		
S3Q31	K2Q52B	allergy	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q52A	everaller09	YNDKRFF.		
S3Q32	K2Q51B	joint	YNDKRFF.	0506 asked whether child had XYZ issue. 0910 asked whether the child "currently" had XYZ issue.	No solution.
	K2Q51A	everjnt09	YNDKRFF.		
S3Q01A		S3Q01A	YNDKRFF.		
S3Q01		S3Q01	YNDKRFF.		
S3Q02A		S3Q02A	YNDKRFF.		
S3Q02		S3Q02	YNDKRFF.		
S3Q15AR		S3Q15AR	S3Q15AR.	Format is from 0506 formats	
S3Q22A	K2Q41C	insulin	YNDKRFF.		
S3Q31_A	K2Q52C	fdallgy	YNDKRFF.		
	K2Q32A	everdep09	YNDKRFF.		
	K2Q32B	depress09	YNDKRFF.		
	K2Q33A	everanx09	YNDKRFF.		

	K2Q33B	anxiet09	YNDKRFF.
	K2Q34A	everbehav09	YNDKRFF.
	K2Q34B	behav09	YNDKRFF.
	K2Q35D	autage09	YNDKRFF.
	K2Q35DA	autageunit09	YNDKRFF.
	K2Q36A	everdd09	YNDKRFF.
	K2Q36B	dd09	YNDKRFF.
	K2Q44A	evertbi09	YNDKRFF.
	K2Q44B	tbi09	YNDKRFF.
	K2Q46CX01	anemia09	YNDKRFF.
	K2Q46CX02	sickle09	YNDKRFF.
	K2Q46CX03	hemophl09	YNDKRFF.
	K2Q46CX04	bloodother09	YNDKRFF.
	C95Q01	adhdmedwk09	YNDKRFF.
	C95Q02	adhdmedyr09	YNDKRFF.
	C95Q03	adhdtx09	YNDKRFF.
	C95Q04	adhdsupp09	YNDKRFF.
	C95Q01AR01	adhdmed1	C95Q01AF.
	C95Q01AR02	adhdmed2	C95Q01AF.
	C95Q01AR03	adhdmed3	C95Q01AF.
	C95Q01AR04	adhdmed4	C95Q01AF.
	C95Q01AR05	adhdmed5	C95Q01AF.
	C95Q01AR06	adhdmed6	C95Q01AF.
	C95Q01AR07	adhdmed7	C95Q01AF.
	C95Q01AR08	adhdmed8	C95Q01AF.
	C95Q01AR09	adhdmed9	C95Q01AF.
	C95Q01AR10	adhdmed10	C95Q01AF.
	C95Q01AR11	adhdmed11	C95Q01AF.
	C95Q01AR12	adhdmed12	C95Q01AF.
	C95Q01AR13	adhdmed13	C95Q01AF.
	C95Q01AR14	adhdmed14	C95Q01AF.
	C95Q01AR15	adhdmed15	C95Q01AF.
	C95Q01AR16	adhdmed16	C95Q01AF.
	C95Q01AR17	adhdmed17	C95Q01AF.

		C95Q01AR18	adhdmed18	C95Q01AF.		
		C95Q01AR19	adhdmed19	C95Q01AF.		
		C95Q01AR20	adhdmed20	C95Q01AF.		
		C95Q01AR21	adhdmed21	C95Q01AF.		
		C95Q01AR22	adhdmed22	C95Q01AF.		
		C95Q01A_FLAG	C95Q01A_FLAG	C95Q01A_FLAG.		
		C95Q04A	C95Q04A	YNDKRFF.		
	S5Q13	C6Q11	interpret	YNDKRFF.	Question not used for entire 0910 interview.	No solution.
	S5Q13A	C6Q12	freqinter	HOWOFT.	Question not used for entire 0910 interview.	
		K11Q30	K11Q30	YNDKRFF.		
		K11Q31	K11Q31	YNDKRFF.		
		K11Q32	K11Q32	YNDKRFF.		
		K11Q33	K11Q33	YNDKRFF.		
		K11Q34R	K11Q34R	LOS.		
		K11Q35R	K11Q35R	LOS.		
		K11Q36R	K11Q36R	LOS.		
		K11Q37R	K11Q37R	LOS.		
		K4Q20R	K4Q20R	K4Q20R.		
		K4Q21R	K4Q21R	K4Q21R.		
		MARCOH_PAR	MARCOH_PAR	MARCO.		
		MARCOH_RESP	MARCOH_RESP	MARCO.		
		MARSTAT_PAR	MARSTAT_PAR	MARSTAT.		
		MARSTAT_RESP	MARSTAT_RESP	MARSTAT.		
		C11Q17	C11Q17	YNDKRFF.		
		C3Q35AR	C3Q35AR	C3Q35A.		
		C5Q20	C5Q20	C5Q20R.		

