

**Medical Home for Children with Special Health
Care Needs in North Carolina**

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ABSTRACT

Background: A medical home is a model of care defined by the American Academy of Pediatrics as medical care for children that is accessible, continuous, comprehensive, family-centered, coordinated and compassionate. North Carolina uses the medical home concept as a model for providing high quality care to children with special health care needs (CSHCN). However, information on characteristics of CSHCN, predictors of having a medical home and the impact of having a medical home on outcomes of CSHCN in North Carolina are not available.

Methods: This study uses the data from the National Survey of Children with Special Health Care Needs conducted between 2000 and 2002. A random sample of parents or caregivers of CSHCN was surveyed in the United States.

Information on health status of CSHCN, health care experiences and insurance status was obtained. This study is limited to the data obtained from North Carolina. The characteristics of children with special health care needs are described. Bivariate analysis of socio-demographic factors with medical home and its 5 components (family-centered care, effective care coordination, personal doctor or nurse, usual source, referral problems) was carried out. Multivariate analysis was conducted to identify the predictors of having a medical home. The impact of having a medical home on the outcomes of CSHCN and their families was assessed.

Results: Fifty six percent of CSHCN in North Carolina have a medical home. Race/ethnicity and severity of impairment of CSHCN are independent predictors

of having a medical home in this population. White CSHCN have 1.7 times the odds of not having a medical home compared to non-White CSHCN and those with no limitation of activities due to their condition have 1.6 times the odds of having a medical home compared to those who have limitation of activities.

Children who have a medical home are less likely to have unmet health services needs or to have delayed or foregone care, and respondents were more likely to report that the health services were easy to use and to be satisfied with the services.

Conclusions: This study provides comprehensive information about CSHCN in North Carolina which can be used for needs assessment, and implementation and evaluation of programs for CSHCN in North Carolina. Disparities among CSHCN due to race/ethnicity and severity of their condition should be considered in organizing services for CSHCN in North Carolina. Future studies are needed to evaluate the 5 components of medical home and their impact on child health outcomes.

BACKGROUND

Children with special health care needs (CSHCN) are 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.¹

Based on this definition, an estimated 9.3 million children in the United States have special health care needs, accounting for 13% of all children in the United States.² This estimate would be higher if children who are institutionalized and children who are at increased risk of special needs were included.

CSHCN spend an additional 52 million days ill in bed and have an additional 58 million school absence days annually compared to children without special health care needs.³ Health of CSHCN impacts not only the children, but their families as well. Families of children with disabilities* incur significantly higher out-of-pocket expenses for providing health care for their children than those without disabilities.⁴ Approximately 21% of parents of CSHCN report financial problems due to their child's health and 30% of parents had to decrease their hours of employment or stop working altogether because of their child's condition.²

CSHCN have higher health care utilization than their counterparts. In 1994, CSHCN had more than twice as many physician contacts and 5 times as many

* Defined as presence of limitation in age-appropriate social role activities or receipt of specialized services through early intervention or special education programs.

hospital days than other children.³ According to the Medical Expenditure Panel Survey (MEPS), in 1999-2000, children with disabilities had higher rates of hospital admissions (97 vs. 23/1000 children), physician visits (5 vs. 2), and emergency room visits (250 vs. 30/1000 children) and took more prescription medications (6 vs. 2) compared to children without disabilities.⁴ Though children with disabilities comprised only 7% of children younger than 18 years in this study, they accounted for 23% of total health care expenditures.⁴

In spite of the higher utilization of health services, a larger proportion of caregivers of CSHCN report that the health services needs of their children have not been met (13%) compared to caregivers of those without special needs (6%).³ Satisfaction with care received was also lower among parents of CSHCN (18%) compared to parents of children without special needs (14%).³ A recent survey shows 18% of all CSHCN in the United States had one or more of health care services needs that were not met.²

In order to improve the quality of care for CSHCN, the Maternal and Child Health Bureau (MCHB) has adopted the medical home concept as a model of care for CSHCN. The MCHB uses having a medical home as one of the performance measures to assess a state's progress in implementing services for CSHCN.⁵ Increasing the proportion of children with special health care needs with access to a medical home is one of national Healthy People 2010 objectives (16-23).⁶ In 1999, the MCHB and the American Academy of Pediatrics (AAP) established the

National Center of Medical Home Initiatives for Children with Special Health Care Needs with a goal to ensure that all CSHCN have access to a medical home.

The term “medical home” was conceived by the AAP in 1967.⁷ In 1992, for the first time, the AAP defined the medical home in its policy statement: The AAP believes that the medical care of infants, children and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective and be delivered or directed by well-trained physicians who provide primary care and help to manage essentially all aspects of pediatric care. The physician should be known to the child and the family and should be able to develop a partnership of mutual responsibility and trust with them. These characteristics define the medical home.⁸ In 2002, the AAP operationalized the medical home concept in its policy statement by describing 37 characteristics under 7 domains that constitute a medical home.⁸

There is substantial empirical evidence for the effectiveness of individual components of the medical home concept (i.e. continuity of care, comprehensive care, coordinated care and usual source of care) in improving child-level and family-level outcomes of children with special health care needs. Studies show that comprehensive and coordinated disease management results in decreased severity of illnesses, decreased school absences, decreased hospitalizations and improved receipt of preventive care in children with chronic medical conditions like asthma and diabetes.⁹⁻¹⁵ Comprehensive care has been found to improve

clinical outcomes of high-risk children as well. In a study of 887 very low birth weight infants, children who received comprehensive care had less life threatening illnesses and fewer intensive care admissions compared to children who received routine care.¹⁶ A study of children with diabetes who lived in low-income households showed that children who experienced high continuity of care had lower hospitalizations due to diabetic ketoacidosis and better preventive care than children who did not have continuity of care.¹⁷ Continuity of care is associated with fewer emergency room visits and hospitalizations in children with asthma.¹⁸ In a cross-sectional study of parents, there was a significant difference in the satisfaction with care between the patients who had continuous care and those who did not.¹⁹

However, there is limited literature evaluating the medical home concept as a whole. Even among available studies, there is considerable variation in the way the medical home concept is operationalized. This is because the medical home concept is not a single entity but a composite of 37 different characteristics. Presence of after-hours care, usual source of care, comprehensive care, coordinated care have all been used individually or in combination in different studies as a measure of the medical home concept.²⁰⁻²⁴ As a result, comparison of these studies is difficult.

