



STATE OF MARYLAND

DEPARTMENT OF HEALTH AND MENTAL HYGIENE

Prevention and Health Promotion Administration

Maternal and Child Health Bureau

Comprehensive Needs Assessment For Children and Youth with Special Health Care Needs

Prepared by: Timothy Emanzi

Office for Genetics and People with Special Health Care Needs





The following is a summary of the 2015 Maternal and Child Health (MCH) Comprehensive Needs Assessment (CNA) report completed by the Office for Genetics and People with Special Health Care Needs on behalf of Children and Youth with Special Health Care Needs (CYSHCN) with the federal Title V Maternal Child Health Block Grant guidance which requires the completion of a population based needs assessment every five years. This Summary highlights the CNA process and outcomes of the CNA process. The summary also includes the state MCH priority needs and the process for selecting these priority needs. General descriptive data for the state and CYSHCN in Maryland is also included.

For more information about this report contact:
Office for Genetics and People with Special Health Care Needs
201 West Preston Street
Baltimore, MD
21201
(410)-767-6730



Contents

TITLE V NEEDS ASSESSMENT PROCESS 3

 Maryland State Overview 4

 Population Overview 4

CHILDREN WITH SPECIAL HEALTH CARE NEEDS 5

 Data Sources 5

 Priority setting..... 7

 Prevalence of Children and Youth with Special Health Care Needs 11

 Socioeconomic Characteristics of Maryland’s Children and Youth with Special Health Care Needs 15

 Household income 18

 Characterizing the Special Health Care Needs Population 21

 Health Status and Quality of Life 26

 Health Care Needs and Access to Care..... 30

 Impact on Family 34

 Education 38

 Core Outcomes for Children and Youth with Special Health Care Needs in Maryland..... 39

 Family-Professional Partnerships and Satisfaction with Services 46

 Comprehensive Care through a Medical Home 48

 Adequate Insurance and Financing to Pay for Services..... 52

 Early and Continuous Screening..... 61

 Community-Based Services Organized for Easy Use..... 62

 Youth Transition to Adulthood..... 64



TITLE V NEEDS ASSESSMENT PROCESS

The Federal Maternal and Child Health Bureau (MCHB) Title V block grant requires states to complete a comprehensive needs assessment (NA) every five (5) years. The goal of the needs assessment is to identify and address state priority health issues in partnership with community stakeholders that affect the Maternal and Child Health (MCH) populations. In Maryland, the Maternal and Child Health Bureau within the Department of Health and Mental Hygiene (DHMH) provides overall leadership and direction for MCH activities. The office for Genetics and People with Special Health Care Needs (OGPSHCN) in the Maternal and Child Health Bureau provides leadership and direction for services for Children and Youth with Special Health Care Needs and their families.

OGPSHCN maintains a continuous NA process by keeping stakeholders engaged in planning and implementing programs on behalf of CYSHCN. Since the last NA in 2010, input from hundreds of stakeholders was compiled through surveys and interviews from fall 2013 through spring 2015, coupled with other critical information to identify priority issues for this CYSHCN. The NA process was planned and managed by a Steering Committee comprised of the CYSHCN director Donna Harris and CYSHCN medical director Dr. Deborah Badawi who provided guidance, assured progress, and coordinated efforts between work groups. A data manager and a policy analyst provided expertise in developing survey tools, data extraction and data analysis; and priority setting and reporting. The work group also included external advisors from Parent's Place of Maryland (PPMD) who are the major sub-grantees for the OGPSHCN.

The Maryland Consortium of Care (CoC) is a diverse work group of stakeholders, including families, providers, advocates, consumers, administrators, and professionals from the public and private service systems who meet periodically to discuss issues affecting the health of CYSHCN and their families. The CoC was instrumental in selecting priority needs for the NA and in developing the State Performance Measures (SPMs) and in developing the objectives and strategies that aligned with the National Performance Measures (NPMs) and SPMs. The OGPSHCN together with the MCH work group also solicited for input from all the Local Health Departments and from other special interest groups that have a stake in Maryland's MCH population.

In 2013, OGPSHCN together with PPMD conducted the Maryland Transitioning Youth Parent Survey (MTYPS) to assess needs among YSHCN and their families related to health care transition. This was the second round of the MTYPS. OGPSHCN also coordinated with local health department partners to streamline needs assessment activities for CYSHCN in the state; rather than having local jurisdictions conduct needs assessments on their own, they will now work in conjunction with OGPSHCN. OGPSHCN convened a planning meeting for the 2015 Title V Needs Assessment during which existing sources of data were identified and evaluated, gaps in existing data and new sources of data were discussed, and key partners and organizations to engage were listed. In spring 2014, OGPSHCN together with PPMD conducted a statewide Maryland Parents Survey (MPS) for CYSHCN, and convened 4



meetings with the CoC to discuss emerging issues affecting CYSHCN including legislative issues. OGPSHCN also conducted a provider assessment survey to see the number of pediatric providers across the state including specialty providers. In fall 2014 the OGPSHCN data team also started analyzing Maryland state data from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) and 2011/12 National Survey of Children's Health (NSCH).

The OGPSHCN team met periodically with the larger MCH core workgroup team to discuss any administrative issues and provide updates on the ongoing activities and convened a series of monthly meetings with OGPSHCN staff and PPMD staff for updates, data dissemination, and priority setting exercises.

Maryland State Overview

Maryland has been aptly described as "America in Miniature." Although a small state in size and population, Maryland has great geographic and demographic diversity. This diversity creates unique challenges for the health care system in Maryland and barriers to care for many Maryland residents. The State is characterized by mountainous rural areas in the western part of the State, densely populated urban and suburban areas in the central and southern regions along the I-95 corridor between Baltimore and Washington D.C., and flat rural areas in the eastern region. The "Eastern Shore" borders Delaware, the Atlantic Ocean and the Chesapeake Bay, the largest estuary in the U.S. The Bay is a treasured geographic asset but the fact that it bisects the state presents special challenges for Eastern Shore residents. Maryland is comprised of 24 political jurisdictions -- 23 counties and the City of Baltimore. Nine of the counties are on the Eastern Shore. Maryland, like the rest of the nation has been slow to recover from the effects of the 2008 great recession but still maintains its status as a wealthy state.

Population Overview

According to the Census Bureau estimates for 2014, Maryland's population is 5.9 million and is ranked 19th nationwide. There was a slight increase of (0.63%); about 38,000 people from the 2013 census estimates. Maryland saw a slight decrease in the rate of population growth in 2014 compared to previous years, but still has a faster population growth than the nation¹. Non-Hispanic Whites are still the largest demographic in Maryland making up about 53% of the state's population though this number has been declining steadily over. Non-Hispanic Blacks make up about 29.2% of the population while people of Hispanic origin make up about 9% of the population. Asians make up about 6% of the population and about 2.6% are two or more races. Maryland's minority population has been growing at a faster rate than the non-minority population and as of 2013 was at 46.7% of the state's population. 52% of Maryland's population is female and 48% are male. Persons under 17 years old make up about 23% of Maryland's population. About 45% are Non-Hispanic Whites, and 31% were Non-Hispanic Blacks. Hispanics were about 13%. The number of minority groups in Maryland has been steadily increasing in the last 10 years and Maryland is poised to be among the very few states where the number

¹ Maryland Department of Planning (Population Growth Slows for Maryland in 2014)



of minority children outpaces that of Whites². According to the Maryland State Department of Education (MSDE), 874,514 students were enrolled in Maryland public schools while another 126,320 were enrolled in non-public schools.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The Maternal and Child Health Bureau defines children with special health care needs as "*those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally*"³. The NSCH and the NS-CSHCN compile data on the health status indicators for CSHCN in the United States⁴. These data comprise national and state prevalence rates and other health outcomes indicators. According to the 2011/12 NSCH, the prevalence of CYSHCN in Maryland was 19.7% among children ages 0-17⁵. This is an estimated 265,000 children. The prevalence declined slightly from 20.1% according to the 2007 NSCH.

Data Sources

Quantitative Assessment

The OGPSHCN data analyst compiled data from multiple sources that were used in the 2015 NA. A significant amount of the data for the CSHSCN population domain was obtained from the 2011/12 NSCH housed in the Data Resource Center. The Data Resource Center takes the results from the NSCH and makes them easily accessible to parents, researchers, community health providers and anyone interested in maternal and child health. Data on this site are for the nation and for each state⁶. These data were analyzed based on socio-demographic characteristics including (race, age, gender, household education and income, health insurance coverage), and health outcome indicators (medical home, general health status, dental status, transition of youth into adult care, health disparities, service delivery and quality).

Other sources of data used included:

National Databases

Maryland and national data from two modules of the State and Local Area Integrated Telephone Survey (SLAITS) were examined: the 2011/12 National Survey of Children's Health (NSCH) and the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN).

The NSCH allows comparisons among states as well as nationally on the estimated prevalence among children aged 0 to 17 years for a variety of physical, emotional, and behavioral child health indicators in combination with information on the child's family

² Annie E. Casey Foundation. (Kids Count Data Center).

³ McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140, 1998

⁴ 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN). <http://childhealthdata.org/learn/NS-CSHCN>

⁵ 2011/12 National Survey of Children's Health (NSCH). Data Resource Center. Retrieved 03/10/2015

⁶ Data Resource Center. (About the Surveys. 2011/12 NSCH)



context and neighborhood environment. It also allows a comparison between individuals with special needs and those without special needs to ascertain health outcomes of the two groups. The survey was conducted for the first time during 2003-2004 and for the second time during 2007-2008, and time-trend comparisons for some indicators are possible.

2009 was the third time the NS-CSHCN was conducted after 2000-2001 and 2005-2006. This survey was used to provide estimates of the health needs and issues confronting Maryland children and youth with special health care needs under 18 years old. Data is available by state about the CSHCN population overall, and for subgroups such as age, race/ethnicity, family structure, and household income.

The NS-CSHCN can be compared across states or nationwide and most but not all indicators can be compared across the 3 years that the survey was conducted.

State Surveys

The 2014 Parents' Place of Maryland Survey of Parents of CYSHCN is a non-randomized survey conducted by The Parents' Place of Maryland (PPMD) and OGPSHCN to obtain information about the impact of caring for CYSHCN. Responses were gathered from 1090 parents across Maryland using Survey Monkey and on paper during March through May of 2014. The survey was disseminated through PPMD contacts, the PPMD website and electronic newsletter, various listservs, disability and support group newsletters, and other agency partners. The survey explored a variety of issues related to access to health care for CYSHCN. The Parent's survey has evolved over time so that the questions on the survey are structured by the 6 core outcomes for CYSHCN and is now conducted every 4 years. The Parents Survey includes a qualitative component.

The 2013 Transitioning Youth Survey is a non-randomized survey conducted by PPMD and OGCSHCN in order to gather information from parents/caregivers of CSHCN who were receiving health care transition services. Survey results are reported and used to estimate aspects of healthcare transition services across the state for CSHCN. The Transitioning Youth Survey also contains a qualitative component where parents can provide feedback about service delivery and access issues.

The 2015 Maryland CSHCN priorities Poll was developed and conducted by OGCSHCN in conjunction with PPMD and the Maryland CoC to obtain information about issues affecting CSHCN and their families, including emerging issues. The Priorities Poll asks respondents to scale a list of priorities that they think the state should address. The survey is distributed to the CoC, a CSHCN stakeholder group active in addressing CSHCN issues including legislative action.

The 2015 Transition and Care Coordination Gap Analysis is an online survey conducted for the first time this year to assess capacity of local health departments and other collaborating agencies about services provided to youth and families pertaining to



health care transition and care coordination. The survey also included a training needs component for staff that are providing the above services, and if they were interested in participating in any training activities.

The CoC member survey is conducted every year to assess collaboration efforts among members of the CoC. The 2014 version was conducted on paper at the July CoC meeting. Collaboration was determined based on the 5 Cs (communication, co-operation, coordination, contribution and collaboration).

Maryland State Department of Education enrollment reports provided us with information about CSHCN who are enrolled in Maryland public schools and IFSP and IEP recipients.

Priority setting

The Title V MCH Block Grant guidance requires each state to select 7-10 state priority needs based on findings of the needs assessment. MCHB also required states to align their state priorities with the National Performance Measure Framework. The priority setting process for OGPSHCN started with a review of the previous priorities from the 2010 needs assessment.

1. **Healthy and Productive Youth and Young Adults – Transition to adulthood**

To improve supports for the successful transition of all youth to adulthood

Proposed State Performance Measure: *The percent of YSHCN families who participate in transition planning for their child*

2. **Strategic Partnership:**

Sustain, strengthen and maximize the strategic partnerships through the CoC to address CSHCN core outcomes in Maryland.

Proposed state performance measure: *The percent of CoC members who report five or more collaborative activities in the previous 12 months.*

3. **Improve data systems and sharing**

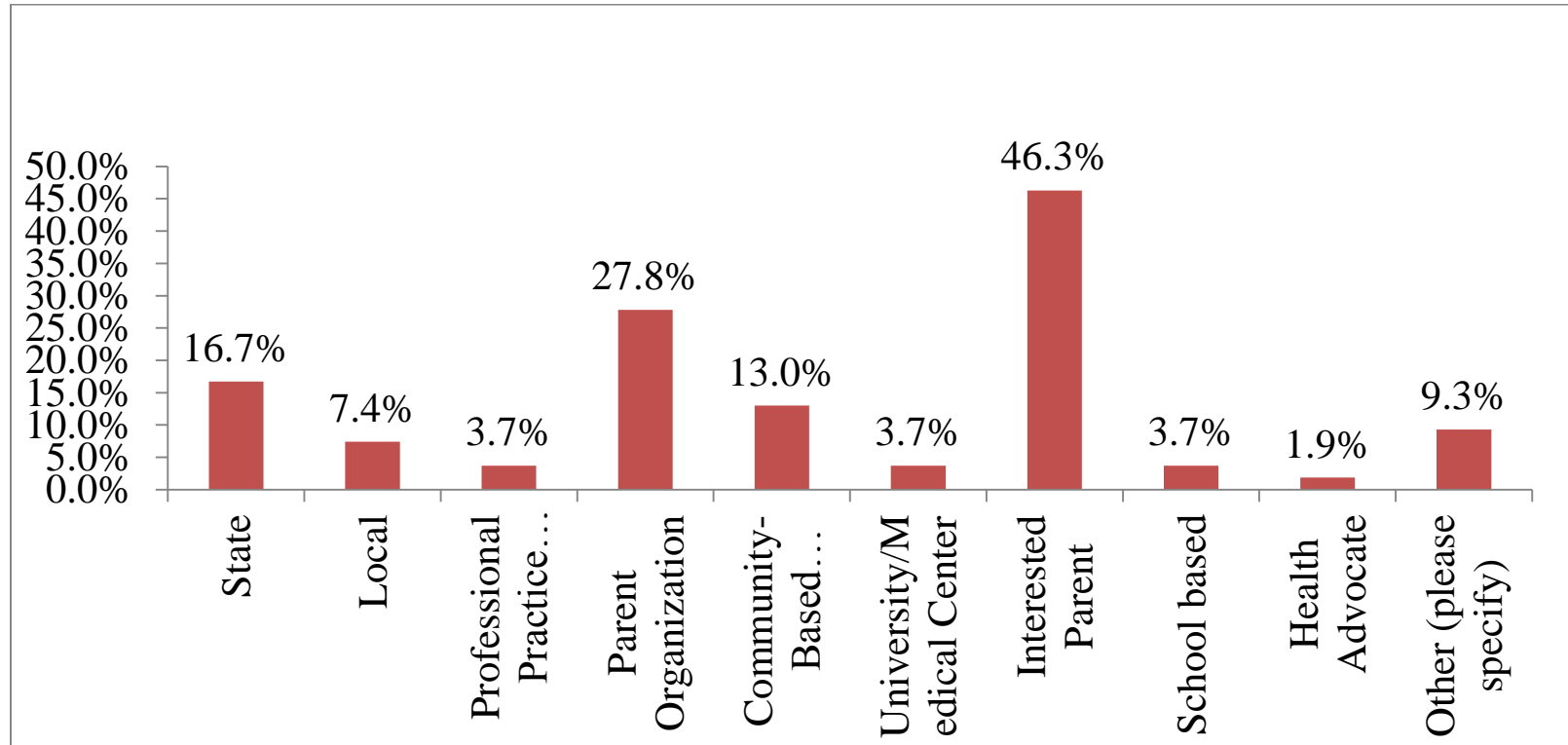
Improve state and local capacity to collect, analyze, share, translate and disseminate MCH data and evaluate programs

Proposed State Performance Measure: *The percent of performance measure benchmarks Maryland has reached toward implementing a data sharing plan*

The priority setting phase was a collaborative process between OGPSHCN, PPMD, and the CoC. A list of priority needs was developed and a priority survey poll was conducted through the CoC and other interested parties. In total, about 50 people responded to the priorities poll. About 46% of respondents were interested parents, and another 30% belonged to either parent groups or community based organizations. 16.7% belonged to state government while about 8% were from local health departments. In total, over 60% said

that they were either a parent of CSHCN or family members. Out of a list of 20 priorities, 10 were selected. Findings were shared with stakeholders who were surveyed.

