

ABSTRACT

Sreelakshmi Talasila, Factors Associated with Difficulty in using the Community Based Services Among Children with Special Health Care Needs. Master of Public Health (Biostatistics), December 2009, 73 pp, 5 tables, 1 illustration, bibliography, 36 titles.

Despite various advances in the health care system, children with special health care needs (CSHCN) face difficulty in accessing required services. The purpose of this study was to identify factors associated with difficulty in using community based services, individual barriers and institutional barriers for CSHCN. Data were obtained from National Survey of CSHCN 2005-06. The Andersen Health Behavioral Model was used to identify predisposing, enabling and need factors. Logistic regression was performed. Education, region, race/ethnicity, number of children, insurance and satisfaction with services were associated with community based services. Results suggest functional limitations and severity of illness are associated with difficulty in using community based services. Further investigation is required to improve health care system.

FACTORS ASSOCIATED WITH DIFFICULTY IN USING THE COMMUNITY
BASED SERVICES AMONG CHILDREN WITH
SPECIAL HEALTH CARE NEEDS

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THESIS

Presented to School of Public Health
University of North Texas
Health Science Center at Fort Worth
in Partial Fulfillment of the Requirements

for the Degree of

Master of Public Health

By

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Fort Worth, Texas

December 2009

ACKNOWLEDGEMENTS

First and foremost I offer my sincerest gratitude to my mentor, Dr. Kimberly Fulda who has supported me throughout my thesis with her patience and knowledge whilst allowing me the room to work in my own way. I attribute the level of my Masters degree to her encouragement and effort and without her this thesis, would not have been completed or written.

I am heartily thankful to my committee members Dr. Sejong Bae and major professor Dr. Karan Singh whose encouragement, guidance and support from the initial to the final level enabled me to develop an understanding of the subject. I am deeply grateful to Dr. Bae, who helped me in the analysis during the difficulty times. In addition, they were always accessible and willing to help us. As a result, research life became smooth and rewarding for me.

My sincere thanks to the Primary Care Research Institute for giving me the opportunity to work with them as part of my thesis work. I offer my thanks to all of my friends who had shared their knowledge for helping me to complete my thesis with their best possible feedback and special thanks to my friend Radhika.

My deepest gratitude goes to my family for their unflagging love and support throughout my life. Last of all, I would like to acknowledge my husband, Sita Ram Raju. We have lost a lot due to my studies away from home. Without his presence in my life it would have been simply impossible for me to go for higher studies.

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CHAPTER I

INTRODUCTION

Summary

According to the World Health Organization (WHO), health is defined as “ a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 2003). Proper and timely health care is essential for maintaining this state of physical, social, and psychological well being of any individual. Keeping this aspect in consideration, it is essential to provide not only proper health care, but make sure that available health care facilities are properly accessible to maintain quality of life. The importance of health care access is emphasized by the fact that it is included as one of the goals in Healthy People 2010. Individuals affected with chronic illness and poor health need better access to health care for proper monitoring of their health conditions. Children suffering with chronic conditions, especially children with special health care needs (CSHSN), require special attention and health services for their well-being. Often, poor families are affected with inappropriate health services. Therefore, proper access to health care plays a critical role to provide good health for this population.

The risks of chronic medical, behavioral, developmental or emotional disorders are increasing not only in adults but also in children. These groups of children are termed children with special health care needs (CSHCN), as they need a large amount of attention and quality health services. They are prone to poor health conditions like behavioral problems and developmental disabilities like autism, Down syndrome,

difficulty in learning, understanding or paying attention, cerebral palsy, and chronic illness like asthma, diabetes.

The definition of CSHCN, given by the Maternal Child Health Bureau (MCHB), varies from today's perception because their definition was not built on required medical diagnoses (McPherson et al., 1998). Identifying children who are in need of special health care services and focusing on the health care and support services to satisfy their needs are the two principal objectives of the current definition of CSHCN. As per the new definition, results of the National Survey of CSHCN demonstrated that 13.85% of children have special health care needs (McPherson et al., 2004; P. W. Newacheck & Kim, 2005).

Instead of differentiating from other children, families and communities should accept CSHCN as part of the family and community as any other individuals. They should have the opportunity to share everyday family and community experiences and participate in normal day to day activities. The primary challenge in making this happen is to provide easy accessibility to health care needed to make this possible. Resources such as early intervention programs, special education, nutrition, and vocational rehabilitation services should be made available based in the child's home community (Brewer, McPherson, Magrab, & Hutchins, 1989). These points highlight the importance of community based care for children.

Over the past few decades, for children with chronic conditions beyond the age of 10, the survival rates have increased due to medical advances (Mohler Kuo, 2009). It is stated that children's health care cost is less than the total health care cost for children

with chronic health conditions. There can be significant psychological and developmental impacts upon children as well as families of CSHCNs compared to other families.

Financial burdens, employment difficulties and waiting times affect accessing health care for CSHCN (Mohler Kuo, 2009). Above all, one study showed that compared to other families, out-of-pocket expenditure for health care is on average two times higher among families of CSHCNs (P. W. Newacheck & Kim, 2005). Most of the Latino needy families reported that barriers to health care access for children are language problems, transportation difficulties, lack of health insurance, cultural differences, poverty, and long waiting times (Flores, Abreu, Olivar, & Kastner, 1998). During the last two decades, different health services provided to children have become a burning national issue. Unfortunately, this problem still exists and is an obstacle for lack of quality of health care and service. Thus, it is being subjected to extensive study and controversy (Betz, Baer, Poulsen et al., 2004). This controversy has given rise to studies to identify factors associated with accessing these services.

Health beliefs are perceptions, knowledge about health and health care services, and attitudes towards health or health care services. These beliefs can affect the opinion towards need and utilization of health services. Not only do health beliefs affect utilization of services, but they can also explain how social structures control required enabling, apparent need and successive usage of these services. In this context, an individual's social structure including socio-economic conditions, available transportation, and eligibility criterion for various programs, influence their subsequent access to available health care. At the same time, an individual's personal beliefs and

perception about the benefits of health care influence their decision to access health care required for a particular condition.

Statement of Purpose

The purpose of this study is to identify the factors associated with difficulty in accessing community based services among CSHCN. As easy access to these services is affected by both internal (no information, not enough time) and external factors (lack for transportation, long waiting times), detailed examination of this phenomenon should be performed, and the root causes must be identified for poor health care service use.

Another purpose is to identify factors associated with individual and institutional barriers which are making it difficult for children in need to access community based services.

This research also has the objective to identify the limitations of present special health care services and to provide the necessary suggestions that can help to improve the system, so that CSHCN can have better and easier access to and receive adequate health care.

Research Questions

1. What are the factors associated with problems and issues in accessing community based systems of care among CSHCN?
2. What are the predisposing, enabling and need factors associated with institutional and individual barriers for CSHCN which are making it difficult for them to access the community based systems of care?

Hypothesis

1. Difficulties in using community based systems among children with special health care needs depends on:
 - a. Predisposing factors
 - b. Enabling factors
 - c. Need factors
2. Predisposing, enabling and need factors are associated with the individual barriers for CSHCN who have difficulty accessing community based systems of care.
3. Predisposing, enabling and need factors are associated with institutional barriers for CSHCN who have difficulty accessing community based systems of care.

Limitations

These data were collected using a cross-sectional study design, at one point of time in 2005-2006. Therefore, causality cannot be inferred from this analysis. Since it is a snap shot of one point in time, the results may be different from one time point to another time point. There is also a possibility of recall bias since data collected for the National Survey of CSHCN were collected from parents via telephone interviews without any verification from actual medical records. Another limitation could be that all families with children with special health care needs might not have phone access and therefore were not be able to participate in the National Survey of CSHCN. Future surveys designed with the aim of eliminating these limitations will prove to be more beneficial.

Definition of Terms

Children with Special health Care Needs: According to the Maternal Child Health Bureau, children with special health care needs are those “who have or are at increased risk of 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).

Community Based Services: The National Survey of CSHCN defined community based services as any of the given list of services such as early intervention programs, child care facilities, vocational education and rehabilitation programs, and other community programs other than medical services.

Andersen Behavioral Model:“The Andersen Behavioral Model was developed in the 1960’s and since has been expanded and modified. The modern study of health care use and access has shifted from an individual level focus to a combination of the individual, the health care system, the external environment, and the effects that each have on the others” (Andersen, 1995).

Predisposing factors: In Andersen's Behavioral Model, predisposing factors influence a person/family to receive health care access when they are in need. Predisposing factors are demographic factors such as age and gender, social structure such as education, race,

ethnicity, and health beliefs such as attitudes, values, and knowledge that can affect the perceptions of need and use of health services (Aday, Lee, Spears et al., 1993).

Enabling factors: Enabling factors are resources for health care service use and are open to interventions. The Andersen Model suggests that enabling factors influence health care services use and are classified as two categories. They are community enabling resources such as health resources and services available in the community and personal or family related resources such as knowledge of accessing these services and using of health care services (Aday et al., 1993).

Need factors: Need factors include the level of illness as it is experienced by the child's parents or reported by the health care professionals. Need factors include severity of the illness and functional limitations such as not being able to do daily activities (Aday et al., 1993).