Palfrey et al. (2004) evaluated a medical home model of care which consists of appointing a case manager, identifying a parent consultant, developing an

individualized health plan for each CSHCN and providing continuing medical education for practitioners.²¹ They studied 117 CSHCN in 6 practices. With this model of care, the authors observed a statistically significant decline in hospitalizations among CSHCN and the need for parents to miss work. At the end of intervention, a significantly higher percentage of parents reported that the services were easy to use compared to the baseline estimation. Since the study was limited to a group of practices in one geographical area, it is difficult to generalize their results to other practice situations. The other limitation of this study is that it cannot be compared to other studies because of lack of uniform measurement criteria.

Strickland et al. (2004) conducted the first population-based evaluation of the medical home concept using the National Survey of Children with Special Health Care Needs data.²⁵ This survey does not address all the components of medical home as defined by the AAP. But, by systematic evaluation, a set of items in this survey has been identified to represent the medical home concept.²⁶ In this survey, medical home was considered to be present if a CSHCN has all of the following 5 components: (1) a usual source of care, (2) a personal doctor or nurse, (3) no difficulty in obtaining needed referrals, (4) care coordination when needed and (5) family-centered care.^{5, 25, 27}

Using the criteria mentioned in the previous paragraph, 53% of CSHCN in the United States have a medical home.²⁵ Strickland et al. found race/ethnicity,

income level and severity of the condition of CSHCN to be statistically significantly associated with not having a medical home.²⁵ Hispanic CSHCN had 1.9 times the odds of not having a medical home and Black CSHCN had 1.7 times the odds of not having a medical home compared to White CSHCN. Children who had severe limitations of their activities had 2.7 times the odds of not having a medical home compared to those who did not have any limitation of their activities. The odds of not having a medical home decreased with increasing income level of the family. Not having a medical home increased the odds of having delayed or foregone care and having unmet needs for health services and family support services, even after adjusting for socio-demographic factors.²⁵

Systems of care for CSHCN are developed and implemented through the states with the help of Title V funds from the MCHB. The MCHB in turn requires the states to report on the needs, services and performance measures on services for CSHCN.²⁸ In North Carolina, the Women and Children's Health Section of the Division of Public Health collaborates with the North Carolina Pediatric Society, private pediatric practices, Access II/III networks and the Family Support Network in planning and implementing programs for CSHCN.²⁹ To provide a comprehensive approach to the development of medical homes for CSHCN in North Carolina, The Medical Home Initiative for Children with Special Health Care Needs has been designed by the Division of Public Health.²⁹ Information on characteristics of CSHCN, risk factors for having a medical home and the impact of having a medical home on CSHCN in North Carolina is lacking. Such

information will be valuable in designing and implementing programs that are tailored to the needs of CSHCN in North Carolina. This information will also serve as a baseline for future evaluation of the state's performance.

Until recently, state-level data on CSHCN were not available. The National Survey of Children with Special Health Care Needs was designed to obtain state-level as well as national-level prevalence estimates, to describe the services this population of children needs and to assess possible areas in need of improvement in the systems of care for CSHCN.² The data has been collected in a manner that allows comparison across the states and the nation.³⁰ The National Survey of Children with Special Health Care Needs data was used in this study to obtain estimates of CSHCN in North Carolina that are necessary for program evaluation and needs assessment.

The objectives of this study are (1) to describe the prevalence and characteristics of CSHCN in North Carolina, (2) to assess the demographic risk factors associated with having a medical home for CSHCN in North Carolina, and (3) to evaluate the impact of having a medical home in the above population. The results from this study will be compared with the national-level estimates on medical home and its components reported in 2 previous studies using the same survey.^{2, 25} The report by Strickland et al. will henceforth be referred to as the national study.

METHODS

Data Source:

The National Survey of Children with Special Health Care Needs was sponsored by the MCHB and conducted by the National Center for Health Statistics (NCHS) between October 2000 and April 2002. A random-digit-dial sample of households with children under 18 years was selected from each of the 50 states and the District of Columbia.³⁰ First, selected demographic information was obtained for all children in the household. Next, children were screened for special health care needs using the screener questionnaire. When more than one child with special health care needs was identified in the screener interview, one child was randomly chosen. Finally, for each child with special health care needs chosen, detailed information on health and functional status, access to and use of health services, health insurance coverage, care coordination, satisfaction with care and impact on the family of the child with special health care needs was collected.

The data were obtained through a complex sample design. Three sampling weights were developed for the survey: (a) a household screener weight to account for non-response and multiple telephone lines, (b) a child screener weight to represent the demographics of the United States, and (3) a child interview weight to account for multiple-child households. The weight adjusted sample will represent the population characteristics of the United States as estimated by 2000 census and the Current Population Survey.³⁰

The survey has 4 files: (a) a screener file (b) an interview file (c) an insurance file and (d) a household file. The screener file has information on each child with a CSHCN screener interview. Information on health and functional status, access to and use of health service, health insurance coverage, care coordination, satisfaction with care and impact on the family is available on the interview file. The household file has information at the household level regarding the household size, state of residence, metropolitan status of residence, number of CSHCN in the household and household income level. The insurance file has insurance information on the children identified as CSHCN.

All the survey data are publicly available at the National Center for Health Statistics website.³¹ All the 4 files were merged prior to analysis. This study is limited to the data from CSHCN in North Carolina.

Variable Description:

The study sample was CSHCN in North Carolina. A child was identified as having a special need if he or she: (1) needs or uses more medical care, mental health services, or educational services than is usual for most children of the same age because of a medical, behavioral or health condition that is expected to last 12 months or longer; (2) needs or uses prescription medication because of a medical, behavioral or health condition that is expected to last 12 months or longer; (3) has a limitation in abilities to do the things that most children of the same age can do because of a medical, behavioral or health condition that is expected to last 12

months or longer; (4) needs or gets special therapy such as physical, occupational, or speech therapy because of a medical, behavioral or health condition that is expected to last 12 months or longer; or (5) has an emotional, developmental or behavioral problem that is expected to last or lasted for 12 months or longer for which he or she needs treatment or counseling.

Having a medical home is the outcome of interest. It is a dichotomous variable. The medical home variable was derived from 5 variables (component variables) which in turn were derived from multiple variables (sub-component variables). The medical home variable was derived from a total of 12 variables as follows:

1. The child has a usual source of care.
 - i) The child has a usual source for sick care.
 - ii) The child has a usual source for preventive care.
2. The child has a personal doctor or nurse.
3. The child has no problems obtaining referrals when needed.
4. Effective care coordination is received when needed.
 - i) The child has professional care coordination when needed.
 - ii) Doctors communicate well with each other.
 - iii) Doctors communicate well with other programs.
5. The child receives family-centered care.
 - i) Doctors usually or always spend enough time.
 - ii) Doctors usually or always listen carefully.

iii) Doctors are usually or always sensitive to family's values and customs.

iv) Doctors usually or always provide needed information.

v) Doctors usually or always make the family feel like a partner.