Appendix E

2009-2010 NS-CSHCN Cell Phone Strata for Access Problem Analysis

```
. tabstat weight_i, by (state) statistics(n mean min max), if sample==2

Summary for variables: weight_i
    by categories of: state (DERIVED. State of residence)
```

Cell phone strata with problematic cell sizes.

```
state     |          N      mean       min       max
------    -+    ----------  ----------  ----------  ----------
WY        |         49  8.555192  1.384375  48.42345
SD        |         45  10.95648  1.225195  51.02334
HI        |         38  22.49515  0.532138  93.10551
MT        |         46  23.63183  4.824633  105.9758
ND        |         42   25.0563  3.207766  146.8511
AK        |         41  25.76108  7.264949  72.83745
DC        |         25  33.94025  4.445183  94.27792
VT        |         48  43.74882  11.15766  205.2416
RI        |         40  45.53305  12.90142  192.5778
ID        |         46  47.97959  8.270827  320.0499
DE        |         44  57.73498  12.99616  251.6511
NH        |         42  64.57444  8.711107  347.8334
ME        |         42  65.04717  11.51248  264.2262
IA        |         55  73.74449   13.4253  400.6766
NE        |         48  90.49767  17.65544  250.4236
NV        |         45   113.077  13.94196  447.8432
NM        |         47  127.4385  18.23026   490.714
WV        |         45  128.8907  17.13448  497.9618
MN        |         57  137.2021  5.964333  901.7306
CO        |         51  149.2438  7.960583  529.3587
AR        |         68  157.3255  16.44954  1111.126
MO        |         60  169.8218  4.782635  992.3677
WI        |         55  173.0384  10.77091  616.7393
TN        |         67   186.766  22.77206   1254.12
IN        |         65  187.0766  21.40553   1435.57
MA        |         54  199.2584  13.87253  1040.251
CT        |         48  220.3087   29.5064  853.1633
UT        |         49  232.0471  43.28854  822.6212
OR        |         51  232.4576  47.23176  778.8035
KS        |         53  233.3861  45.50932  1492.268
MS        |         52   257.665  28.02193  858.9676
OK        |         50   264.185  31.19859   666.569
NJ        |         48  278.9164  36.71257   769.355
AL        |         49  296.2012  62.82903  852.5045
```

VA	|	67	316.9315	19.57931	3493.363
IL	|	90	317.1676	16.38487	1744.457
SC	**|**	**47**	**325.7178**	**57.69586**	**1668.073**
MD	|	56	339.0408	11.1307	1893.88
LA	|	53	341.3611	43.06915	2140.395
Total	|	2991	355.558	0.532138	6335.096
KY	|	44	405.8549	74.87167	1808.438
WA	|	56	409.0247	13.44786	2108.154
AZ	|	57	413.698	146.3609	1685.96
PA	|	66	424.5115	35.07769	1934.523
OH	|	89	441.7826	39.0016	2477.584
NY	|	71	534.99	126.2418	3131.412
MI	**|**	**64**	**570.4155**	**10.89649**	**3756.589**
GA	|	83	606.451	103.5947	4542.696
NC	|	75	617.3585	87.9178	1864.955
FL	|	120	772.0977	65.76485	2644.518
CA	|	131	1133.507	94.0912	6161.936
TX	|	157	1211.507	74.63078	6335.096

	Sample size state 1	Sample size state 2	Sample size state 3	Sample size state 4	Total sample size
*Collapse WY and SD	49	45			94
*Collapse HI, MT, ND, AK	38	46	42	41	167
*Collapse DE,NH, ME	44	42	42		128
*Collapse IA,NE,NV	55	48	45		148
*Collapse NM, WV,MN	47	45	57		149
*Collapse CO,AR	51	68			119
*Collapse MO, WI	60	55			115
*Collapse TN,IN, MA	67	65	54		186
*Collapse CT,UT,OR,KS	48	49	51	53	201
*Collapse MS,OK,NJ	52	50	48		150
*Collapse AL,VA,IL	49	67	90		206
*Collapse SC,MD, LA	47	56	53		156

*Collapse KY,WA,AZ	44	56	57		157
*Collapse PA,OH	66	89			155
*Collapse NY,MI	71	64			135
*Collapse GA,NC	83	75			158
*Collapse NV, NE, IA	45	48	55		148
*Collapse DC,VT,RI,ID	25	48	40	46	159
FL remains alone	120				120
CA remains alone	131				131
TX remains alone	157				157

Appendix F

Institutional Review Board Approval

VIRGINIA COMMONWEALTH UNIVERSITY
VCU
Make it real.