Figure 1: Breakdown of stakeholder group by area of specialization



Data Source: 2015 stakeholder analysis

Out of a list of 20 priorities, 10 were selected. Findings were shared with stakeholders who were surveyed.

1. Access to needed therapies (Speech, behavioral, occupational, physical)
2. Youth Transition to adulthood
3. Adequate Insurance and Health Care Financing
4. Financial Assistance for medical services and devices
5. Access to Needed Specialty Care including dental
6. Coordinating with schools on services for CYSHCN



- 7. Training for school personnel to better meet the needs of CYSHCN
- 8. Provider education and capacity to meet the needs of CYSHCN
- 9. Family support services, training, education
- 10. Effective Collaboration across agencies

CYSHCN staff and PPMD convened an all workgroup meeting to garner input was from staff, stakeholders, literature reviews, and existing data. After the discussion, the group used prioritization process/criteria to develop a short-list of 4 priority areas. The group used a multi-voting technique to narrow the list down to 6 initially, and then to 4.

Health Indicator	Round 1 Vote	Round 2 Vote
1. Access to Needed Therapies	7	7
2. Youth Transition	8	10
3. Adequate Insurance and Health Care Financing	5	
4. Financial Assistance for medical services and devices	5	
5. Access to Needed Specialty Care including dental	5	
6. Coordinating with schools on services for CYSHCN	7	
7. Training for school personnel to better meet the needs of CYSHCN	6	7
8. Provider education and capacity to meet the needs of CYSHCN	5	
9. Family support services, training, education	10	10
10. Effective Collaboration across agencies	7	

The criteria used included

- 1. Impact
 - a. What is the magnitude of the problem?
 - b. Urgency of the problem
 - c. What impact will an action produce?



- d. Cost & return on investment
- e. Availability of Solutions

2. Feasibility

- a. Do we have the capacity and responsibility?
- b. Does it align with MCHB and Title V goals?
- c. What resources do we have to solve the problem? (Internal and external)
- d. Are there systems already in place to solve the problem?

3. Does the strategy align with the national performance measure framework?

- a. Expertise to implement the solution
- b. Effectiveness of the solution
- c. Ease of implementation
- d. Negative consequences
- e. Legislative mandates

The final list of priorities included

1. Access to needed therapies including speech, behavioral, occupational and physical therapies
2. Transition of YSHCN from pediatric health care to adult health care
3. Training for school personnel to better understand and meet the needs of CSHCN
4. Support for families including training, and education.

The selected 4 priorities were linked to the National Performance Measure framework.

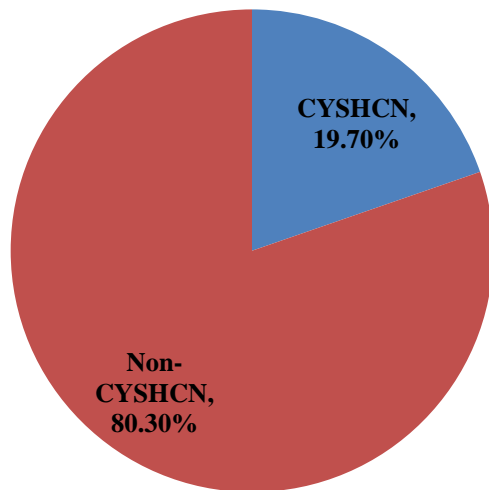
Prevalence of Children and Youth with Special Health Care Needs

According to the U.S census bureau, Maryland’s population estimate for 2014 is 5,976,407, representing a 3.5% increase from 2010. Children less than 18 years of age comprise approximately 23% of Maryland’s population in 2014.

National and state level data for Children with Special Health Care Needs (CSHCN) is collected through the National Survey of Children’s Health (NSCH), and the National Survey of Children with Special Health Care Needs (NS-CSHCN). Data from the two surveys are not comparable because of differences in survey methodology.

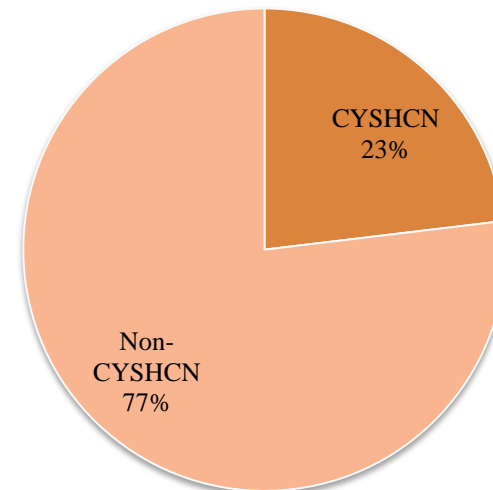
There is an estimated 264,729 children with special health care needs among 0-17 year olds in Maryland ⁷

Figure 2: Prevalence of CYSHCN in Maryland



Data Source: 2011/12 NSCH

Figure 3: Prevalence of CYSHCN households in Maryland



Data Source: 2009/10 NS-CSHCN

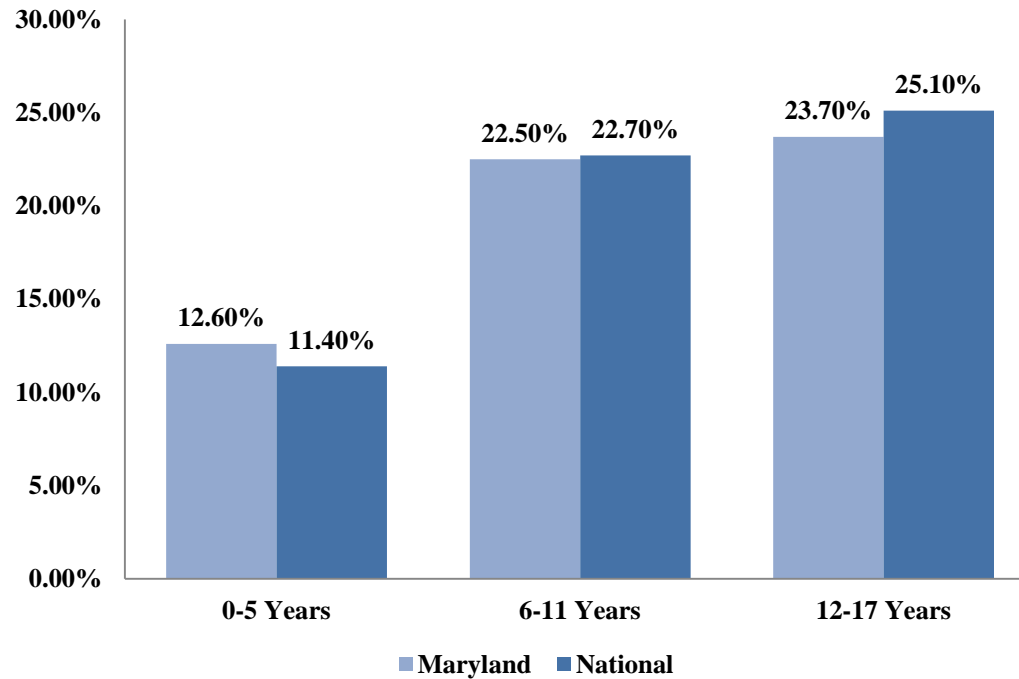
⁷ National Survey of Children’s Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [3/18/2015] from www.childhealthdata.org.



According to the 2011/12 NSCH, the prevalence of CYSHCN in Maryland aged 0-17 years is 19.7%, corresponding to approximately 264,729 children and youth. This is almost the same as the national prevalence of 19.8%. The prevalence of CYSHCN in Maryland has slightly decreased from 20.14% in the 2007, and the national prevalence has increased from 19.2% from the 2007.

According to the 2009/10 NS-CSHCN, 23% of all households in Maryland and 23.1% nationwide report having one or more CYSHCN

Figure 4: Prevalence of CYSHCN based on age groups. Maryland and U.S comparisons

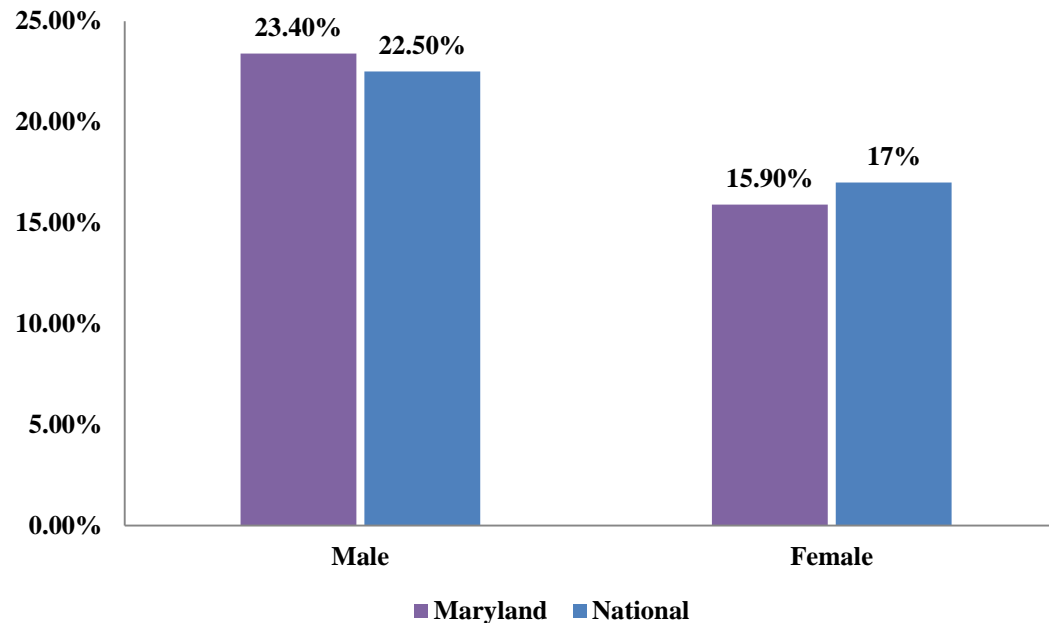


Data Source: 2011/12 NSCH

As expected, the prevalence of special needs is greatest in Maryland’s children and youth over the age of 5 years, reaching a high of 23.7% of children and youth between the ages of 12 to 17 years based on data from the 2011/12 NSCH (see Figure 3 above), even though there has been a significant decline in this age group from 28.1% from the 2007 prevalence. The prevalence among the 0-5 year old increased from 11.2% to 12.6% while the prevalence among 6-11 year olds increased from 20.7% to 22.5%.

In Maryland, mirroring the nation as whole, special needs are present more frequently in males than in females; it is estimated that in Maryland, 23.4% of male children aged 0 to 17 years have special health care needs, compared to 15.9% of female children (Fig 4). The prevalence was 21.8% and 18.4% respectively in the 2007 NSCH.

Figure 5: Gender characteristics of CYSHCN in Maryland and Nationwide



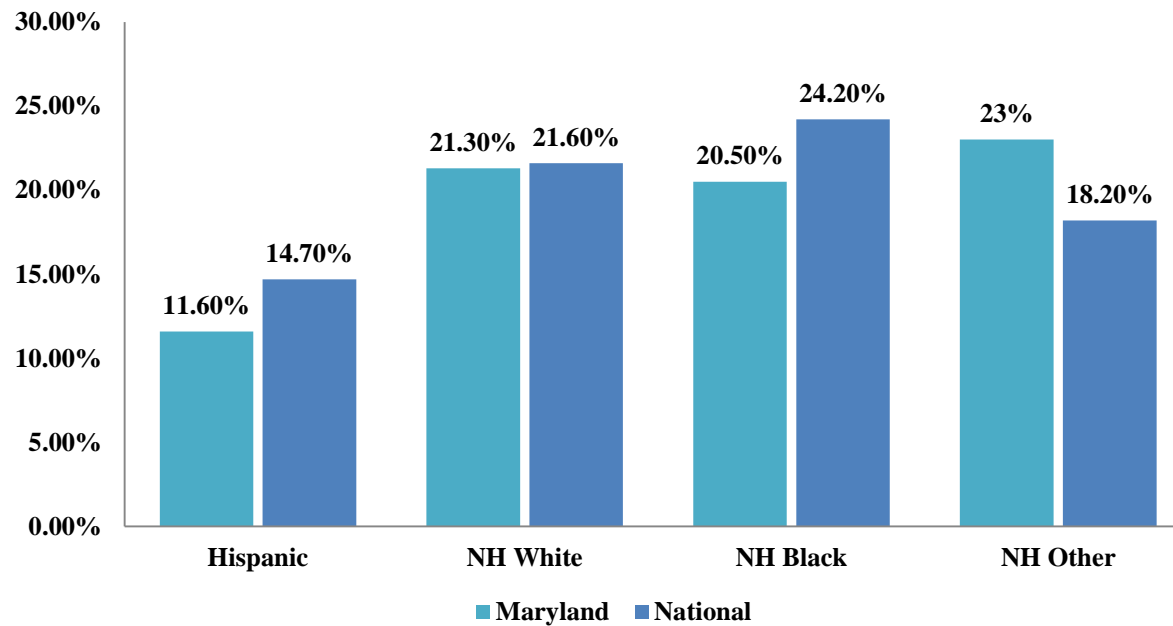
Data Source: 2011/12 NSCH

Special health care needs seem to be diagnosed in minority children and youth as much as in non-minority groups (see Figure 5). The highest prevalence of special health care needs by Hispanic origin and race estimated in Maryland was 21.6% among all non-



Hispanic whites between 0-17, a slight increase from 21.5% in the 2007 NSCH. The prevalence of SHCN among Hispanic and Non-Hispanic black children in Maryland is significantly less than the U.S average. Conversely, the prevalence of SHCN among children of non-Hispanic ethnicity who have more than one race, or fall in the other race category are significantly higher in Maryland than the U.S average.

Figure 6: Prevalence of CYSHCN based on racial and ethnic groups in Maryland and the U.S



Data Source: 2011/12 NSCH

According to the 2011/12NSCH, among Maryland households with income under 100% of the federal poverty level, 21.4% reported having at least one child between 0-17 with a special health care need, compared to 20% of households above 400% FPL.



The rates across the different income levels are slightly higher than the national average but the trend is similar except for households between 100-199% FPL which is significantly lower than the national average in the same income category. (See Table 1 below)

Table 1: CYSHCN prevalence by household income

	Maryland	Nationwide
0-99% FPL	21.4%	20.8%
100-199% FPL	15.6%	19.9%
200-399% FPL	20.9%	19.6%
400% FPL or more	20.0%	19.2%

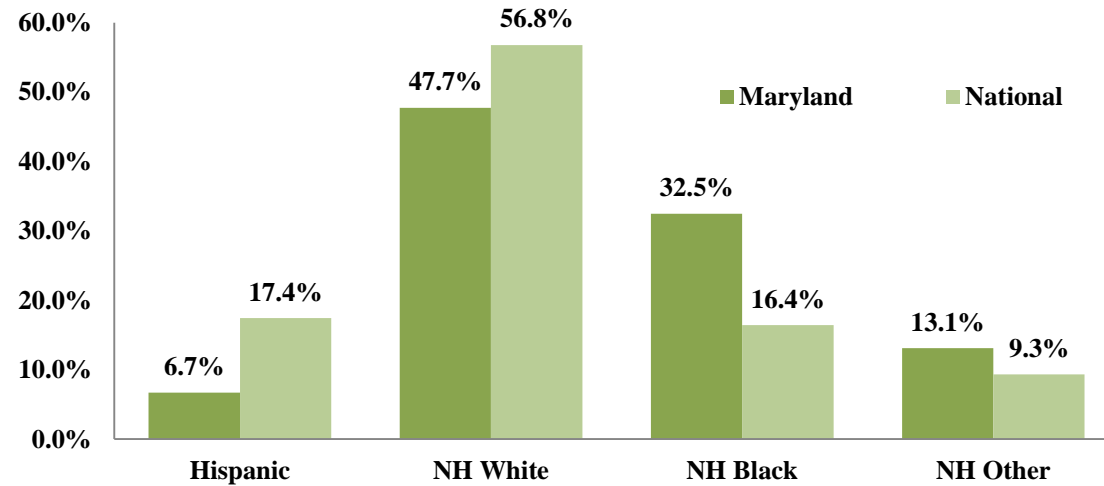
Source: 2011/12 NS-CSHCN

Socioeconomic Characteristics of Maryland’s Children and Youth with Special Health Care Needs
(characteristics *within* Maryland’s CYSHCN population)

a) Race and Ethnicity

The majority of Maryland’s CSHCN are non-Hispanic whites just like nationwide; almost a third are non-Hispanic African American; and over 7% are Hispanic, while other races including those with more than one race make up just over 10% (see Figure 6 below). The percent of Non-Hispanic Whites declined both in Maryland and nationwide from 54.24% and 60.9% respectively from the 2007 NSCH. Data from the NSCH also indicate a declining proportion of Non-Hispanic Whites among CSHCN in Maryland. Conversely, the prevalence among other racial groups has been increasing steadily. For example, the rate for Non-Hispanic Blacks was 30.4% in 2007 for Maryland and 16% nationwide. This trend is supported by data from the NS-CSHCN.

Figure 6: Racial/Ethnic distribution among CYSHCN in Maryland and the U.S.