If a child did not meet any one of the sub-component variables, then the component variables were considered to have not been met. If a child did not meet any of the component criteria, then he or she was considered not to have met the criteria for medical home. This strategy of deriving the medical variable was based on the method described elsewhere.²⁷

Age, gender, race/ethnicity, impact of the child's condition on his or her activities, metropolitan status of residence, income level of the household, mother's education, type of insurance and adequacy of insurance were the independent variables of interest. All of these variables were categorical variables. Age was categorized into: (a) 0 to 5 years, (b) 6 to 11 years and (c) 12 to 17 years. Race/ethnicity was categorized into 4 categories: (a) Hispanic, (b) Non-Hispanic White, (c) Non-Hispanic Black and (d) Non-Hispanic other races and multiracial. Education level of the mother of CSHCN was categorized into 3 categories: (a) less than high school education, (b) high school education and (c) more than high school education. Metropolitan status had 2 values: (a) residence inside metropolitan statistical area (MSA) and (b) residence outside MSA. Income level of the household was categorized into: (a) income less than 100% Federal Poverty

Level[†] (FPL) (b) 100 to 399% FPL and (c) more than 400% FPL. The impact of the child's condition on his or her activities is an indirect measure of the severity of the child's condition. It was derived from 2 variables and categorized into 3 categories: (a) CSHCN whose condition did not affect them in the previous 12 months, (b) CSHCN whose condition affected them sometimes in the previous year or caused very little or some impairment of their activities, and (c) CSHCN whose condition affected them usually or always in the previous year or caused a great deal of impairment of ability. Insurance type had 4 categories: (a) uninsured at the time of interview or had gaps in insurance in the year prior to the interview, (b) private insurance, including insurance obtained through an employer or union, (c) public insurance, which includes Medicaid, State Children's Health Insurance Plan (SCHIP), military insurance, unspecified public insurance, comprehensive insurance from a facility supported by the Indian Health Service or a Native American Corporation, or Title V coverage, and (d) both public and private insurance or an insurance that could not be classified as either private or public. Adequacy of insurance was derived from 5 variables as described previously.²⁷ To be considered to have adequate health insurance, a child needed all of the following:

1. The child has public or private insurance at the time of interview.
2. The child has no gaps in insurance coverage in the year prior to the interview.
3. Insurance usually or always meets the child's needs.

[†] Based on Year 2000 Federal Poverty Guidelines published by the Department of Health and Human Services

4. Costs not covered by insurance are usually or always reasonable.

5. Insurance usually or always permits child to see needed providers.

If the child did not meet any one of the criteria mentioned above, insurance was considered inadequate.

The proportion of CSHCN needing health services was calculated for each of the following services: routine preventive care, specialist care, dental care, prescription medicines, therapy services, mental health care or substance abuse treatment, home health care, vision care, hearing aids, mobility devices, communication aids, medical supplies and medical equipment.

Finally, the impact of having a medical home on CSHCN and their families was assessed. Six categorical variables were used as impact measures:

1. Family's satisfaction with services received by CSHCN (present or absent)
2. Ease of use of health services (usually/ always easy to use or never/ sometimes)
3. Time spent by the caregiver on coordinating care for CSHCN (less than an hour per week or more than an hour per week)
4. Unmet need for any needed health services listed above (present or absent)

5. Unmet need for any needed family support services, which includes respite care, genetic counseling and mental health care or counseling (present or absent)
6. Delayed or forgone care of CSHCN in the year prior to interview (yes or no).

Statistical Methods:

First, univariate analysis was performed on the study population. Prevalence estimates among the demographic factors were obtained. Then, the characteristics of CSHCN were tabulated. Bivariate analysis was performed to determine the association of each one of the independent variables to the presence of medical home and its components. Pearson chi-square test was used to examine the association between categorical variables.

Since the observations in certain categories of the variables were small, changes to the variables were made in order to obtain valid population estimates of the odds ratio of having a medical home. Age was used as a continuous variable. Race/ethnicity was categorized into: (a) Non-Hispanic White and (b) all other races and multiracial. Impairment in activities was changed into a 2-category variable: (a) no impairment of activities and (b) some or severe impairment of activities. Insurance type was categorized to: (a) uninsured or had gaps in insurance in the previous years and (b) is currently insured with no gaps in insurance in the previous year. Dummy variables were created for poverty status.

Education of the mother of CSHCN was changed to 2 categories by combining “more than high school education” and “high school education”. Unadjusted odds ratios for the presence of medical home were obtained for each one of these independent variables.

Independent variables that had significant odds ratios for the presence of medical home in bivariate analysis were included in multivariate analysis. All the remaining variables were analyzed to determine if they confounded the relationship of the independent variables to the outcome. If the variables were not confounders, they were not included in the model. Pearson correlation coefficient was used to examine correlation among the variables in the model. Logistic regression model was used for multivariate analysis.

In order to obtain population-level estimates, appropriate survey weights were used in the analysis. Survey statistics were used for all analysis. NCHS recommends that attention be paid to standard errors (S.E) of the estimates in the analysis.³⁰ According to NCHS, if the relative standard error of an estimate is greater than or equal to 30, then the estimate is not a reliable or precise population estimate. Relative standard error (RSE) was calculated as follows³²:

$$RSE = (S.E / Estimate) * 100$$

At each step of the analysis, relative standard error was calculated for the estimate. When RSE was equal to or greater than 30, the estimate was considered inaccurate. Variables that did not have a RSE of less than 30 were not used for

further analysis. A p value of less than 0.05 was considered to be statistically significant. Stata Intercooled version 8.2 was used for statistical analysis. Institutional Review Board approval was obtained for our study.

RESULTS

Using the National Survey of Children with Special Health Care Needs, there are an estimated 280,770 children with special health care needs in North Carolina, accounting for 14% all children less than 18 years of age. The prevalence is higher among boys compared to girls (16% vs. 11%). The characteristics of CSHCN in North Carolina are described in Table 1. A higher proportion of CSHCN are boys (61%) and are non-Hispanic White (71%), live in a metropolitan area (70%) and have private insurance (51%). Eighty one percent of CSHCN are older than 5 years of age. The prevalence is 17% in this population compared to 8% among children younger or equal to 5 years.

The health services needs of CSHCN are summarized in Figure 1. The most commonly needed health service for CSHCN was prescription medicines (91%) followed by dental care (80%) and routine preventive care (74%). Valid estimates for substance abuse treatment services and communication aids could not be obtained because of the small number of children using these services. When categorized by age, 85% of children younger than or equal to 5 years reported needing routine preventive care. A smaller proportion of children in the 6 to 11 year age group (74%) and 12 to 17 year age group (70%) reported a need for

routine services. Unmet needs for any type of health service was 14%. Unmet needs for specific health services used by CSHCN could not be measured because of the very small number of CSHCN reporting an unmet need for a specific service.