Barriers to health Care: Barriers to health care are problems within the health care system. These barriers prevent susceptible populations from getting required health care. Compared to privileged populations the susceptible population receives substandard health care (National Health Service Corps & National Association of Community Health Centers, 2009).

Individual Barriers: Individual barriers can be defined as “reflected factors that inhibit seeking help that originate from the within the individuals themselves” (Hines-Martin, Malone, Kim, & Brown-Piper, 2003). Examples include lack of knowledge or being unable to communicate

Institutional/Organizational Barriers: Individual barriers can be defined as “factors related to accessing the resources identified by the participants” (Hines-Martin et al., 2003). Examples include lack of interpreters, long appointment, and long wait times.

Importance of the study

Results of the National Survey of CSHCN demonstrates that only 11% of families nationwide do not have access to community based services; whereas, the majority (i.e. 89%) have simple and easy access to these systems (Frasier A, Upchurch H, Welch E, & O'Connor KS, 2007). This study shows the importance and value of quality service that is required for the growth of a health care system for CSHCN. The importance of this study lies in the fact that this demonstrates the significance of each component of quality care for the complete development of the comprehensive care system on the whole. This study will be beneficial to the field of public health, as this will help bring the necessary attention to current policies prevalent in providing effective community based services to CSHCN. Results of the proposed study could help educate and inform policymakers about information related to community based services so that they can formulate and

make new amendments in policies to improve these services and make them more effective. These are the significant mile stones that are planned through this research.

CHAPTER II

LITERATURE REVIEW

This section provides a comprehensive review of the previous research done related to this particular research topic. Findings from previous research formed a platform for further research to identify factors which are associated with difficulty in using community based services, individual barriers and institutional barriers.

For more than a decade, the target of health professionals at both the national and state levels has been confirming a high quality system of health care services for women and children, especially for children with special health care needs (McPherson et al., 1998). Several studies have estimated the extent and quality of available care and unfulfilled needs for children during the past two decades. Lack of insurance, race/ethnicity and income level are disparities in the access of health care services among the CSHCN (P. W. Newacheck, Hung, & Wright, 2002; P. W. Newacheck, McManus, Fox, Hung, & Halfon, 2000). Families with CSHCN face financial difficulties due to higher financial burden, especially common in low income families. Apart from the above mentioned factors, language barriers also affect access to the health care. This can be illustrated by the example that when parents were interviewed in any other language than English, they had more difficulty in coordinating required health care (Yu, Nyman, Kogan, Huang, & Schwalberg, 2004).

The National Survey for CSHCN provides information to develop, improve and follow the system of health care that are closely in align with the needs of CSHCN. Thus, the success of the new developments and interventions is measured with the help of

information provided by this survey. At present, one of the biggest challenges for the health care system in the US is to provide quality care services to the needy. Challenges include transportation issues, various ethnic and culture population and delivery of the services in urban areas. It has been demonstrated that almost one third of the CSHCN's families face at least one or more of the above mentioned challenges. There is a need for detailed studies focusing on these challenges. Emphasis should be put on the collaboration between national and state level agencies to stay involved for improvement in the availability and quality of services for CSHCN.

Barriers

This study emphasizes the barriers and factors associated with accessing community based services. Some studies show that the lack of knowledge about the services; lack of transportation, long waiting appointment times, and differences in treatment were the factors that affected community based services (Kelly, Binkley, Neace, & Gale, 2005). These are also viewed as barriers. These barriers can be categorized into institutional and individual barriers.

One of the primary barriers for families with disabled children is the organization and delivery of health care (Betz et al., 2004). The system is differentiated by a lot of paperwork and rules, service division and insufficient refund for services (Betz et al., 2004).

In one of the studies, the most often reported barriers for health care were related to thoughts or knowledge insufficiently, beliefs or attitudes, limitation or time issues, family or community problems, and the rules. Among all this, thoughts or insufficient knowledge and beliefs or attitudes were considered as individual level barriers. The categories of time issues or limitation and rules were identified as the institutional barrier level (Hines-Martin et al., 2003). These categories can afford to approach the procedure for required services for the children and give the proper direction for future studies to explore more.

Individual and Institutional Barriers

Based on information provided by Martin et al, providers of health care, lack of workforce, coordination of care, cost and insurance and location from services were identified as institutional barriers. Individual barriers contain lack of awareness of personal risk, lack of knowledge of services and resources and lack of trust/fear of discrimination.

History of Governmental Programs for Maternal and Child Health

In order to “Investigate and report on matters related to welfare of children and child life among all classes” the Children’s Bureau was established on April 9, 1912 (Hutchins, 1994). In 1930 chaos in politics and policies of the children’s Bureau led to the resignation of pediatricians from the American Medical Association, thereby, paving the way to the American Academy of Pediatrics (AAP). The federal government

provided financial support to the state level policies framed by the children's Bureau for the improvement of maternal and child health programs.

Differences/Disparities in Health Care for Children

For developing high-quality service systems, it has become very important to understand the disparities in health care access among CSHCN. Information regarding disparities for children in health care access can be provided by national surveys.

Previous studies indicated that white children with special health care needs were more likely to have used physician services than their minority counterparts (88.6 vs 85.0; $P < .01$); however, during the past year, minority CSHCN were more likely to have been hospitalized (7.6% vs 6.3%; $P < 0.5$) (McPherson et al., 2004; P. W. Newacheck et al., 2002; P. W. Newacheck, McManus et al., 2000).

The fundamental principle of family centered care system is “the organizational policies, procedures and provider practices should be made flexible so that the services cater to the needs, cultural values and beliefs of each family” (Pettoello-Mantovani, Campanozzi, Maiuri, & Giardino, 2009). There may be some other organization and practice factors that might contribute to black/white disparities in ease of using health care services. These could be patient attitudes and provider, discrimination, waiting times for appointments, lack of transportation, and limited availability of providers and any other specialized services in minority communities. These findings suggest the need for additional studies to find ways to eliminate these disparities in health care (Ngui &

Flores, 2006). Thereby health care community services can be improvised to reach all children and families irrespective of racial discrimination.

Predisposing Factors

Race/Ethnicity

Several studies examined racial and ethnic differences in access to health care and utilization of health care. One of the previous studies demonstrated that among CSHCN, compared to white children, minorities had greater odds of having no insurance coverage (10.3% vs 13.2%), having no usual source of care (4.3% vs 6.7%), and being unable to get needed medical care (2.8% vs 3.9%) (P. W. Newacheck et al., 2002). Previous studies proved that among CSHCN families, racial/ethnic disparities exist in satisfaction with care in use of services (Ngui & Flores, 2006).

Non-Hispanic black (OR: 1.60; 95% CI: 1.46-1.57), white (OR: 1.86; 95% CI: 1.72-2.01) and other racial/ethnic (OR: 1.39; 95% CI: 1.20-1.61) groups had increased odds of having CSHCN compared with Hispanic families (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). However, in one of the other studies black (OR: 2.26; 95% CI: 1.55 – 3.28) and Hispanic (OR: 2.64; 95% CI: 1.84-3.80) parents reported that use of health care services was not easy compared with white parents for CSHCN (Ngui & Flores, 2006).

Parent/Guardian's Education

Parent/Guardian's education can affect access to health care and use of needed services. Parents of CSHCN may not be aware of how to utilize the available programs for CSHCN due to lack of education. Additionally, education can also give more information regarding health insurance and its benefits (P. W. Newacheck, Inkelas, & Kim, 2004). Families who had a high school education or less (OR: 0.699, p-value: <0.05) were less likely to not receive one or more needed services and have an unmet service need (Warfield & Gulley, 2006). However, parent's education was significantly associated with difficulty in accessing health care. Parents with less than a high school degree were more likely to report difficulty in using health care services (37.1% vs 22.7%) compared with parents with a college graduate degree (Ngui & Flores, 2006).

Region

Impact on quality of care also differs by the region of residence. There is a difference in access to health care among families residing in different regions as in the Northeast, Midwest, South and West. This difference can be attributed to health insurance coverage policies specific to a particular region/state (Lo & Fulda, 2008). In the South, Midwest, and Northeast household education and race were significant factors for receiving preventive health care. Not only the above, but the number of children living in the household was also a significant factor by region for receiving health care (Lo & Fulda, 2008).

Total number of Children and Adults in the household

The number of children and adults living in the household also plays a significant role in access to needed health care for any services. It will be difficult to spend more time with CSHCN compared to normal children. In families with more than one child, the parent's time will be more demanded to spend with them, so it may not be possible all the time to dedicate the needs for those children. Prevalence of CSHCN was greater in single-parent families (23.3% vs 16.2%) compared to two parent families (P. W. Newacheck et al., 1998). Households with a family size of more than 5 (OR: 1.10 vs OR: 1.0) were more likely to have unmet need of health care compared to family size less than 5 (P. W. Newacheck, Hughes, Hung, Wong, & Stoddard, 2000). Family size 5-9 or more than 9 was a predictor for preventive care utilization in black families (Alio & Salihu, 2005). Children with single mother families (OR: 2.59; 95% CI: 1.95-3.43) were more likely to have unmet need of services compared to two parent families (Heck & Parker, 2002). As the number of children in the household increases (p-value:0.02), CSHCN were less likely to access all required mental health care (Fulda, Lykens, Bae, & Singh, 2009).