Office of Research Subjects Protection
BioTechnology Research Park
BioTech One, 800 E. Leigh Street, #3000
P.O. Box 980568
Richmond, Virginia 23298-0568
(804) 828-0868
(804) 827-1448 (fax)

DATE: June 6, 2013

TO: Shelly J. Lane, PhD
Occupational Therapy
Box 980008

FROM: Lisa M. Abrams, PhD
Chairperson, VCU IRB Panel B
Box 980568

RE: **VCU IRB #: HM15229**
Title: Access to Therapy for Children with Autism: A Population-Based Analysis

On May 29, 2013 the following research study ***qualified for exemption*** according to 45 CFR 46.101(b) Category 4. This determination includes the following items reviewed by this Panel:

RESEARCH APPLICATION/PROPOSAL: NONE

PROTOCOL: Access to Therapy for Children with Autism: A Population-Based Analysis, version 1-4/20/13, received 5/2/13

The Primary Reviewer assigned to your research study is Donna S. Gross, BA. If you have any questions, please contact Ms.Gross, IRB Coordinator, VCU Office of Research Subjects Protection, at dsgross@vcu.edu or 827-2261.

Attachment – Conditions of Approval (PLEASE NOTE RECENT CHANGES TO #3)

Conditions of Approval:

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must *(as applicable):*

1. Conduct the research as described in and required by the Protocol.

2. Provide non-English speaking patients with a translation of the approved Consent Form in the research participant's first language. The Panel must approve the translation.

3. The following changes to the protocol **must be** submitted to the IRB panel for review and approval before the changes are instituted. Changes that do not meet these criteria do not have to be submitted to the IRB. If there is a question about whether a change must be sent to the IRB please call the ORSP for clarification.

   THESE CHANGES MUST BE SUBMITTED:
   a) Change in principal investigator
   b) Any change that increases the risk to the participant
   c) Addition of children, wards of the state, or prisoner participants
   d) Changes in survey or interview questions (addition or deletion of questions or wording) that change the level of risk or adds questions related to sexual activity, abuse, past or present illicit drug use, illegal activities, questions reasonably expected to provoke psychological anxiety, or would make participants vulnerable, or subject them to financial, psychological or medical risk
   e) Changes that change the category of exemption or add additional exemption categories
   f) Changes that add procedures or activities not covered by the exempt category(ies) under which the study was originally determined to be exempt
   g) Changes requiring additional participant identifiers that could impact the exempt category or determination
   h) Change in inclusion dates for retrospective record reviews if the new date is after the original approval date for the exempt study. (ex: The approval date for the study is 9/24/10 and the original inclusion dates were 01/01/08-06/30/10. This could be changed to 01/01/06 to 09/24/10 but not to end on 09/25/10 or later.)
   i) Addition of a new recruitment strategy
   j) Increase in the planned compensation to participants

4. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.

5. Report Unanticipated Problems (UPs), following the VCU IRB requirements and timelines detailed in <u>VCU IRB WPP VIII-7</u>).

6. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.

7. The VCU IRBs operate under the regulatory authorities as described within:
   a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
   b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
   c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).

Appendix G

Coefficients for Logistic Regression Models

	Base Model [a]	**Predisposing Model [b]**	**Enabling Model [c]**	**Need Model [d]**	**Full Model [e]**
***β* Coefficient (s.e *β*)**					
Current ADHD	Reference	Reference	Reference	Reference	Reference
Current ASD	.507 (.102)**	.525 (.102)**	.483 (.107)**	.303 (.107)**	.285 (.111)*
Current CP	.243 (.152)	.202 (.154)	.211 (.164)	.022 (.167)	-.049 (.180)
Year--2005	Reference	Reference	Reference	Reference	Reference
Year—2009	.341 (.096)**	.335 (.100)**	.393 (.101)**	.319 (.098)**	.388 (.106)**
Landline sample	Reference	Reference	Reference	Reference	Reference
Cell-phone sample	.221 (.236)	.180 (.229)	.211 (.249)	.194 (.234)	.140 (.240)
Age (continuous)		-.021 (.012)			-.032 (.012)**
Gender					
Male	Reference	Reference	Reference	Reference	Reference
Female		.209 (.107)			.241 (.112)*
Race					
White	Reference	Reference	Reference	Reference	Reference
Black		.051 (.150)			.107 (.161)
Multiple[a] (avail in 2005-06 dataset only)		.226 (.270)			.294 (.271)
Other		.000 (.162)			-.092 (.182)
Ethnicity					
Non-Hispanic	Reference	Reference	Reference	Reference	Reference
Hispanic		.174 (.148)			.174 (.160)
Poverty Level					
<200% FPL			-.058 (.129)		-.192 (.138)
201-400% FPL			.116 (.137)		.050 (.138)
>400% FPL	Reference	Reference	Reference	Reference	Reference
MSA Status					
Non-urban	Reference	Reference	Reference	Reference	Reference
Urban			.111 (.121)		.109 (.123)
Insurance Status					
Insured	Reference	Reference	Reference	Reference	Reference
Uninsured			1.18 (.237)		1.18 (.246)**
Need Characteristics					
Condition Impact on Function					
Never	Reference	Reference	Reference	Reference	Reference
Sometimes				.364 (.222)	.341 (.238)
Usually				.934 (.231)**	.889 (.244)**
Always				1.153 (.219)**	1.134 (.234)**
Problem Behavior					
No	Reference	Reference	Reference	Reference	Reference
Yes				.282 (.098)**	.266 (.106)*
Constant	-2.009	-1.900	-2.155	-2.891	-2.719