Among the CSHCN, 91% had a usual source of care, 86% had a personal doctor or nurse, 78% received family-centered care, 48% received effective care coordination, and 81% had no difficulty obtaining referrals. Fifty six percent of the children met all the 5 components of medical home in North Carolina and an additional 29% met 4 of the 5 components. Of the 29% who met 4 components of medical home, more than half lacked family-centered care.

Results of bivariate analysis of the independent variables with medical home and all of its components are presented in Tables 2 and 2a. There was significant difference between the categories of race/ethnicity and the presence of medical home ($p=0.02$). While 60% of non-Hispanic White CSHCN had a medical home, only 38% of Hispanic CSHCN had one. Forty-six percent of CSHCN who were non-Hispanic Blacks and of other race had a medical home. A higher percentage of children whose condition was reported to never have had an impact on their activities (62%) had a medical home compared to those who reported that their illness caused some impairment (51%) or severe impairment (51%). Poverty status showed a significant association with the presence of medical home ($p=0.04$). Compared to children living in households with income less than 100%

FPL, a higher percentage of children living in households with income greater than 400% FPL had a medical home (43% vs. 63%). Though type of insurance was not associated with medical home in this sample, a higher percentage of children having adequate insurance (60%) had a medical home compared to those who did not (49%). This association was statistically significant ($p=0.02$). Age, gender, residence and mother's education were not significantly associated with the presence of medical home by bivariate analysis.

Statistically significant differences were found among categories of some demographic factors and certain components (family-centered care and having a personal doctor or nurse) of medical home (Tables 2 and 2a). Income level of the household was significantly associated with the presence of a personal doctor or nurse ($p=0.004$). Seventy-one percent of children who lived in households with income less than 100% FPL reported having a personal doctor or nurse. A higher percentage of children living in households with income between 100 to 399% and income more than 400% FPL reported having a personal doctor or nurse (87% and 92% respectively). Receipt of family-centered care was significantly associated with race/ethnicity, type of insurance, adequacy of insurance and limitation of activities of CSHCN.

Unadjusted odds ratios for each one of the independent variables to the presence of medical home are summarized in Table 3. White children compared to non-White, CSHCN with no limitation of activities compared to those with some or

severe limitation of activities and children with adequate insurance compared to those without adequate insurance had higher odds of having a medical home. Though poverty was significantly associated with medical home in bivariate analysis, only CSHCN who belonged to the highest income households (≥ 400 FPL) had significantly higher odds of having a medical home than CSHCN of the poor household. There was no difference between CSHCN of higher-income households ($>400\%$ FPL) and those of medium-income households (100% to 399% FPL). When household income level was collapsed to 2 categories of $<100\%$ FPL and $\geq 100\%$ FPL, no significant difference in the odds of having a medical home was observed.

Race/ethnicity, impact on activities and adequacy of insurance were the independent variables used in the logistic regression model. None of the other variables (age, gender, residence, income status, type of insurance and mother's education) confounded the relationship of the 3 independent variables and the presence of medical home. Hence these variables were not included in the model. There was no correlation among the three variables used in the model. The model had 92% of observations of the study sample.

The results of multivariate analysis are presented in Table 4. The associations of race/ethnicity and impact on activities with the presence of medical home persisted even after adjusting for the other 2 variables in the model. However, after adjusting for race/ethnicity and impairment of activities, adequacy of

insurance was not associated with the presence of medical home. In North Carolina, non-White CSHCN have 1.7 times the odds of having a medical home compared to White children, adjusted for impairment of activities and adequacy of their insurance. For the same population, children with no impairment of activities have 1.6 times the odds of having a medical home compared with children who have some or severe impairment of activity.

The results of bivariate associations of having a medical home and each one of the 5 impact measures are summarized in Table 5. The percentages of CSHCN who reported ease of use of services and satisfaction with services were higher among those who had a medical home. Children with a medical home had less delayed care compared to those without ($p=0.003$). Children without a medical home had more unmet needs for health services than children with a medical home ($p=0.02$). The percentage of families who spent more than an hour coordinating care was not different in the 2 groups. The association between unmet need for family support services and having a medical home could not be examined because of the small number of observations.

DISCUSSION

The objectives of this study are to describe the characteristics of CSHCN in North Carolina, to identify the demographic factors associated with having a medical home and to describe the impact of having a medical home on CSHCN and their families. Fifty six percent of CSHCN in North Carolina have a medical home.

Children who belong to the minority groups and children whose conditions cause limitation of their activities have significantly higher odds of not having a medical home compared to their counterparts. Having a medical home is associated with lower unmet health services needs and delayed or forgone care, and higher parental satisfaction with health care services and parental perception of ease of use of health services.

The prevalence of CSHCN in North Carolina is similar to the national estimate of 13%. Previous state-level estimates are not available for comparison. In the past, prevalence estimates of children with special needs have ranged from 5% to 30%. This huge variation in prevalence estimates is due to the various definitions used to identify children with special health care needs. When condition lists were used to describe children with special needs, the prevalence was higher because conditions which were chronic, but did not require excessive use of services were included.³³ When the study population was limited to disabling conditions, it excluded children who did not have severe limitation of activities though they needed more services because of their health condition. Hence the prevalence was much lower when the study population was limited to disabling conditions.³⁴ To alleviate the problems due to lack of a uniform definition, a new definition of CSHCN was developed in 1998. Using this definition in the 1994 Health Interview Survey, Newacheck et al estimated 18% of children in the United States to have special health care needs.³ However, the Health Interview Survey was not designed to identify CSHCN. The prevalence estimate in this study was obtained

retrospectively using the 1998 definition of CSHCN. On the other hand, the screening tool to identify CSHCN in the National Survey of Children with Special Health Care Needs was developed based on the current CSHCN definition.³⁵ Hence there is a difference in the prevalence estimates in these 2 studies, although the same definition was used. Our study did not include children who are institutionalized and children who are at risk of a medical condition that will need excess health services. Currently, there is not a single tool available to identify children who are at risk.