Enabling Factors

Language

Previous literature examined the relation between the parent's language of interview and access to health care for CHSCN. Among CSHCN, non English speaking, low income, lack of insurance, and less education were factors associated with health

care access (Yu et al., 2004). Non-English speaking families were more likely to lack a usual source of care (OR: 22.01; 95% CI: 7.45-65.02) and lack visits to the doctor (OR: 42.23; 95% CI: 7.71-231.42) in the last year compared with English speaking families (Javier, Huffman, Mendoza, & Wise, 2009). Families for whom the interview was conducted in Spanish (42.8% vs 24.8%) were more likely to have difficulty in using health care services compared with families for whom the interview was conducted in English (Ngui & Flores, 2006).

Health Insurance

For CSHCN, health insurance plays a major role in access to care and use of services. Health insurance becomes more essential for CSHCN to access health services. Families with health insurance coverage can prevent financial burdens that arise from health care expenses. This is the advantage that each family can receive to access the health services and hence protect their families and children from the illness (P. W. Newacheck, McManus et al., 2000). Newacheck et al, showed that 89% of the children had health insurance coverage. Most of the coverage provided was by private insurance companies. Insured children were more likely (96.9%vs79.2%) to have a usual source of care compared with uninsured children. Insured children also had increased odds (87.6%vs80.7%) of having a regular clinician compared with uninsured children. Uninsured children were more likely to report being unable to reach needed medical care (10.5% vs 2.2%), dental care (23.9% vs 6.1%) and mental health care (3.4 % vs 0.9%) compared with insured people. Not only uninsured children, but also children who had

public insurance, were more likely to have unmet need of health care (P. W. Newacheck et al., 2000).

The Maternal and Child Health Bureau core outcomes for CSHCN are satisfaction with care and partnering with families in decision making, access to medical home, easy to use community based services. All these factors were associated with under insurance compared with insured children (Wood et al., 2009).

Poverty level

Poverty level is also a significant factor for CSHCN. Families in households of federal poverty level (FPL) with <200 poverty level (OR: 1.15; 95% CI: 1.08-1.23) were more likely to have CSHCN compared with >400 FPL. Families with less FPL reported dissatisfaction with care for any unmet need for specific care services (26.8 % vs 8.6%), family support services (6.8% vs 2.8%) and no usual source of care (8.0% vs 6.4%) compared with high poverty level (van Dyck et al., 2004). Families with <100% FPL were more likely to have unmet need of routine care (OR: 1.97; 95% CI: 1.23-3.14) and specialty care (OR: 2.50; 95% CI: 1.49-4.18) compared to families with >200% FPL (Mayer, Cockrell Skinner, & Slifkin, 2004). Families with <100% FPL (36.8%) were more likely to have issues in accessing health care services compared with families >200% FPL (21.5%), after adjusting for other factors. Even though poverty level was not a significant factor, the odds of difficulty in use of services was 20% more for <100% FPL (OR: 1.20; 95% CI: 0.75 – 1.92) compared with >200% FPL (Ngu & Flores, 2006).

Satisfaction with the services

Good care and service play a vital role in satisfying families. Therefore, these qualities are considered to be important indicators in evaluating/measuring the performance of health care systems.

Families who had children with a greater severity of the conditions reported that they were less satisfied in terms of communication and health care coordination compared to families with less severity of illness. Families with children more than 12 years of age were less satisfied compared to families with younger children (Wood et al., 2009). As compared to white parents, black and Hispanic parents were significantly more likely to be not satisfied with care (7% vs 13% and 16%). These families reported that they had difficulties in use of health care services (35% and 34% vs 23%). Lack of insurance, parental interview other than English (Spanish), and severity of the child's condition were significant factors for satisfaction of the health care services (Ngui & Flores, 2006).

The percentage of patients and their families that are unhappy with health care services is approximately 8%. Twenty-five percent of families expressed dissatisfaction towards the ease of using health services. Few also mentioned reasons for their unhappiness could be because of communication barriers (unknown language), no proper insurance, race/ethnicity and inadequate family-centered care (Ngui & Flores, 2006).

Need Factors

Severity of Condition

Severity of the condition also plays an important role in accessing health care services. Children usually affected by their condition of the illness report difficulty in accessing health care services. Severity of the condition was associated with need of services. CSHCN who had a severe condition were more likely to have needed services such as specialty doctors (89.5% vs 81.4%), speech therapy (60.2% vs 43.9%), home health (50.4% vs 16.7%) and mental health (20.7% vs 16.2 %) compared to children with a mild condition (Warfield & Gulley, 2006). Prevalence of unmet need for routine care (5.05% v 1.67%) and specialty care (7.95% vs 2.63%) were greater for most severe children compared to less severe or mildly severe. Children with modest severity of illness were more likely to have an unmet need of specialty care (OR: 2.01; 95% CI:1.42-2.86) compared with less severity of illness (Mayer et al., 2004).

Functional Limitation

Previous studies demonstrated that CSHCN who have functional limitations are not able to access health care. Nageswaran, Johnson et al, broadly classified functional limitations into three parts. As per their description, CSHCN with severe limitations are 7.5 times more often and those with few limitations are 2.2 times more often than those with no limitation to get early intervention (Nageswaran, Silver, & Stein, 2008). From these studies, it was concluded that access to the health care was not increased adequately

to meet the increased demands of health care services due to the rapid increase in the number of functional limitations in CHSCN.

The above studies showed that these predisposing, enabling and need factors are important for accessing health care for CSHCN. Therefore, these factors were included in the present study.

CHAPTER III

METHODOLOGY

Summary

This chapter summarizes the methods about how the data were obtained and used in this research. It explains the variables such as dependent variables and independent variables used in the analysis for different research questions. It also explains how the data were analyzed by using different statistical methods.

The National Survey of CSHCN is intended for children less than 18 years of age who are randomly chosen from 50 states and the District of Columbia. The procedure of this survey involves identifying children with special health care needs and then organizing a detailed interview for one such child by randomly choosing him/ her from the sample data. Interviews were conducted for a different sample of children where parents or guardians who are aware of child's health were respondents. To generate estimates for CSHCN and comparisons with CSHCN for all study measures, a detailed interview was conducted for separate national sample of children. For this research, data were downloaded from National Survey of CSHCN website for the year 2005-2006.

“The National Survey of CSHCN 2005-2006 was conducted as part of the State and Local Area Integrated Telephone Survey (SLAITS) program. SLAITS, sponsored by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS), is a broad-based, ongoing survey system available at national, state, and local levels to track and monitor the health and well-being of children and adults” (Stephen J. Blumberg, Erin B. Foster, Alicia M. Fraiser, Jennifer, & Ben Skalland, 2009).

Data Collection

For this research, no primary data were collected. The National Survey of CSHCN is a publicly available source (<http://www.cdc.gov/nchs/slait/cshcn.htm>). The data were presented in SAS files such as: Screener, Interview, and Household. Each contained a list of variables. The sample size identified in the Household sample was 191,640; Interview was 40,723; and Screener was 363,183. For the purposes of this research, variables used for the analysis were obtained from the combination of the three files. A total sample size of 40,723 was used for the analysis. Study procedures for this analysis were reviewed and approved by the University of North Texas Health Science Center Institutional Review Board, Fort Worth, Texas.

The current study focused on the ease of using community based services. The Andersen Behavioral Model was used to identify factors that affect difficulty in accessing community based services (Andersen, 1995). Even though this model was developed four decades ago, it is still useful in health administration and health care services research. This model includes predisposing factors such as demographics, health beliefs, social structure; enabling factors such as personal resources or family resources, availability of services in the community, and need factors such as severity of health condition in health care (Aday et al., 1993; Andersen, 1995).