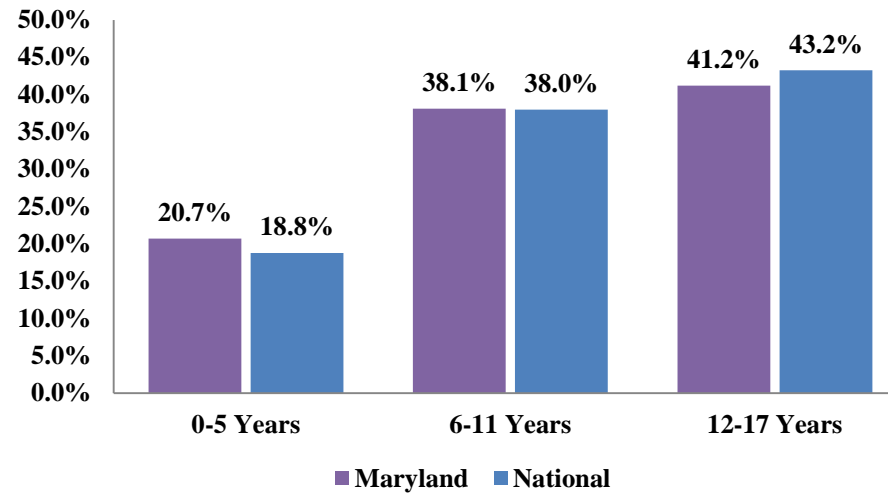
Data Source: 2011/12 NSCH

b) Age

In the population of CYSHCN in Maryland, the majority fall between the ages of 12-17 years of age (41.2%) compared to 43.2% nationally (Fig 7). Children between 0-5 years make up about 21% of all CYSHCN in Maryland and 19% nationwide. In 2007, 12-17 year olds were almost 48% of all CSHCN while 6-11 year olds made up about 33% and 0-5 year olds made up 18%.



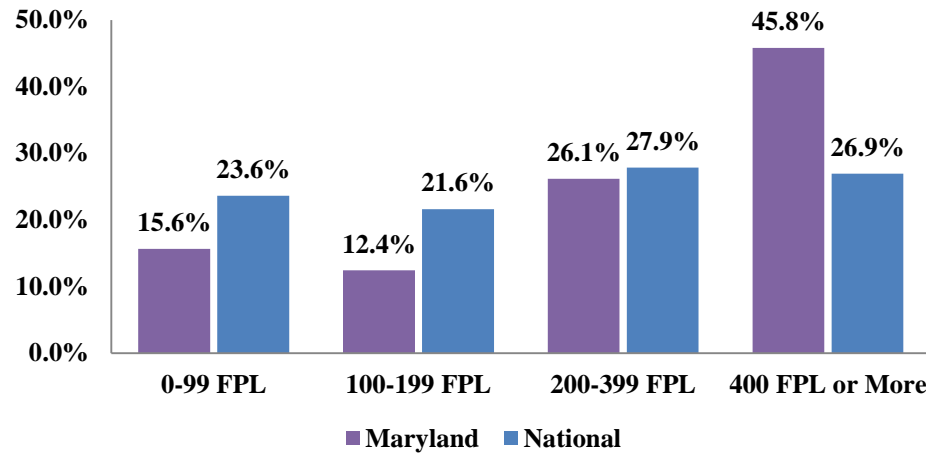
Figure 7: Age distribution of Maryland CYSHCN in 3 age categories compared to the U.S



Data Source: 2011/12 NSCH

c) Household income

Figure 8: Comparing household income for CSYCHN between Maryland and the U.S

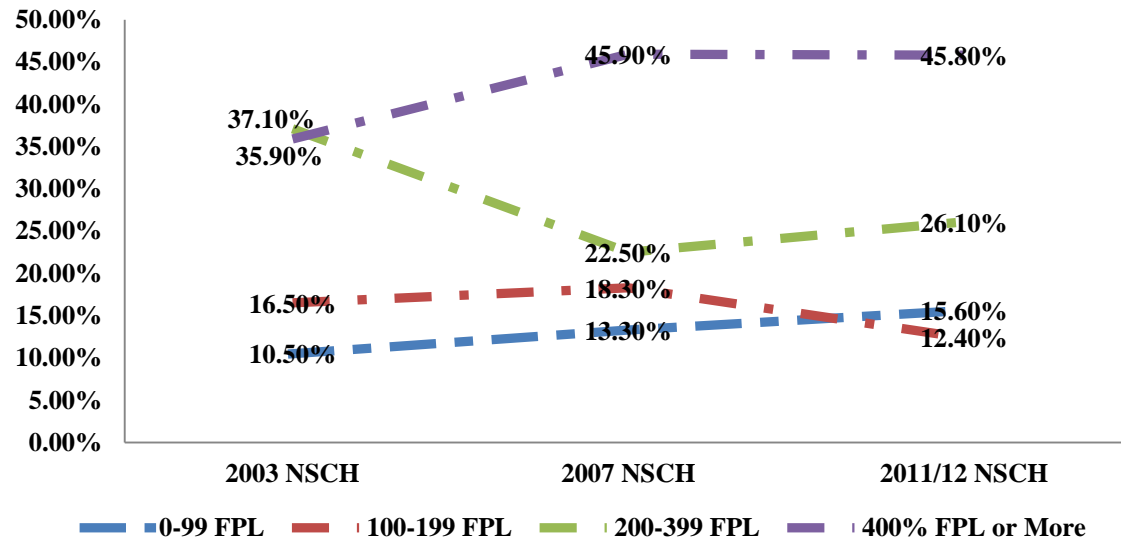


Data Source: 2011/12 NSCH

15.6% of CYSHCN in Maryland live in households at 0-99% FPL while almost 46% live in households at 400% FPL or greater (see Figure 8.) This is quite different from the national average where 23.6% of CYSHCN live in households between 0-99% FPL and 29% live in the highest income category. These data reflect Maryland’s status as one of the wealthier states in the nation; however the proportion of CYSHCN in Maryland who live in households below 99% FPL slightly increased from 13.3% according to the 2007 NSCH while those living in households with 100-199% FPL declined significantly from about 18.3% to 12.4% in the same time. (See Fig 9 below)

“ABA is not covered. Other services are extremely expensive because we are "middle class" and have high copays, deductibles or have to pay OOP because EVERYONE who treats his conditions is out of network”. Parent comment about difficulty in paying for services. 2014 Maryland Parent Survey.

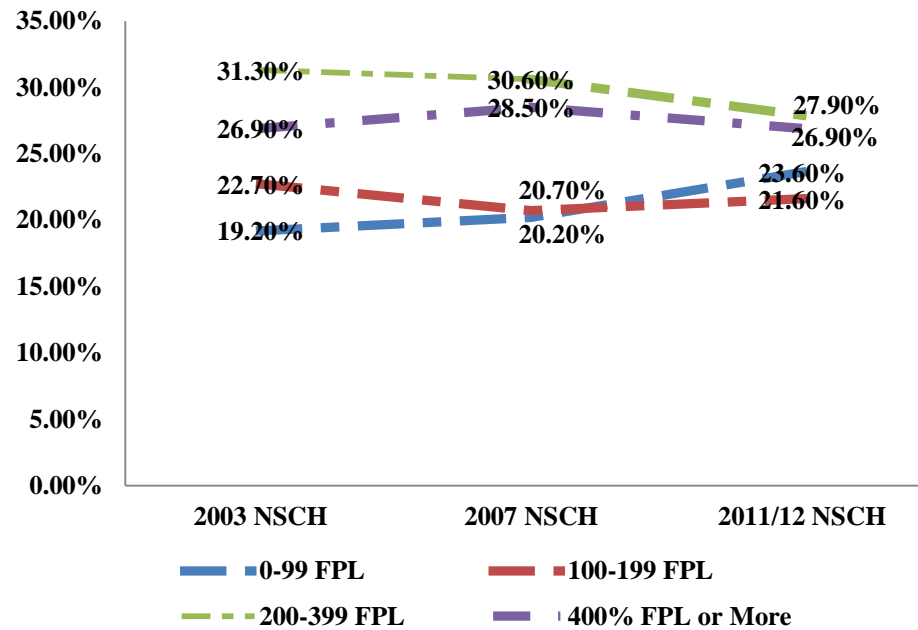
Figure 9: Changes in household income distribution of CYSHCN over the 3 survey years



Data Source: 2001, 2003, 2011/12 NSCH

The 2003 NSCH data show that at that time, only 10.5% of CYSHCN in Maryland were living at 0-99% FPL yet in 2011 that number increased significantly to 15.6%, while the number of CYSHCN living at 100-199% FPL has decreased over the same time period from 16.5% to 12.4% (see Figure 9). Likewise, the number of CSHCN living in households over 400% FPL has increased significantly in the same period from 35.9% to 45.8%, while those in households with 200-300% FPL has significantly declined from 37.1% to 26.1%. This trend differs from the nationwide pattern of CYSHCN living above or below the federal poverty level; which is largely unchanged over the years. Furthermore, based on the 2011/12 NSCH data, there isn't a significant variation between CYSHCN living in households under 100% FPL and those living in households above 400% FPL nationally as is seen in Maryland data (See Fig 10 below).

Figure 10: Percent of CSHCN nationwide based on household income



Data Source: 2009/10 NS-CSHCN

The 2014 Maryland Needs Assessment Parent Survey (Maryland Parent Survey) found that, of the responding families with at least one CYSHCN, over 32.6% were receiving some form of assistance through the Free and Reduced Meal program, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), or Food Stamps.

d) Insurance Status

According to the 2011/12 NSCH, the majority of CSHCN in Maryland, over 65% had private health insurance plans compared to about 53% nationwide and 32% had public insurance compared to almost 44% nationwide. Only 2.4% were uninsured in Maryland. Data from the 2014 Maryland Parents Survey show that 56% of respondents were insured privately while 33% had public



insurance⁸. CSHCN without a medical home, those with more complex needs, and those with E/B/D were less likely to be insured. Data from the 2009/10 NS-CSHCN show that Hispanics and those living in households with incomes between 100-199% FPL were more likely to be uninsured.

Characterizing the Special Health Care Needs Population

The CSHCN classifies CYSHCN in a non-categorical fashion by the consequences of their chronic conditions using a screener. The CSHCN Screener identifies children across the range and diversity of childhood chronic conditions and special needs – allowing a more comprehensive and robust assessment their needs and health care system performance than is attainable by focusing on a single diagnosis or type of special need⁹. To meet the CSHCN Screener criteria a child’s parent must report the child has an ongoing health condition for which he/she experiences one or more of the following:

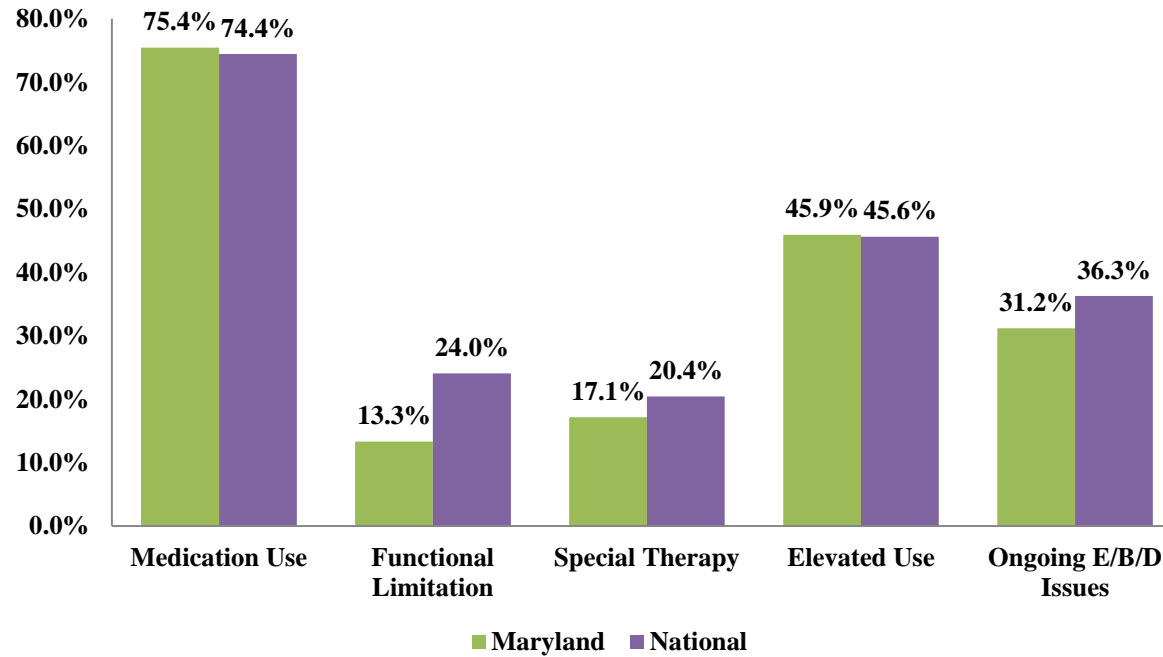
1. Need or use of prescription medications;
 2. Above routine use of services;
 3. Need or use of specialized therapies or services;
 4. Need or use of mental health counseling
- Functional limitation

Data from the recent 2011/12 NSCH show that 75% of CSHCN in Maryland qualified on the screener because of elevated need or use of prescription medication (See Fig 11).

⁸ 2014 Maryland Parents Survey

⁹ Children with Special Health Care Needs Screener. Fast Facts (<http://childhealthdata.org/docs/cshcn/cshcn-screener-cahmi-quickguide-pdf.pdf>). Retrieved 03/23/2015

Figure 11: Percent of CYSHCN who qualified on specific screener questions. Comparing Maryland with the U.S



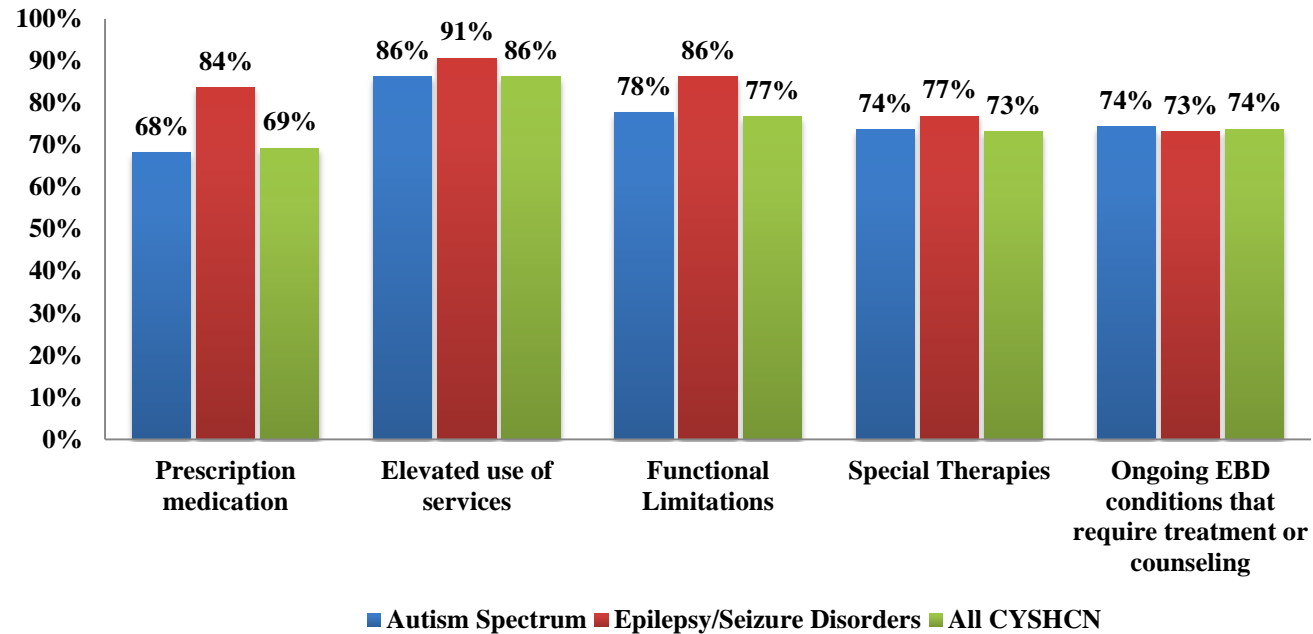
Data Source: 2011/12 NSCH

Note: Percents may not add up to 100% because CYSHCN can fall with in more than one category.

Among all CYSHCN in Maryland, 13.3% reported functional limitations due to their conditions. 75.4% reported use prescription medications to manage their condition. This is supported by data that show that among the 33% of CSHCN have ADD/ADHD and of those, around 80% were using medication for ADD. About 17% of Maryland’s CYSHCN require specialized therapies while almost 46% reported an elevated use of services.

Data from the 2014 Maryland Parents Survey for Children and Youth with Special Health Care Needs replicated the screener question. Among the respondents to the survey, 70% reported use of prescription medication while over 85% qualified on functional limitations (See Fig 12 below). The Maryland Parents Survey over represents CSHCN with significant health problems.

Figure 12: Percent of CYSHCN who qualified on specific screener questions. 2014 Maryland Parents Survey



Data Source: 2014 Maryland Parent's Survey

NOTE: The Maryland parent survey is an online survey conducted every year by the Office for genetics and people with special health care needs together with the Parent's Place of Maryland. Because of the special characteristics of the target population, this survey is always over representative of non-minority whites, and by CSHCN who significantly have more special needs, and have more functional difficulties.