Similar to North Carolina, nationally, the prevalence of CSHCN among boys is higher than among girls. The higher prevalence of CSHCN among boys, that is observed in our study and other prior studies is probably due to the higher prevalence of certain conditions in boys.^{3, 5} A higher prevalence is also noted among children older than 5 years compared to those younger than 5 years.² This difference is probably because conditions requiring special needs and services manifest more often and are diagnosed more often as children grow older and enter school. Though nationally, the prevalence of CSHCN is higher among low-income populations (less than 100% FPL), this difference is not seen in North Carolina.^{2, 36}

The prevalence of CSHCN among Hispanic children in North Carolina is much lower (7%) than other racial or ethnic groups. A similar trend is found nationally, with a prevalence of 9% among Hispanics and 14% among non-Hispanic Whites.²

Commenting on this disparity, van Dyck et al. (2004) hypothesize that the low prevalence is either due to a true difference in the health status, a diagnostic bias due to poor access to health care, or language barrier in responding to the survey instrument.² Past studies show similar low CSHCN prevalence among Hispanic children, but this gap is not as wide as it is in the current survey: in 1994, 15% of Hispanic children were identified or presumed to have special needs compared to 19% of White children.³ To assess if language was contributing to this disparity, the prevalence of CSHCN among Hispanics who were interviewed in English was determined. Interestingly, when the language of interview was accounted for in the analysis, the gap narrowed: 15% of Hispanics in North Carolina who were interviewed in English reported having a CSHCN. Hence it is unlikely that Hispanic children are at lower risk of having a special health care need. Whether the difference is due to underdetection of Hispanic CSHCN because of poor access to care or due to misinterpretation of questions used in the survey because of language barrier, needs to be determined.

Prescription medicines, dental care, routine preventive care, specialist care and vision care are the 5 most commonly needed health services for CSHCN in North Carolina. The results are similar to that of the United States.³⁶ A higher percentage of CSHCN in North Carolina (91%) report needing prescription medicines compared to the nation (88%). It is of concern that only 75% of all CSHCN and just 70% of children in the 12 to 17 year age group reported a need for routine care in the year prior to the survey.

Compared to the nation, a higher percentage of CSHCN in North Carolina had a medical home (56% vs. 53%), received family-centered care (71% vs. 67%) and effective care coordination (48% vs. 40%) and had no difficulty obtaining referrals (81% vs. 78%). While the percentage of CSHCN with a usual source of care is similar to the nation, only 86% of CSHCN in North Carolina had a personal doctor or nurse compared to 89% in the nation. However, these differences in results between North Carolina and the nation are small.

Bivariate analysis in our study showed statistically significant associations between race/ethnicity, poverty status and adequacy of insurance and the presence of medical home. The national study did not analyze bivariate associations of socio-demographic factors and the presence of medical home. However, the results of bivariate analysis of socio-demographic factors and the presence of the 5 medical home components in our study are similar to that of the nation for the most part. Similar to our study, differences among categories of race/ethnicity groups and limitation of activities in the receipt of family-centered care was noted in the national study. Unlike the national study, statistically significant associations between poverty status and age categories, and the presence of family-centered care were not noted in our study. Poverty status was significantly associated with the presence of having a personal doctor or nurse both in our study and the national study. In addition, the national study showed limitation of activities to be associated with having a personal doctor or nurse and having

referral problems. We found statistically significant differences in the categories of insurance type and adequacy of insurance in the receipt of family-centered care. Since insurance was not studied in the national study, we could not compare North Carolina and national results. Bivariate analysis of medical home and its components and socio-demographic factors in North Carolina were very similar to the nation for most of the factors that could be compared. The reason for some of the associations to be statistically significant at the national level but not significant for North Carolina is likely because of the relatively small size of the North Carolina sample. However, two associations showed a large difference between North Carolina and the nation: the percentage of CSHCN who belong to low-income household with a personal doctor was much lower in North Carolina than the nation (71% vs. 82%); among the same population, the trend was reversed with regards to family-centered care (62% and 50% in North Carolina and the nation respectively).

The results of multivariate analysis from our study were compared with the results of the studies of Strickland et al. and van Dyck et al.^{2, 25} Strickland et al. used age, gender, race/ethnicity, income level and limitation of activities as the independent variables in their logistic regression model to predict the presence of medical home among CSHCN. Insurance type, adequacy of insurance, metropolitan status of residence and mother's education were not used in their model. van Dyck et al. used age, gender, race/ethnicity, income level, presence or absence of insurance, limitation of activities and geographical area of the country in their logistic

regression models to predict receipt of family-centered care, difficulty in obtaining referrals, presence of a personal physician or nurse and presence of a usual source of care. Hence, the odds ratios obtained from our study and the studies of Strickland et al and van Dyck et al should be interpreted in the context of the other socio-demographic factors used in the model.

Similar to the national study, race/ethnicity was an important predictor for not having a medical home in North Carolina.²⁵ CSHCN of the minority groups had higher odds of not having a medical home compared to White CSHCN (aOR[‡]=1.5 for Hispanics, aOR=1.4 for Blacks and other races).²⁵ Because of the small number of the minority families surveyed, the odds for each minority group in North Carolina could not be estimated. van Dyck et al. found racial disparities among the components of medical home: compared to White CSHCN, Black and Hispanic CSHCN had higher odds of not receiving family-centered care and Hispanic CSHCN had higher odds of not having a usual source of care and having problems in obtaining referrals. Previous studies show that children with special health care needs who belong to the minority groups lack a usual source of care, receive care outside the doctor's office and are hospitalized more often than children who do not belong to the minority groups.^{37, 38} The impact of children with special needs on their families is more pronounced among minority groups.^{25, 37, 39} Our study provides further evidence of racial disparities in access

[‡] aOR is Odds Ratio adjusted for other demographic factors like insurance and poverty

to medical care among children with special health care needs. Attention should be paid to racial disparities in organizing services for CSHCN.

Severity of the child's condition was another independent factor for not having a medical home in this study. The same trend was seen in the national study.²⁵

Nationally, CSHCN with severe impairment of their activities had much higher odds (aOR=2.7) of not having a medical home than those with no impairment of their activities. Among the components of the medical home, children with severe impairment had greater problems with obtaining referrals and received less family-centered care compared to those without an impairment.² Disparities for children with severe limitations of activities have been widely reported in the literature. As the severity of the condition of CSHCN increases, the impact on the children (school absences, hospitalizations and emergency room visits) and their families (time spent on care and employment changes) becomes more pronounced.^{2, 25, 38, 39} However, disparities due to severity of children's condition have not been the focus of previous studies. Future studies are needed to understand the causes for disparities related to the severity of the condition of children with special health care needs.

Type of insurance and adequacy of insurance were evaluated for their association with the presence of medical home in this study. Our study showed no association between the type of insurance and having a medical home. The national study did not include insurance status as one of the independent variables in the model for

predicting the presence of medical home. van Dyck et al found uninsured CSHCN to have higher odds (aOR=1.8) of not receiving family-centered care, having referral problems (aOR=1.3), not having a personal doctor (aOR=2.3) and not having a usual source of care (aOR=2.1) compared to insured CSHCN.