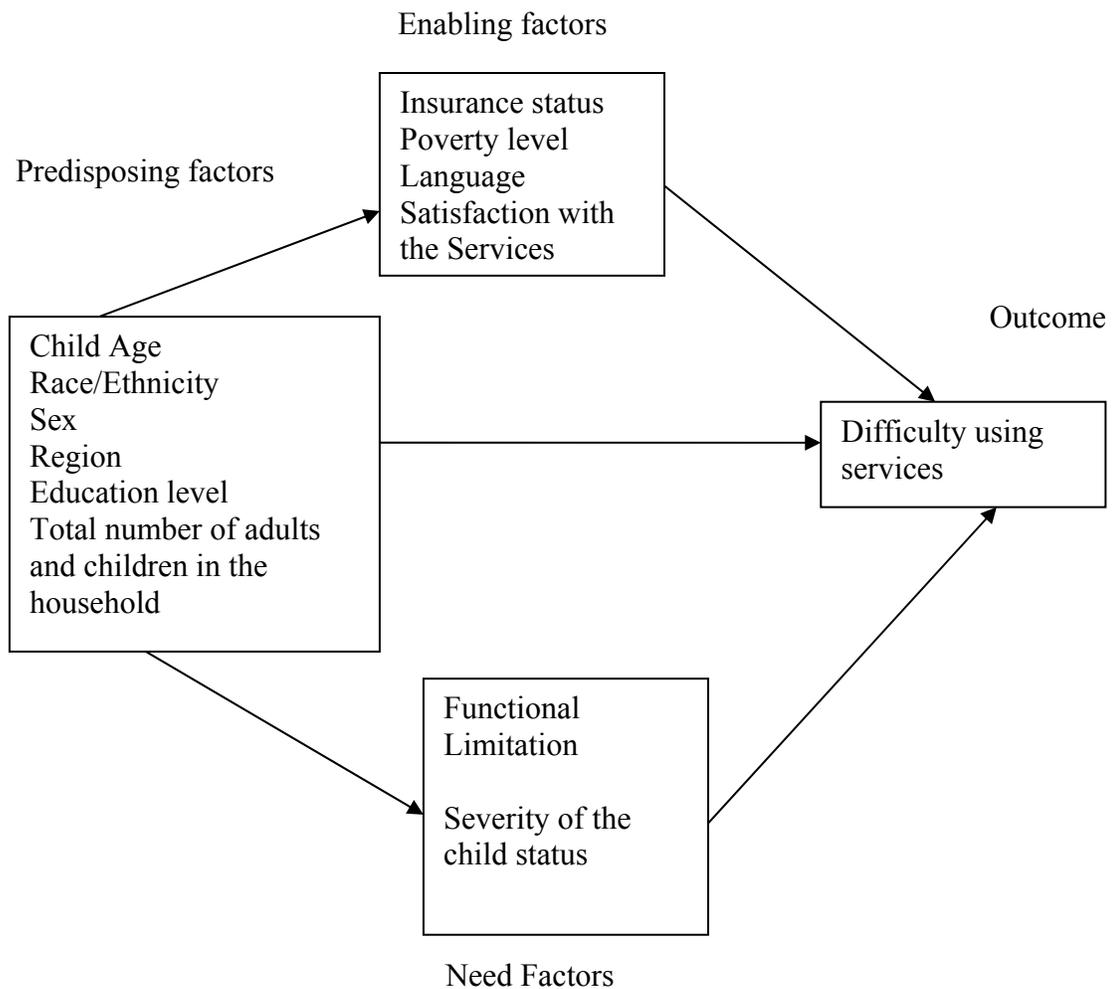


Figure 1: Andersen's Model

Variables

Dependent Variable(s)

Q1: What are the factors associated with problems and issues in accessing community base systems of care among children with special health care needs?

The dependent variable was measured by families who responded to the given question "have you had any difficulties trying to use these (community based) services (if age= 12

months or greater, show: during the past 12 months; else show: since (his/her) birth)?” in accessing community based services (given list of services such as early intervention programs, child care facilities, vocational education and rehabilitation programs, and other community programs other than medical services.

Reasons for difficulty in accessing community based services: Families who reported they have difficulty in accessing community based services were then asked a series of yes/no questions regarding common barriers to care, including “cost too much,” “health plan problem,” “care not available in area/transportation,” “not convenient times,” and “communication problem.” These were reported as barriers to care and accordingly divided into two groups as individual and institutional barriers.

Q2: What are the factors associated with individual barriers in accessing community base systems of care among children with special health care needs? Individual barriers were categorized as ‘yes’ whoever reported ‘could not get info’ or ‘not enough money’ or ‘communication problems’ or ‘language/cultural problems’ or ‘skills’ or ‘not enough time’ and any other responses were categorized as ‘no’.

Q3: What are the factors associated with institutional barriers in accessing community base systems of care among children with special health care needs? Institutional barriers were categorized as ‘yes’ if the response was ‘too much paperwork’ or ‘transportation problem’ or ‘could not get when needed’ or ‘long waiting list’ or ‘unavailable in area’ or ‘Not eligible’ or ‘used up eligible benefits’ and any other responses were categorized as ‘no’.

Independent variables

Predisposing factors: Demographic characteristics were commonly considered predisposing factors, and this study included the following variables in the model:

- Child's age: As per the previous studies, the categories were classified as birth to five (≤ 5 years old), elementary school (6-11 years old), and high school (≥ 12 years old).
- Sex: The categories were male and female.
- Race/Ethnicity: Parents were asked if the child was Hispanic or Non-Hispanic. For race, the parent was asked to select from the following categories: white, black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander or Other. For the purposes of this study, race/ethnicity was categorized into non-Hispanic white, non-Hispanic black, Hispanic, and others. The "other" category included American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander and other. This category was created by the National Center for Health Statistics to protect the confidentiality of small groups.
- Geographic Region: States were classified into 4 regions including Midwest, Northeast, South and West.
- Parent/Guardian's Education: The educational level was coded into three categories (<high school; high school; some college or more).

- Total number of children: Total number of children in the household was categorized into 4 groups: 1 child, 2 children, 3 children, and 4 or more.
- Total number of Adults: As per the survey, total numbers of adults in the household was categorized into 4 groups: 1 adult, 2 adults, 3 adults, and 4 or more.

Enabling factors: Enabling factors are resources for health care service use and are open to interventions. Enabling factors included the following variables in the model:

- Federal Poverty Level (FPL): Household income was classified as <100% of the federal poverty level (FPL), 100% to 199% of the FPL, 200% to 299% of the FPL, and more than 300% of the FPL.
- Insurance: Type of Insurance was classified as private only, public only, both private and public, other comprehensive insurance and uninsured. Insurance coverage was classified as uninsured if there was discontinuation or a break in insurance coverage at any time during the last year.
- Language: The Language was classified as Interview was conducted in any other language versus English.
- Satisfaction with the services: The responses from the given question “about [your child’s] health needs and the service (he/she) receives, how satisfied or dissatisfied are you with those services?” Were very satisfied, somewhat

satisfied, somewhat dissatisfied and very dissatisfied. These were categorized as satisfied (very/somewhat satisfied) and dissatisfied (somewhat/very dissatisfied).

Need factors: Need factor means the level of illness and as it is reported by the child's parents or reported by the health care professionals (Aday et al., 1993; Andersen, 1995).

The following variables were considered as need factors in the model:

- Severity of the illness: Severity of the illness was categorized into Minor, Moderate and Severe based on the question "Overall, how would you rate the severity of the difficulties caused by (S.C.)'s health problems? Would you say minor, moderate, or severe?"
- Functional Limitation: Functional limitation was categorized based on the given responses as 'yes' if the answer was usually or always and 'no' if the answer was never or sometimes from the question "[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?"

Analysis

The data set was created, and variables were recoded using SAS Version 9.1.3.

There were three steps in the analysis:

- 1) Descriptive analysis
- 2) Simple logistic regression analysis and

3) Multiple logistic regression analysis

All statistical results were analyzed at 5% level of significance. These data were collected based on the national survey using random sampling techniques. Statistical analysis accounted for survey weighting and the sample design. Multicollinearity was tested in logistic regression between the independent variables. No correlation was found between the variables.

Q1: What are the factors associated with problems and issues in accessing community base systems of care among children with special health care needs?

Descriptive statistics such as frequency and percentage for categorical variables were calculated. Chi-square test was used to test for statistically significant differences between children who have ease accessing community based services and those who have difficulty in accessing such services, examining differences in predisposing, enabling, and need factors. Logistic regression was used to examine the effects of predisposing, enabling and need factors on not obtaining community based services. The analysis excluded data with any missing records. Simple logistic regression was performed on individual factors without adjusting for other confounders. Multiple logistic regression was performed for adjusting for all other factors.

The Q2 and Q3 included respondents who had difficulty accessing services.

Q2: What are the factors associated with individual barriers in accessing community based systems of care among children with special health care needs?

Chi-square test was used to test for statistically significant differences between children who have individual barriers in accessing community based services and those who do not have individual barriers, examining differences in predisposing, enabling, and need factors. Logistic regression was used to examine the effects of predisposing enabling and need factors on individual barriers in accessing community based services. The analysis excluded data with any missing records. Simple logistic regression was performed on individual factors without adjusting for other confounders. Multiple logistic regression was performed for adjusting for all other factors.

Q3: What are the factors associated with institutional barriers in accessing community base systems of care among children with special health care needs?

Chi-square test was used to test for statistically significant differences between children who have institutional barriers in accessing community based services and those who do not have such institutional barriers, examining differences in predisposing, enabling, and need factors. Logistic regression was used to examine the effects of predisposing, enabling and need factors on institutional barriers in accessing community based services. The analysis excluded data with any missing records. Simple logistic regression was performed on individual factors without adjusting for other confounders. Multiple logistic regression was performed for adjusting for all other factors.

CHAPTER IV

RESULTS

Table 1 presents data for CSHCN who had difficulty accessing services in the last 12 months. Out of 40,723 CSHCN represented, 4,418 (approximately 11%) had difficulty accessing community based services. Among these CSHCN, there were 637 (16.73%) children of age 0-5 years old, 1,755 (38.78%) children of the age 6-11 years old and 2,026 (44.49%) children of age more than 12 years. Among the CSHCN who had difficulty in accessing services, there were 566 CSHCN who had individual barriers and 518 who had institutional barriers.

Based on the previous literature and predictor variables, interaction was also estimated for insurance*region, education*region, severity*region, severity*race/ethnicity, but there was no interaction found between these terms.

Community Based Services

Hypothesis 1: Difficulty in using community based systems among children with special health care needs depends on:

- a. Predisposing factors
- b. Enabling factors
- c. Need factors

Predisposing Factors

Age, gender, region, racial/ethnic group, total number of children and total number of adults in the household were statistically significant for having difficulty in accessing community based services. Table 2 represents unadjusted odds ratios. In the age group birth to five (0-5 year old), there was a 27% (OR: 0.73; 95% CI: 0.62-0.86) decrease in the odds of having difficulty in accessing community based services compared with CSHCN in high school (12-18 years old).