The data from the 2014 Maryland Parent's survey show a significant disparity among CSHCN with different diagnoses. For example, CSHCN with epilepsy or seizure disorders seem to use more medication significantly higher than those with an autism/ASD diagnosis (84% vs. 68%). CSHCN with epilepsy or seizure disorders also use services more than those with ASD or all other CSHCN. Almost 67% of respondents met 4 or more criteria.



Mental health and developmental problems are particularly prevalent in CYSHCN. According to the 2009/10 NS-CSHCN, more than 54% of CYSHCN in Maryland had difficulty with one or more emotional, behavioral, or developmental factors – which included anxiety, stress, depression, acting out, fighting, bullying, difficulty making or keeping friends.

More recently, data from the 2011/12 NSCH show that CYSHCN ages 6-17 reported to be almost three times more likely to consistently exhibit problematic behaviors than children and youth without special health needs. For example, 37.5% of CSHCN had more than one incident where the school had to contact their parents, compared to only 16.1% of Non-CSHCN.

The 2010 and 2014 Maryland Parent Survey asked respondents if their children engaged in or experienced specific problematic behaviors. Among families of CYSHCN, 46% reported that their child had problems with anger/conflict management, double the rate in 2010. Almost 30% reported experience with bullying increasing from 20% in 2010 and 1 in 4 reported that their child had experience with depression while more than 65% reported experiencing some anxiety. The number of children experiencing suicidal behavior also increased from 4.8% to 8%. (See Table 2)

Table 2. Experience with Problematic Behaviors among CYSHCN

	2010	2014
Anger/conflict management	23.0%	46.0%
Bullying	20.0%	29.0%
Depression	19.8%	25.0%
Peer pressure	16.0%	N/A
Overweight/obesity	10.1%	N/A
Suicidal behaviors/suicide	4.8%	8%
Eating disorders	4.0%	N/A
Drugs	3.3%	N/A
Risky sexual behavior	3.2%	N/A
Alcohol	2.5%	1.8%
Delinquency	0.9%	N/A
Anxiety	N/A	66.0%

Source: 2014 Maryland Parent Survey



The 2011/12 NSCH reported state-specific data on different chronic conditions that are prevalent among CYSHCN, including ADD or ADHD and asthma. In Maryland, 33.4% of respondents reported that their child currently had or previously had ADD or ADHD. CYSHCN with more complex needs were also more likely to report having ADD or ADHD than CYSCHN with less complex needs (44.6% vs. 16.8%). Furthermore, CYSHCN with a Medical Home were less likely to report ADD or ADHD than those without a medical home (6.0% vs. 10.1%). Likewise, CYSHCN with E/B/D problems were significantly more likely to report having ADD or ADHD than those without EBD problems. 58% of those with EBD reported ADD or ADHD compared to only 22% of those without EBD. There were no significant variations between Maryland and the country in these measures. Almost 19% of those with ADD or ADHD rated their condition as moderate or severe, and the similarities are maintained as above. CYSHCN with EBD, more complex needs and those without a Medical Home were consistently more likely to report their ADD or ADHD as moderate or severe. 23.5% of CYSHCN with ADD or ADHD were taking medication at the time of the survey. Almost 3% of CYSHCN reported currently having asthma or previously had asthma. Not surprisingly, CYSHCN with less complex needs, those without a medical home and those without EBD were more likely to report having asthma than those with more complex needs and those with EBD. 8.0% of parents with CYSHCN reported the condition as moderate or severe, compared to 10% nationwide.

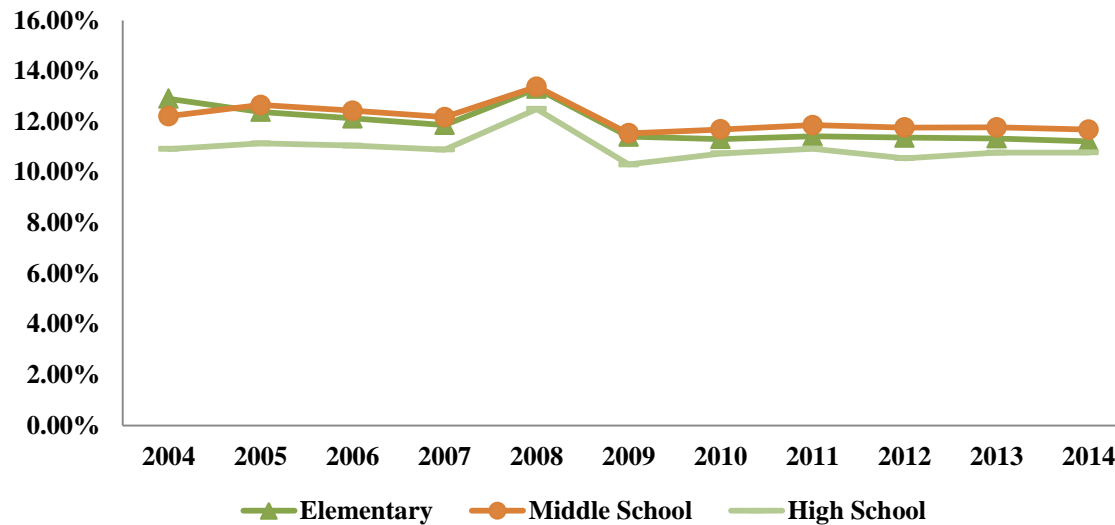
Data from a number of programs serving CYSHCN in Maryland can also help characterize this population. In Maryland as of December 2013, there were 146,890 SSI recipients making up just 1.4% of all SSI recipients in the country. Children and youth under 17 years were 25,693 making up about 17.5% of all SSI recipients. 11,844 children under 17 were on SSI due to disability¹⁰ Data from the Mental Hygiene Administration, which administers the State funded mental health system, reports that it served 122,067 people in 2010 of which 56,610 were children and young adults under the age of 21 making up about 46%¹¹.

Data from the Maryland State Department of Education indicate that as of October 2014, there were 104,136 children ages 3-21 receiving publicly funded special education services in Maryland. This represents about 12% of the population of children enrolled in Maryland public schools, demonstrating a slight reduction compared with 2004. (See Fig 13 below).

¹⁰ Annual Statistical Report on the Social Security Disability Insurance Program, 2013 (http://www.ssa.gov/policy/docs/statcomps/di_asr/2013/di_asr13.pdf)

¹¹ Maryland Mental Hygiene Administration. Annual Report Fiscal Year 2010. (<http://bha.dhmh.maryland.gov/RESOURCES/Documents/Reports/FY%202010%20MHA%20Annual%20Report.pdf>)

Figure 13: Special Ed students attending Maryland public schools as a percent of all students 2004-2014



Data Source: 2014 MSDE state of the state report

Preschoolers made up the majority of all special education students at 9.69% and the rest were averaging between 4% for high school and 9.59%¹². The majority of the special needs populations have specific learning disabilities (29.73%), autism (10.17%), and speech and language deficiency (17.1%). The majority of the children receiving special education services were male (68.7%) and Black or African American (41.8%), though the proportion of African American students with disabilities has increased from 2003 (40.2%) to 2008 (43.1%) while the proportion of white students with disabilities has decreased (52.0% in 2003). Children with specific learning disabilities account for the highest percentage at approximately 32%. There were about 1.8 times more children receiving services under the autism category than in 2003.

As of October 2014, there were 7,729 children ages 0-3 years receiving services through the Infants and Toddlers program in Maryland, an increase of 5.6% since 2008¹³.

Health Status and Quality of Life

¹² Maryland Special Education/Early Intervention Services. Census Report 2014. October 1, 2014

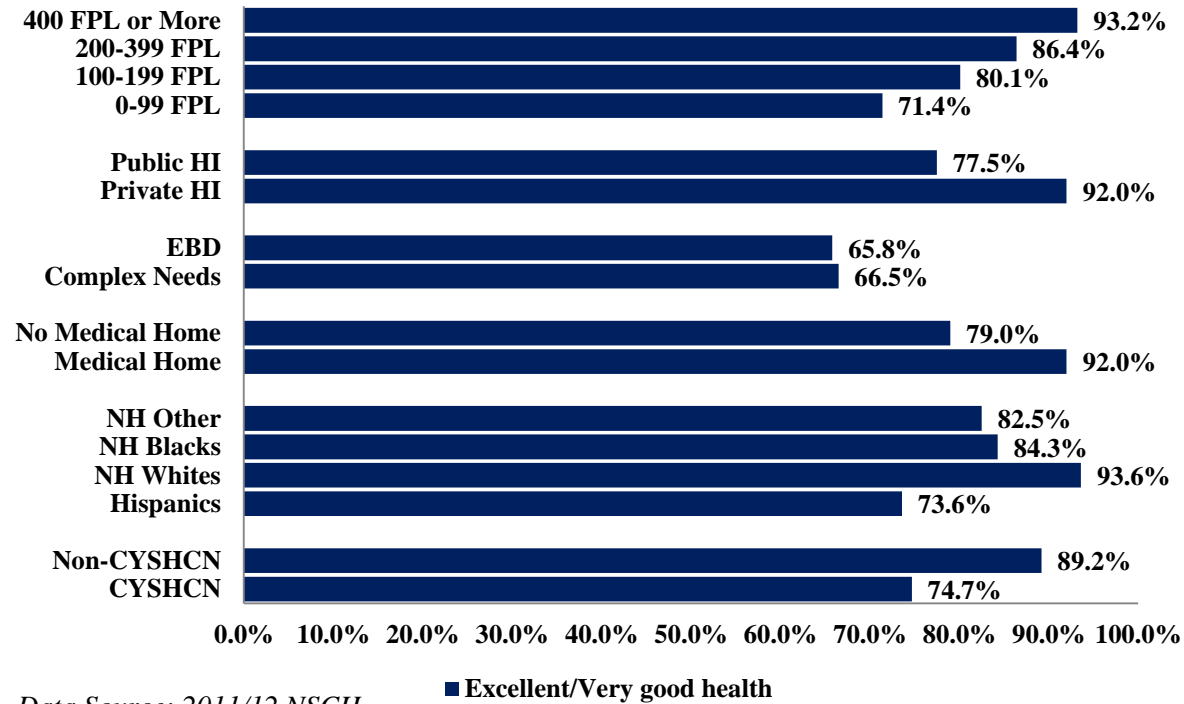
(http://www.marylandpublicschools.org/MSDE/divisions/planningresultstest/doc/20142015Student/2014-2015_SpecEd.pdf)

¹³ Maryland Special Education/Early Intervention Services Census Data & Related Tables, October 2008. (http://www.marylandpublicschools.org/NR/ronlyres/805A7BDE-C5E7-4106-81D9-D1F4008CCFC8/20037/sped08_rev.pdf)



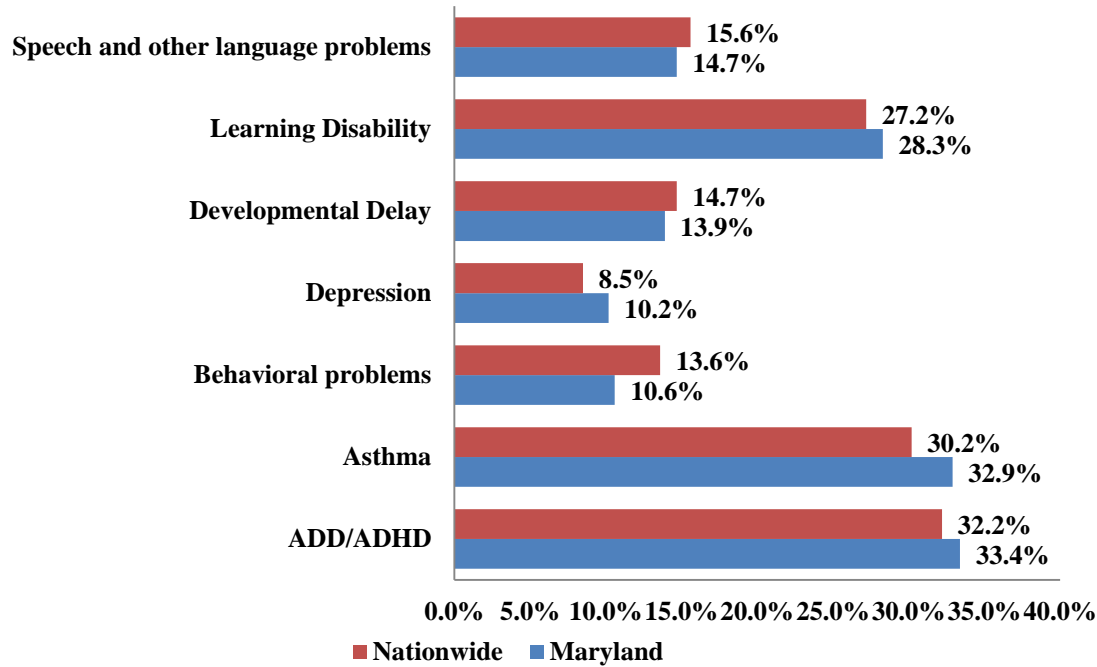
On the 2011/12 NSCH, the majority of Maryland parents of CYSHCN described their child’s health as excellent or very good (74.7%). As is expected, CSHCN without a medical home, those with EBD, those with more complex needs, and those with public health insurance were more likely to report lower rates of excellent or very good health. Hispanics were also more likely to report that their health was fair or poor than Non-Hispanic Whites. (See Fig 14 below)

Figure 74: Percent of CSHCN who were in excellent or very good health



Data Source: 2011/12 NSCH

Figure 15: Prevalence of the most common problems affecting CSHCN in Maryland compared to the U.S

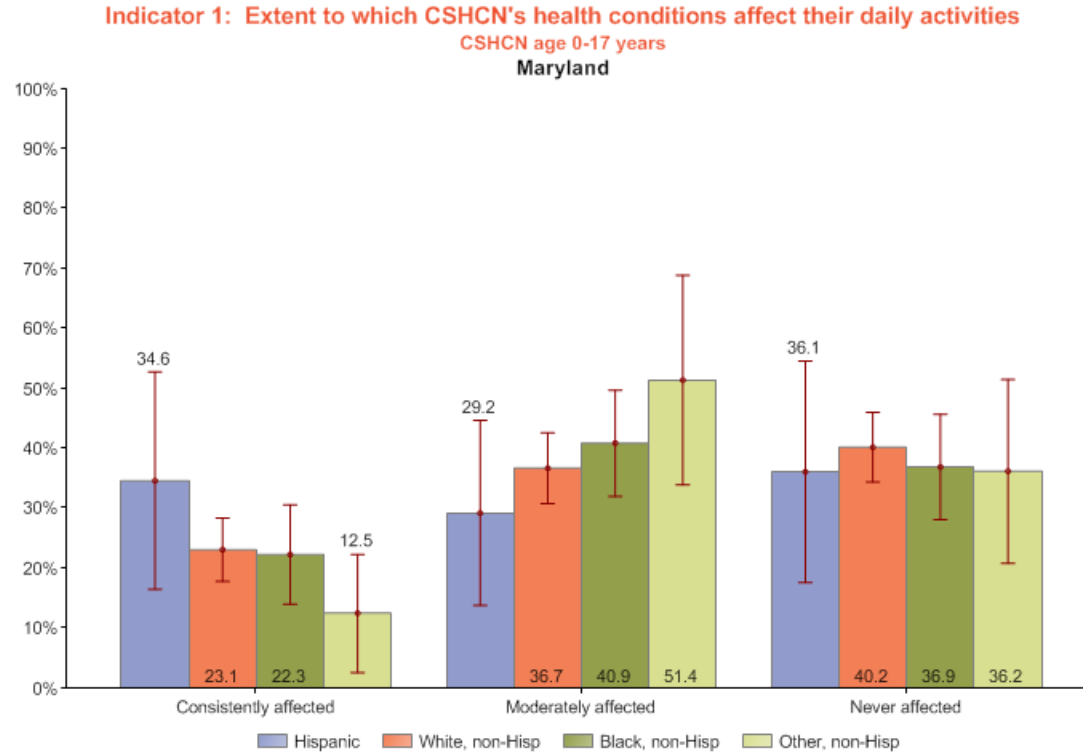


Data Source: 2014 Maryland Parent's Survey

Fig 15 above shows that the most common conditions affecting CSHCN in Maryland is ADD/ADHD and asthma with about 1 in 3 children reporting these conditions. For CSHCN, over 40% reported two or more of these conditions occurring at the same time.

In the 2009/10 NS-CSHCN, 38.5% of parents reported that their child's condition never affects his/her daily activities (see Figure 16); this is significantly less than in 2001 (45%). About 23% of parents reported that their child's condition consistently affected his/her daily activities and 38.7% reported moderate effects on their child's daily activities. CSHCN with more complex needs, those with EBDs, those without a medical home, and those living in households with less than 100% FPL were more likely to report that their condition often greatly affected their daily activities. As expected, children with 4 or more functional limitations were most affected in their daily activities, with almost 42% consistently affected and almost 43% moderately affected. Hispanic children were more likely to report effects on their daily activities than other races.

Figure 16. How often CYSHCN’s conditions affect daily activities by type race

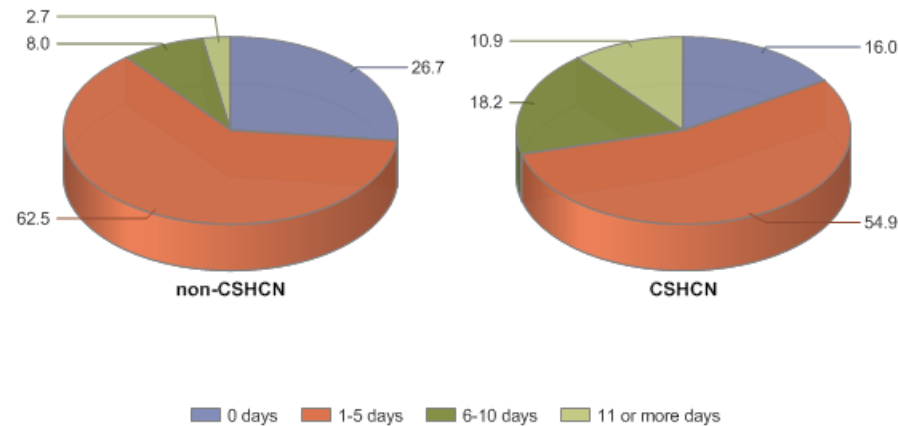


Source: 2009/10 NS-CSHCN

According to the 2011/12 NSCH, more than half of CSHCN (54.9%) missed only 0-3 days of school in the year prior to the survey due to their condition (see Figure 17). However, almost 11% were reported to have missed 11 or more school days. Children with more complex needs and those with EBDs were more likely to report more school days missed than those without.

Figure 17. CSHCN ages 5-17 missing school days due to illness or injury

Number of school days missed due to illness or injury during the past 12 months
 Children age 6-17 years
 Maryland



Source: 2011/12 NSCH

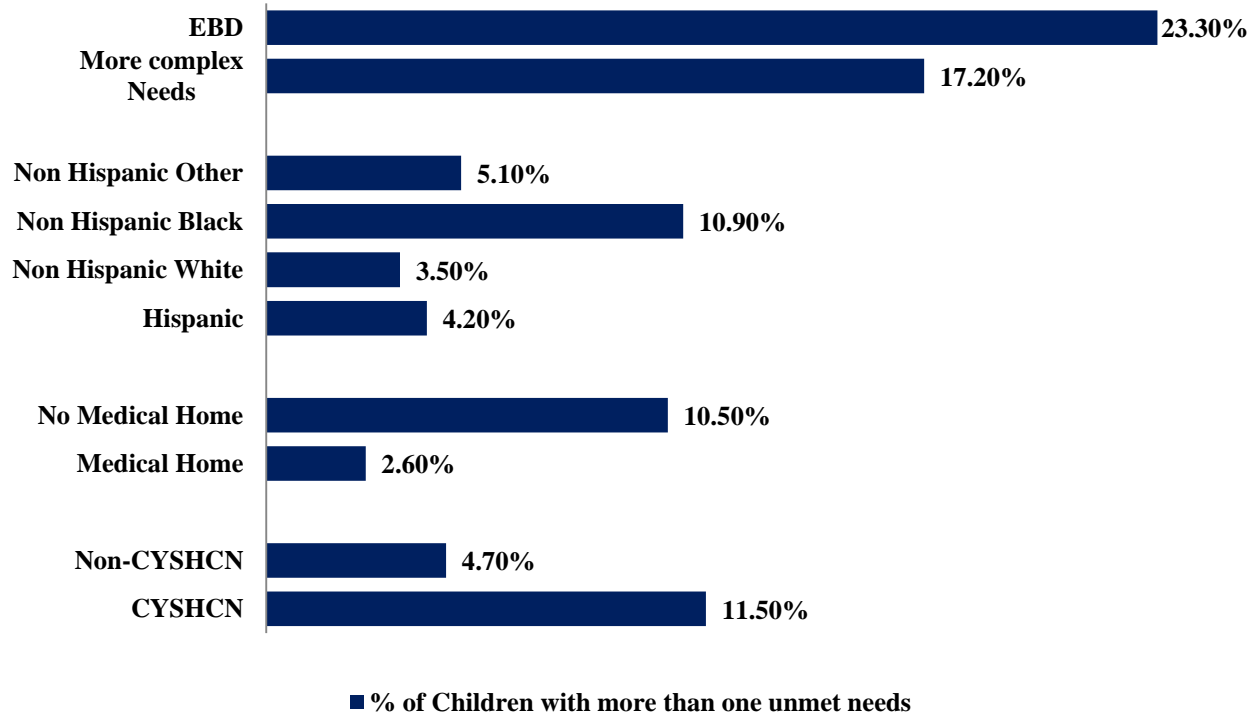
According to the 2009/10 NS-CSHCN, 13.3% of CSHCN ages 5-17 reported that their condition or illness affected their ability to attend school while 19.4% of those between 1-4 years old reported that their illness affected their ability to play with peers.

Health Care Needs and Access to Care

Unmet Health Care Needs

CYSHCN often require access to a wide range of health and related services. CSHCN experience more unmet health care needs than non-CSHCN. These include need for general medical and dental services, mental health services and vision services. Unmet needs can also involve the whole family of a CSHCN. According to the 2011/12 NSCH, 11.5% of all CSHCN in Maryland had at least one or more unmet needs compared to only 4.7% of non-CSHCN. CSHCN without a medical home, those with EBD, and those with more complex needs were significantly more likely to report one or more unmet needs. Non-Hispanic Blacks were more likely to report unmet needs than Non-Hispanic Whites or Hispanics.

Figure 18: % of CSHCN who reported one or more unmet needs



Source: 2011/12 NSCH

According to the 2009/10 NS-CSHCN, the services required the most by CYSHCN were prescription medications (89.0%), routine preventive health care (95.2%), preventive dental care (88.9%), and specialist care (51.7%). Other services that were needed frequently included vision care or eyeglasses (33.7%) and mental health care or counseling (31.0%) (See Table 3).



Table 3. Percent of CYSHCN requiring each of 15 specific health care services

	2001	2005-06	2009/10
	%	%	%
Prescription medications	90.4	88.3	89.0
Routine preventive health care	81.7	79.7	95.2
Preventive dental care	81.0*	79.5	88.9
Specialist care	52.6	52.5	51.7
Vision care or eyeglasses	38.0	32.1	33.7
Mental health care or counseling	27.0	28.5	31.0
Other dental care	*	24.8	28.5
Physical, occupational, or speech therapy	22.6	21.9	20.2
Disposable medical supplies	24.3	15.0	**
Durable medical equipment	9.5	11.4	10.3
Hearing aids or hearing care	7.1	4.5	5.1
Mobility aids or devices	3.9	4.4	3.2
Home health care	3.4	3.6	2.3
Communication aids or devices	1.1	3.2	2.8
Substance abuse treatment or counseling	3.8	2.3	3.9**

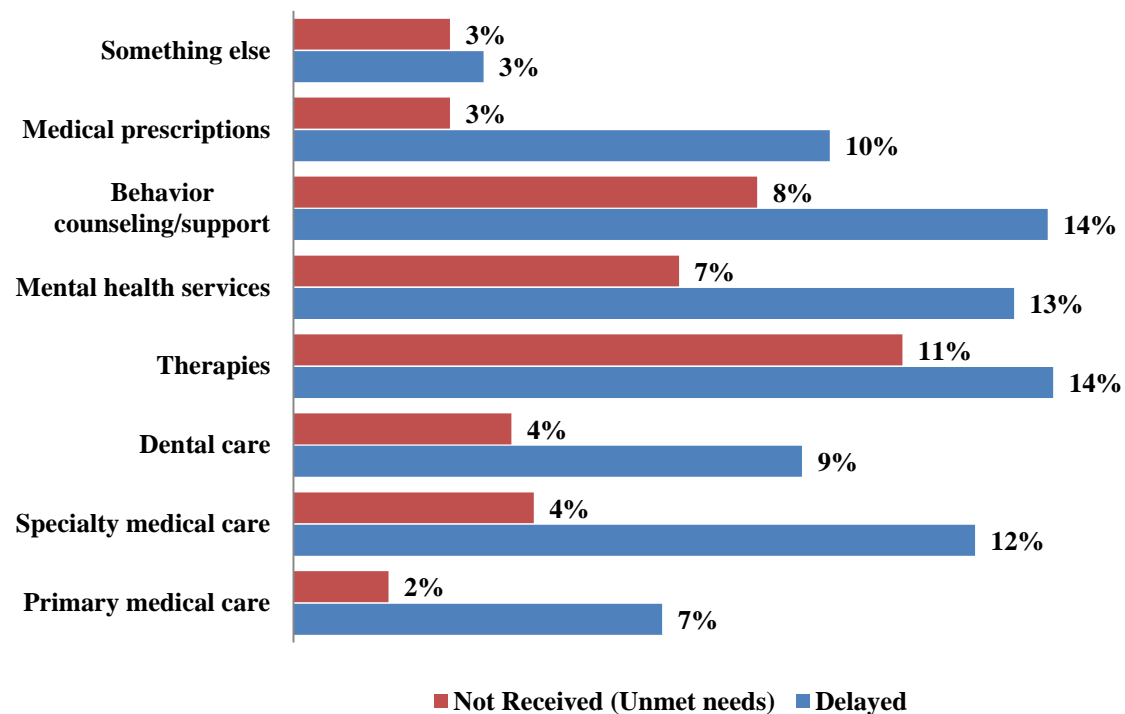
*Source: 2001, 2005, 2009 NS-CSHCN (*in 2001 there was only one category for 'dental care')*

The 2011/12 NSCH reports that CYSHCN who need specialty care in Maryland are almost 4 times more likely than non-CYSHCN to have problems getting it. Of those families whose child needed referrals, 8.2% reported problems getting them compared to only 2.9% of Non-CSHCN. According to the 2009/10 NS-CSHCN, CYSHCN with public insurance only, are more likely to report having problems getting a referral for needed specialist care.

According to the 2014 Maryland Needs Assessment Parent Survey (Maryland Parent Survey), 13% of parents of CYSHCN reported that their family needed dental care that was delayed or not received; over 23% reported that their family needed mental health services that were delayed or not received; 9% reported that their family needed medical care that was delayed or not received

(see Figure 19). Furthermore, only 52% of CSHCN receiving Infants and Toddler Services on an IEP reported that they were satisfied with their current service plans and only 62% of those with an IFSP said they were satisfied.

Figure 19. Unmet Needs (Care Delayed or Not Received) for Specific Services among CYSHCN Families



Source: 2014 Maryland Parent Survey

In addition to the above listed services that were delayed or not received, services such as occupational, physical, speech, and behavioral therapies were frequently reported as being delayed, often because these service were not covered or inadequately covered through the child’s health insurance.

“We have insurance. The problem is that it doesn't cover many of the services we need like speech therapy, MAPS/DAN doctors; physical therapy; occupational therapy, etc.” Parent Respondent, 2014 Maryland Parent Survey

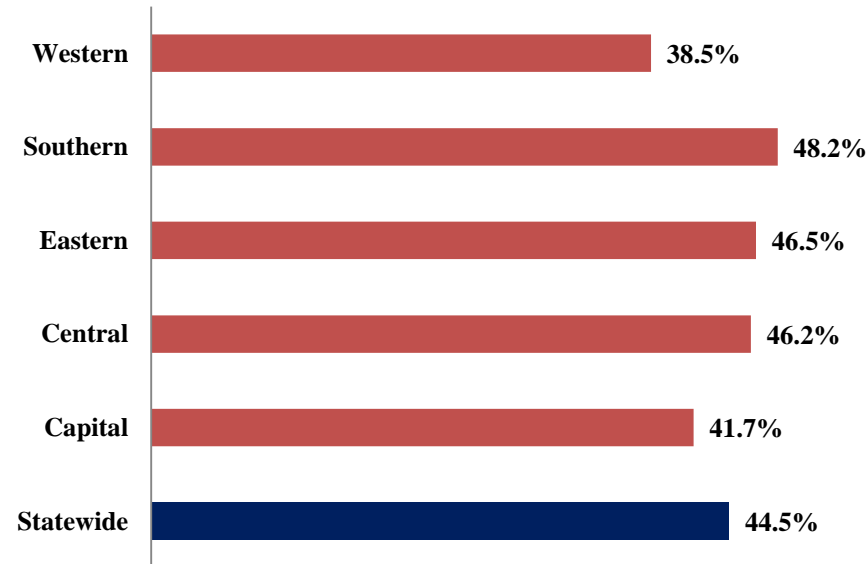


Impact on Family

Impact on Employment

Caring for CYSHCN can have a significant impact on families. The needs of CYSHCN vary greatly. For instance, some children receive care from several providers and have frequent medical appointments. Some are dependent upon technology and may need assistance with basic activities of daily life such as feeding. Others may need to take medications. According to the 2011/12 NSCH, while only 41.3% of Non-CSHCN receive 10 or more hours of outside care, that number jumps to 63.3% for CSHCN. This proportion increases to 74.4% for those with EBD, and 71% for those with more complex needs. This translates to more money spent on CSHCN for their care. Furthermore, families with one or more CSHCN reported more parental stress than non-CSHCN by a margin of more than 10%. According to the 2009/10 NS-CSHCN over 9% of families spent 11 or more hours per week providing or coordinating their child's care. Some families find it necessary for a caregiver to cut back on work hours in order to be able to meet the multiple demands of caring for a CYSHCN. Over 10% of families responded that a family member had to cut back or stop working due to the health of a CYSHCN. The poorest families are more likely than others to cut back on work hours or to stop working. More recent data from the 2014 Maryland Survey found that, among families of CYSHCN, over 44.5% reported that they found it necessary to change their working hours or stop working to care for their CYSHCN.

Figure 20: Percent of respondents who reported cutting back or completely stopped working (2014 Maryland Parents Survey)



Data Source: 2014 Maryland Parent’s Survey

Basic Needs

“We tried to get MA and were told no because we make too much money. My daughter is on 15 or more medicines a day. She would qualify for REM but our income stops her from getting it. As a teacher and a police officer, we struggle daily to pay our bills due to having 2 disabled children. Parent respondent, 2014 Maryland Parent Survey.

The 2014 Maryland Parent Survey asked respondents whether or not they were having difficulty paying for basic needs, such as clothing and food. Table 4 shows the percentage of families of CYSHCN who have difficulty paying for particular needs from the 2010 and 2014 Maryland Parents Survey. Of the families with CYSHCN, 16.0% reported difficulty paying for medical prescriptions, a decline of about 7% from 2010. 19.4% had difficulty paying for utilities, and about 17% reported difficulties paying for housing and 16.6% had difficulties paying for food.

Table 4. Difficulty Paying for Basic Needs among Families of CYSHCN

	2010 Parent Survey	2014 Parent Survey
Medical Rx	23.2%	16.0%
Utilities	20.7%	19.4%
Clothing	17.0%	16.4%
Housing	16.8%	17.1%
Food	13.5%	16.6%
Transportation	13.1%	14.0%
School Supplies	12.4%	8.5%
Phone	12.1%	10.3%

Source: 2010 and 2014 Maryland Parent Survey

Child Care

Lack of quality child care certainly contributes to the impact that having CYSHCN can have on employment. According to the Maryland Parent Survey, almost 45% of responding families with CYSHCN needed assistance with child care and of those families, only 30% received help with finding child care services. Among the families that needed assistance, almost 25% did not get any help and 21% responded that it was very difficult to get the help they needed.

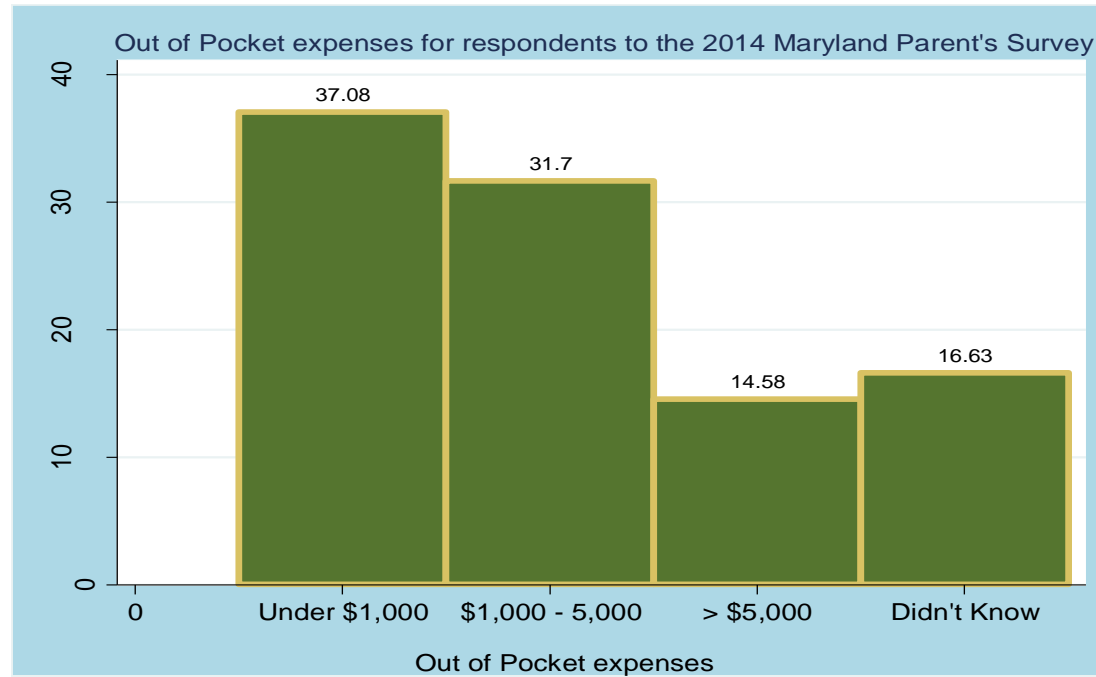
Financial Impact

Cutting back on work hours or stopping work altogether can significantly impact a family’s finances. In addition, the costs associated with providing care for CYSHCN can be great. 22.3% of families reported out-of-pocket health care costs above \$1000 per year on the 2009/10 NS-CSHCN. 18.3% of families reported having experienced financial problems due to their CYSHCN health conditions.

“Before October 2013 my children had no medical insurance, and were unable to get it because we made too much money. My husband was laid off and I was able to get it.” Parent Respondent, 2014 Maryland Parent Survey

The poorest families, Hispanic families, CYSHCN whose insurance is not adequate, and CYSHCN with functional limitations are more likely to have negative financial impacts from health conditions. More recent data from the 2014 Maryland Parent Survey indicates that out-of-pocket costs for families of CYSHCN in Maryland are rising; of the responding families with CYSHCN, over one-quarter spent \$1000-\$5000 on out-of-pocket expenses for their CYSHCN care, while almost 15% spent over \$5000 (see Figure 21)

Figure 21. Out-of-Pocket Expenses for CYSHCN Medical Care



Source: 2014 Maryland Parent Survey

“Travel costs for medical care (hotel, gas, food, etc. to see specialists in Ohio and Pennsylvania for care that we can't get here”
 Parent Respondent, 2014 Maryland Parent Survey

The issues discussed above can put stress on family members of CYSHCN. According to the 2011/12 NSCH, parents of CYSHCN were more likely to report their mental and/or physical health fair or poor relative to parents of children without special health needs (see Table 5).

Table 5. Children & youth with mothers and fathers whose mental health are fair or poor

	Overall Health	CSHCN	Non-CSHCN
% Maryland children currently living with a mother in the household whose mother's mental/emotional health are fair or poor	47.6	12.3	6.0
% Maryland children currently living with their father whose father's general health and mental/emotional health are both excellent or very good	40.6	5.3	3.6

Source: 2011/12 NSCH

The need for regular respite activities for families is a recurring theme in all local health department needs assessments. According to the 2010 Maryland Parent Survey, almost 34% of responding families with CYSHCN needed assistance with respite care. Almost 45% of those families sought assistance for respite care, and of those families, less than 22.6% reported that they found it very difficult to obtain the service while another 38% simply did not get the services. Only about 9% reported that it was easy accessing the services for respite care. The 2009/10 NSCH reported that among Maryland parents of CSHCN, 9% were always or usually irritated by failure to find services for their child while another 26% said that they were sometimes irritated by failure to find services for their child.

Education

The 2014 Maryland Parent Survey asked respondents whether or not their child needed certain services typically provided through public schools; and whether or not they were satisfied with the services they received. Among those who answered the question, 17.39% said they had an IFSP, 78.8% had an IEP, 11.5% had a 504 Plan, and 9.9% had a Nursing Care Plan. (Table 6). Satisfaction rates varied – the highest rate of satisfaction was reported among those with a Nursing Care Plan with about 88% reporting satisfaction.



Table 6. School-based services needed by families of CYSHCN

Type of Service	% of families whose CYSHCN received services	% of families of CYSHCN who were satisfied with services received
IFSP	17.39%	60.84%
EIP	78.8%	57.52%
504 Plan	11.5%	57.41%
Nursing Care Plan	10%	88.64%

Source: 2014 Maryland Parent Survey

Children receiving special education services through public schools have Individualized Education Plans, or IEPs. Students who don't qualify for an IEP but still require some modifications or accommodations in the public education setting have 504 plans. Children receiving early intervention services have Individualized Family Service Plans, or IFSPs. The 2014 Maryland Parent Survey asked respondents if their CYSHCN had an IEP, IFSP, or 504 plans and if so, were they satisfied with the services the child was receiving through the plan. 17.4% reported having an IFSP while almost 79% had an IEP. Almost 11.5% said their child has a 504 plan. Less than 10% of all respondents had a nursing care plan through their school or county. Over 60% of those with an IEP reported that they were satisfied with the plan while about 58% of those with an IEP reported being satisfied with the plan. , 57% of those with a 504 plan reported being satisfied with their plan and those with a nursing care plan reported the highest satisfaction with over 88% reporting being satisfied with the nursing plan.

Core Outcomes for Children and Youth with Special Health Care Needs in Maryland

The current national priorities for CYSHCN focus on six core outcome areas identified by MCHB as critical indicators of success in implementing community-based systems of services mandated for all CYSHCN under Title V and Healthy People 2020. This section of the report focuses on data and information related to Maryland's performance on each of the core outcomes. First is a summary table (Table 7) containing broad information on all six outcomes; this is followed by more detailed information for each outcome.



Table 7. Summary of CSHCN Core Outcome Performance in Maryland

Core Outcome	Title V Performance Measure	2001 Maryland (Nationwide)	2005-06 Maryland (Nationwide)	2009-10 Maryland (Nationwide)	Issues	Strengths in Maryland	Barriers in Maryland
<p>Families partner in decision-making</p>	<p>Percent of children with special health care needs (CSHCN) age 0 to 18 years whose families partner in decision-making at all levels and are satisfied with the services they receive</p>	<p>68.1 (57.5) Maryland ranked 2nd in the nation</p>	<p>54.8 (57.4) Maryland ranked 42nd in the nation</p>	<p>69.3 (70.3) Maryland ranked 37th nationwide</p>	<p>Families with CSHCN in one or more of the following subgroups were the least likely to report feeling like partners or to be satisfied with care: families with younger CSHCN under 6; minorities; family income less than 100% FPL; those with functional limitations; those without a medical home, and those who had both private and public insurance</p>	<p>Willingness of stakeholders to work together; Existing models of partnerships; Strong families; availability of data. PPMD doing a pilot with parent navigators in pediatric practices</p>	<p>Inadequacies in: professional and family training opportunities; support for culturally and linguistically competent supports and services; family and professional supports including time, reimbursement, and financial support; County and regional variances; lack of value for family wisdom, experiences, expertise and knowledge; and existing partnerships are not consistently implemented across systems statewide.</p>



Core Outcome	Title V Performance Measure	2001 Maryland (Nationwide)	2005-06 Maryland (Nationwide)	2009-10 Maryland (Nationwide)	Issues	Strengths in Maryland	Barriers in Maryland
Medical Home	Percent of CSHCN age 0 to 18 years who receive coordinated, ongoing, comprehensive care within a medical home	56.3 (52.6) Maryland ranked 10 th in the nation	45.6 (47.1) Maryland ranked 38 th in the nation (2005-06 data cannot be compared to 2001 data due to significant changes in how this indicator is derived.)	44.2 (43.0) Maryland ranked 28 th nationwide (Data is comparable to the 2005-06 survey)	Families with CSHCN in one or more of the following subgroups were less likely to report care consistent with a medical home: families with older CSHCC over 12; Hispanic and African American-non-Hispanic and those whose primary language is not English; CSHCN in families with less than a HS educated adult; CSHCN with one or more E/B/D; CSHCN with functional difficulties; family income less than 100% FPL; and CSHCN with both private and public insurance;	Ongoing partnerships and relationships among stakeholders; strong interest among stakeholders in promoting the Medical Home model; Current MH workgroup exploring care coordination efforts within the state led by OGPSHCN MH coordinator	Provider characteristics including communication, empathy, paternalism, competence, and cultural sensitivity, lack of knowledge, skills and resources to implement the Medical Home; parent characteristics including lack of information, not prepared to effectively coordinate child's care, isolation and lack of platform for education in Medical Home requirements and expectations, and care coordination; Care coordination agency fragmentation and lack of standards; lack of compensation for care coordination, non-face-to-face care, and non-physician care;



Core Outcome	Title V Performance Measure	2001 Maryland (Nationwide)	2005-06 Maryland (Nationwide)	2009-10 Maryland (Nationwide)	Issues	Strengths in Maryland	Barriers in Maryland
<p>Adequate Insurance</p>	<p>Percent of CSHCN age 0 to 18 years whose families have adequate private and/or public insurance to pay for the services they need</p>	<p>67.5 (59.6) Maryland ranked 5th in the nation</p>	<p>65.5 (62.0) Maryland ranked 14th in the nation</p>	<p>61.3 (60.6) Maryland ranked 25th nationwide</p>	<p>Families with CSHCN in one or more of the following subgroups were less likely to report having adequate insurance: Older CSHCN 12-17; Hispanic; households where the adult has more than a HS education; functional limitations; those with private insurance; and without a medical home</p>	<p>MCHIP expansion; Medicaid waiver for children with autism; Medicaid buy-in for employed individuals with disabilities; Kids First Act. Recent changes in EPSDT services; Medicaid expansion, and the ACA. Maryland Health Exchange uptake</p>	<p>No comprehensive plan to address the needs of how services for CYSHCN are paid for; state budget cuts; long waiting lists for waiver programs; large disparity in the availability of needed providers in rural vs. urban areas; limits on scope of benefits; difficult to navigate health plans; erosion of employer-based benefits; lack of care coordination; lack of clarity about eligibility for services; and insurance not keeping pace with technological advances in therapies or Durable Medical Equipment</p>



Core Outcome	Title V Performance Measure	2001 Maryland (Nationwide)	2005-06 Maryland (Nationwide)	2009-10 Maryland (Nationwide)	Issues	Strengths in Maryland	Barriers in Maryland
<p>Early and Continuous Screening</p>	<p>Percent of CSHCN who are screened early and continuously for special health care needs</p>	<p>N/A (Not measured)</p>	<p>65.7 (63.8) (rank not available)</p>	<p>81.2 (78.6) Maryland ranked 16th nationwide</p>	<p>According to the 2011/12 NSCH, almost 38% of all parents in MD reported concerns about their child’s development between 0-5; Hispanics were more likely to report concerns; but more than 46% were never asked during a doctor’s visit if they had any concerns; Hispanics and Blacks were significantly more likely to not get asked about developmental concerns relative to Non-Hispanic Whites. Children without a Medical Home were also more likely to report not discussing developmental concerns during a doctor’s visit relative to those with a medical home.</p>	<p>Effective statewide models of screening for selected conditions; increasing awareness of the importance of screening, particularly for developmental health issues. OGPSHCN together with PPMD have continuously advocated for developmental screening within the state</p>	<p>Poor communication and information-sharing between providers, agencies and families; need for comprehensive statewide systems; need for improved education and professional development of providers; Need for improved parent/family education and training.</p>



Core Outcome	Title V Performance Measure	2001 Maryland (Nationwide)	2005-06 Maryland (Nationwide)	2009-10 Maryland (Nationwide)	Issues	Strengths in Maryland	Barriers in Maryland
<p>Community-Based, Easy-to-use Systems</p>	<p>Percent CSHCN age 0 to 18 years whose families report the community-based service systems are organized so they can use them easily</p>	<p>70.6 (74.3) Maryland ranked 42nd in the nation</p>	<p>89.3 (89.1) Maryland ranked 26th in the nation (cannot be compared to 2001 data)</p>	<p>65.1 (65.1) Maryland ranked 29th nationwide. (Data is not comparable to previous surveys due to changes in survey methodology)</p>	<p>Families with younger CSHCN 0-5 were more likely to report achieving this outcome relative to older CSHCN; Hispanic CSHCN, those with functional limitations, E/B/D, those with public insurance only, and those with household incomes under 100% FPL were least likely to report successfully achieving this outcome</p>	<p>There are many resources and services for families as well as good potential for infrastructure to improve these services.</p>	<p>Redundancy (ex: multiple entities offer case management); fragmentation; lack of acknowledgement of disparities; lack of knowledge among care providers of resources and services; turf issues among agencies.</p>



Core Outcome	Title V Performance Measure	2001 Maryland (Nationwide)	2005-06 Maryland (Nationwide)	2009-10 Maryland (Nationwide)	Issues	Strengths in Maryland	Barriers in Maryland
<p>Youth Transition To Adulthood</p>	<p>Percent of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence</p>	<p>5.8 (these data deemed unreliable due to sample size and other concerns)</p>	<p>37.4 (41.2) Maryland ranked 42nd in the nation (cannot be compared to 2001 data)</p>	<p>36.8 (40.0) Maryland ranked 40th nationwide. (data can be compared to 2005 survey)</p>	<p>Families with minority CSHCN were more likely to lack proper transitioning services; those without a medical home, living in poor households, and those with public insurance were also more likely to lack proper transition services.</p>	<p>Maryland currently has many government and parent-led activities focused on improving transition. OGPSHCN conducted a gap analysis on transition and is focusing on transition as one of its priorities for FY16-FY20.</p>	<p>The current status of Transition to Adult Services in Maryland is characterized by fractured activities with no common end. Despite the activities focused on Transition in Maryland (see below), the state continues to lack a clearly defined, comprehensive, coordinated, community based, culturally competent, collaborative, youth/family centered system of care to facilitate success in transition from pediatric- to adult-based health care. This issue is compounded by the problem of this age group accessing their own health insurance.</p>

Data come from the National Survey of Children with Special Health Care Needs (NS-CSHCN)



Family-Professional Partnerships and Satisfaction with Services

The Healthy People 2020 objective on health communication and health information technology includes outcomes for partnered decision making between the medical professionals and families and caregivers. The NS-CSHCN collects data on a broad range of outcomes including how often the doctor or medical professional makes parents feel like they are partners in the care of their child; how often doctors of other health care providers make it so that the parents are comfortable asking questions and expressing their concerns; how often the doctors are sensitive to family and cultural values and norms; and how often doctors respect parents’ treatment choices. Data from the 2009/10 NS-CSHCN are shown in table 8. Subgroup analysis of the data shows that CSHCN without a medical home were significantly more likely to report lower levels of successfully achieving these outcomes relative to those with a medical home.

Table 8. 2009/10 NS-CSHCN Indicators used to measure partnership

Indicator	Maryland %	Nation %
CSHCN whose families are partners in shared decision-making for child's optimal health	69.3%	70.3%
CYSHCN whose health providers are usually or always sensitive to family and cultural values and norms	88.7%	88.9%
CYSHCN whose doctors or HCP usually or always respected the parent’s treatment choices	82.2%	84.4%
CYSHCN whose doctors usually or always made it easy for parents to ask questions and raise concerns	86.4%	86.2%

Source: 2009/10 NS-CSHCN

Family-Professional Partnerships

Over 69% of families of Maryland CYSHCN report that their child’s health care providers helped them feel like a partner in care on the 2009/10 NS-CSHCN. Data from the 2014 Maryland Parents Survey found that 75.54% felt like partners in decision making most of the time and 20% felt like partners in decision making sometimes. In the same survey, when asked if the doctor or HCP respected their treatment choices, 74.5% reported that the doctor respected their decisions most of the time while almost 20.5% reported that the doctor respected their decisions some of the time. Almost 70% said they were encouraged to ask questions or raise concerns most of the time and 24% said they were encouraged some of the time.



Maryland has a strong history of including parents and families in decision-making at all levels. The Office for Genetics and Children with Special Health Care Needs (OGCSHCN) in the Maryland Department of Health and Mental Hygiene (DHMH) supports The Parents' Place of Maryland (PPMD) with a yearly grant and has maintained a successful relationship with PPMD that has been a model for promoting family-professional partnerships and family involvement in policymaking at state and local levels. PPMD is a non-profit, family-directed and staffed center serving parents of children with disabilities and special health care needs and currently serves as the statewide Parent Training and Information Center (PTI) and Family to Family Health Information Center (F2FHIC) as well as being home to Maryland Family Voices. PPMD and OGCSHCN have an ongoing partnership in a number of activities including a variety of workshops (held across the state) for both parents and professionals aimed at increasing partnership and advocacy skills and effectively accessing health care services for CYSHCN. Additionally, OGCSHCN was instrumental in the award to PPMD of a State Implementation Grant for Integrated Community Systems for CYSHCN from MCHB. PPMD and OGCSHCN work together to carry out the work for this grant through the Maryland Community of Care Consortium for CSHCN (CoC). The CoC meets quarterly and has identified priorities which include building relationships between families and professionals through education and joint training. The CoC is facilitating family-professional partnerships through parent attendance and participation in workshops and trainings for providers centered on the early and continuous screening for special health care needs and medical home. Through the CoC, parent members receive regular updates on state activities for CYSHCN, and they also continuously contribute to shaping state goals and priorities for Title V activities. PPMD leadership has participated closely in all Title V 2015 Needs Assessment activities.

Satisfaction with Care

Patient satisfaction is a critical indicator of health care quality. Patients' attitudes and expectations, as well as patients' cultural values and norms contribute to patient satisfaction. According to the 2011/12 NSCH, almost 10% of families with CSHCN reported being usually or always frustrated in trying to obtain care for the child. Only 4% of Non-CSHCN families reported being usually or always frustrated. Families with more complex CSHCN and those with E/B/D problems reported higher rates of frustration. (13.5% and 15.4%). The 2014 Maryland Parent's Survey asked with respondents if they were satisfied with their child's doctor's ability to identify need and refer the child to appropriate agencies (See table 9).

Table 9: Parent satisfaction with ability to identify need and refer to appropriate agencies (2014 Maryland Parent's Survey)

Service	Percent satisfied with HCP ability to identify	Percent satisfied with HCP ability to refer
Medical evaluation	84.9%	77%
Developmental evaluation	66.3%	64.3%
Early Intervention Services	33.33%	33.67%
Physical Therapy	33.83%	34.58%
Occupational Therapy	39.3%	38.95%
Speech and Language Therapy	43.21%	40.77%
Behavioral Services	43.43%	40.14%

Strengths and Barriers

Maryland continues to pave the way for families to be involved. OGPSHCN and PPMD have been instrumental in developing strategies to involve families in decision making of CSHCN with the CoC being a critical link for families and professionals. PPMD and OGPSHCN have undertaken a pilot project for involving parent navigators in pediatric practices to provide resources for new families of CSHCN and preliminary results are positive. Maryland still lags behind among non-English speaking families and focus will be placed on inclusion of non-English speaking families.

Comprehensive Care through a Medical Home

Medical Home Prevalence

While having a medical home is important for all children, CYSHCN in particular need the type of care embodied by this model. According to the 2011/12 NSCH, just under 48% of Maryland CYSHCN are receiving care that meets criteria for a medical home compared almost 60% for Non-CSHCN. In Maryland, certain variables are associated with the rate of successfully achieving this core outcome: age; race/ethnicity; type of SHCN; incidence of behavioral, emotional, or developmental issues; household income; consistency of insurance coverage; and type of insurance. Subgroups that show a lower rate of successfully achieving comprehensive care through a medical home (see Table 10) include CSHCN age 6 to 11 years; children who have one or more periods of being uninsured in a year; children with public insurance only; children who have one or more emotional, behavioral or developmental issues; children from low-income (0-199% FPL) households, children who are African American or Hispanic, children who have an above routine need/use of services, and children who live in rural areas.



Table 10. Percent of CYSHCN in Maryland Achieving a Medical Home – Subgroups

	% CSHCN successfully achieving medical home in Maryland (Nationwide)
Overall	47.77 (46.8)
Age Group	
0-5 years of age	58.36
6-11 years of age	36.99
12-17 years of age	41.96
Household income	
0-99% FPL	40.96
100-199% FPL	40.85
200-399% FPL	46.68
400% FPL or More	52.60
Type of Insurance	
With private insurance only	55.21
With public insurance only	37.30
Emotional/Behavioral/Developmental Issues	
No emotional, behavioral, or developmental issues	59.3
One or more emotional, behavioral, and developmental issues	22.0

Source: 2011/12 NSCH

OGPSHCN conducted a gap analysis to measure care coordination – an important factor in medical home implementation – among Local Health agencies and schools in Maryland as part of the comprehensive needs assessment. Preliminary results show that the biggest barriers to care coordination are lack of funding (60%) and lack of staffing (44%). Maryland is planning to implement the “Central hub” model for care coordination which is expected to improve care coordination activities across the state.

Usual Sources of Care

Having a usual source of care is a starting point for a medical home. 94.3% of Maryland CYSHCN is reported to have a usual source of care on the 2011/12 NSCH. A personal doctor or nurse for their CYSHCN was reported by 96.4% of families on this survey.



On the 2014 Maryland Parent's Survey, the just above half of all respondents (53.3%) indicated that their child is seen most often by a primary provider like a generalist or pediatrician compared to 46.7% who were seen by a specialist. Among those who were receiving care through a primary provider, the majority (81%), were solely seeing a pediatrician and 17% were seeing a generalist.

Coordinated Care

"I have MCHP. Due to my own learning disabilities it is hard for me to know what paperwork I need to send in, and when. A case manager where I go for medical care for myself helped me apply in 2010. But once I got it, she was off the case. I'm supposed to have a contact at Baltimore City Dept. of Health, but I find it difficult to reach a person there, I always get different answers to my questions, and no one knows my whole file. Parent Respondent, 2014 Maryland Parent Survey

On the 2011/12 NSCH, 58.1% of respondents were found to have effective care coordination for their CYSHCN when needed, a slight improvement from 57.7% in the 2007 NSCH. A key issue in care coordination is communication. On the 2011/12 NSCH, almost 66.8% of families of CYSHCN who needed care coordination reported that they were very satisfied with their doctor's communication with other health care providers compared to 73.6% for Non-CYSHCN families. This indicates an improvement in Maryland since 2007, when only 60% of families whose CYSHCN needed care coordination reported that their doctor's communication with other health care providers was excellent or very good. However, there is evidence that barriers to effective care coordination still exist in the state especially for sub groups of CYSHCN. For example, even though 66.8% of all CSHCN families were satisfied with communication as stated above, the percentage drops to about 50% for CSHCN with E/B/D issues and 61% for those with more complex needs. The 2014 Maryland Parents Survey found that almost 24% of responding parents reported that they found it very difficult when they needed assistance to get assistance, and almost 14% never got the assistance they needed.

Accessible Care

Accessibility of care is a critical medical home component. On the 2011/12 NSCH, over 96% of families of CYSHCN reported that their child has a personal doctor or nurse and over 94% reported that their child has a usual source of care when sick. Data from the 2014 Parent's Survey indicate that accessing primary care is more difficult for families of CYSHCN in certain counties in Maryland; caregivers in Calvert and Caroline counties were more likely to report having to travel 50 or more miles to see a specialist.

Access to specialty care, oral health care, and mental health care are problematic issues for CYSHCN in Maryland. In the 2015 Maryland Needs Assessment Stakeholder Survey access to therapies including speech, occupational, physical, and dental was the number one priority for CYSHCN in Maryland. According to the 2011/12 NSCH, 12.2% of CYSHCN in Maryland needed and had problems getting specialist care in the year before the survey was conducted compared to only 5.6% of non-CYSHCN. The 2009/10 NS-CSHCN indicates that over 23% of CYSHCN in Maryland had problems obtaining referrals when they were needed.



Family-Centered Care

Another important pillar of the medical home model is family-centered care. The 2011/12 NSCH estimates that over 66% of Maryland CYSHCN received care that is family-centered compared with almost 68.8% for Non-CSHCN. Maryland ranked 35th nationally which is disappointing because Maryland has been known nationally as setting the trend on family centered care. The NSCH also estimated that almost 61.8% of CYSHCN families felt that their child’s doctors or other health care providers always listen carefully to them, compared to 71.9% for Non-CSHCN. Almost 69% felt that their child’s doctors are sensitive to the family’s customs and values, compared to over 75% for Non-CSHCN. Over 67% felt they got the specific information they needed from their child’s doctors compared to 66.4% for Non-CSHCN. 56.8% felt that their child’s doctors spend enough time with them compared to 60.4% for Non-CSHCN. These data are also reflected in the 2014 Parents survey. (Table 11)

Table 11: Results of family- centered care from the 2014 Maryland Parent's Survey

	No Response	Never	Sometimes	Most of the time	Total
Listen carefully to you?	0.39% 4	0.87% 9	16.81% 173	81.92% 843	1,029
Get you the specific information you needed?	0.39% 4	3.30% 34	27.02% 278	69.29% 713	1,029
Help you feel like a partner in your child’s care?	0.29% 3	3.79% 39	20.02% 206	75.90% 781	1,029
Discuss with you the range of options to consider for her/his treatment or care?	0.29% 3	7.87% 81	26.82% 276	65.01% 669	1,029
Encourage you to ask questions or raise concerns?	0.29% 3	6.41% 66	23.91% 246	69.39% 714	1,029
Consider and respect what treatment or care choices you thought would work best for your child?	0.29% 3	4.86% 50	20.12% 207	74.73% 769	1,029

Strengths and Barriers

Maryland has several strengths around this core outcome. These include tremendous opportunities based on Maryland's ongoing partnerships and relationships among stakeholders, and strong interest of stakeholders in promoting the Medical Home model. There are also barriers in the areas of providers and practices, family readiness and education, care coordination and aligning compensation with supporting medical home improvement. Certain provider characteristics are challenging, including a lack of communication and empathy, paternalism, competence, and cultural sensitivity, lack of knowledge, skills and resources to implement the medical home model. Challenges among parent characteristics include a lack of information; they are not always prepared to effectively coordinate child's care, isolation and the lack of a platform for education in medical home requirements and expectations. Additional challenges include care coordination agency fragmentation and a lack of standards; a lack of compensation for care coordination, non-face-to-face care, and non-physician care; and a perceived lack of interest in medical home on a statewide level¹⁴

Adequate Insurance and Financing to Pay for Services

"Wasn't until I finally got food stamps that he got medical assistance. He had a gap when we had no coverage because I lost my job when his accident happened and couldn't afford cobra" Parent respondent from the 2014 Maryland Parent Survey.

Rate and Type of Insurance Coverage

According to the 2011/12 NSCH, 32.4% of CSHCN in Maryland were publicly insured compared to 28% for Non-CSHCN. 65.1% had private health insurance compared to 67.1% of Non-CSHCN. 96.4% of Maryland families of CYSHCN reported that their child had no gaps in health insurance in the year prior to the survey. While the overall rate of insurance coverage for Maryland CYSHCN is high, CYSHCN from poorer families, especially those living between 100-199% FPL, and those without a medical home are more likely to lack insurance coverage. It is possible that these families miss the eligibility cut-offs for public insurance programs such as Medicaid.

"We have insurance. The problem is that it doesn't cover many of the services we need like speech therapy, MAPS/DAN doctors; physical therapy; occupational therapy, etc." Parent respondent, 2014 Maryland Parent Survey

According to the 2014 Maryland Parent Survey, 8.6% of families with CYSHCN had a problem getting health insurance for their child with special needs. When asked what problems they had in obtaining insurance for their child, respondents reported long waiting periods for public insurance, issues with eligibility, limits on benefits, and aging out of parents' plans. The most frequently cited issues were trying to qualify for Medicaid without first quitting their job or spend down, and dealing with the paperwork.

¹⁴ Maryland Transition and Medical Home Gap Analysis for the 2015 Needs Assessment



“We tried to get MA and were told no because we make too much money. My daughter is on 15 or more medicines a day. She would qualify for REM but our income stops her from getting it. As a teacher and a police officer, we struggle daily to pay our bills due to having 2 disabled children”. Parent Respondent, 2014 Maryland Parent Survey.

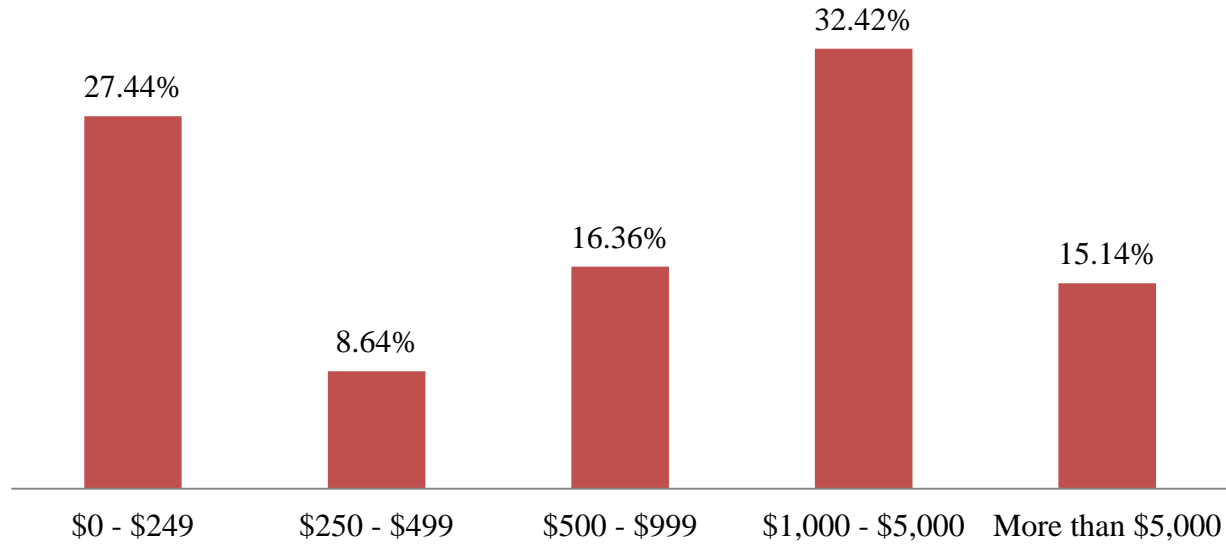
Adequacy of Insurance

Adequacy of health insurance is the greater challenge for CYSHCN in Maryland. According to the 2011/12 NSCH, 30.2% of Maryland CYSHCN didn't have insurance that was adequate to pay for the services they need. The poorest families; those with public insurance only; those with an above routine need/use of services; those with one or more emotional, behavioral, or developmental issues; and those without a medical home are less likely to report having adequate insurance.

Out-of-Pocket Costs

One issue related to insurance adequacy is out-of-pocket costs. On the 2011/12 NSCH, almost 63% of Maryland families of CYSHCN reported that they paid out of pocket medical expenses on top of copays. In the 2014 Maryland Parent Survey, aside from copays, parents also reported paying out of pocket for dental care (35%), medications (37%), vision care (26.6%) and other services like speech therapy and mental health services. On the NSCH, parents of CYSHCN who reported that costs not covered by insurance were never or only sometimes reasonable were almost 30% and almost 20% of CSHCN parents said that they had problems or were unable to pay all medical bills. About 10% also reported experiencing frustration when trying to obtain health insurance for their child. Data from the 2014 Parents survey clearly shows the wide range of out of pocket payments that CSHCN families pay on top of copays.

Figure 21. Out-of-Pocket Medical Expenses for CYSHCN in Maryland



Source: 2014 Maryland Parent's Survey

Data from the 2014 Maryland Parent Survey indicate that, of those responding families with CYSHCN, over 32% spent between \$1000-\$5000 on out-of-pocket expenses for their CYSHCN care, while 15.14% spent over \$5000.

Access to Needed Providers

Another critical issue is access to needed providers. According to the 2011/12 NSCH, only 79.4% of CSHCN were allowed to see needed health care providers compared to 88% of Non-CSHCN.

“Most providers are out of network and there is very little to no coverage. I have to submit claims myself. Sometimes I have to pay for pre-authorization”. Parent respondent from the 2014 Parents Survey



"I Have health insurance but doesn't cover dental well. Can't get her dental work done as she needs to be under anesthesia and we can't afford that bill." Parent Respondents, 2014 Maryland Parent Survey

Other Scope of Benefits

Maryland prides itself for being among the first states to expand Medicaid and implement a state insurance exchange. Many children and adults have acquired insurance since then but the problem of adequacy still remains. Many insurance packages have gaps in coverage for key services, including mental health, ancillary therapies, home health care, and durable medical equipment. The Maryland general assembly also passed the Maryland habilitative Services Mandate in 2014 which allows for services like ABA, but is only limited to private insurance companies licensed within the state of Maryland. That means that the CSHCN who have public insurance or are insured through out of state private companies are still unable to access these services without paying for them out of pocket.

Early and Continuous Screening

Screening for Development and Behavioral Problems

The 2011/12 NSCH estimated that almost 28% of Maryland children aged 4 months to 5 years are at moderate or high risk for developmental delay, significantly lower than the nation as a whole (50.6%) but are higher than Non-CSHCN who are about 21% at moderate or high risk. However, the NSCH survey also reports that only 31.8% of SHCN were screened for being at risk for developmental, behavioral, or social delays using a parent screening tool within the 12 months prior to the survey. 66% of families of children ages 0-5 years report that they were asked by their providers if they had concerns about their child's learning, development, or behavior in the past year.

According to the 2011/12 NSCH, almost 95% CYSHCN in Maryland received some preventive medical care during the previous 12 months, compared to 86.6% for Non-CSHCN. However there are many disparities among subgroups in the state with respect to early and continuous screening as well as receipt of preventative medical care. For screening, CSHCN who are in families living below 200% FPL, are African American, don't have a medical home, are not insured or who have public insurance only, those whose insurance adequate, and those who had some periods of insurance are below the state average.

State programs in Maryland provide other data on developmental screening. As of 2012, 643,569 individuals were eligible for Maryland's Health Kids Program (also known as the Early Periodic Screening, Diagnostic and Treatment benefit, or EPSDT). According to CMS data from 2012, Maryland achieved an EPSDT screening ratio of 94% and a participation ratio of 64%. 332,479 children received dental services of any kind, with 305,394 receiving preventive dental services.



Strengths and Barriers

Maryland has effective statewide models of screening for selected conditions, and there is an increasing awareness of the importance of screening, particularly for developmental and mental health issues. Barriers to progress on this core outcome, include poor communication and information-sharing among providers, agencies, and families; an insufficient and dwindling availability of appropriate resources; a need for comprehensive statewide systems involving multiple stakeholders; the need for improved education and professional development of providers; and the need for improved parent/family education and training.

Community-Based Services Organized for Easy Use

Organization for Easy Use

CYSHCN and their families must often access a number of health-related and family support services to meet their needs. Ideally, all of the services that a child and family require would be easily available and accessible within that child's community. According to the 2009/10 NS-CSHCN, 65%% of families of CYSHCN reported that community based services were easily accessible but disparities existed. For example, Hispanics, those with E/B/D issues, and those in households with less than 200% FPL were least likely to report that community based services were easily accessible. Similarly, difficulties or delays in receiving services due to eligibility, availability of services, appointment issues, cost, and trouble getting needed information or other delay issues were prevalent across Maryland for CSHCN. Table 12 shows the percent of CYSHCN families, by subgroup, who reported difficulties or delays in accessing services. Parent frustration in obtaining services is an indicator of easy to use community based services. On the 2009/10 NS-CSHCN, almost 9% of CSHCN families reported frustration within the 12 months prior to the survey. Hispanics were more likely to report frustration than non-Hispanics. Those with functional limitations, those with E/B/D issues, those with public insurance, those living in households under 200% FPL, and those without a medical home were also more likely to be frustrated. More recent data from the 2011/12 NSCH show that the number of CYSHCN families who were frustrated with trying to access services for their children increased to 9.7% though both surveys aren't comparable.

Table 12. Percent of CYSHCN reporting delays in accessing services

		% CSHCN families reporting difficulties or delays in accessing services (Nationwide)
	Overall	34.2 (34.1)
	Subgroups	
Race/ Ethnicity	Hispanic	51.5
	White, non-Hispanic	31.2
	Black, non-Hispanic	36.0
	Other, non-Hispanic	30
Specific Types of Health Need	Functional Limitations	58.9
	Managed by Rx Meds	19.4
	Above routine need/use of services	44.1
	Rx meds AND service use	33.3
Emotional/ Beh. /Dev Issues.	One or more emotional, behavioral, and developmental issues	47
	No emotional, behavioral, or developmental issues	27.8

Source: 2009/10 NS-CSHCN

Local Access to Services and Transportation

Between 2011 – 2013, the Maryland Center for Developmental Disabilities (MCDD) at the Kennedy Krieger Institute (KKI) conducted focus groups, key informant interviews, and a statewide survey for individuals with developmental disabilities, parents/caregivers, and other providers. A key need that was repeatedly identified that relates to user friendly systems was the need for transportation to medical appointments, work, and recreational activities. Also identified was a need for more professionals trained in developmental disabilities, including physicians, therapists, child care providers and teachers – particularly on the Eastern Shore and Western Maryland¹⁵. According to the 2009/10 NS-CSHCN, 9.8% of Maryland families of CYSHCN who reported having trouble

¹⁵ Kennedy Krieger Institute (Community Health Needs Assessment). June 2013



accessing services said it was because the needed services were not available in their area. This proportion increased to 29.3% for individuals living in households under 100% of FPL.

Strengths and Barriers

Maryland has many resources and services for families in Maryland, and great potential for infrastructure to improve those services. For example, KKI through the LEND and RISE programs provides multiple training programs across the state with roughly around 650 trainees annually. However, barriers to improving *systems* and *ease of use* include: redundancy (ex. multiple entities offer case management) and fragmentation (too many specialty areas); lack of acknowledgement of disparities; lack of knowledge of care providers of resources and services available for families; and turf issues among agencies. There are also regional issues that need to be dealt with at the community level. Different agencies provide families and caregivers with confusing, complicated and inconsistent information.

Youth Transition to Adulthood

“There needs to be some sort of focus on helping transition aged youth with disabilities to understand age appropriate ADLs, and to assist both youth and their families with instruction and guidance in this area. Families need to be encouraged to foster as much independence as possible in their family member with a developmental disability, while at the same time, understanding how to successfully foster said independence”. Focus Group Member

According to the 209/10 NS-CSHCN, 36.8% of Maryland families of youth with special health care needs (YSHCN) aged 12 to 17 reported that their child received the services necessary to make appropriate transitions to adult health care, work, and independence (see Table 13).

Table 13. Transition Indicators for Maryland CYSHCN

Indicator	Maryland %	Nation %
Core Outcome #6: CYSHCN ages 12-17 who receive the services necessary to make appropriate transitions to adult health care, work and independence	36.8	40.0
Hispanic	23.2	25.3
Non-Hispanic White	44.3	45.7
Non-Hispanic Black	26.9	28.1
Non-Hispanic Other	18.7	40.2
Medical Home		
CYSHCN with a Medical Home	52.2	55.0
CYSHCN without a Medical Home	27.5	29.2
Household Income		
0-99% FPL	18.2	25.4
100-199% FPL	22.5	31
200-399% FPL	44.1	43.3
400% FPL or above	42	52.2

Source: 2009/10 NS-CSHCN

Health Care Transition Process

Transition must take place in a number of different arenas. Health care transition is helping young people with special health care needs plan their move from the child-centered health care system to the adult-centered health care system. On the 2009/10 NS-CSHCN, about 45.3% of families of CYSHCN reported that they had providers who have talked with them about changing needs as an adult. On the 2013 Maryland Transitioning Youth Parents Survey, 32.4% of respondents with CYSHCN aged 13 years or older reported that their child’s primary care doctor has talked to them about how their child’s needs might change as he/she becomes an adult¹⁶.

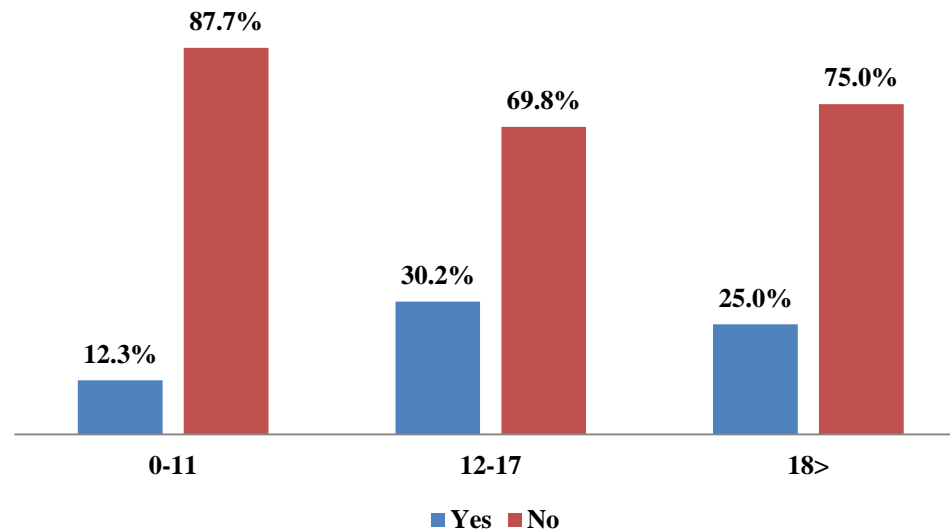
“Currently, I have been using information from the gottransition.org web site and from Florida Hats and other State agencies that are providing transition planning for youth transitioning to adult health care. I am interested in a care plan that I can roll out to pediatric

¹⁶ 2013 Maryland transitioning Youth Parents Survey

offices that would help them plan and manage the transition process and in a care plan for the receiving Adult medical provider receiving these youth so they can monitor the transition process”. Respondent to the Transition Gap Analysis

Developing a transition plan for CYSHCN is an important tool in the process of moving to adulthood. Only 16.5% of respondents on the 2013 Maryland Transitioning Youth Parents Survey reported that they had participated in transition planning for their child. However over 50% also reported that their child was never involved in the transition process. Fig 22 shows parent participation in transition planning based on age groups.

Figure 8: Percent of CSHCN parents who participated in transition planning for their child



Change to Adult Providers

One aspect of health care transition is the change to adult health care providers. On the 2009/10 NS-CSHCN, 21.8% of CYSHCN families in Maryland reported that a discussion with the youth’s doctors about a shift to adult health care providers would have been helpful but had not occurred. Similarly on the 2013 Transitioning Youth Survey, only 12% of respondents reported having received any information on health care transitioning planning with only 15% between the ages of 12-17 reporting receiving any information.



“Not clear what our role is in facilitating health care transition. We see both children and adults. Role needs to be better defined first. Not much collaboration between specialty facility and PCPs to promote successful health care transition” Respondent to the Transition Gap Analysis.

Health Insurance

Maintaining health insurance into adulthood is a concern for YSHCN. According to the 2009/10 NS-CSHCN, only about 20% of families of CYSHCN in Maryland report that their child has had someone discuss how to obtain or keep health insurance as he/she becomes an adult. An overwhelming number of respondents to the Transitioning Youth survey (96%) no one had discussed with them how to obtain or keep insurance coverage as the child becomes an adult. The ACA should ease on some of the burdens of obtaining health insurance especially for those with private insurance.

Strengths and Barriers

Maryland has multiple activities in the state focused on improving this core outcome, but these attempts seem fractured and do not appear to have a common end goal. In 2015, OGPSHCN conducted a gap analysis for transition services in the state and also brought together a group of stakeholders who are tasked with improving health care transition services across the state. One of the themes that came out of the gap analysis was that even though a significant number of facilities were doing transition activities (71%), many of them were centered around education, and even more alarming was that the majority (75%) did not have an onsite transition coordinator, and more significantly, when asked if the person completing the survey was the transition coordinator, none of the respondents said that they were transition coordinators.

“We have 2500 employees across multiple programs that service children with disabilities. We also see adults with some conditions. We have transition coordinators for our high school, but we do not have dedicated health care transition coordinators for our medical programs. Each program may have a coordinator who addresses the health care transition needs of its population, to some extent”. Respondent to the Transition Gap Analysis when asked if the program had a transition coordinator



Appendix A:

2015 CYSHCN Stakeholder Priorities Poll

The purpose of the needs assessment is to identify and establish Maryland's priorities for work to be carried out over the next 5 years under the federal Title V Block Grant. The Office for Genetics and People with Special Health Care Needs (OGPSHCN) performs the needs assessment on behalf of Maryland's Children and Youth with Special Health Care Needs (CYSHCN)

As part of this needs assessment, OGPSHCN would like to reach a broad and diverse group of individuals with interest in the above groups to obtain their views about top priorities for improving systems of care for Maryland's CYSHCN. This poll will help OGPSHCN to describe the broad range of potential needs, leading to a set of priority issues that will be addressed in Title V Block Grant activities during 2015-2020.

Your input is critical to this process.

Taking the poll

The poll is comprised of information about you (demographic information) and items that you will need to rank. To do this, you will need to

- 1) Identify your top 10 priority needs for CYSHCN in Maryland, and
- 2) Rank your top 10 choices from 1-10 (with 1 being most important)

You must rank 10 priorities.

The poll allows you to add "Other Needs" that are not listed.

Added priorities should be realistic and within the scope of the state's capacity and not a combination of those already listed.

It should take you approximately 10 minutes to complete the survey.



Thank you for your help.

1. Please indicate which stakeholder category you represent in terms of your Consortium participation (Check all that apply)

- State Government Agency
- Local Government Agency
- Professional Practice Organization
- Advocacy Organization
- Community-Based Agency Representative
- University/Medical Center
- Insurance Plan
- Interested Parent

Other (please specify)

* 2. What county do you currently work/focus your work for CYSHCN?

- Statewide
- Allegany
- Anne Arundel



- Baltimore City
- Baltimore
- Calvert
- Caroline
- Carroll
- Cecil
- Charles
- Dorchester
- Frederick
- Garrett
- Harford
- Howard
- Kent
- Montgomery
- Prince George's
- Queen Anne's



- Somerset
- St. Mary's
- Talbot
- Washington
- Wicomico
- Worcester

* 3. Identify your top 10 priority needs for Children and Youth with Special Health Care Needs (CYSHCN) in Maryland. Rank your top 10 choices from 1 -10 (with 1 being most important). If you do not see a priority need on the list, record that need in “Other Need.” If you add an “Other Need” it must be included in your top 10 ranking.

Do not combine priorities already listed to create a new priority



Effective Collaboration across different cross sector organizations

Developmental Screening

Community Services that are easily accessible and easy to use

Inclusive Child Care Training

Youth Transition to Adulthood

Coordinating with schools on aspects of care for CYSHCN

Access to needed care including dental and specialty care

Provider education and/or capacity to meet the needs of CYSHCN

Health Disparities in health of CYSHCN (Racial and ethnic; socioeconomic; regional)

Access to convenient and accessible transportation

Financial Assistance for medical services (Including equipment)

Training for school personnel to better meet the needs of CYSHCN

Access to needed therapies (Speech, behavioral, occupational, physical)

Adequate insurance and health care financing

Resource Coordination Services

Improve data gathering and sharing between different organizations



Access to needed primary care

Family support services, training, and education

Other (please specify)

Appendix B

Table 14: Strategies and objectives developed for addressing CYSHCN issues in Maryland

NPMs	NOMs	Strategy Goals and Objectives	Evidence based informed strategies	Evidence based Informed Strategy Measures
Medical Home The % of children with and without special health care needs who have a medical home	% CSHCN receiving care in a well-functioning system	Increase by 10% the number of CSHCN and their families who have access to appropriate patient and family centered care coordination by FY 2020	Develop and implement an evidence based framework for standardized measures of care coordination across the state to make it easier to assess the capacity and knowledge base of care coordinators and other HCP among private and public providers	The % of CSHCN families who report to be very satisfied with care coordination on the Maryland parent survey
	% Children in excellent or very good health	Reduce the prevalence of CSHCN disparities in access to quality care coordination services across the state	Assess capacity and knowledge base of private and public providers regarding care coordination activities	% of CSHCN who report travelling more than 50 miles round trip to receive specialty services on the Maryland Parents survey
			In collaboration with stakeholders and partner agencies, develop and implement an evidence based care coordination training curriculum	Number of CSHCN receiving services through an evidence based telehealth program
			Support ongoing care coordination activities across the state by providing capacity building and competency skills, infrastructure, and technical leadership to private and public health workforce to effectively and efficiently address care coordination	Number of specialty clinics and LHDs participating in an evidence based telehealth program
			Provide care coordination training for private and public HCPs including MCOs specialty coordinators using an evidence based training curriculum	



NPMs	NOMs	Strategy Goals and Objectives	Evidence based informed strategies	Evidence based Informed Strategy Measures
			Evaluate the effectiveness, accessibility and quality of care coordination training programs	
			Provide a safety net for CSHCN who lack care coordination services through an evidence based regional hub model	
			Collaborate with school health, ACCUs and other agencies to link CSHCN to community and family health services and assure access to comprehensive and quality care	
			Develop and implement an evidence based telehealth program in collaboration with specialty consultant clinics and LHDs to improve geographical access to quality care	



NPMs	NOMs	Strategy Goals and Objectives	Evidence based informed strategies	Evidence based Informed Strategy Measures
Transition % of adolescents with and without special health care needs who receive services necessary to make transition to adult health care	% of children with and without special health care needs receiving care in a well-functioning system	Increase by 10% the number of CSHCN families who are participating in transition planning for their YSHCN	Engage youth and their families by leveraging the power of social media tools like Facebook, Twitter, and YouTube to disseminate resources and information	The % of CSHCN families who report participating in transition planning activities for their YSHCN on the Transitioning Youth Parent Survey
	% of children in excellent or very good health	Increase the number of CSHCN ages 12-17 who receive preparation, planning, and coordination to achieve successful transition to adult health care	Provide expertise, resources and technical assistance to the Maryland Statewide Health Care Transition Initiative to support the development of culturally competent, age appropriate health education materials for use by health plans, providers, and families of YSHCN	% of providers who received CEU credits from transition training
			Collaborate with school transition councils and other state and local agencies to develop and implement standard transition assessment tools to identify and address emerging issues for YSHCN and their families	The number of pediatric and adult practices participating in transition pilot projects
			Support the development and implementation of demonstration studies to help improve the understanding of longstanding and emerging issues affecting YSHCN and their families pertaining to transitioning into adult health care settings	The number of hits on the OGPSHCN Facebook, twitter and YouTube channels
			Increase the use of the My Health Care Notebook among YSHCN and their families by providing outreach activities in collaboration with school health and F2F agencies	



NPMs	NOMs	Strategy Goals and Objectives	Evidence based informed strategies	Evidence based Informed Strategy Measures
			In collaboration with the Maryland Chapter of AAP and MedChi, develop and implement a transition training curriculum for pediatric and adult health care providers who provide transition services to YSHCN	
			Support the Maryland Health Care Transition Leadership Team, comprised of key cross-agency decision makers, youth and families to address challenges, to provide solutions, and to shape policy and practice to improve the quality and delivery of services using Got Transition, Six Core Elements of Health Care Transition 2.0.	
			Support the adoption of transition pilot projects between pediatric and adult sites of primary and/or specialty care using quality improvement methods.	
			Create mechanisms to share information about health care transition and measurement results from transition QI projects to other pediatric and adult clinicians, consumers, and payers.	



For inquiries, please contact

Office for Genetics and People with Special Health Care Needs
Maternal and Child Health Bureau
Prevention and Health Promotion Administration
Maryland Department of Health and Mental Hygiene
201 West Preston Street
Baltimore, MD
21201
(410)-767-6730