Though adequacy of insurance was associated with having a medical home in the bivariate analysis, the association was not significant after adjusting for limitation of activities and race/ethnicity in a multivariate model. A larger percentage of Whites reported having adequate insurance compared to non-Whites (60% vs. 51%). Similarly, a higher percentage of children who had no limitation of activities reported having adequate insurance compared to those with limitation of activities (61% vs. 54%). Though race/ethnicity and limitation of activities were not significantly associated with adequacy of insurance individually, together they acted as confounders in the relationship of adequacy of insurance. Hence, according to our study, adequacy of insurance is not an important factor for having a medical home in North Carolina after adjusting for race/ethnicity and limitation of activities.

There is substantial evidence to show that being insured positively influences the health care experiences of CSHCN.^{2, 4, 39, 40} It is interesting that we did not find insurance status to be associated with having a medical home in our study. Insurance status is probably more critical for some components of medical home (e.g. usual source of care and personal doctor) than others (e.g. care coordination).

Rosenbach et al. compared children who participated in an expanded health insurance program for low-income children to those who did not participate in the program in 3 different states. All the 3 states in this study provided insurance coverage to low-income children who participated in the program, but only one of the states provided comprehensive care. The state which provided comprehensive care to children showed a significant reduction in unmet needs and emergency room visits compared to uninsured children in that state. On the contrary, no difference in outcomes was noted in the states that did not provide comprehensive care.²⁰ This study is limited to a certain group of children in 3 different states. However, it illustrates how quality of health care delivery is important to achieve better outcomes in children. The effect of insurance type and adequacy of insurance on medical home should be investigated using the national data.

Nationally, children living in a household with an income level of less than 100% FPL had 2.4 times the odds of not having a medical home compared to those who lived in a household with an income of more than 400% FPL.²⁵ The odds of having a medical home increased with increasing income level. Income level could not be used in the logistic regression model in our study because only one category of income level (<100% FPL) was significantly different from the other (>400% FPL). However, bivariate analysis in our study showed a trend in disparities among income groups that was similar to the nation. van Dyck et al report CSHCN who live in households with an income less than 100% FPL to have higher odds of having difficulties in obtaining referrals, not having a

personal doctor or nurse and not receiving family-centered care compared to CSHCN who live in households with an income more than 400% FPL. The effect of poverty on access to medical care of children with special health care needs is well documented in the literature.^{2, 25, 38, 39} The impact of having a child with special needs on the family is more pronounced in low-income families.^{2, 4, 25}

Similar to the national study, age was not a significant factor for medical home in our study. Among the components of medical home, children in the age group of 12 to 17 years had 1.3 times the odds of not receiving family-centered care.² Lack of family-centered care and usual source of care might contribute to the fact that only 70% of CSHCN in this age group report a need for routine care. Prior studies report age associated differences in access to health care, health care utilization and the outcomes of CSHCN. Parents of younger children report spending more time arranging and coordinating care of their children's condition and report having to change employment because of their child's condition.² On the other hand, older children have more unmet needs for health services and lack a usual source of care more often than younger children.^{2, 39} Services for CSHCN in the older age group need to be strengthened.

Our study did not show association between gender and the presence of medical home. The national study showed a slight increase in the odds of not having a medical home for boys (aOR=1.1).²⁵ No gender-associated disparities in access to

health services, utilization of health services and the outcomes of CSHCN are reported in the literature.

The national study did not analyze mother's education and metropolitan status of residence in their regression model. Our study did not find disparities in having a medical a home due to mother's education or the place of residence. However, there are disparities in receipt of health care services related to the education of the parent and the metropolitan status of residence reported in the literature: CSHCN whose parents have less than high school education use less physician visits and utilize less therapeutic services compared to CSHCN whose parents have college education; CSHCN from metropolitan areas are more likely to have unmet needs for specialty care compared to their non-metropolitan counterparts.^{38,}

39

Our study demonstrated the benefits of having a medical home for CSHCN and their families. Similar to the national study, significantly lower percentages of parents of CSHCN who have a medical home reported that the care was delayed or forgone and that they had unmet health care needs. In addition, our study also showed higher satisfaction with services by parents of CSHCN who have medical home. Since, effective care coordination is a component of the medical home concept, one would expect that a lower percentage of families of CSHCN who have a medical home to spend time coordinating care of their children than those who do not have a medical home. Interestingly, we did not find this difference in

our study. It is possible that there is no actual difference or the dichotomous variable we used was not a good measure of the impact of having a medical home. The impact of having a medical home should be studied in longitudinal studies.

Limitations

There are certain limitations to our study. Although the National Survey of CSHCN was designed to make it possible to perform state-level analyses, in depth analysis could not be performed because the sample size for North Carolina was small. Because of this reason, specific categories among the socio-demographic factors could not be examined. The next limitation is that this survey did not include institutionalized CSHCN and children who are at risk of developing chronic conditions. Hence, this study cannot be generalized to these 2 populations of CSHCN. The third limitation involves the measure of medical home in this study. Though this survey has information that can be used to measure the medical home concept, it does not include all the characteristics of the medical home concept. If a different set of items is used to measure the presence of medical home, the results may be different. Hence, the results of this study can be compared only with other studies that use the same items to measure the medical home concept. This point is important to know when comparing studies across the states and the nation, and studies in the future. Recognizing the need for an adequate measure of the medical home concept, a new measure has been used in the National Children's Health Survey which has just been completed.⁴¹ This survey has an entire module on medical home. Results from that survey might be

different from the current study. Because of cross-sectional nature of this study, causality between the socio-demographic factors and the presence of medical home, and between the presence of medical home and the impact measures cannot be established. Longitudinal studies are needed to evaluate the impact of medical home. Lastly, this measure of the medical home concept which is very helpful in planning and evaluating the medical home concept at a population level is not suitable for practice level interventions. Practice-level program implementation requires a tool like the Medical Home Index that will help organize services at practices.²³

Conclusions and Implications

This study provides comprehensive baseline information about characteristics and health services needs of CSHCN in North Carolina. This information will be useful for Title V needs assessment reporting by the state to the MCHB. CSHCN belonging to the minority groups and CSHCN whose conditions cause severe impairment of their activities were identified as vulnerable groups for low access to a medical home. These disparities in access to a medical home should be considered in program planning for CSHCN using the medical home model. Our study can be used to compare the performance of North Carolina with the nation and with other states, and to evaluate the performance of North Carolina in the future.

Certain areas for future research are identified in this study. The effect of insurance status in having a medical home should be evaluated using the national sample. Language as a factor in access to a medical home deserves further exploration. Research should be directed to understand the factors associated with disparities due to severity of the condition of CSHCN. The differences between the nation and North Carolina on disparities due to income level should be evaluated further. It is important to understand if these differences are due to variation in services among the states in providing care to low-income CSHCN.