There was a 16% (OR: 1.16; 95% CI: 1.04-1.30) increased odds of having difficulty in accessing community based services among males compared with females. In the Midwest (OR:0.58; 95% CI:0.49 - 0.68), Northeast (OR:0.74; 95% CI:0.63 - 0.88) and South (OR:0.73; 95% CI:0.63 - 0.85), there was a 42%, 26% and 27% decrease in the odds of having difficulty in these services compared with the West region. Hispanics (OR: 1.66; 95%CI: 1.31 – 2.11) and other races (OR: 1.41; 95%CI: 1.21 – 1.65) were 66% and 41% more likely to have difficulty in accessing these services compared with non-Hispanic white CSHCN. CSHCN households with one child (OR: 1.25; 95% CI: 1.01-1.54) were 25% more likely to have issues in accessing community based services compared with households with 4 or more than 4 children. CSHCN in households with 2 (OR: 0.78; 95% CI: 0.62-0.97) and 3 adults (OR: 0.71; 95% CI: 0.55-0.91) had a decreased odds of having access issues compared with CSHCN in households with 4 or more adults.

After adjusting for all factors: the Midwest region remained a significant factor. There was a 23% (OR: 0.77; 95% CI: 0.63-0.94) less odds of having difficulty in accessing community based services compared with the West region. Compared to households with a highest education of more than high school, having less than a high school degree (OR: 0.61; 95% CI: 0.44-0.85) or high school degree (OR: 0.61; 95% CI: 0.50-0.75) was associated with decreased odds of having difficulty in accessing community based services. Non-Hispanic black CSHCN also had less odds of having difficulty (OR: 0.67; 95% CI: 0.54-0.84) in accessing community based services compared with non-Hispanic white CSHCN. CSHCN households with one child (OR: 1.55; 95% CI: 1.18-2.03) or three children (OR: 1.47; 95% CI: 1.10-1.97) had increased odds of having difficulty in accessing community based services compared with households of four or more children.

Enabling Factors

Primary language used for the interview, type of insurance, poverty level and satisfaction with services were statistically significant for difficulty in accessing community based services. CSHCN for which the interview was conducted in a language other than English were 2.26 times more likely (OR: 2.26, 95% CI: 1.70-3.01) to have difficulty in accessing community services compared with CSHCN for which the interview was conducted in English. CSHCN who were not continuously covered by insurance over the last year were 4.11 (OR: 4.11; 95% CI: 3.34–5.07) times more likely to have issues in accessing community services compared with CSHCN who were

covered under private insurance. Additionally, CSHCN who had public (OR: 1.60; 95% CI: 1.39-1.82) and CSHCN who had both public and private (OR: 1.84; 95% CI: 1.53-2.21) insurances were also more likely to have difficulty accessing community services compared with private insurance. Poverty level also significantly affected having difficulty in accessing community based services within the last 12 months. Compared to households at or above 300% of the federal poverty level (FPL), CSHCN in households at <100 of the FPL (OR: 1.91; 95% CI: 1.65-2.22), 100 –199% of the FPL (OR: 1.71; 95% CI: 1.48-1.98) and 200-299% of FPL (OR: 1.30; 95% CI: 1.11-1.52) were more likely to have difficulty in accessing community services. Parents who were not satisfied with any of other services (OR: 20.07; 95% CI: 17.55-22.94) were more likely to have difficulty accessing community services compared with parents who were satisfied with the services.

After adjusting the other factors, CSHCN who were not continuously covered by insurance (uninsured) over the last year (OR: 2.54; 95% CI: 1.89–3.41) were 2.54 times more likely to have difficulty in accessing community services compared to the CSHCN who had private insurance. Parents who were not satisfied with the services were 15.62 times (OR: 15.62; 95% CI: 13.23-18.43) more likely to have difficulty in accessing community services compared with parents were satisfied with the services.

Need Factors

Functional limitation and severity of the child were statistically significant for accessing community based services. CSHCN who had functional limitations were more likely (OR: 3.97; 95% CI: 3.55 – 4.43) to have difficulty in accessing these services

compared with CSHCN who had no functional limitation. Additionally, CSHCN who had severity of illness as severe (OR: 3.33; 95% CI: 2.91–3.81) or moderate (OR: 7.17; 95% CI: 6.07-8.45) were more likely to have difficulty in accessing community based services.

After adjusting for other factors similar results were observed. CSHCN who had functional limitations were (OR: 1.79; 95% CI: 1.52-2.11) more likely to have difficulty in accessing services compared with CSHCN who had no functional limitation. Additionally, severity of the condition who had moderate (OR: 2.40; 95% CI: 2.02-2.85) or severe (OR: 3.56; 95% CI: 2.79-4.54) were more likely to have difficulty in accessing community based services compared with who had minor severity of the illness.

Individual Barriers

Hypothesis 2: Predisposing, enabling and need factors are associated with individual barriers for CSHCN who have difficulty accessing community based systems of care.

Predisposing Factors

Household education, racial/ethnic group and, total number of children in the household were statistically significant.

Table 2 presents unadjusted odds ratio. CSHCN from families with a highest household education of less than high school (OR: 3.10; 95% CI: 1.37-7.02) and high school degree (OR: 2.43; 95% CI: 1.54-3.82) were 3.10 and 2.43 times more likely to have individual barriers compared with CSHCN families having a highest household

education of more than high school degree. Hispanics were 3.61 times (OR: 3.61; 95% CI: 1.63-8.00) more likely to have individual barriers compared with non-Hispanic white CSHCN. CSHCN households with one child (OR:0.41; 95% CI: 0.24-0.69), two (OR:0.42; 95% CI:0.24-0.71) or three (OR:0.39; 95% CI: 0.21-0.74) children were about 60% less likely to have individual barriers compared with CSHCN in households with more than 4 children .

Table 3 presents the associated factors with individual barriers after adjusting for all other factors. Even though the overall p-value is not statistically significant, individual regions showed that there is marginally significant difference in the association compared with West region. In Northeast (OR: 0.50; 95% CI: 0.26-0.93) and South (OR: 0.52; 95% CI: 0.29-0.92) regions, CHSCN were approximately 50% less likely to have individual barriers compared with the West region. Compared to households with a highest education of more than high school, having a high school degree (OR: 1.94; 95% CI: 1.08-3.47) was associated with increased odds of having individual barriers.

Enabling Factors

Satisfaction with the services, type of insurance and poverty level were statistically significant.

CSHCN who were not continuously covered by insurance over the last year were 3.40 (OR: 3.40; 95% CI: 1.45–8.01) times more likely to have individual barriers compared with CSHCN who were covered under private insurance. CSHCN who were covered under public (OR: 2.11; 95% CI: 1.44-3.09) and CSHCN who were covered

under both public and private insurances were approximately 2 times (OR: 1.99; 95% CI: 1.16-3.41) more likely to have individual barriers compared with CSHCN who were covered under private insurance in the last 12 months. Poverty level was also significantly associated with CSHCN who had individual barriers within the last 12 months. Compared to households at or above 300% of the federal poverty level (FPL), CSHCN households at <100 of the FPL (OR: 3.25; 95% CI: 1.93–5.48), 100 –199% of the FPL (OR: 1.80; 95% CI: 1.14-2.84), and 200-299% of the FPL (OR: 1.70; 95% CI: 1.08-2.68) were more likely to have individual barriers. Additionally, satisfaction with the services was associated with individual barriers. Parents who were not satisfied with the other services were 1.80 (OR: 1.80; 95% CI: 1.24-2.62) times more likely to report individual barriers compared with parents who were satisfied with the services.

After adjusting for all other factors, none of the enabling factors were associated with the outcome individual barriers.

Need Factors

Functional limitation and severity of the child were statistically significant. CSHCN who had severity of illness as moderate (OR: 1.77; 95% CI: 1.21–2.57) or severe (OR: 3.27; 95% CI: 1.90-5.62) were 1.77 times and 3.27 times more likely to have individual barriers compared with CSHCN who had minor severity of illness. CSHCN with functional limitation were 1.88 times more likely (OR: 1.88; 95% CI: 1.37-2.60) than those with no functional limitation to have had individual barriers.

After adjusting for other factors, severity of the illness was marginally statistically significant. Compared to the minor severity of the illness, CHSCN who had severity of illness as moderate (OR: 1.53; 95% CI: 0.98-2.40) or severe (OR: 2.51; 95% CI: 1.08-5.83) were more likely to have individual barriers.

Institutional Barriers

Hypothesis 3: Predisposing, enabling and need factors are associated with institutional barriers for CSHCN who have difficulty accessing community based systems of care

Predisposing Factors

Household education and total number of children were statistically significant for CSHCN with institutional barriers. Table 2 presents unadjusted odds ratios. Compared to CSHCN in households with a highest education of more than high school, CSHCN in households with less than high school degree (OR: 1.92; 95% CI: 1.15-3.21) were 1.92 times more likely to have institutional barriers. In households with two (OR: 0.57; 95% CI: 0.33-0.97) or three children (OR: 0.51; 95% CI: 0.28-0.96), CSHCN were 43% and 49% less likely to have institutional barriers compared with CSHCN from households of four or more children.