Note. Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.

[a] Number of obs=62913, Subpop number of obs=8875, Imputations=5, Strata=153, PSUs=62913, F(4,62758)=11.04, $p<.001$.

[b] Number of obs=62840, Subpop number of obs=8802, Imputations=5, Strata=153, PSUs=62840, F(10,57863)=5.12, $p<.001$.

[c] Number of obs=62145, Subpop number of obs=8107, Imputations=5, Strata=153, PSUs=62145, F(8,61990)=8.73, $p<.001$.

[d] Number of obs=62846, Subpop number of obs=8808, Imputations=5, Strata=153, PSUs=62846, F(8,62691)=13.46, $p<.001$.

[e] Number of obs=62042, Subpop number of obs=8804, Imputations=5, Strata=153, PSUs=62042, F(18,61268)=7.28, $p<.001$.

* $p<.05$, **$p<.01$

Appendix H

Imputed Multivariate Logistic Regression Results Predicting Unmet Need for Therapy with CP Group as Indicator

	Did not receive therapy services			
	Odds Ratio	β Coefficient	95% CI of β	*p*
Current CP	Reference			
Current ASD	1.396	0.333	-.005, .672	.05*
Current ADHD	1.050	0.049	-.304, .402	.79
Year--2005	Reference			
Year--2009	1.474	0.388	.179, .596	<.001**
Landline sample	Reference			
Cell-phone sample	1.150	0.140	-.320, .610	.56
Predisposing Characteristics				
Age (continuous)	0.968	-0.033	-.058, -.008	.01**
Male	Reference			
Female	1.278	0.241	.021, .462	.03*
White race	Reference			
Black race	1.112	0.107	-.210, .423	.52
Multiple race	1.342	0.294	-.238, .826	.29
Other race	0.912	-0.092	-.450, .266	.61
Non-Hispanic ethnicity	Reference			
Hispanic ethnicity	1.189	0.174	-.140, .487	.26
Enabling Characteristics				
≤200% FPL	0.824	-0.193	-.463, .078	.17
200-400% FPL	1.051	0.050	-.220, .320	.74
> 400% FPL	Reference			
Non-urban	Reference			
Urban	1.115	0.109	-.131, .349	.35
Insured	Reference			
Uninsured	3.260	1.182	.699, 1.665	<.001**
Need Characteristics				
How often condition affected ability to do things—Never	Reference			
How often condition affected ability to do things—Sometimes	1.406	0.341	-.125, .807	.15
How often condition affected ability to do things—Usually	2.433	0.889	.410, 1.367	<.001**
How often condition affected ability to do things—Always	3.108	1.134	.675, 1.593	<.001**
Problem behaviors--No	Reference			
Problem behaviors--Yes	1.305	0.266	.059, .473	.01**

Note. Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009-2010.
Overall model: Linearized F-test (18, 61268)=7.28, $p<.001$. Strata=153, PSU=62042, Subpopulation obs=8004, Imputations=5
* $p\leq.05$, ** $p\leq.01$

Vita

Teal Wisniewski Benevides was born on July 17, 1980, in Jacksonville, Florida, and is an American citizen. She graduated from C.D. Hylton High School, Woodbridge, Virginia in 1998. She received her Bachelor of Science in Psychology from The College of William and Mary, Williamsburg, Virginia in 2002. She received her Masters of Science in Occupational Therapy from Thomas Jefferson University, Philadelphia, PA in 2004.