Each component of the medical home model needs to be investigated further and should be considered in planning, implementing and evaluating CSHCN programs in the state. Among the components of medical home, increasing the proportion of CSHCN who receive family-centered care will have the greatest impact on achievement of medical home for CSHCN in North Carolina. Since our performance is lowest in providing effective care coordination, strategies to improve our performance in this area should be identified. In addition, longitudinal studies are needed to assess the impact of having a medical home on the outcomes of CSHCN and their families.

Finally, there appears to be a complex interaction of socio-demographic factors, severity of the condition of CSHCN, utilization of health care services, access to medical home (or the components), outcomes of CSHCN and impact on their families. This interaction is conceptualized in Figure 2. It will be important to

evaluate if care using a medical home model will not only improve outcomes of CSHCN but also help decrease or eliminate disparities in the outcomes of CSHCN.

North Carolina is performing better than the nation in providing care to CSHCN using a medical home model. While we continue to maintain our success in providing certain components of medical home such as usual source of care, we need to work to improve effective care coordination and family-centered care in order to achieve the Healthy People 2010 objective of providing medical home to all CSHCN in North Carolina.

Table 1: Characteristics of CSHCN in North Carolina

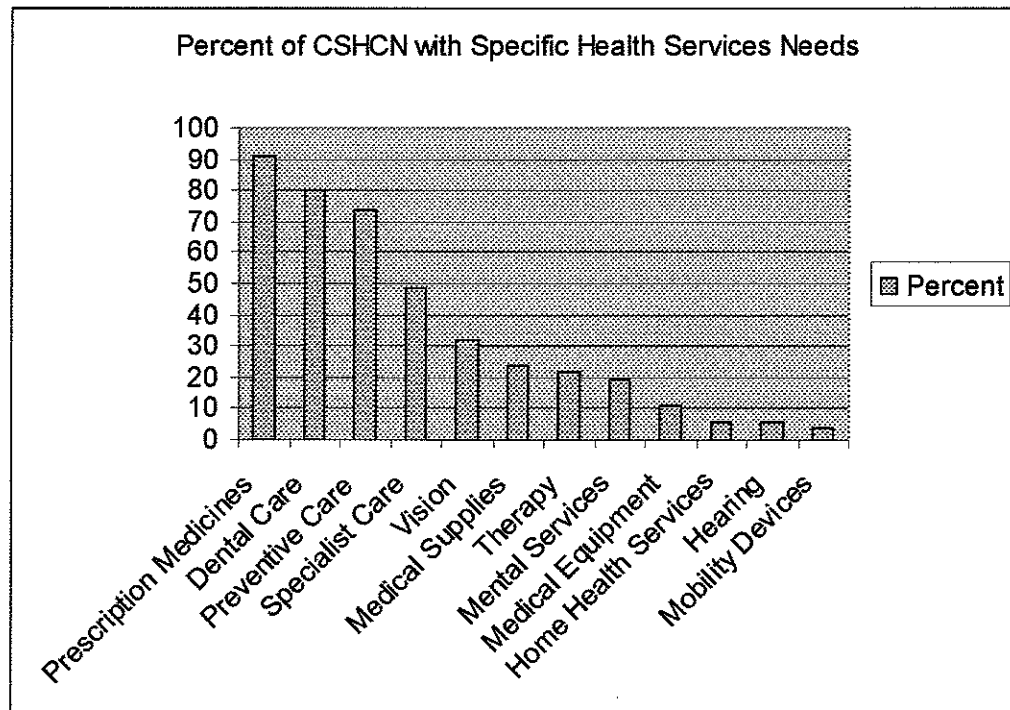
Characteristic	Sample Size	Proportion of CSHCN with the characteristic [@]	Standard Error
Age, years	739		
0 to 5		19	2.2
6 to 11		41	2.3
12 to 17		40	1.8
Sex	738		
Male		61	2.2
Female		39	2.2
Race/ethnicity	739		
Hispanic		3	2.2
Non-Hispanic White		71	0.6
Non-Hispanic Black		23	2.2
Non-Hispanic other & multiracial		3	0.7
Residence	739		
Metropolitan		70	2.1
Non-metropolitan		30	2.1
Poverty status, % FPL	676		
<100		15	1.8
100 to 399		57	2.3
≥ 400		28	2.0
Impact on activities	737		
Never affects activities		42	2.2
Sometimes affects activity		36	2.2
Usually/ always/ great deal affects activity		22	1.9
Type of Insurance	739		
Uninsured/ had gaps in insurance in the past year		13	1.6
Private		51	2.3
Public		25	2.1
Combined		12	1.5
Adequacy of insurance	716		
Adequate		57	2.3
Not adequate		49	2.3
Mother's education	721		
More than high school		56	2.4
High school		31	2.2
Less than high school		13	2.0

[@] Population-level estimates

Highlighted value has relative standard error ≥ 30

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs 2001.

Figure 1: Health services needs of CSHCN in North Carolina



Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs 2001.

Table 2: Association of socio-demographic factors with medical home and its components@:

Characteristic	Usual source of care	Personal doctor/ nurse	No referral problem	Effective care coordination	Family-centered care	Medical home
Sample Size, n	736	734	358	81	681	701
Entire population (%)	91	86	81	48	71	56
Age (%)						
0-5	91	84	82	74	76	59
6-11	89	84	78	31	68	50
12-7	93	89	83	47	72	60
Gender (%)	90	86	80	51	69	55
Male	92	85	84	40	74	57
Female						
Race/ethnicity (%)						
Hispanic	89	74	68	25	53*	38^
Non-Hispanic White	92	89	81	57	76	60
Non-Hispanic Black	89	77	80	28	58	46
Non-Hispanic other & multiracial	84	84	93	58	53	46
Residence (%)						
Metropolitan	91	85	81	53	70	55
Non-metropolitan	91	88	80	38	74	57
Impact on activity (%)						
Never affects activities	91	85	89	70	82 *	62
Sometimes affects activities	90	89	77	48	62	51
Usually/ always/ great deal affects activities	94	82	75	38	65	51

@ Population-level estimates

* P value <0.01

^ P value <0.05

Highlighted values have relative standard errors ≥ 30

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs 2001.

Table 2a: Association of socio-demographic factors with medical home and its components[@]:

Characteristic	Usual source of care	Personal doctor/ nurse	No referral problem	Effective care coordination	Family-centered care	Medical home
Poverty status, % FPL						
<100	88	71*	73	70	62	43^
100 to 399	92	87	82	42	73	57
> 400	91	92	87	64	75	63
Type of Insurance (%)						
Uninsured/ had gaps in insurance in the past year	85	84	64	22	67^	55
Private	92	89	87	52	78	59
Public	91	80	74	50	62	52
Combined	94	88	80	43	65	55
Adequacy of insurance						
Adequate	90	85	85	36	77*	60^
Not adequate	92	87	75	55	61	49
Mother's education (%)						
More than high school	75	87	68	46	62	44
High school	90	81	82	43	70	57
Less than high school	95	88	83	48	74	58

[@] Population-level estimates

* P value<0.01

^ P value <0.05

Highlighted values have relative standard errors \geq 30

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs 2001.

Table 3: Unadjusted odds ratios of socio-demographic factors with medical home[@]

Characteristic (Referent group)	Unadjusted Odds Ratio (95% C.I)	S.E	P value
Age	1.0(1.0,1.1)	0.02	0.4
Sex (Female) Male	0.9(0.6,1.3)	0.2	0.6
Race/ethnicity (All other races and multiracial) Non-Hispanic White	1.8(1.2,2.8)	0.4	0.007
Residence (Non-metropolitan) Metropolitan	1.1(0.7,1.6)	0.2	0.8
Poverty status (> 400), % federal poverty level) <100 100 to 399	0.4(0.2,0.9) 0.8(0.5,1.2)	0.1 0.2	0.02 0.3
Impact on activity (Sometimes/ usually/ always/ great deal affects activities) Never affects activities	1.8(1.1,2.3)	0.3	0.02
Type of Insurance (All other insurance) Uninsured/ had gaps in insurance in the past year	1.0(0.6,1.9)	0.3	0.9
Adequacy of insurance (Not adequate) Adequate	1.6(1.1,2.3)	0.3	0.02
Mother's education (< High school) ≥ High school	1.2(0.8,1.8)	0.2	0.3

Highlighted value has relative standard errors ≥ 30

[@] Population-level estimates

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs 2001.

Table 4: Adjusted odds ratios of socio-demographic factors with medical home in a logistic regression model* @

Characteristic (Referent group)	Adjusted Odds Ratio (95% C.I)	S.E	P value
Race/ethnicity (All other races and multiracial) Non-Hispanic white	1.7(1.1,2.7)	0.39	0.02
Adequacy of insurance (Not adequate) Adequate	1.5(0.99,2.2)	0.29	0.06
Impact on activities (Sometimes/ usually/ always/ great deal affects activities) Never affects activities	1.6(1.1,2.3)	0.32	0.03

* Adjusted for other 2 variables in the model

@ Population-level estimates

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs 2001.

Table 5: Bivariate analysis of presence and absence of medical home on outcome measures @

	Medical Home		No medical home		P value
	%	S.E	%	S.E	
Ease of using services	89	2.5	72	4.6	<0.001
Satisfaction with services	83	3.4	50	5.4	<0.001
Coordinating care was more than an hour/ week	47	3.1	52	3.7	0.3
Delayed/ forgone health care	7	3.1	15	2.6	<0.001
Unmet need for health services	11	1.9	19	2.7	0.02

@ Population-level estimates

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs 2001.

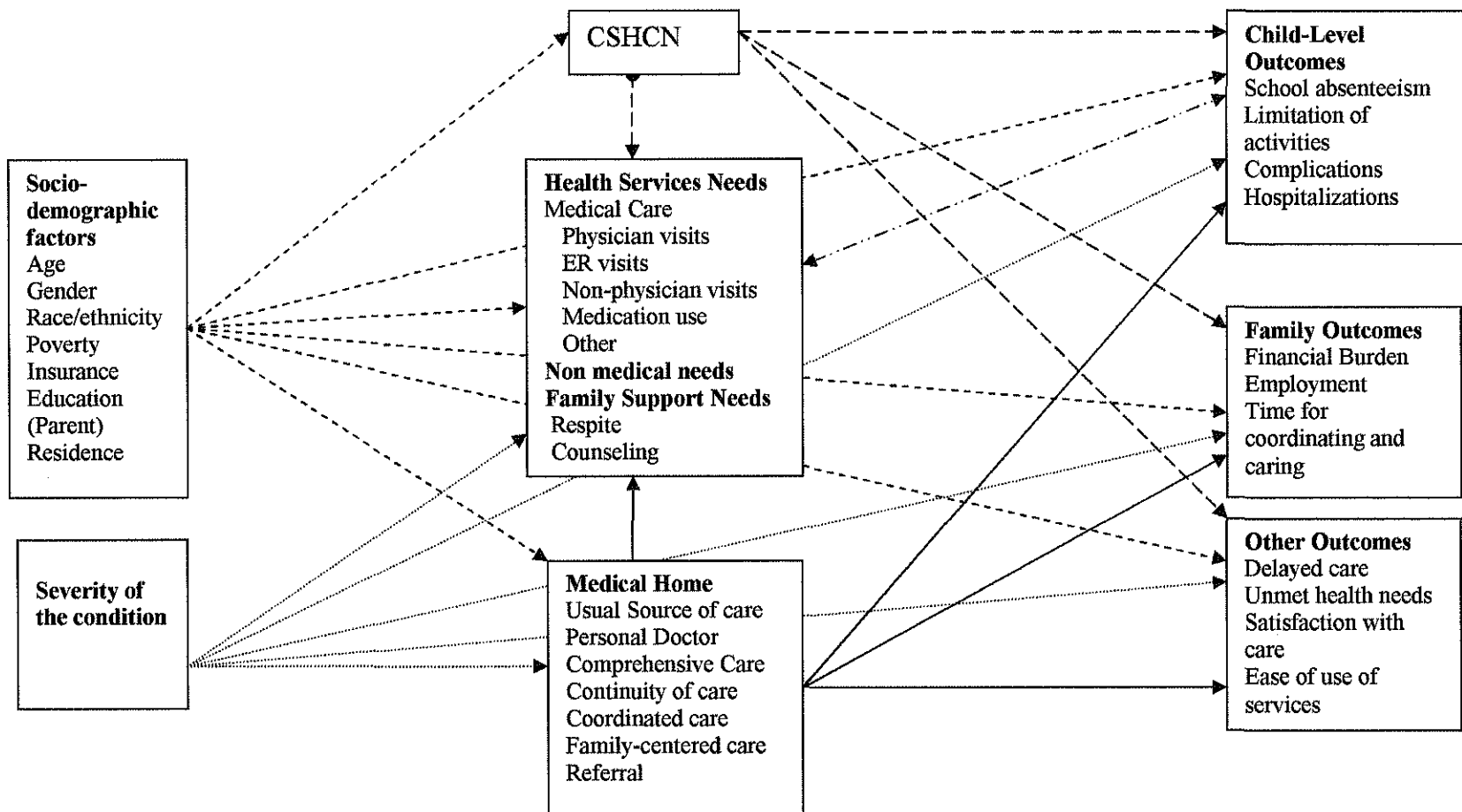


Figure 2: Interaction of socio-demographic factors, health services utilization, medical home and outcomes of CSHCN

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