After adjusting for all other factors, there were no statistical association between predisposing factors and institutional barriers.

Enabling Factors

Satisfaction with any of the health services and type of insurance were statistically significant. CSHCN who were covered by both public and private insurances over the last year were 1.65 (OR: 1.65; 95% CI: 1.07–2.53) times more likely to have institutional barriers compared with who were covered by private insurance in the last 12 months. Additionally, satisfaction with the services was also associated with institutional barriers. Parents who were not satisfied with the other services were 2.19 times more likely (OR: 2.19; 95% CI: 1.59-3.02) to report institutional barriers compared with parents who were satisfied with the services.

After adjusting the other factors, similar results were observed. Parents who were not satisfied with the services were 2.46 (OR: 2.46; 95% CI:1.63-3.71) times more likely to report institutional barriers compared with parents who were satisfied with the services.

Need Factors

Functional limitation and severity of the child were statistically significant. CSHCN with functional limitation were 1.69 times more likely (OR: 1.69; 95% CI: 1.28-2.23) to have institutional barriers than CSHCN without functional limitation. Additionally, CHSCN who had severity of illness as severe were 2.59 times more likely (OR: 2.59; 95% CI: 1.68–4.00) to have institutional barriers compared with CSHCN who had minor as severity of illness.

After adjusting for other factors, functional limitation and severity of the child remained statistically significant. CSHCN with functional limitation were 1.55 times (OR: 1.55; 95% CI: 1.06-2.25) more likely to have institutional barriers compared to CSHCN with no functional limitation. CSHCN who had severity of illness as severe were also more likely (OR:1.84; 95% CI: 1.03-3.28) to have institutional barriers compared with who had minor as severity of the illness.

CHAPTER V

DISCUSSION AND CONCLUSION

Discussion

This study focused on factors associated with difficulty in accessing community based services, individual barriers and institutional barriers.

Difficulty in accessing community based services

Among 13 risk factors examined for difficulty in accessing community based services, eight significantly predicted having difficulty accessing community based services in the past 12 months for CSHCN 0-18 years of age. These included four predisposing factors (education, region, race/ethnicity, total number of children living in the household), two enabling factors (type of insurance and satisfaction with the services) and two need factors (functional limitation and severity of the child).

Previous literature suggests (Mayer et al., 2004; P. W. Newacheck, McManus et al., 2000; van Dyck et al., 2004; Yu et al., 2004) demographic variables (race and ethnicity, education, child age and poverty level), type of health insurance, language used during the interview, severity of the condition, and functional limitation significantly affect accessing any kind of services among CSHCN. In this study, similar results were associated with difficulty in accessing community services. Child age, poverty level, language used during the interview and public insurance were associated with difficulty in accessing these services before adjusting for various factors. Interestingly, after adjusting for other factors, these variables (factors) were no longer associated with difficulty in accessing the services. Type of insurance, race/ethnicity, region, severity of

the condition, and functional limitation were associated with the outcome even after adjusting for potential confounders. These results are consistent with the previous studies.

A similar study by Baruffi et al. (2005) found insufficient insurance, lack of coordinated care in a medical home and lack of involvement in decision making (which included satisfaction with the services) as main obstacles in accessing community based services (Baruffi, Miyashiro, Prince, & Heu, 2005). However, the present research study included only satisfaction with the services but the results were consistent with the Baruffi et al. study. In previous research conducted by Baruffi et al, certain factors such as functional limitation and severity of the child were not associated with accessing community services. In contradiction to previous results, the present research study showed that as severity of the illness increases, the odds of difficulty in accessing community services increases. The reason for this might be the complexities involved in the official procedure (paperwork, waiting time etc) required for accessing to community based services during severe illness. Similarly presence of functional limitation is also associated with difficulty in accessing community services. Parent's attitude and perception of the illness as well as their knowledge about the assistance available through community based services might influence their motivation to access these services.

Baruffi et al. (2005) did not investigate access to community based services among different racial/ethnic groups, education groups or by region. In the current research, racial/ethnic group, region and education were associated with difficulty in accessing community based services. Non-Hispanic black CSHCN and CSHCN in the Midwest were less likely to have difficulty in accessing community services compared

with non-Hispanic white CSHCN and CSHCN residing in the West respectively. This is consistent with research by Newacheck et al. (2000). Additionally, the total number of children in the household also affects for difficulty in accessing community services. CSHCN in households with one child or three children had an increased odds of having access issues compared with CSHCN in households with 4 or more children. Compared to households with a highest education of more than high school, having less than high school degree or high school degree was associated with a decreased odds of having difficulty in accessing community based services.

Van Dyck et al. (2004) studied the association of factors associated with one's satisfaction with family centered care. Age, minority population, region (west), lack of insurance, FPL and functional limitation were associated factors for satisfaction with family centered care. In this study, lack of satisfaction with the health care services and functional limitation were significantly associated with difficulty in accessing community based services. However, age and poverty level were associated with this outcome before adjusting for other factors. After adjusting, these were not association.

From the Ngui study (Ngui & Flores, 2006), before adjusting for the factors, there was a significantly increased odds ratio for black and Hispanic parents compared with white parents reporting that services for their CSHCN were not easy to use. These disparities were not significant after adjustment for other child characteristics, socioeconomic status, and access factors. Even after adjustment for all other variables, compared with white parents, black parents had significantly increased odds in reporting

that health care services were not easy to use. The current research results were consistent with the above study.

Individual barriers and Institutional barriers

Among 13 risk factors included in the model, two predisposing (education and region), and two need factors (functional limitation and severity of the illness) were significant for predicting having individual barriers while difficulty in accessing community based services in the past 12 months for CSHCN 0-18 years of age.

Yu et al. (2004), suggest that a higher risk of experiencing difficulty in accessing care is associated with the language in which the interview was conducted. Especially in Hispanic families, CSHCN with non-English speaking parents were from less educated and lower income families and were more likely to lack insurance and have severity of conditions that greatly affected their activities. The current study categorized barriers into groups as individual and institutional barriers. After adjusting for all factors, in this study, education and severity of the condition were significant with individual barriers, (language is one of the condition for individual barriers) in difficulty accessing community services. Race, type of insurance, poverty level and satisfaction with services were associated with individual barriers before adjusting for other factors. Surprisingly, after adjustment for all other factors, these variables were no longer associated with the individual barriers. These results were consistent with the above study (Ngui & Flores, 2006). Interestingly region and education were significant factors associated with the

individual barriers only after adjusting for other factors. This implies CSHCN who live in different regions and have less education experience difficulty in accessing health care.

Few studies revealed barriers for not receiving health care services in any families are cost, health plan problems, availability in area, transportation problems and, not convenient times (Wang & Watts, 2007). The new key point in this research is information about individual and institutional barriers and factors associated with them. However, the results were consistent with barriers for difficulty in accessing other services individually not by categorization.

Satisfaction with the services, functional limitation and severity of the child were significant factors for Institutional barriers. These results are consistent with research conducted in the African American population (Hines-Martin et al., 2003). While comparing factors associated with individual and institutional barriers, the present research study found that more factors were statistically associated with institutional barriers among CSHCN with difficulty in accessing these services than individual barriers. Further investigation showed that these factors (education, and severity of the child) in turn affected individual barriers.

In the previous study conducted on health care services in African American population (Hines-Martin et al., 2003), the researchers stratified the barriers into individual and institutional. But this was done in mental health care services for general population and not applied to CSHCN. This could be one of the basic necessities for reducing barriers to access health care access in CSHCN.

In the present study, there were no appropriate measures to calculate the barriers: individual perceptions or institutional (organizational). This is one of the limitations of the study. This restricts to divide appropriately and measure the factors associated with these barriers. Another limitation is, many respondents might not have knowledge about the existence or services provided by community based services. Due to this, the respondents might report difficulty in accessing these services but in reality they might not be aware of their existence.

Conclusion:

The findings of this study show the factors associated with difficulty in accessing community services and their role in access to health care services for CSHCN. Although 90% of the children have easy access to community services, this study suggests that functional limitation, severity of the child's illness and need of other services are associated with greater difficulty in accessing community based services. Results of difficulty in accessing services confirmed that education level, non-Hispanic black, region and health insurance were significant factors after adjusting for all other factors. This definitely requires detailed investigation in future studies so that policies focused on overcoming barriers by taking into consideration these associated factors should be made. These factors should be considered for National/State policies when planning for health care services for CSHCN to optimize the utilization of the services provided. This might prove beneficial by increasing the access to these services by overcoming present obstacles faced while accessing these services. Future research should provide detailed knowledge about reasons leading to difficulty in accessing services and suggest possible measure to tackle these difficulties.

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APPENDICES

APPENDIX A

Overall Demographic Characteristics Table

Table 1. Over all Demographics for Difficulty in using community based services, Individual and Institutional Barriers

	Difficulty in using Community services			Individual Barriers			Institutional Barriers		
	yes	no	p-value	yes	no	p-value	yes	no	p-value
	n (%)	n (%)		n (%)	n (%)		n (%)	n (%)	
Predisposing Factors									
<i>Age</i>			<0.01			0.81			0.54
Birth to Five (≤5)	637(16.73)	6,724(19.13)		566(16.63)	71(17.78)		518(16.38)	119(18.52)	
Elementary School (6 to 11)	1,755(38.78)	13,223(32.99)		1,575(38.99)	180(36.55)		1,441(39.37)	314(35.78)	
High School (≥12)	2,026(44.49)	15,979(36.97)		1,842(44.37)	184(45.67)		1,724(44.25)	302(45.70)	
<i>Gender</i>			<0.01			0.8			0.09
Male	2,833(62.56)	21,086(52.55)		2,553(62.47)	2,80(63.49)		2,358(62.38)	475(63.51)	
Female	1,571(37.44)	14,779(36.57)		1,417(37.52)	154(36.51)		1,313(37.62)	258(36.49)	
<i>Highest education</i>			0.35			<0.01			0.02
Less than high school	267(7.80)	1,622(5.95)		251(8.27)	16(3.33)		225(8.45)	42(4.71)	
High school graduate	688(23.10)	5,696(20.56)		640(24.13)	48(12.39)		587(23.26)	101(22.28)	
More than high school	3,454(69.10)	28,539(62.56)		3,084(67.60)	370(84.28)		2,863(68.29)	591(73.01)	
<i>Region</i>			<0.01			0.3			0.79
Midwest	820(19.11)	8,745(21.92)		736(19.09)	84(19.24)		654(18.72)	166(21.07)	
Northeast	873(17.74)	6,456(15.91)		773(17.34)	100(21.99)		733(17.87)	140(17.11)	
South	1,381(37.91)	11,843(34.48)		1,242(37.85)	139(38.55)		1,153(37.94)	228(37.75)	
West	1,344(25.24)	8,882(16.79)		1,232(25.72)	112(20.22)		1,143(25.47)	201(24.07)	

	Difficulty in using Community services			Individual Barriers			Institutional Barriers		
	yes	no	p-value	yes	no	p-value	yes	no	p-value
	n (%)	n (%)		n (%)	n (%)		n (%)	n (%)	
<i>Race</i>			<0.01			<0.01			0.27
Hispanic	297(8.47)	1,748(4.96)		280(9.02)	17(2.83)		244(8.38)	53(8.94)	
Non Hispanic White	2,945(60.00)	25,850(58.36)		2,624(59.29)	321(67.36)		2,410(59.03)	535(64.97)	
Non Hispanic Black	436(15.09)	3,713(14.44)		403(15.43)	33(11.49)		382(15.83)	54(11.29)	
Other	740(16.44)	4,615(11.34)		676(16.26)	64(18.32)		647(16.75)	93(14.80)	
<i>Total number of children</i>			<0.01			<0.01			0.1
1	1,836(37.16)	12,333(26.88)		1,663(36.96)	173(39.30)		1,547(37.34)	289(36.27)	
2	1,438(31.68)	13,726(33.86)		1,287(31.53)	151(33.19)		1,169(31.33)	269(33.48)	
3	758(20.35)	6,604(18.61)		684(20.14)	74(22.53)		636(19.78)	122(23.28)	
≥4	386(10.81)	3,263(9.76)		349(11.37)	37(4.97)		331(11.55)	55(6.97)	
<i>Total number of adults</i>			<0.01			0.2			0.62
1	819(20.65)	5,043(14.13)		766(21.13)	53(15.56)		696(20.83)	123(19.69)	
2	2,710(61.33)	23,642(58.13)		2,413(60.67)	297(68.26)		2,233(60.85)	477(63.83)	
3	591(11.68)	5,114(12.16)		542(11.87)	49(9.77)		499(11.71)	92(11.52)	
≥4	273(6.34)	1,835(4.65)		242(6.33)	31(6.41)		236(6.61)	37(4.96)	
Enabling Factors									
<i>Primary language</i>			<0.01						
English	4,190(92.95)	34,840(86.19)							
Any other language	204(7.05)	779(2.89)							
<i>Type of Insurance</i>			<0.01			<0.01			0.08
Private	1,993(47.37)	22,528(55.81)		1,727(45.60)	266(64.44)		1,614(46.63)	379(51.03)	
Public	1,103(31.61)	7,555(23.35)		1,021(32.62)	82(21.88)		953(32.24)	150(28.46)	
Both	448(9.83)	2,322(6.31)		408(10.11)	40(7.19)		381(10.42)	67(6.92)	

	Difficulty in using Community services			Individual Barriers			Institutional Barriers		
	yes	no	p-value	yes	no	p-value	yes	no	p-value
	n (%)	n (%)		n (%)	n (%)		n (%)	n (%)	
Comprehensive	82(1.77)	808(1.74)		70(1.71)	12(2.34)		69(1.81)	13(1.56)	
Uninsured	333(9.42)	1,081(2.69)		319(9.96)	14(4.13)		270(8.89)	63(12.01)	
<i>Poverty level</i>			<0.01			<0.01			0.22
<100	886(25.45)	4637(16.13)		838(26.64)	48(12.95)		768(26.32)	118(20.90)	
100 to below 200	1,057(26.74)	6649(18.99)		966(27.03)	91(23.76)		894(26.86)	163(26.12)	
200 to below 300	702(15.34)	5914(14.29)		643(15.43)	59(14.38)		591(15.36)	111(15.26)	
≥300	1,444(32.47)	15425(39.39)		1,240(30.90)	204(48.90)		1,149(31.46)	295(37.72)	
<i>Satisfied with the services</i>			<0.01			<0.01			<0.01
Yes	2,481(54.14)	33,646(95.95)		2,179(52.92)	302(66.92)		1,972(51.15)	509(69.62)	
No	1,897(45.86)	1,404(4.05)		1,768(47.08)	129(33.08)		1,682(48.84)	215(30.38)	
Need Factors									
<i>Functional Limitation</i>			<0.01			<0.01			<0.01
Yes	2,161(47.70)	6,239(16.66)		2,001(49.03)	160(33.81)		1,867(49.78)	294(36.92)	
No	2,245(52.30)	29,584(72.44)		1,973(50.97)	272(66.19)		1,807(50.22)	438(63.08)	
<i>Severity of the child</i>			<0.01			<0.01			<0.01
Minor	1,009(23.30)	16,735(48.07)		868(22.05)	141(37.01)		781(21.84)	228(30.73)	
Moderate	2,260(52.38)	10,632(32.44)		2,050(52.60)	210(4.09)		1,883(51.87)	377(55.01)	
Severe	996(24.32)	2,099(7.01)		942(25.34)	54(2.77)		896(26.29)	100(14.26)	

Above percentages are based on weighted analysis

Individual barriers and Institutional barriers are population who had difficulty in using community based services

APPENDIX B

Unadjusted Factors Table

Table 2. Unadjusted Risk Factors for difficulty in using Community based services, Individual barriers and Institutional Barriers

Variables	Difficulty in using Community Services			Individual Barriers			Institutional Barriers		
	OR	95% CI		OR	95% CI		OR	95% CI	
Predisposing Factors									
<i>Age(in years)</i>									
Birth to Five (≤ 5)	0.73	0.62	0.86	0.96	0.57	1.62	0.91	0.60	1.39
Elementary School (6 to 11)	0.98	0.87	1.10	1.10	0.79	1.54	1.14	0.84	1.54
High School (≥ 12)	---	---	---	---	---	---	---	---	---
<i>Gender</i>									
Male	1.16	1.04	1.30	0.96	0.69	1.34	0.95	0.70	1.30
Female	---	---	---	---	---	---	---	---	---
<i>Highest education</i>									
Less than high school	1.19	0.95	1.50	3.10	1.37	7.02	1.92	1.15	3.21
High school graduate	1.02	0.89	1.17	2.43	1.54	3.82	1.12	0.75	1.66
More than high school	---	---	---	---	---	---	---	---	---
<i>Region</i>									
Midwest	0.58	0.49	0.68	0.78	0.48	1.26	0.84	0.55	1.28
Northeast	0.74	0.63	0.88	0.62	0.38	1.02	0.99	0.64	1.53
South	0.73	0.63	0.85	0.77	0.48	1.24	0.95	0.63	1.44
West	---	---	---	---	---	---	---	---	---

Variables	Difficulty in using Community Services			Individual Barriers			Institutional Barriers			
	OR	95% CI		OR	95% CI		OR	95% CI		
<i>Race</i>										
Hispanic	1.66	1.31	2.11	3.61	1.63	8.00	1.03	0.60	1.76	
Non Hispanic Black	1.02	0.86	1.20	1.53	0.89	2.63	1.54	0.91	2.62	
Other	1.41	1.21	1.65	1.01	0.64	1.59	1.25	0.79	1.98	
Non Hispanic White	---	---	---	---	---	---	---	---	---	
<i>Total number of children</i>										
1	1.25	1.01	1.54	0.41	0.24	0.69	0.62	0.36	1.06	
2	0.85	0.68	1.05	0.42	0.24	0.71	0.57	0.33	0.97	
3	0.99	0.78	1.25	0.39	0.21	0.74	0.51	0.28	0.96	
≥4	---	---	---	---	---	---	---	---	---	
<i>Total number of adults</i>										
1	1.07	0.84	1.37	1.38	0.68	2.77	0.79	0.42	1.51	
2	0.78	0.62	0.97	0.90	0.49	1.65	0.72	0.41	1.24	
3	0.71	0.55	0.91	1.23	0.61	2.49	0.76	0.41	1.43	
≥4	---	---	---	---	---	---	---	---	---	
Enabling Factors										
<i>Primary language</i>										
Any other language	2.26	1.70	3.01							
English	---	---	---							

Variables	Difficulty in using Community Services			Individual Barriers			Institutional Barriers			
	OR	95% CI		OR	95% CI		OR	95% CI		
<i>Type of Insurance</i>										
Public	1.60	1.39	1.82	2.11	1.44	3.09	1.24	0.86	1.79	
Both	1.84	1.53	2.21	1.99	1.16	3.41	1.65	1.07	2.53	
Comprehensive	1.20	0.80	1.81	1.03	0.43	2.50	1.27	0.46	3.54	
Uninsured	4.11	3.34	5.07	3.40	1.45	8.01	0.81	0.51	1.29	
Private	---	---	---	---	---	---	---	---	---	
<i>Poverty level</i>										
<100	1.91	1.65	2.22	3.25	1.93	5.48	1.51	0.99	2.31	
100 to below 200	1.71	1.48	1.98	1.80	1.14	2.84	1.23	0.85	1.79	
200 to below 300	1.30	1.11	1.52	1.70	1.08	2.68	1.21	0.83	1.75	
≥300	---	---	---	---	---	---	---	---	---	
<i>Satisfaction</i>										
No	20.07	17.55	22.94	1.80	1.24	2.62	2.19	1.59	3.02	
Yes	---	---	---	---	---	---	---	---	---	
Need Factors										
<i>Functional Limitation</i>										
Yes	3.97	3.55	4.43	1.88	1.37	2.60	1.69	1.28	2.23	
No	---	---	---	---	---	---	---	---	---	

Variables	Difficulty in using Community Services			Individual Barriers			Institutional Barriers			
	OR	95% CI		OR	95% CI		OR	95% CI		
<i>Severity of the child</i>										
Moderate	3.33	2.91	3.81	1.77	1.21	2.57	1.33	0.96	1.84	
Severe	7.16	6.07	8.45	3.27	1.90	5.62	2.59	1.68	4.00	
Minor	---	---	---	---	---	---	---	---	---	
* OR = Odds Ratio; CI = Confidence Interval										
Bolded values represent significant factors at p < 0.05										
~Represents reference group										

APPENDIX C

Adjusted Factors Table

Table 3. Adjusted Risk Factors for difficulty in using Community based services, Individual barriers and Institutional Barriers

Variables	Difficulty in using Community services			Over all p- value	Individual Barriers			Over all p- value	Institutional Barriers			Over all p- value
	OR	95% CI			OR	95% CI			OR	95% CI		
Predisposing Factors												
<i>Age(in years)</i>				0.20				0.83				0.07
	Birth to Five(<=5)	0.89	0.72	1.09		0.84	0.46	1.54		1.14	0.63	2.06
	Elementary School(6-11)	1.07	0.92	1.24		1.01	0.68	1.50		1.53	1.06	2.20
	High School(>=12)	---	---	---		---	---	---		---	---	---
<i>Gender</i>				0.12				0.71				0.27
	Male	1.12	0.97	1.30		1.07	0.73	1.55		0.82	0.58	1.16
	Female	---	---	---		---	---	---		---	---	---
<i>Highest education</i>				<0.01				0.02				0.43
	Less than high school	0.61	0.44	0.85		2.82	0.95	8.38		1.32	0.65	2.63
	High school graduate	0.61	0.50	0.75		1.94	1.08	3.47		0.83	0.53	1.29
	More than high school	---	---	---		---	---	---		---	---	---
<i>Region</i>				0.07				0.11				0.24
	Midwest	0.77	0.63	0.94		0.66	0.37	1.21		0.58	0.34	1.01
	Northeast	0.90	0.72	1.13		0.50	0.26	0.93		0.60	0.34	1.07
	South	0.84	0.68	1.03		0.52	0.29	0.92		0.68	0.40	1.16
	West	---	---	---		---	---	---		---	---	---

<i>Race/Ethnicity</i>				<0.01				0.27				0.96
	Hispanic	1.09	0.78	1.52		2.01	0.78	5.14		1.08	0.52	2.22
	Non Hispanic Black	0.67	0.54	0.84		0.95	0.43	2.08		1.12	0.64	1.95
	Other	0.82	0.65	1.03		0.74	0.43	1.27		1.02	0.67	1.82
	Non Hispanic White	---	---	---		---	---	---		---	---	---
<i>Total number of children</i>				<0.01				0.29				0.38
	1	1.55	1.18	2.03		0.53	0.27	1.06		0.93	0.46	1.84
	2	1.29	0.98	1.69		0.57	0.29	1.14		0.72	0.36	1.42
	3	1.47	1.10	1.97		0.48	0.22	1.08		0.68	0.31	1.51
	≥4	---	---	---		---	---	---		---	---	---
<i>Total number of adults</i>				0.03				0.87				0.75
	1	1.02	0.73	1.43		1.16	0.46	2.94		0.98	0.46	2.08
	2	0.99	0.73	1.35		1.26	0.56	2.56		0.81	0.42	1.55
	3	0.74	0.53	1.05		1.42	0.58	3.46		0.92	0.41	2.07
	≥4	---	---	---		---	---	---		---	---	---
Enabling Factors												
<i>Primary language</i>								0.25				
	Any other language	1.34	0.81	2.21								
	English	---	---	---								
<i>Type of Insurance</i>				<0.01				0.11				0.42
	Public	1.25	0.99	1.57		1.05	0.54	2.03		0.86	0.46	1.61
	Both	1.25	0.99	1.59		1.71	0.84	3.47		1.41	0.74	2.68
	Comprehensive	1.30	0.78	2.19		0.51	0.18	1.43		0.56	0.17	1.85
	Uninsured	2.54	1.89	3.41		2.34	0.79	6.91		1.11	0.45	2.71
	Private	---	---	---		---	---	---		---	---	---

<i>Poverty level</i>					0.78				0.12			0.80
	<100	1.10	0.83	1.46		1.87	0.73	4.85		1.06	0.51	2.18
	100 to below 200	0.99	0.80	1.23		0.96	0.48	1.93		1.29	0.64	2.59
	200 to below 300	1.07	0.87	1.30		1.52	0.91	2.55		1.21	0.73	1.99
	≥300	---	---	---		---	---	---		---	---	---
<i>Satisfied with the services</i>					<0.01				0.19			<0.01
	No	15.62	13.23	18.43		1.31	0.86	1.98		2.46	1.63	3.71
	Yes	---	---	---		---	---	---		---	---	---
Need Factors												
<i>Functional Limitation</i>					<0.01				0.08			0.02
	Yes	1.79	1.52	2.11		1.49	0.94	2.36		1.55	1.06	2.25
	No	---	---	---		---	---	---		---	---	---
<i>Severity of the child</i>					<0.01				0.07			0.03
	Moderate	2.40	2.02	2.85		1.53	0.98	2.40		1.00	0.65	1.53
	Severe	3.56	2.79	4.54		2.51	1.08	5.83		1.84	1.03	3.28
	Minor	---	---	---		---	---	---		---	---	---

* OR = Odds Ratio; CI = Confidence Interval

Bolded values represent significant factors at $p < 0.05$ at individual level factors

~--Represents reference group

APPENDIX D
Enabling Factors

Table 4. Description of the variables based on the Survey questions for Enabling Factors

Label of the variable	Variable	Description of the questions
Insurance Status (Families of CSHCN have adequate insurance to pay for the services they need)	TYPEINS	Type of insurance coverage at interview
	C7Q03	Now I have a few questions about health insurance and health care coverage for (S.C.) . At this time, is (S.C.) covered by health insurance that is provided through an employer or union?(to find out either it is private or public)
	C8Q01_A	The next questions are about (S.C.) 's health insurance or health care plans. Does (S.C.) 's health insurance offer benefits or cover services that meet (his/her) needs? Would you say:
	C8Q01_B	Are the costs not covered by (S.C.) 's health insurance reasonable? Would you say:
	C8Q01_C	

		Does (S.C.)'s health insurance allow (him/her) to see the health care providers (he/she) needs? Would you say:
Families of CSHCN are partners in decision making and are satisfied with services received	C6q06	(During the past 12 months/ [WHEN S.C. IS YOUNGER THAN 12 MONTHS] Since (his/her) birth), how often did (S.C.)'s doctors or other health care providers help you feel like a partner in (his/her) care? Would you say never, sometimes, usually, or always?
	C6q0c	Thinking about (S.C.)'s health needs and the services (he/she) <u>receives</u> , how satisfied or dissatisfied are you with those services? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied?
Language need	Lang2	WHICH LANGUAGES WERE NEEDED TO COMPLETE THIS INTERVIEW?

APPENDIX E

Need Factors

Table 5. Description of the variables based on the Survey questions for Need Factors

Label of the Variable	Variable	Description of the question
Severity of the health condition	C3Q10	Overall, how would you rate the severity of the difficulties caused by (S.C.)'s health problems? Would you say minor, moderate, or severe?
Functional limitation	C3Q02	[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? Would you say:

