

JUNE 2013

Community Health Needs Assessment

CHANGING MARYLAND COMMUNITIES FOR THE BETTER



Kennedy Krieger Institute
kennedykrieger.org

Kennedy Krieger Institute Community Health Needs Assessment

Table of Contents

Letter from President and Board of Directors, Chair	ii
Executive Summary	iii
I. Introduction	1
a. Overview of Kennedy Krieger Institute	1
b. Our History	1
c. The Community We Serve	2
d. Target Population	3
II. Approach/Methodology	4
a. Community Health Needs Assessment (CHNA)	4
i. MCDD Needs Assessment	4
ii. Title V	4
iii. Parents' Place of Maryland / Office for Genetics and People with Special Health Care Needs Surveys	5
b. Healthy People 2020	5
c. Community Needs Index (CNI)	5
d. Other Available Data	6
e. Data Gaps	6
f. Prioritization of Needs	6
III. Findings	7
a. Summary Characteristics	7
b. Priority Needs	9
i. Training	9
ii. Access to Healthcare	11
iii. Transportation	14
iv. Partnership and collaboration between agencies and organizations	16
v. Youth Healthcare Transition to Adulthood	16
IV. Summary and Implementation Plan FY 2014	19
a. Training	21
b. Access to Care	22
c. Transportation	22
d. Advocacy	22
e. Transition	23
References	27
Appendix A. Community Forum Attendees	28
Appendix B. MCDD Statewide Summary of 18 Community Forums (MCDD, 2011)	29
Appendix C. Stakeholder Online Survey Results	30
Appendix D. Data Sources and Resources	31
Appendix E. List of Major Community Programs, Partner Agencies, and Advocacy Groups	32
Appendix F. List of Acronyms	32



Kennedy Krieger Institute

*A comprehensive
resource for children
with disabilities*

June 26, 2013

Dear Maryland Community,

For the past 75 years, Kennedy Krieger Institute has been a leader in providing patient care for children and young adults with developmental disabilities and injuries. As the president of Kennedy Krieger and the chair of the Institute's Board of Directors, we take seriously our commitment to the model of care set forth in 1937 by our founder, Dr. Winthrop Phelps, that combines treatment, education, research, training, and community support all under one roof to help unlock the potential of individuals we serve. Kennedy Krieger has long been dedicated to collaborating, partnering, and building capacity with the community to enhance the health and wellness of Maryland's children and young adults with disabilities and their families.

In compliance with the new regulations in the Affordable Care Act, we are proud to present our Community Health Needs Assessment (CHNA) and implementation plan, which presents the needs of our target population. By statute, the CHNAs must take into account input from "persons who represent the broad interests of the community served by the hospital facility, including those with special knowledge of or expertise in public health." Our Maryland Center for Developmental Disabilities, the primary community agent for Kennedy Krieger, completed a comprehensive needs assessment across Maryland regions; our long-standing partner, Maryland's Title V agency, contributed to this comprehensive assessment of health needs across the state through data collected during their recent regional forums.

The goals of these assessments are to 1) provide an understanding of the health needs in our community; 2) guide our collaborative planning efforts for the next three years; and 3) to serve as the basis of an implementation strategy that addresses prioritized needs.

If you have comments or questions regarding the Community Health Needs Assessment, please email communitybenefit@kennedykrieger.org.

Sincerely,

Gary W. Goldstein, MD
President

Atwood Collins, III
Chair, Board of Directors

Executive Summary

Located in Baltimore, Maryland, Kennedy Krieger Institute is an internationally recognized institution dedicated, since its foundation in 1937, to improving the lives of children and young adults with developmental disorders and injuries through patient care, special education, research, and professional training. The focal community arm of Kennedy Krieger is the Maryland Center for Developmental Disabilities (MCDD), which is dedicated to promoting independence, productivity, and inclusion for people with intellectual and developmental disabilities within their communities.

In order to serve the community most effectively, a community health needs assessment was conducted by the MCDD as part of its ongoing needs assessment and planning process. Since 84 percent of the hospital's patients are Maryland residents, representing every county in the state, this assessment targeted children and young adults with developmental disabilities and other disorders in Maryland. The MCDD assessment included a series of 18 public forums held across the state, and an online survey that was open from June 2011 to April 2012 to gather input from community members and stakeholders. Other demographic, quantitative, and qualitative data at regional, state, and national levels were collected from other needs assessment reports from state agencies and available private, federal, and state databases. The data was reviewed and analyzed to identify, prioritize, and develop a plan to address the community's most pressing needs. The top five priority areas selected through this process are:

- **Training** needs of educational and health professionals working with children and youth with developmental disabilities and their families
- Improving **access to care** for families who encounter barriers related to payment, insurance, and other issues
- Addressing **transportation** needs of families to access medical care and employment opportunities
- **Advocacy** for families and self-advocates through stronger inter-agency, cross-regional partnership and collaboration
- **Youth healthcare transition to adulthood**

I. Introduction

a. Overview of Kennedy Krieger Institute

The Kennedy Krieger Institute (Kennedy Krieger) is a non-profit, Maryland-licensed pediatric rehabilitation and specialty hospital, school, and research center located in Baltimore, MD. The Kennedy Krieger Institute dedicates itself to helping children and adolescents with disorders of the brain, spinal cord, and musculoskeletal system achieve their potential and participate as fully as possible in family, school, and community life, while striving to excel in providing safe and effective care of the highest quality.

Kennedy Krieger serves a diverse patient population. The staff, faculty, and researchers are leaders in the worldwide effort to prevent and treat developmental disorders and injuries. Kennedy Krieger is committed to sharing our knowledge, which can be adapted and used by other healthcare and public health organizations to benefit people throughout Maryland, across the country, and around the world. Kennedy Krieger's professional training programs reach across the United States and internationally, to recruit trainees that will train at Kennedy Krieger and then return to their home state or country to implement the knowledge learned.

Over half of the core Kennedy Krieger staff, faculty, and researchers have public health experience and/or education, and Kennedy Krieger's current leadership team has been together for over 20 years, offering significant growth and stability for the organization and the community. Kennedy Krieger provides a diverse range of inpatient, outpatient, and community services that contribute to the health and development of people with developmental disorders and injuries in facilities totaling over eight hundred thousand square feet. Kennedy Krieger's annual budget is \$204 million. A financial audit was performed for fiscal year 2012 and the report issued on October 3, 2012 by PricewaterhouseCoopers, LLP.

The Maryland Center for Developmental Disabilities (MCDD), the University Center of Excellence in Developmental Disabilities for the State of Maryland, resides at Kennedy Krieger Institute. The MCDD is part of a national network and serves as the statewide community agent to provide pre-service and continuing education/training, community service/technical assistance, research and evaluation, and information dissemination to the community. The MCDD determines its focus by assessing strengths and gaps, and developing priorities for Maryland stakeholders focusing on the population served.

b. Our History

Winthrop Phelps, MD, studied orthopedics at Harvard Medical School and then became the chair of the orthopedic faculty at Yale. He recognized that simply helping children with developmental disabilities adapt to their environment was not enough. From the start, Dr. Phelps and his colleagues sought to transform that environment by developing new treatments and therapies, and new approaches to integrating children with special needs into the community.

In the summer of 1937, Dr. Phelps rented a large home on Reisterstown Road in rural Baltimore County, Maryland, to house Kennedy Krieger, paying the first three months' rent out of his own pocket. Kennedy Krieger officially opened on October 1, 1937, with a small staff of teachers, physical and occupational therapists, a dietician, and a billy goat that served as its mascot. A medical board composed of specialists in orthopedics, pediatrics, neurology, ophthalmology, otolaryngology, dentistry, physical medicine, and psychiatry worked closely with the staff to provide care for the children. Once a week, the entire staff met to discuss the progress of each child and tailor approaches to meet their needs.

Kennedy Krieger was also a place where physicians, therapists, and researchers interested in helping special needs populations could come to train and conduct research. By 1938, Kennedy Krieger had started training professionals in the field of cerebral palsy and occupational therapy. During this time, Dr. Phelps conducted research and published studies, traveling around the country to lecture in clinics and medical societies, sharing his methods and results. This innovative model of care spread rapidly throughout the United States, giving rise to hundreds of similar institutions by the mid-1950s, many of which were staffed by physicians and therapists who had trained with Dr. Phelps and his team.

In the 1960s, Kennedy Krieger established an affiliation with the Johns Hopkins University School of Medicine and began searching for a location near the school's East Baltimore campus. From the beginning, Kennedy Krieger's founders understood that by bringing together the disciplines of medicine, therapy, and education, they could profoundly change the lives of children with complex developmental disabilities and injuries. At a time when there were few proven treatment options, the concept of providing individualized care and education—all in the same setting—was groundbreaking. It was during this time that landmark legislation championed by the Kennedy family produced the first federally funded grant to expand professional training, as well as the care, services, and support Kennedy Krieger could provide for individuals with developmental disabilities.

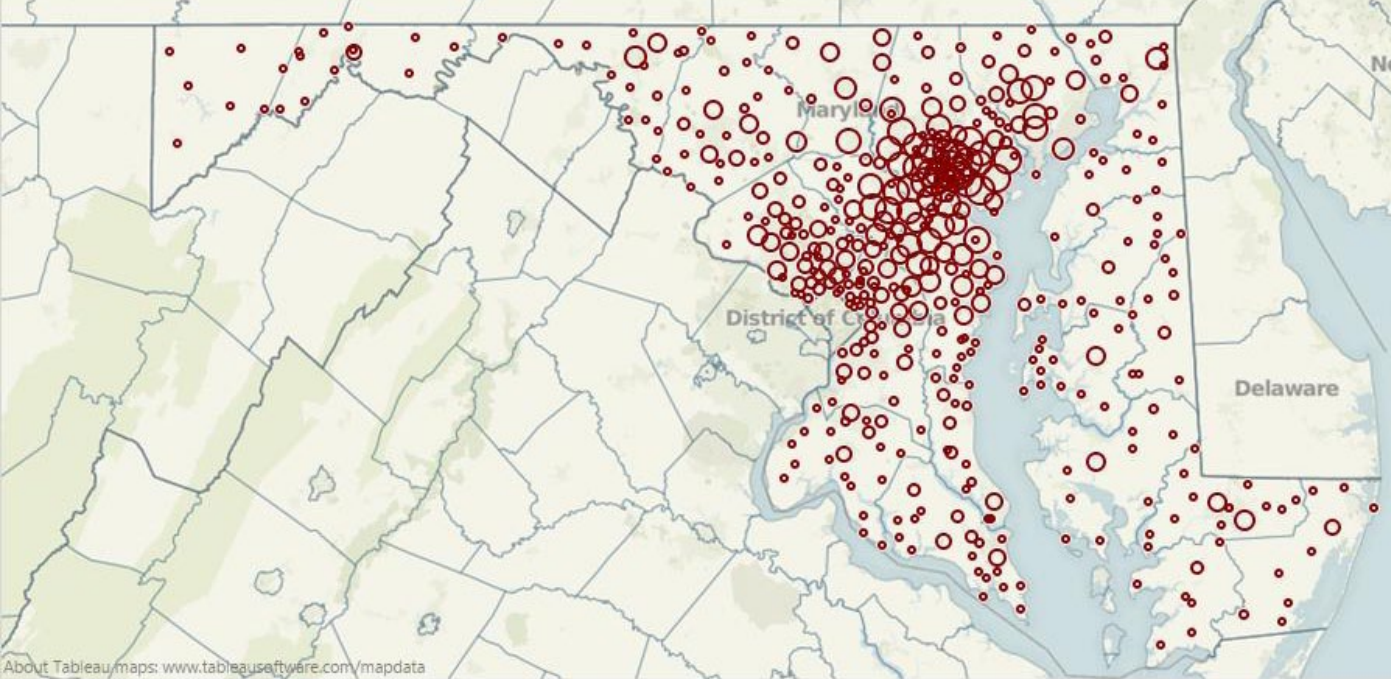
In the 1990s, the mission of Kennedy Krieger broadened to encompass helping children and adolescents with not only developmental disabilities but also other types of injuries achieve their potential. The opening of the International Center for Spinal Cord Injury in 2004, the launch of the Interactive Autism Network in 2005, and the naming of the Hugo W. Moser Research Institute at Kennedy Krieger in 2007 brought additional recognition to Kennedy Krieger during this time. New programs continue to open to meet the needs of the population served.

Today our fundamental commitment remains clear: helping children and adolescents with developmental disorders and injuries achieve their potential and participate as fully as possible in family, school, and community life, while striving to excel in providing safe and effective care of the highest quality. This focus continues to guide Kennedy Krieger’s administration and staff as they meet the opportunities and needs of the Maryland community.

c. The Community We Serve

Kennedy Krieger Institute serves children, adolescents, and adults from Maryland, across the United States, and internationally. Data analyzed during the last three fiscal years—2011, 2012, and 2013—indicates that 84% of all inpatients and outpatients served by the Institute are Maryland residents. Thus, the Institute views the State of Maryland as the community that it serves. What is remarkable is that patients come from every Maryland county, as represented in Figure 1, the Institute’s patient population mapped by Zip code from fiscal year 2011 through 2013.

Figure 1. Patient Population Distribution by Zip Code 2011-2013



Map based on Zip Code. Size shows details about total count of Number of Records.

d. Target Population

The organization serves persons with a variety of developmental disorders and injuries. The top diagnoses seen at Kennedy Krieger over the last three fiscal years include attention deficit disorders, conduct disturbances, disorders of the brain and central nervous system, language disorders, and autism spectrum disorders. Because of the complexity in diagnosis, the data reflects only one primary diagnosis per patient served in each fiscal year. Patient characteristics typically include multiple primary diagnoses.

During the last three fiscal years (2011-2013), the Institute averaged 262 inpatient admissions annually. The Institute serves a diverse population. The trend from 2011 through 2013 has remained relatively stable. According to the 2010 U.S. Census, the demographics of the population served by the Institute is representative of Maryland (Table 1).

Our average age range has remained relatively stable over the last three years. The insurance coverage by unique patient type is almost a 50/50 split between public and private coverage.

Table 1. Demographics (includes Kennedy Krieger inpatients and outpatients)

	Kennedy Krieger unique patients Fiscal Year 2011	Kennedy Krieger unique patients Fiscal Year 2012	Kennedy Krieger unique patients Fiscal Year 2013	Maryland (US Census, 2010)
TOTAL	17,631	19,139	20,010	5,773,552
AGE				
0-2	10%	9%	8%	
3-5	17%	17%	17%	
6-8	20%	19%	19%	
9-11	18%	18%	18%	
12-14	14%	14%	14%	
15-17	9%	10%	10%	
18-20	4%	4%	4%	
21+	9%	10%	10%	
RACE				
White	46%	47%	48%	54.7%
Black	35%	34%	33%	29%
Hispanic	3%	3%	4%	8.2%
AI/Pacific Islander	.3%	.4%	.3%	5.5%
Asian	2%	3%	3%	0.24%
Multi-Racial/Other	4%	5%	5%	2.4%
GENDER				
Male	64%	64%	64%	
Female	35%	35%	35%	

II. Approach/Methodology

a. Community Health Needs Assessment (CHNA)

Community health needs assessments are increasingly conducted through public-private community partners, such as divisions of state health departments, private non-profit organizations receiving federal funding, and other private entities. This community health needs assessment for the Kennedy Krieger Institute was conducted by the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute as part of its ongoing needs assessment and planning process. This included a series of 18 public forums and an online survey that was open from June 2011 through April 2012. The forums took place all over the state of Maryland, including substantially rural areas.

Additionally, the MCDD participated in regional statewide needs assessment forums conducted by the Department of Health and Mental Hygiene, Office for Genetics and People with Special Health Care Needs (Maryland's Title V Office) in 2012. Other needs assessment reports from state agencies and private organizations, federal databases, and trended data from Kennedy Krieger were collected, analyzed, and integrated to present a collective picture of the needs of the population served by Kennedy Krieger across the State of Maryland. A plan has been developed and implemented, focused on major social determinants of health for this Maryland-targeted population.

i. MCDD Needs Assessment

In 2011, the Maryland Center for Developmental Disabilities conducted a statewide needs assessment in the area of developmental disabilities, which included community forums, an online survey, review of various publicly available data sets, and follow-up meetings.

During summer and fall of 2011, there were 18 community forums held in two communities from each of the primary Maryland regions (Western, Central, Eastern Shore, and Southern) and Baltimore City. The meetings were attended by 238 participants, listed in Appendix A, comprised of a broad range of persons, including consumers, family members, self-advocates, service providers, and agency partners, representing the broad interests of each community. During each forum, three questions were openly discussed:

- What is working well,
- What is not working well, and
- What solutions are recommended for the future

The discussion notes were recorded and analyzed to identify common themes within and across regions. The statewide summary of the findings from the forums is located in Appendix B.

MCDD adopted a survey used by the Maryland Developmental Disabilities Council (DD Council) to ask the respondents to rank a number of key issues based on their priority, and rate the status of these issues in the state. The list of key issues was created based on the preliminary findings of the community forums. The survey was administered online via Survey Monkey using a number of mailing lists through the MCDD and its agency and organizational partners. The survey was not only administered online; hard copies were distributed and collected across Kennedy Krieger campuses to ensure that those without access to the internet could participate. In addition, families/caregivers could complete a survey while at an appointment and request assistance if needed through the Resource Finder. Three hundred and fourteen people completed the survey from June 1, 2011, to April 30, 2012, and the results are summarized in Appendix C.

Upon completion of the community forums and the online survey, and review of multiple quantitative data sets, the synthesized summaries were presented in three follow-up meetings, where input was elicited from the community members on the meaning of the findings.

ii. Title V

The Title V Maternal and Child Health Block Grant provides federal funds to states to improve the health of mothers, children, and families. In Maryland, the Title V Children and Youth with Special Health Care Needs (CYSHCN) Program is administered by the Office for Genetics and People with Special Health Care Needs (OGPSHCN). From September 2011 to September 2012, OGPSHCN conducted a comprehensive needs assessment on children and youth with autism spectrum disorders and other developmental disabilities in Maryland. Three hundred and thirty-six respondents completed an online priorities poll and ranked the top five from 22 pre-selected priorities. In addition to gathering existing data, the assessment also entailed five in-person regional meetings where stakeholders identified, evaluated, and ranked priority needs identified for the state and each

region. The needs assessment incorporated qualitative data from a Spanish language focus group with non-English proficient families of children and youth with autism spectrum disorders (ASD)/developmental disabilities (DD). Each regional group developed action plans to address each of the priority areas identified. During the strategic planning meetings, findings of the needs assessment and the final top five priorities for each region were presented. These meetings were attended by a wide variety of stakeholders (parents, caregivers, local pediatricians, local and state health department representatives, local and state special education representatives, community and family service group representatives, support and advocacy groups, and other agency representatives). The following year, 2012-2013, validation meetings were held in each region to validate the findings and action plans from the original forums.

iii. Parents' Place of Maryland / Office for Genetics and People with Special Health Care Needs Surveys

The Parents' Place of Maryland (PPMD) is a non-profit, family-directed and -staffed center, serving parents of children with disabilities and special healthcare needs. In close partnership with OGPSHCN, PPMD serves an integral role in design and implementation of services for children and youth with special health care needs (CYSHCN) and their families. In 2010, as part of the Maryland 2010 Title V Needs Assessment, a statewide survey of parents of children and youth was conducted. The survey was conducted by email, in person, and by phone with 939 families. Of those 939 families, 781 had at least one child with a special healthcare need. This survey is not statistically representative of all CYSHCN in Maryland, due to the convenience sampling techniques; however, it is the only outcome source of data for the CYSHCN population in Maryland. The survey results provide data on impact and unmet needs of families with CYSHCN at the state and regional level of Maryland.

b. Healthy People 2020

Healthy People 2020 provides 10-year national goals for improving the health of the country, and sets specific targets and monitors progress (U.S. Department of Health and Human Services, 2013). The objectives focus on reducing and/or eliminating illness, disability, and premature death among individuals and communities. The identified priorities, especially in maternal, infant, and child health and disabilities categories, guided the focus of our community health needs assessment, as well as prioritization of the identified needs.

Several Healthy People 2020 objectives most relevant to our target population include:

- Reduce the proportion of people with disabilities who report delays in receiving primary and periodic preventive care due to specific barriers (DH-4).
- Increase the proportion of youth with special healthcare needs whose healthcare provider has discussed transition planning from pediatric to adult healthcare (DH-5).
- Reduce the proportion of people with disabilities who encounter barriers to participating in home, school, work, or community activities (DH-8).
- Increase the proportion of young children with an autism spectrum disorder (ASD) and other developmental delays who are screened, evaluated, and enrolled in early intervention services in a timely manner (MICH-29).
- Increase the proportion of children, including those with special healthcare needs, who have access to a medical home (MICH-30).
- Increase the proportion of children with special healthcare needs who receive their care in family-centered, comprehensive, and coordinated systems (MICH-31).

c. Community Needs Index (CNI)

The Community Needs Index was developed by Catholic Health Care West, now Dignity Health, in 2005 to identify the severity of health disparities and the relation between need and usage (Dignity Health, 2013). The CNI score for each Zip code aggregates five socioeconomic indicators that are known to contribute to health disparity, including income, culture/language, education, housing status, and insurance coverage. This index serves as a tool to assess healthcare disparities within and across geographic regions. Although the available data is not specific to our target population, the CNI scores were utilized in our community needs assessment by mapping the scores to identify the areas of high disparities and to guide effective resource allocation.

d. Other Available Data

In addition, various existing data were leveraged to obtain a holistic view of the needs of the population. Data available at different levels—local, state, and national—were collected, analyzed, and synthesized from previously conducted needs assessments and other available resources. Our internal patient data was also reviewed for demographics and service utilization of our patient population. Appendix D lists major sources of data reviewed and used for our CHNA. Discussions to establish a collaborative data-sharing consortium are underway with several state entities.

e. Data Gaps

Although every attempt was made to collect the most relevant, up-to-date data for a comprehensive needs assessment of the community, data gaps and limitations exist. Data from children and youth with special healthcare needs, particularly those with developmental disabilities, are extremely limited and not as plentiful as would be found for an adult with diabetes.

- CHNA data was collected from varying data sets. There were inconsistencies in definitions of conditions, age groupings, and geographic boundaries among different indicators.
- Specific data on children and youth with developmental disabilities and disorders of the brain and spinal cord was sometimes unavailable. Some data was specific to those with developmental disabilities only and some data covered all CYSHCN, which includes our target population and other types of special healthcare needs.
- Some indicators were only available at national and/or state levels, and regional sub-analysis could not be done.
- Certain data, like health insurance coverage, prevalence of certain chronic diseases, and health risk behaviors, were not available specifically for children with developmental disabilities and disorders of the brain and spinal cord.
- There are gaps in accurate information on the number and location of available resources for our target population (i.e., health services—including pediatric primary care providers—who treat children with DD and related disorders, pediatric and adult specialty care providers, family support services such as respite care providers, parent support groups, transportation services, community support services including recreation and day habilitation, and vocation services).
- Although our community forums and survey participants were diverse in makeup, there are still gaps in community input from certain socioeconomic and/or racial groups, especially non-English speakers. While an effort was made to reach out to various groups in the community, such limitation in reaching underserved populations may reinforce health inequities

f. Prioritization of Needs

Prioritization of a number of identified needs included several considerations. The results of the MCDD online survey and the OGPSHCN online survey and meetings were combined to form a preliminary list of priority needs derived from the needs assessment and reflect what the community stakeholders perceived as priority needs. Each priority was then considered by the following criteria:

- National / State Priorities: Does the identified need align with the national and state priorities, such as Healthy People 2020 objectives and Maternal and Child Health Bureau performance measures?
- Responsibility / Capacity: Is addressing the identified need within the responsibility of the Institute or within our capacity?
- Availability of Resources / Feasibility: Does the Institute and/or our partner agencies have adequate resources available to address the identified need?
- Magnitude / Severity: What proportion of the target population is affected by the priority need? How do the data and indicators of the identified need compare to those of the nation and other states?

Based on the process described above, five priority needs were selected and will be further described in the following section.

III. Findings

a. Summary Characteristics

Across the United States, the number of children with developmental disabilities and other special health needs has been increasing. In the 2010 National Survey on Children with Special Health Care Needs (NS-CSHCN), prevalence of children with special healthcare needs age 0-17 has been estimated as 15.7% in Maryland, or 211,442 children, and 15.1% nationwide. Of this group, 53.4% are whites, 28.2% blacks, 7.9% Hispanics, and 10.4% others, thus 46.5% non-whites.

This group of children with special healthcare needs encompasses other conditions beyond what our target population includes, making a more accurate estimate of prevalence more difficult. The most recent National Survey on Children’s Health (NSCH), conducted from 2011 to 2012, has estimated the prevalence rates of 18 chronic health conditions. Table 2 summarizes the prevalence rates for selected conditions relevant to our target population.

Table 2. Prevalence of Developmental Disabilities and Other Disorders of the Brain, Spinal Cord, and Musculoskeletal System (Source: 2012 NSCH) (N/A: Estimated state level prevalence rates are not available for certain conditions, due to too small sample size to meet the standard of reliability or precision.)

Chronic Health Condition	Prevalence (Maryland)	Prevalence (National)
ADD or ADHD (Age 2-17)	7.8%	7.9%
Autism, Asperger’s disorder, PDD, or other autism spectrum disorder (Age 2-17)	N/A	1.8%
Behavior or conduct problems (Age 2-17)	2.7%	3.2%
Brain injury or concussion	N/A	0.3%
Cerebral palsy	N/A	0.2%
Developmental delay (Age 2-17)	3.3%	3.6%
Intellectual disability or mental retardation (Age 2-17)	N/A	1.1%
Learning disability (Age 3-17)	7.5%	8%
Epilepsy or seizure disorder	N/A	0.7%
Speech or other language problems	4.7%	4.8%
Hearing problems	0.3%	1.2%
Vision problems	1.5%	1.3%
Bone, joint, or muscle problems	1.6%	2.2%
Tourette syndrome (Age 2-17)	N/A	0.2%

Figure 2 shows Maryland child poverty rates in 2011 by jurisdiction, which ranges from 7.3% to 35.6%. There are geographic disparities, with certain counties with vastly higher poverty rates, such as Baltimore City, Somerset, Wicomico, and Garrett (The Annie E. Casey Foundation, 2013). While specific rates are not available, child poverty may disproportionately affect children with special healthcare needs. In Figure 3, distribution of household income among families with children of age 0-17 is shown by child’s health status. Among families with children with SHCN, 14.2% live under the poverty level and 16.8% under 200% of the federal poverty level, and these proportions are higher than non-SHCN families. Such higher burden of poverty could be due to the socioeconomic impact that families of SHCN children often face, as illustrated in Figure 4, according to the 2010 Maryland Parent Survey. While regional differences exist, about 42.5% have to pay \$1,000 or more out of pocket in medical expenses per year per child, and 37.7% of families cut back or stop working due to children’s conditions.

Figure 2. Child Poverty Rate by County, 2011 (Source: Advocates for Children and Youth)

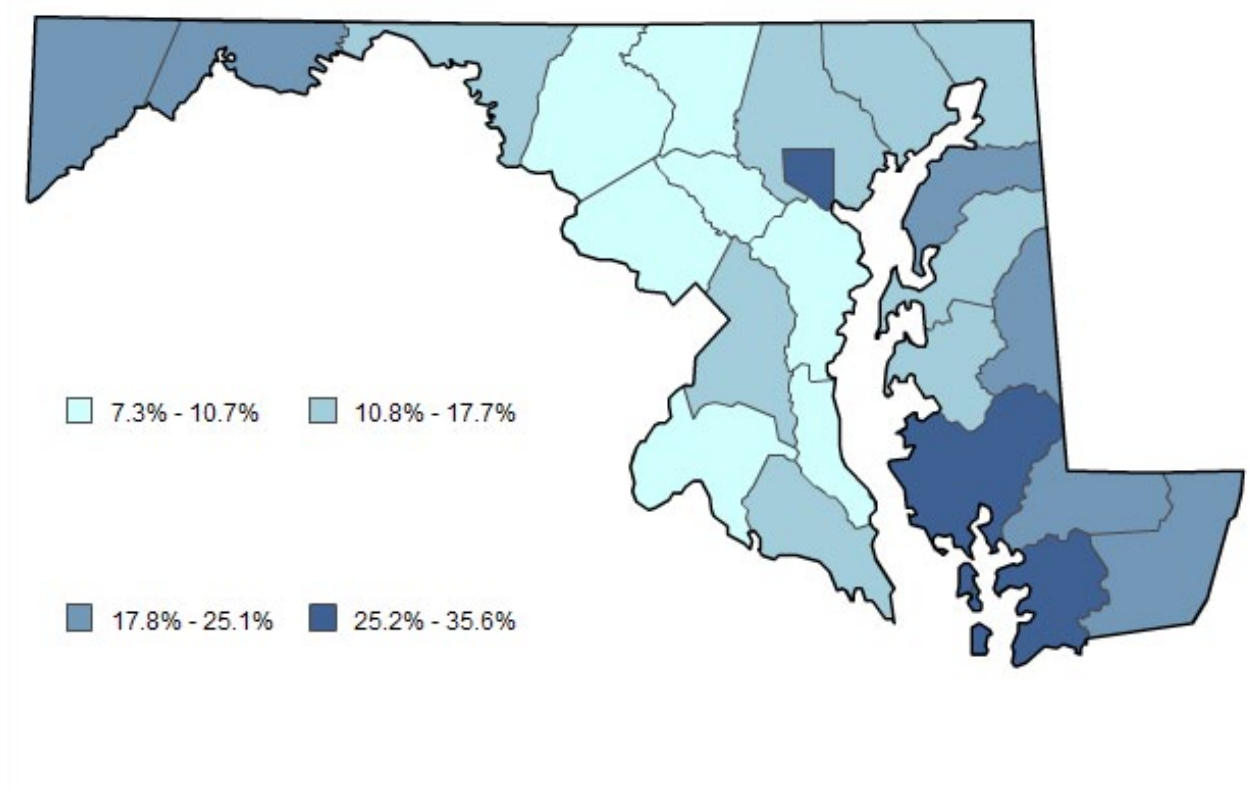


Figure 3. Distribution of Household Income among All Maryland Children, 0-17 years: Non-CSHCN vs. CSHCN (Source: 2010 NS-CSHCN)

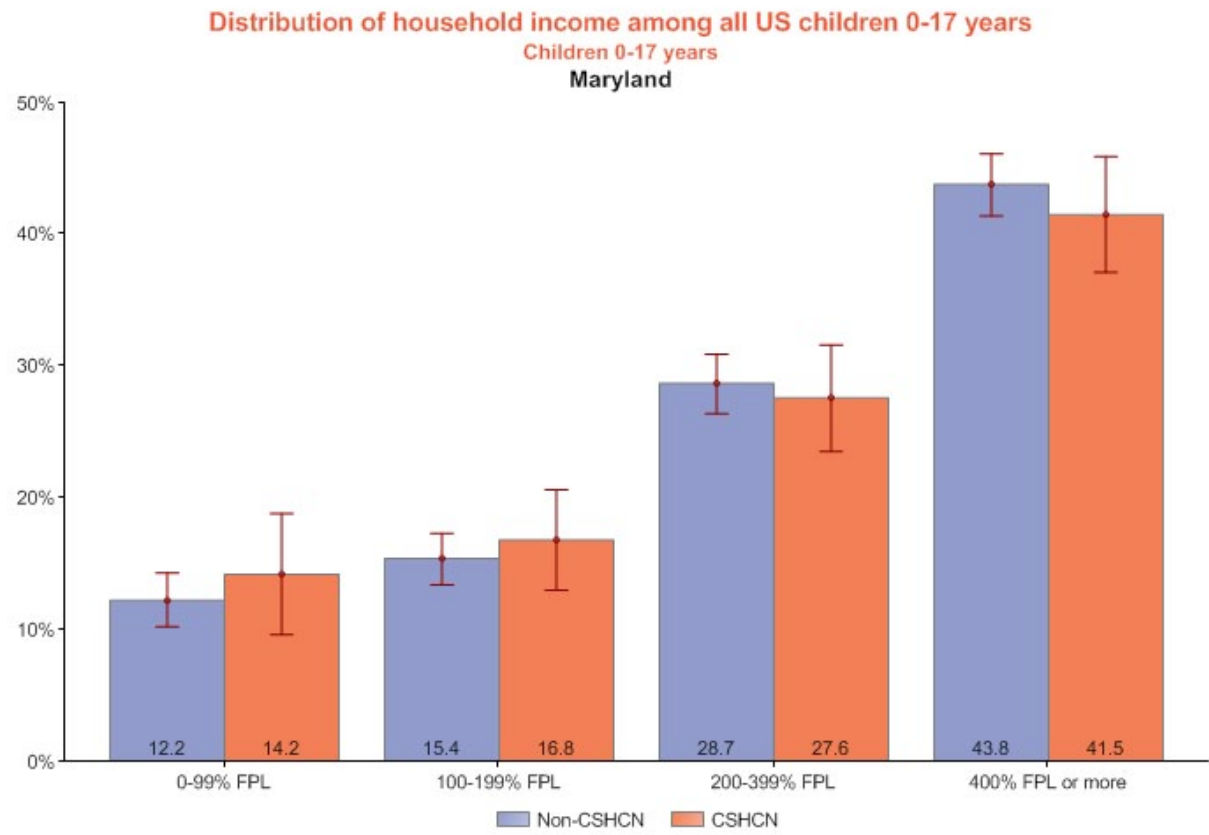
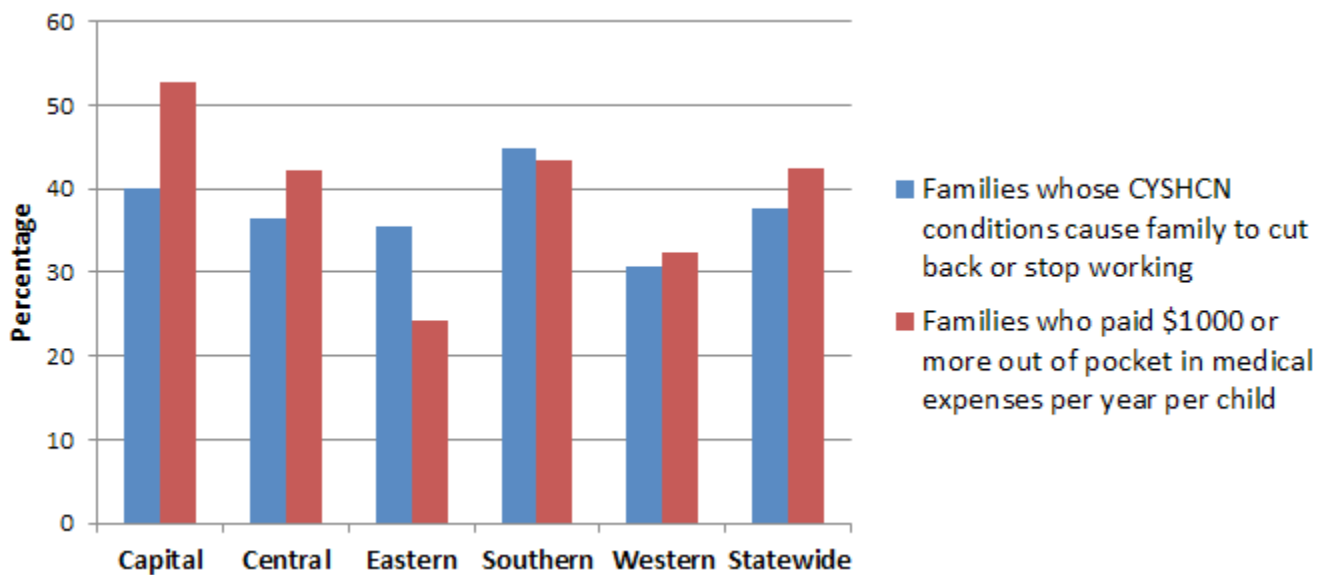


Figure 4. Socioeconomic Impact on Families with CYSHCN (Source: 2010 Parent Survey)



b. Priority Needs

i. Training

i.a. Enhancing Capacity of Existing Providers—Health and Educational Professionals

During the series of community forums, the most frequently identified need throughout the state was knowledge/education/information/training among providers and families. Similarly, stakeholders repeatedly mentioned the need for consistent and reliable information and its effective dissemination among families and service providers. Parents recounted frequent interactions with pediatricians and other health service providers unfamiliar with developmental disorders and/or other special healthcare needs, which often led to delays in diagnoses and referrals to the needed services. Inadequate training among educational professionals in how to meet the needs of children was also raised as a major concern. In fact, more than one third of respondents named training of school personnel as a top priority in the 2011 OGPSHCN Priorities Poll.

i.b. Training New Future Providers—Pre-Service Training

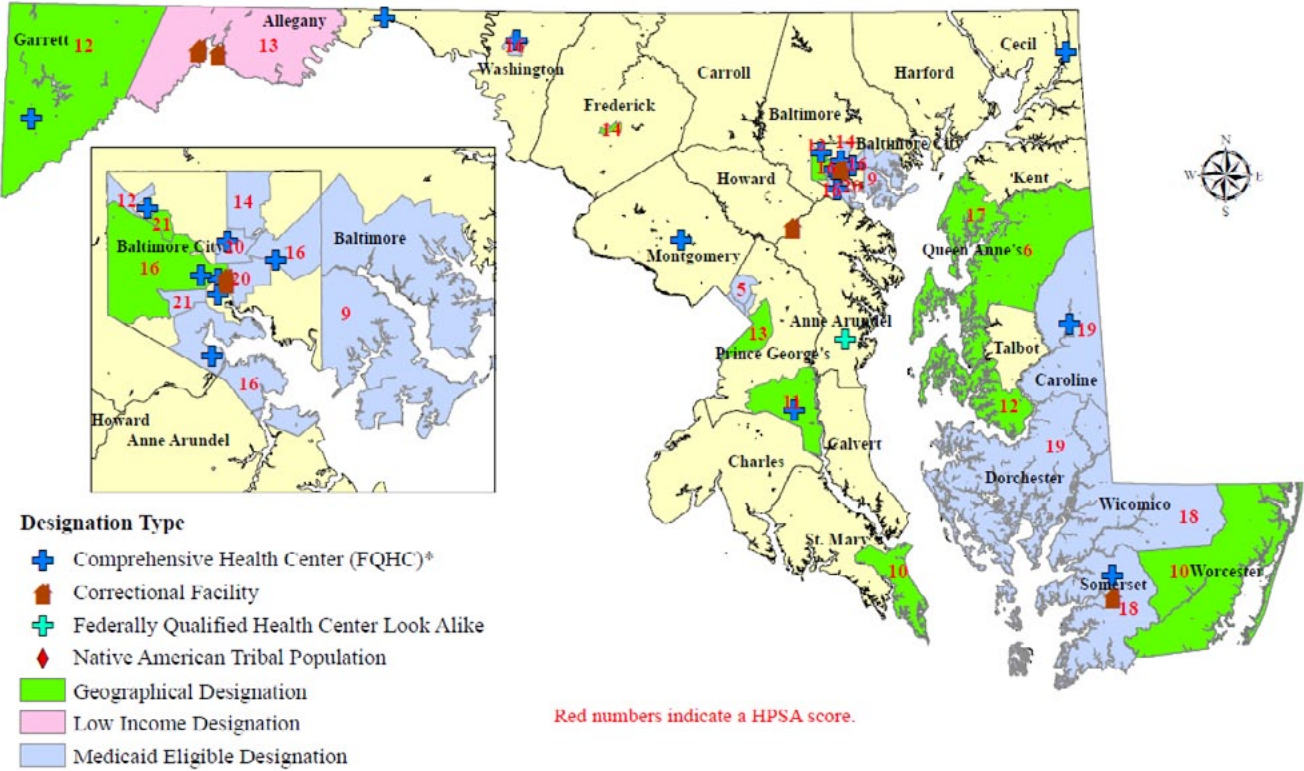
Maryland is home to several world-class healthcare facilities and providers who are capable of providing a wide array of specialty and subspecialty pediatric care. Currently, there are about 2,476 pediatricians, equivalent to approximately 1.75 pediatricians per 1,000 children, a ratio higher than the national average, 1.01 (Catalyst Center, 2011). Table 3 summarizes the number of certificates of specialty issued in Maryland by selected specialty and subspecialty. As providers can and often do receive more than one certificate, these numbers do not reflect the true number of providers trained in these specialties.

Table 3. Total Number of Certificates by Specialty/Subspecialty in Maryland as of 2011 (Source: American Board of Medical Specialties)

Specialty	Maryland	Nationwide
Family Medicine	1,190	80,837
Pediatrics	2,476	79,709
• Developmental Behavioral Pediatrics	19	613
• Neurodevelopmental Disabilities	22	248
Child and Adolescent Psychiatry	196	4,592

Despite the availability of the specialty service providers and facilities, most are concentrated in the Central and Capital regions of the state. The providers, including those trained in working with children with developmental disabilities and other special healthcare needs, are unequally distributed throughout the state, leaving the rural, outer regions of the state in critical need of providers. Figure 5 illustrates areas, populations, or facilities that are in shortage of health professionals, as designated by the Health Resources and Services Administration. In 2010, Maryland had 47 primary care Health Provider Shortage Area (HPSA) designations encompassing more than 660,000 people, mostly concentrated on the Eastern Shore and Western regions (Maryland Department of Health and Mental Hygiene, 2011). There are similar and significant shortages of mental health and dental care providers in the state. These HPSAs are not specific to pediatric primary or specialty care, but specialty care provision needs are also unmet. According to the 2012 NSCH, in Maryland, 5.6% of families reported having some problem getting specialist care, while this rate was even greater for families with children with SHCN (12.2%). These data point to the need for increased efforts in recruiting, training, and retaining healthcare providers in these shortage areas, and building adequate knowledge capacity amongst the existing providers.

Figure 5. Maryland Primary Care Health Professional Shortage Area Designation as of 2/2/2013
 (Source: DHMH Office of Primary Care Access)

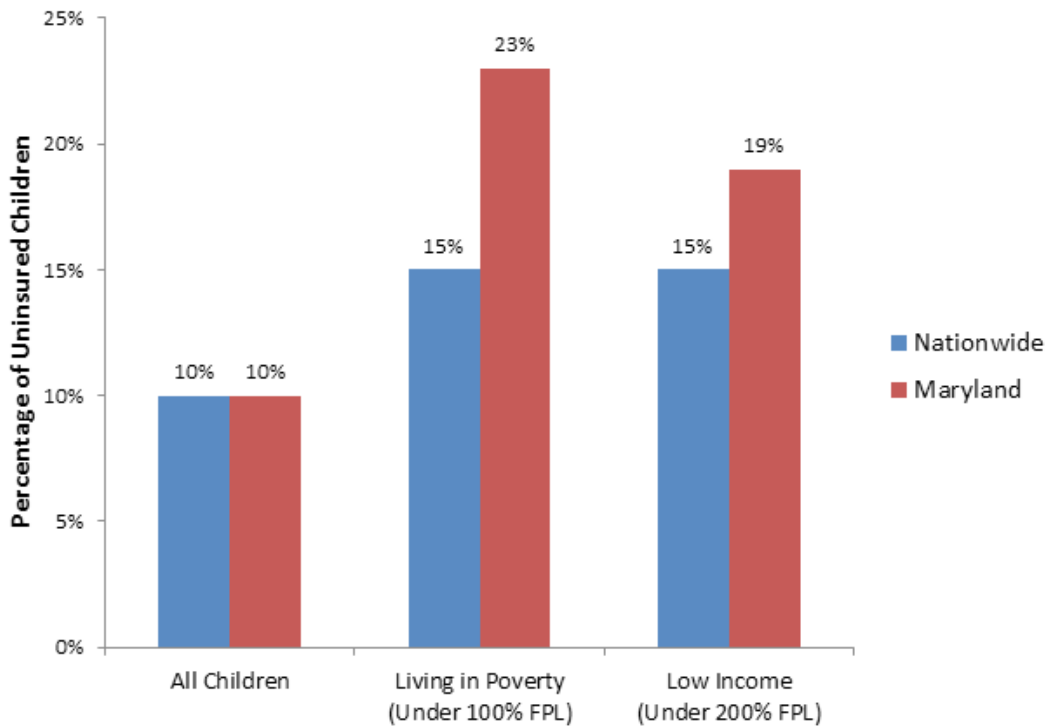


ii. Access to Healthcare

Access to healthcare refers to the ability to obtain needed primary care services, healthcare specialists, and emergency treatment. Increasing access to healthcare services is both a national priority with the ongoing healthcare reform and a target for improvement across Maryland. Insurance coverage, proximity to healthcare providers, availability of providers and services, out-of-pocket costs, and providers accepting a particular health insurance plan are all factors necessary for ensuring adequate access to care. Lack of these, in addition to other barriers, can lead to unmet healthcare needs, such as delays in receiving appropriate care, inability to get preventive services, and preventable hospitalizations, and thus contribute to increased morbidity and mortality. This section primarily focuses on socioeconomic accessibility to care; physical barriers to access, such as distance and transportation, are further discussed in the transportation section.

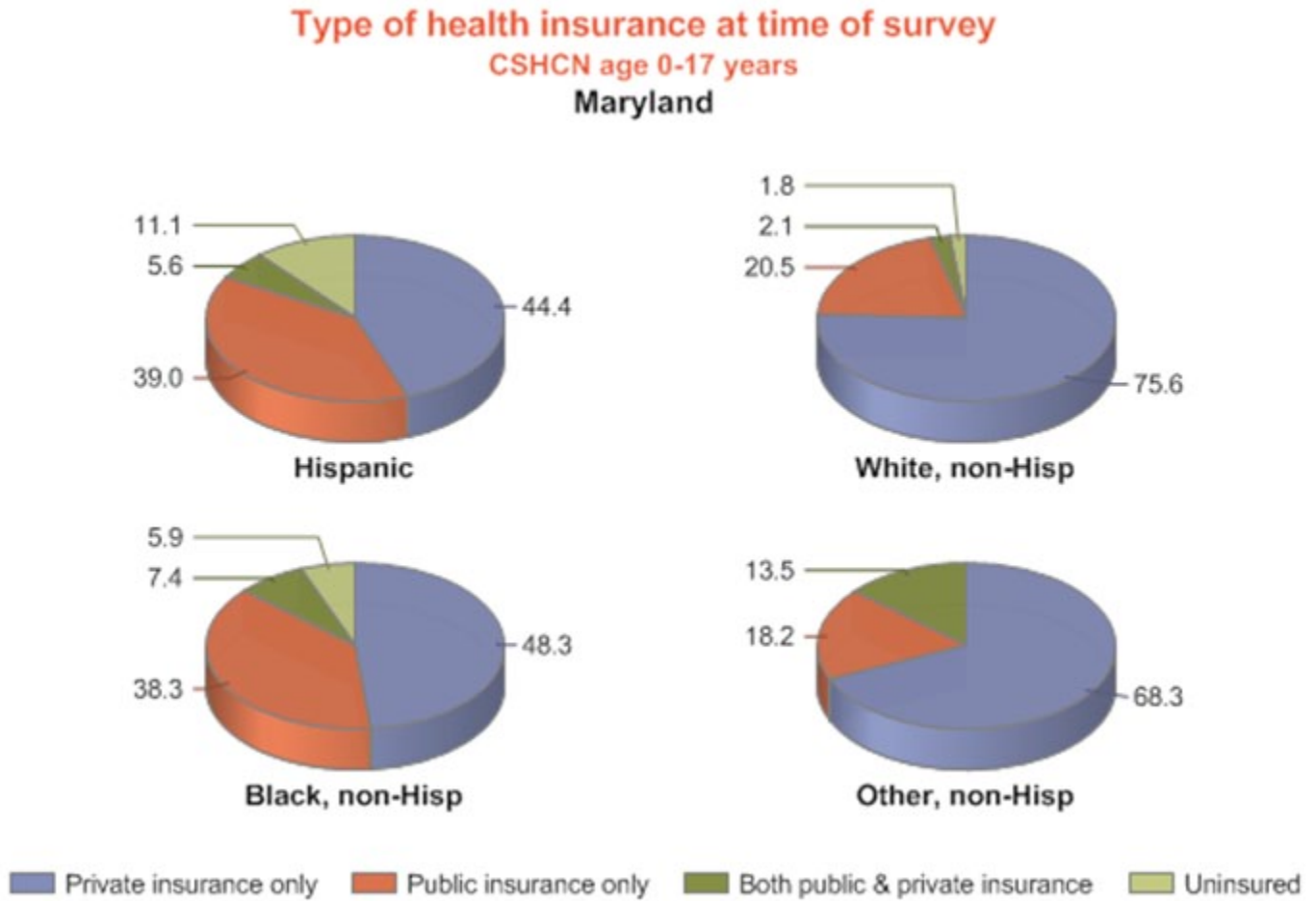
As presented in Figure 6, about 10% of all children age 0 to 18 are uninsured in Maryland. These rates are significantly higher if the family is either living in poverty (23%) or with low income (19%). Many children with SHCN are also uninsured. In the 2010 NS-CSHCN, 7.6% of children and youth with SHCN were without insurance at some point during the past year and among those with insurance, 34.7% reported their insurance is inadequate. Racial disparities also exist in this group. Figure 7 illustrates that among children and youth with SHCN age 0-17, uninsured rates among Hispanics and blacks are more than 6 and 3 times, respectively, that of whites. The high unmet healthcare needs among this population were also noted in the 2010 Maryland Parent Survey. Almost 40% of families reported experiencing some type of unmet or delayed care. The highest rates of unmet or delayed care were for dental care (27.4%), mental healthcare (25.3%), and medical care (21%).

Figure 6. Poverty Rates in All Children, Age 0-18 (Source: Advocates for Children and Youth)



The community stakeholders also viewed access to care as one of the biggest priorities. During the 2011 Priority Poll by OGPSHCN, “access to needed therapies” and “adequate health insurance and financing” were ranked the first and fifth top priority needs, respectively. Major gaps in access to needed primary and specialty healthcare services were commonly described as a major weakness in the MCDD community forums and OGPSHCN strategic planning meetings

Figure 7. Insurance Type at Time of Survey in Maryland by Race (Source: 2010 NS-CSHCN)



ii.a. Community Needs

The needs assessment also noted disparities in barriers to healthcare and unmet need by region and county. The Community Need Index scores of every zip code in Maryland are mapped in Figure 8, which captures the gap between need and access through selected socioeconomic indicators, which are income, culture/language, education, housing status, and insurance coverage. The map illustrates geographic health disparities that exist across the state. Similarly, Figure 9 shows the proportion of families with children and youth with SHCN with unmet need for health care from the 2010 Maryland Parent Survey. While this data does not allow for sub-regional analysis, there are regional differences, and the pattern is similar to the CNI scores in Figure 8, especially in Western and Eastern Shore regions. These disparities should guide development of targeted services and supports.

Figure 8. CNI Score by Zip Code (Source: 2012 Community Needs Index)

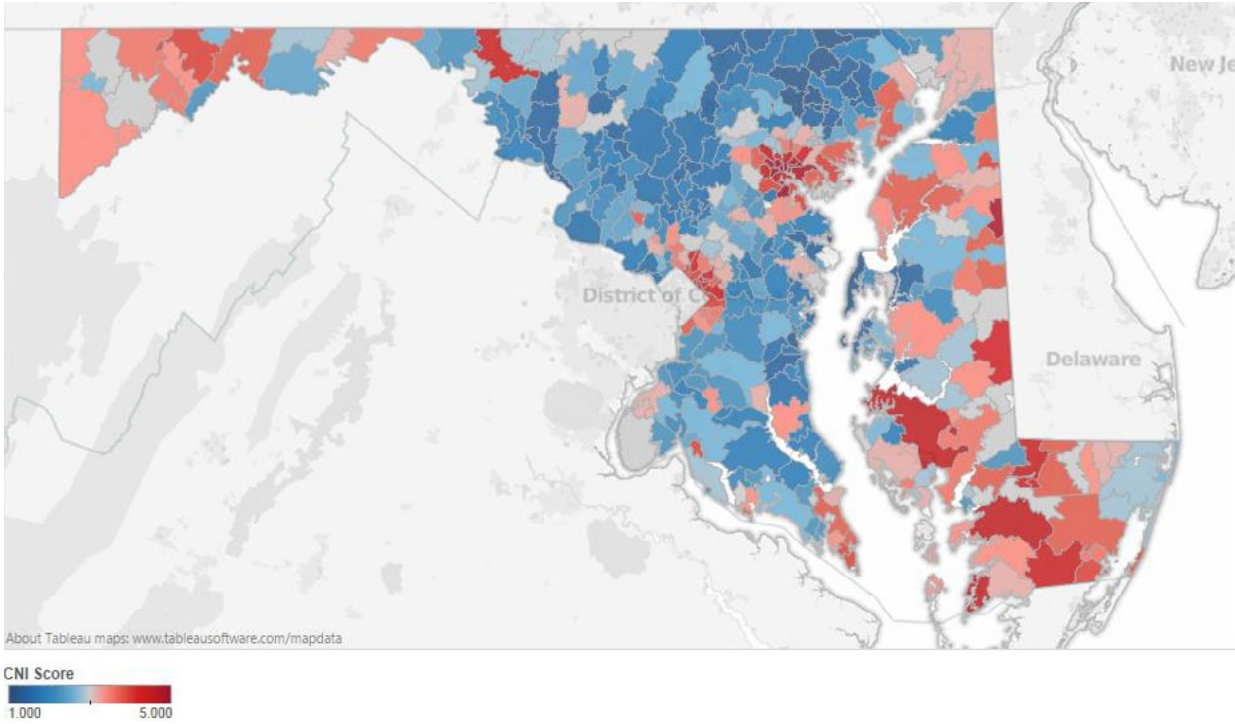
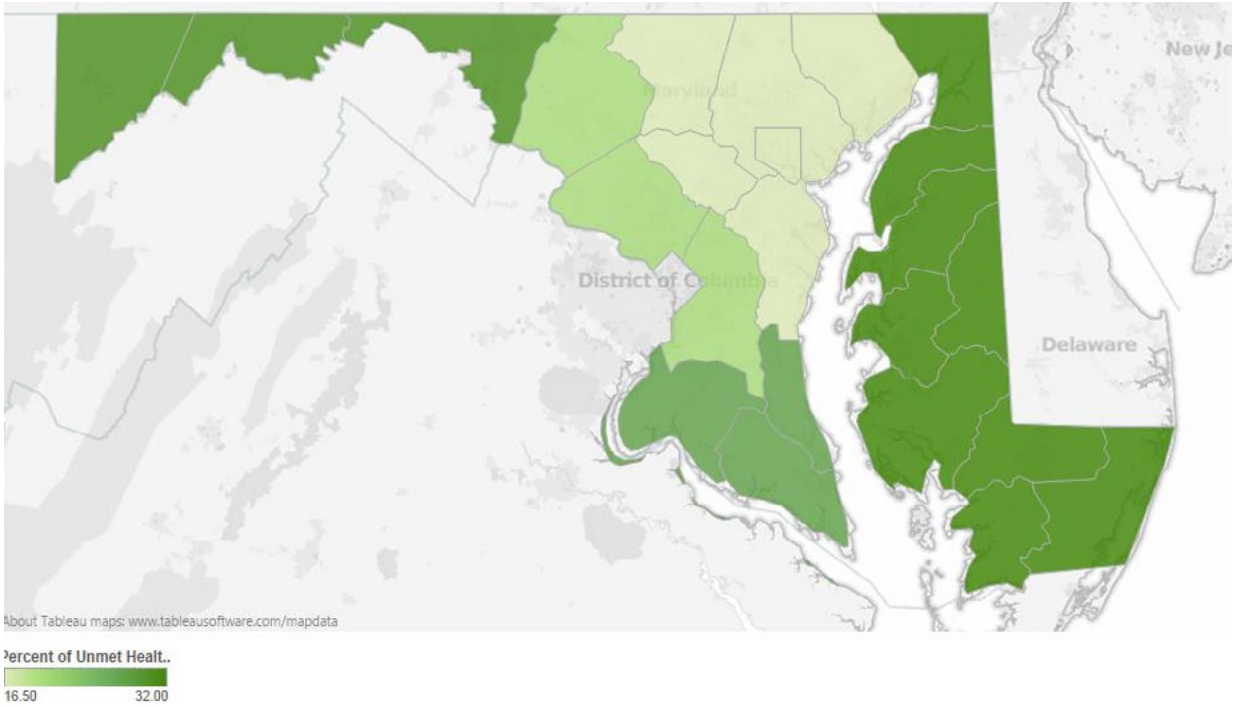


Figure 9. Percent of Unmet Need for Health Care in Families with CYSHCN by Region (Source: 2010 Maryland Parent Survey)



iii. Transportation

Transportation was repeatedly identified as a major barrier and priority need during the community forums, especially in the Southern, Western, and Eastern regions. As a participant described, “transportation is connected with every aspect of life” including work, education, and healthcare. Lack of access to transportation for people with disabilities and special healthcare needs has been widespread across the nation. A national study conducted by the U.S. Bureau of Transportation Statistics in 2002 found that 6 million people with disabilities have difficulties obtaining the transportation they need, a rate four times higher than of nondisabled people (U.S. Department of Transportation, 2003).

A range of accessible transportation options are available in Maryland, including bus and rail services, Mobility/Paratransit,

Figure 10. Fund Allocation of Transportation Aid Grants in Fiscal Year 2011 by County (Source: Department of Legislative Services)

County	Transportation Aid Programs			Total Aid	Per Capita Aid
	Highway User Revenues	Elderly/Disabled	Paratransit		
Allegany	\$223,396	\$141,544	\$68,400	\$433,340	\$6
Anne Arundel	907,049	245,996	416,000	1,569,045	3
Baltimore City	124,816,287	379,335	0	125,195,622	196
Baltimore	1,203,079	395,836	0	1,598,915	2
Calvert	201,872	127,003	76,099	404,974	5
Caroline	146,911	120,217	40,000	307,128	9
Carroll	419,577	151,029	0	570,606	3
Cecil	231,434	134,073	0	365,507	4
Charles	294,055	137,609	175,848	607,512	4
Dorchester	163,159	122,724	50,000	335,883	10
Frederick	563,569	159,159	460,000	1,182,728	5
Garrett	181,776	119,664	0	301,440	10
Harford	482,205	170,371	40,592	693,168	3
Howard	444,761	162,520	430,000	1,037,281	4
Kent	83,067	120,217	0	203,284	10
Montgomery	1,311,419	379,108	0	1,690,527	2
Prince George's	1,151,125	332,819	446,663	1,930,607	2
Queen Anne's	165,246	122,064	0	287,310	6
St. Mary's	223,318	131,054	135,000	489,372	5
Somerset	96,318	117,447	96,667	310,432	12
Talbot	138,772	120,217	0	258,989	7
Washington	362,948	146,917	188,100	697,965	5
Wicomico	280,736	134,507	96,667	511,910	5
Worcester	203,926	134,508	206,666	545,100	11
Total	\$134,296,005	\$4,305,938	\$2,926,702	\$141,528,645	\$25

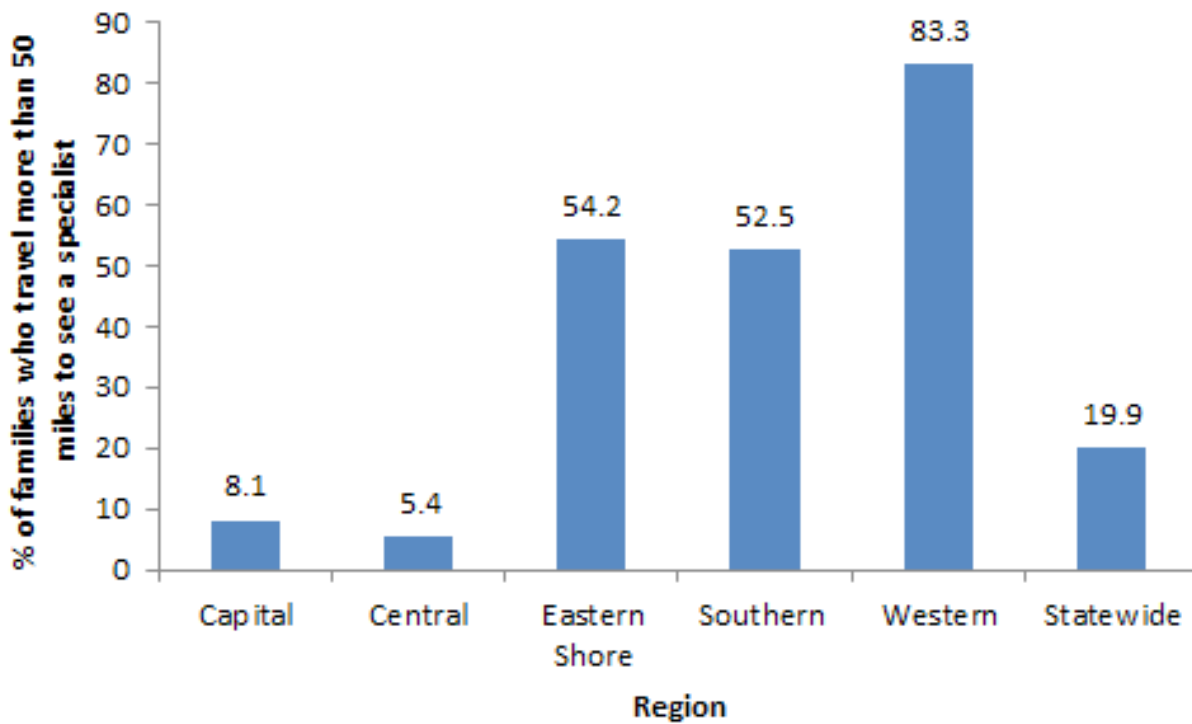
Source: Department of Legislative Services

MetroAccess, and community transportation services operated by counties, service providers, medical transport vehicles, and taxis. In 2011, the Federal Transit Administration initiated a New Freedom grant that aims to provide additional services to overcome existing barriers facing individuals with disabilities (Maryland Local Government, 2010). Despite these efforts, there remains a lack of coordination between counties, and available sources vary across jurisdiction boundaries. Figure 10 summarizes allocation of transportation aid grants in Fiscal Year 2011 based on share of actual expenditures, and shows discrepancies among the counties.

The community forums revealed that transportation was a significant concern in the Eastern Shore, with its rural geography. Its public transportation is costly, with limited routes and long waiting periods, prohibiting people with disabilities from accessing employment and healthcare services. In the Southern region, participants mentioned that despite having MetroAccess and a variety of transportation options, there are increasing safety concerns, a lack of training of MetroAccess staff, unreliable transportation, and increasing cost. Gaps in services and unreliable, unaffordable transportation were issues common to all parts of Maryland. In the 2010 Maryland Parent Survey, over 11% of respondents with children with any SHCN reported having difficulty paying for transportation, and 10% reported that they had unmet healthcare needs due to problems with transportation to appointments.

In addition to disparities in access to transportation, geographic barriers exist within the state. Travel between the Western region

Figure 11. Percentage of Families with any child with SHCN who travel more than 50 miles to see a specialist
(Source: 2010 Maryland Parent Survey)



and the rest of the state is often difficult, especially during the winter, due to inclement weather. The Bay Bridge serves as the Eastern Shore’s primary connector to other regions of Maryland and the District of Columbia, where providers are concentrated. Also, due to lack of certain services—especially specialty healthcare—in these regions, distance is another significant barrier. For example, as shown in Figure 11, a significant number of families with a child with SHCN, as high as 83.3% from the Western region, have to drive more than 50 miles to get to an appointment with a specialist. The need for traveling greater distances, combined with inadequate availability of reliable and affordable transportation, may contribute to widening the disparities in access to healthcare and other services in these regions.

iv. Partnership and collaboration between agencies and organizations

Over the decades, numerous service agencies, advocacy groups, and private and public organizations have evolved to serve the community of children and families with developmental disabilities and special healthcare needs. Appendix E lists the major entities and resource partners of the MCDD/Kennedy Krieger. Although progress has been made in creating a powerful advocacy and resource network for this community, the recurring theme from the community forums and other communication with the stakeholders revolved around the need for more effective collaboration between agencies and organizations. Some of the current issues the community is facing include:

- Navigating the system to find and access available services is often challenging to families
- Different agencies provide caregivers and families with confusing, complicated, inconsistent information
- There are too many redundancies in the system
- Available resources vary greatly by county
- There is not enough communication between agencies, especially between the adult and pediatric system, that would allow smooth transitions.

In addition, in the 2011 OGPSHCN Priorities Poll, of the respondents who represented statewide interests, 44.4% ranked “effective state-level cross-sector collaboration” among their top priorities. This lack of collaboration is leaving the system fragmented and acting as a barrier to full utilization of available services. Stronger public-private partnerships and systematic collaboration across sectors and regions need to be established to maximize the use of currently existing assets and resources.

v. Youth Healthcare Transition to Adulthood

Youth transition to adulthood is one of the six core outcomes identified by the federal Maternal and Child Health Bureau for children and youth with SHCN (USDHHS, 2005). Provision of a family- and/or person-centered, comprehensive, and coordinated system for children with SHCN is a national priority, specified as one of Healthy People 2020’s objectives (USDHHS, 2013). In terms of healthcare, youth transition refers to the process of leaving pediatric or child healthcare services and getting services from adult healthcare providers. But youth transition is beyond just healthcare, and encompasses a shift in educational, health, employment, and independent living services to ensure that youth with disabilities and special healthcare needs can fully participate in education, meaningful employment, and community living as adults. However, major challenges and barriers exist since transition activities and services are often fragmented, and there is still no clearly defined, comprehensive, coordinated, community-based, culturally competent, collaborative youth-/family-centered system of care.

During this CHNA, various inputs from the community repeatedly revealed transition as an unmet priority need. In the MCDD survey, participants rated “transition” as one of the most important issues. Youth transition to adulthood was consistently ranked high across all regions in the online priority poll by OGPSHCN, ranking as the second top priority statewide. During the community forums in the Central and Southern regions, some attendees identified strengths and positive changes in transition services, especially growing collaborative transitioning programs for employment that have resulted in transition fairs to assist youth in finding customizable employment. Yet, others mentioned the gap within services that exists between the ages of 18-21, also known as the “dead zone,” where services are no longer an entitlement. In the open response section of the MCDD survey, some of the responses point to current issues in transition:

- “[I] cannot get definitive process for transitioning students who want to apply for SSI.”
- “There needs to be some sort of focus on helping transition aged youth with disabilities to understanding age-appropriate ADLs, and to assist both the 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.”
- “Transitioning youth options are extremely limited. There needs to be a greater access to the self-directed options for youth.”
- “The gap after high school to adult services needs to be closed, and services that are provided need to be user-friendly.”

The latest data from the 2010 NS-CSHCN also support these findings. Only 36.8% of Maryland families of youth with SHCN aged 12 to 17 reported that their child received the services necessary to make appropriate transitions to adult healthcare, work, and independence, ranking Maryland 40th in the nation. As shown in Figures 12 and 13, even fewer families received transition services if the families were non-white or had inadequate insurance coverage. Furthermore, the majority, or 56.5%, of the families reported having not received the needed anticipatory guidance for transition, such as discussing the shift to adult healthcare providers, changing healthcare needs, and health insurance as the youth becomes an adult.

Figure 12. Percentage of Families with Youth with Any SHCN 12-17 Years of Age Who Received the Necessary Transition Services by Race (Source: 2010 NS-CSHCN)

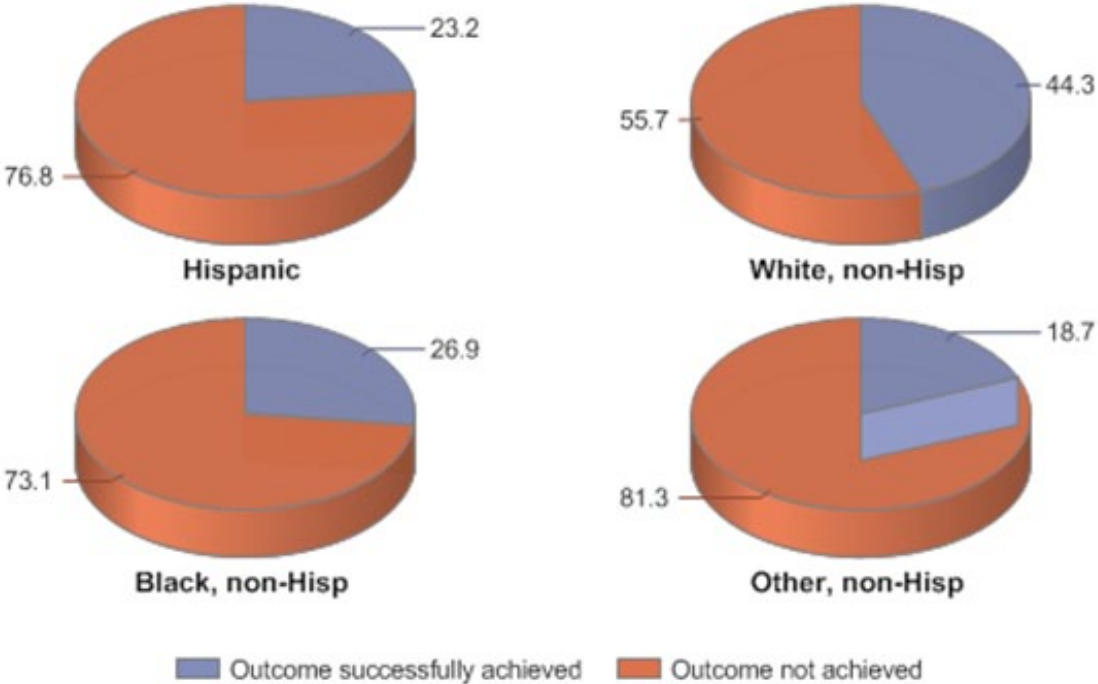
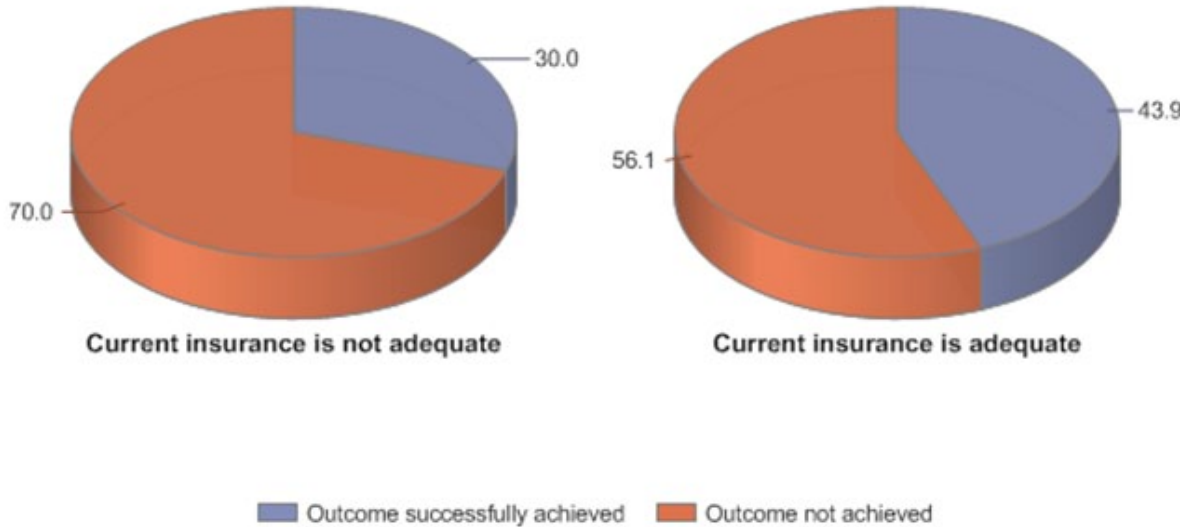
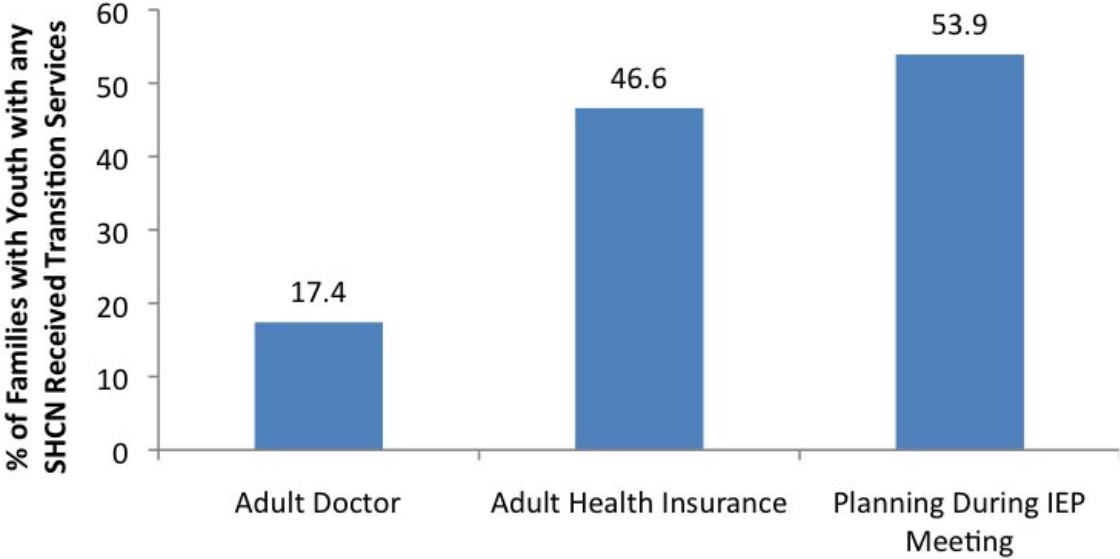


Figure 13. Percentage of Families with Youth with Any SHCN 12-17 Years of Age Who Received the Necessary Transition Services by Adequacy of Current Insurance (Source: 2010 NS-CSHCN)



In the 2010 Maryland Parent Survey, as summarized in Figure 14, only 17.4% of families with children with any SHCN reported having discussed with the child’s current provider about having their child see a doctor who provides adult healthcare services. More families, 46.6%, reported planning future health insurance coverage for their child as they become an adult, and 53.9% have participated in transition planning as part of the Individual Education Program. More recently, in a Youth Transition to Adult Survey conducted in 2012 by PPMD and OGPSHCN, only 17.1% of parents with children with special needs ages 12 through 21 reported having participated in healthcare transition planning, while 39.9% of families had the child’s doctor discuss changing healthcare needs as they become an adult, pointing to the continued unmet need for youth transition services.

Figure 14. Percentage of Families with Youth with Any SHCN Who Received Transition Services by Planning Activity Type, 2010 (Source: 2010 Parent Survey)



IV. Summary and Implementation Plan FY 2014

The data presented has been reviewed and analyzed. Based on the findings, priority items have been identified to develop a plan to address the community's needs. A representative from the Maryland State Department of Health and Mental Hygiene, Office for Genetics and People with Special Health Care Needs, an MCDD partner, has reviewed the needs assessment and provided input from a public health perspective. The top five priority areas selected through this process are:

- Training needs of educational and health professionals working with children and youth with developmental disabilities and their families
- Improving access to care for families who encounter barriers related to payment, insurance, and other issues
- Addressing transportation needs of families to access medical care and employment opportunities
- Advocacy for families and self-advocates through stronger inter-agency, cross-regional partnership and collaboration
- Youth healthcare transition to adulthood

Kennedy Krieger Institute programs and projects that will address the specific prioritized needs are:

TRAINING

- Maryland Center for Developmental Disabilities (all audiences)
- Leadership Education in Neurodevelopmental Disabilities
- RISE Programs
- Maryland Center for Developmental Disabilities Internship Program
- Center for Autism and Related Disorders

ACCESS TO CARE

- Telemedicine Pilot on the Eastern Shore/MD
- Resource Finder
- Centralized intake process

TRANSPORTATION

- Kennedy Krieger provides transportation for several hospital-based programs, free of charge to families
- Resource Finder assists families in finding available transportation options in their communities.

ADVOCACY

- Project HEAL
- Cerebral Palsy Kinetic Connections
- Chesapeake-Potomac Spina Bifida Association, Inc.
- Maryland Developmental Disabilities Council
- Maryland Disability Law Center
- People on the Go
- Maggie's Light

YOUTH HEALTHCARE TRANSITION TO ADULTHOOD

- Adolescent Transition Lecture Series
- Resource Finder
- Project HEAL

a. Training

Through multiple training programs, Kennedy Krieger will contribute to the community need for educational and knowledge capacity building by providing interdisciplinary training and technical assistance opportunities across the state. Collectively, across the Leadership Education in Neurodevelopmental Disabilities (LEND) Program, the Research Initiatives for Student Enhancement (RISE) Programs, and the Maryland Center for Developmental Disabilities (MCDD) training programs, Kennedy Krieger serves over 650 trainees annually who come from across the United States to Maryland at various points in their career trajectory.

The LEND Program prepares trainees from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of interdisciplinary clinical competence in underrepresented minority groups. LEND training is provided to those in disciplines that include audiology, behavioral psychology, genetic counseling, health administration, medicine, nursing, nutrition, occupational therapy, physical therapy, neuropsychology, social work, special education, and speech-language pathology.

RISE Programs (Maternal and Child Health Careers/Research Initiatives for Student Enhancement Program and Dr. James A. Ferguson Emerging Infectious Diseases Fellowship Program), funded by a grant from the Centers for Disease Control and Prevention, are designed to provide educational opportunities for students from underrepresented populations and/or those interested in health disparities. The intent is to spark interest in public health areas of practice, and to include persons with developmental disabilities in their areas of focus.

The MCDD Internship Program provides the opportunity for trainees to shape their experience under the leadership team of the MCDD in the focused four core functions of Pre-Service Preparation and Training, Community Services/Technical Assistance, Research/Evaluation, and Information Dissemination, according to their future goals and interests. All MCDD undergraduates will participate in the Family Perspective Experience. This experience moves education out of the classroom and into the lives and homes of families caring for children and young adults with developmental disabilities. Through family perspective discussions, and spending time with families in their homes and communities, trainees have the unique opportunity to discover, and develop sensitivities to, the complexities and challenges confronting families on a daily basis.

The MCDD has contracts and grants with several state agencies to provide statewide training to diverse stakeholders on disability-focused topics. We have found that when training is inclusive, i.e., includes self-advocates, families, and diverse professional and community participants, the learning and impact are enhanced, as seen by the evaluation results. The MCDD has implemented such trainings in the past to include Adult Autism trainings targeting direct care workers, although attendance has included self-advocates, health/educational professionals, and families/caregivers. MCDD trainings scheduled for FY 2014 include:

- Adolescent Transition Lecture Series scheduled twice in two regions of the state: Western MD and Central MD (health disparate regions, CNI, 2012)
- DDA trainings focused on behavioral health topics (targeting direct service providers but open to the public)
- Informational sessions for Parents of Children with Disabilities on the Eastern Shore, funded by a grant from the DD Council (health disparate regions, CNI, 2012)

Through our Center for Autism and Related Disorders, several initiatives are underway that span multiple fiscal years. The first project involves translational interventions in the public school systems, from the Early Achievements research. The project will address the promise of adaptability in teaching teachers, aides, and speech language pathologists to address behaviors in the classroom; interventions will begin during the third year, where there will be a comparison of educator practices and child social and communication behavior between classes with and without the intervention (FY 2014-2015). The second project, just recently funded for FY 2014, focuses on several Eastern Shore Maryland classrooms. The intervention entails using a composite of the Early Achievements assessment tool, training teachers during didactic sessions over 2-3 days, collecting data, and scoring the effectiveness of guided practice pre and post using the tool in the classroom. Finally, through collaboration with Baltimore and Harford Counties Infant and Toddler Programs, Kennedy Krieger will provide an intervention to families on a one-to-one level in how to engage their children in therapeutic ways.

b. Access to Care

The barriers identified that influence access to care include geography, socioeconomic status, availability of providers and/or knowledgeable providers, and physical/environmental access. Kennedy Krieger will address the geographic barrier to enhance access to care by initiating a telemedicine project with Atlantic General Hospital in Berlin, MD (Worcester County), on Maryland's Eastern Shore. A successful pilot could reduce travel for many families on the shore and enhance the availability of providers through telemedicine. The initial pilot will include only evaluation services in collaboration with one Kennedy Krieger clinic. This pilot is scheduled to begin in late Fall 2013.

The Resource Finder will remain an integral part of assisting Maryland stakeholders in locating resources in their community with the aid of the Resource Coordinator. The MCDD and Kennedy Krieger fund this program. Stakeholders can access the Resource Coordinator via a 1-800 telephone line, email, or walk-in visits to the Center located in our new, accessible outpatient building.

The Kennedy Krieger Institute's outpatient building, which opened in 2009, is a state-of-the-art, accessible facility for those with various types of disabilities. Our treatment rooms, tables, and spaces are open and inviting for all abilities and ages. Families remark about the ease in seeking healthcare services.

We have found that a centralized intake process provides our families with a coordinated and efficient referral process. All Staff engage in continuous training in communications, developmental disabilities, and cultural and linguistic competencies. In addition, the office is also staffed with a registered nurse who provides oversight and training to staff, and handles calls that require specific medical expertise.

c. Transportation

Kennedy Krieger provides free transportation for families that do not have the resources to get to health-related appointments at Kennedy Krieger. These programs include the Specialized Transition Program, Child and Family Support Program, Family Center, and Social Work. The Specialized Transition Program, a comprehensive rehabilitation day model, is part of the continuum of pediatric rehabilitation therapy services offered by Kennedy Krieger. The Specialized Transition Program serves patients who no longer need round-the-clock intensive medical interventions, but still require intensive therapy before full return to the community. The Child and Family Support Program is a center-based program that provides occupational therapy, physical therapy, speech therapy, and caregiver training, as well as mental health counseling for children and their families living in the Baltimore Metropolitan area. The program also assists eligible Baltimore City infants and toddlers and their families by providing service coordination through a family-centered model that views the parents or guardians as the primary decision makers in determining what services their child receives. The Kennedy Krieger Family Center Outpatient Mental Health Program serves another very vulnerable and underserved population in Baltimore City. The Center provides mental health and support services to children, adolescents, and families who experience or may be at risk for trauma through physical abuse, sexual abuse, neglect, and domestic and community violence. Prevention, early intervention, assessment, and treatment are part of the continuum of services. Finally, the Outpatient Social Work Department not only provides transportation for its own patients, but will assist other departments in helping families that require additional transportation resources.

In collaboration with the Resource Finder, the Kennedy Krieger departments work to reduce access barriers related to transportation. The availability of transportation provided, when not otherwise available, for all of these programs facilitates access and delivery to care.

d. Advocacy

The MCDD and Kennedy Krieger support Project HEAL (Health, Education, Advocacy, and Law), which is Maryland's only medical-legal partnership. Project HEAL provides free legal and advocacy services to low-income patients and families who live in Maryland and receive services at Kennedy Krieger. Project HEAL provides advocacy training for Kennedy Krieger patients, families, healthcare professionals, and community members, in addition to legal research and systemic advocacy at the local, state, and national levels. In addition, Project HEAL has engaged in extensive systemic advocacy on behalf of children with disabilities at the state level.

Kennedy Krieger currently supports two community-based family groups and will continue to support them through space, staffing, and organizational support. The Cerebral Palsy Kinetic Connections is an organization of individuals with cerebral palsy, their family members, and interested healthcare professionals. The mission is to provide the cerebral palsy community with a means of connecting with one another for developing and promoting information exchange, education programs, a forum to promote cerebral palsy research, and mutual support. Secondly, the Chesapeake Spina Bifida Association promotes education and support for families, professionals, and individuals with Spina Bifida in the Maryland, DC, and Virginia regions.

Several important entities that partner and collaborate with the MCDD to support the voices of self-advocates across the state include Maryland Developmental Disabilities Council, Maryland Disabilities Law Center, People on the Go of Maryland, and Maggie's Light. The MCDD and Kennedy Krieger have included People on the Go and Maggie's Light as integral components of our organization to assist in active planning and implementation of programs from the perspectives of self-advocates and families/caregivers of persons with disabilities. People on the Go has facilitated a greater number of self-advocates participating on the MCDD's Consumer Advisory Council, and has initiated a greater awareness about self-advocacy for youth and families through presenting at the Adolescent Transition Lecture Series and across the state in other forums. The MCDD, in collaboration with Maggie's Light Foundation, has initiated a Family Perspective Experience (FPE) Program that will become a core component for each MCDD trainee participating in internships at the MCDD. The FPE provides "family perspective" training to college and graduate students studying in health- and disability-related fields. It moves education out of the classroom and into the lives and homes of families caring for children and young adults with developmental disabilities. Through discussions, and spending time with families in their homes and communities, students have the unique opportunity to discover, and develop sensitivities to, the complexities and challenges confronting families and persons with disabilities on a daily basis, which will better prepare them to serve families and individuals with disabilities as they become professionals in their chosen fields.

e. Transition

Healthcare transition for youth with developmental disabilities and other special healthcare needs is an area where all health professionals, families, and self-advocates can contribute. Coordination of care and services, and continuity of care after age 18-21 is a major obstacle for youth and families. Building capacity among health professionals across all disciplines and in higher education will facilitate the transition to adulthood for youth with disabilities. Kennedy Krieger will conduct the Adolescent Transition Lecture Series between October and May in fiscal year 2014. The target audience will include families/caregivers, youth with disabilities, and various professionals and providers from the community. The events will be held in Central and Western Maryland. Topics are determined based on the items identified from stakeholders who have attended other MCDD trainings in FY 2013.

The Resource Finder and Project HEAL will provide resources to families, youth, professionals, and other Maryland stakeholders on various youth to adulthood transition topics in the area of health and education.

Kennedy Krieger Institute 2013 Implementation Action Plan

Objective 1: Training	Action Steps	Accountability	Timeframe	Measure
To increase knowledge of Maryland stakeholders, to include families, caregivers, educators, healthcare and public health professionals, and other interested persons working with children and young adults with developmental disabilities and related disorders.	<p>Provide professional pre-service training and continuing education for healthcare professionals through the following programs:</p> <ul style="list-style-type: none"> • Leadership Education in Neurodevelopmental Disabilities (LEND.) • Maternal and Child Health Careers/Research Initiatives in Research Enhancements (RISE) Undergraduate Program. • James A. Ferguson Fellowship Internship Program (RISE). • Maryland Center for Developmental Disabilities (MCDD) Internship Program 	Vice President, Training; Director, Maryland Center for Developmental Disabilities; Project Director, RISE Programs; Training and Administration Department	<p>July 2013, 2014, 2015: New Cohort of LEND Trainees</p> <p>May 2014, 2015, 2016: New Summer Cohort of RISE Trainees</p> <p>September 2013–August 2016 continuous MCDD Trainees</p>	<p>Record the number of trainees per program.</p> <p>Conduct follow-up at periodic intervals for two years to determine their role in community.</p>
A distance learning course will be developed to enable stakeholders of children with developmental disabilities to benefit from LEND training.		Vice President, Training	FY 2015	<p>Record the number of trainings.</p> <p>Record the audience participation.</p> <p>Record satisfaction and self-assessment of knowledge.</p>
	<p>Provide continuing education (live events and webinars) for families/ caregivers and other stakeholders:</p> <ul style="list-style-type: none"> • Developmental Disabilities Training Monthly Contract (focus on behavioral health for persons with developmental disabilities) • Resource Finder Quarterly Health Transition Adolescent Lecture Series • MCDD Community Trainings 	Director, MCDD and Staff, in collaboration with state public health agencies and community organizations	FY 2014	<p>Record the number of trainings.</p> <p>Record the audience participation.</p> <p>Record satisfaction and self-assessment of knowledge.</p>
	Early Signs Project: Access to an online video for Maryland pediatricians to learn the early signs of autism spectrum disorder.	Center for Autism and Related Disorders	Continuous	Record the number of views of the video online.
	Translation of the Early Achievement Research Program into public schools through a 2-3 day didactic training. Target training population: teachers, teacher's aides, speech language pathologists.	Director, Center for Autism and Related Disorders	Fiscal Years 2014 and 2015	Evaluation of provider ability to learn how to do an assessment after completion of the didactic program. Guided practice scores will be collected with pre and post interventions.

Kennedy Krieger Institute 2013 Implementation Action Plan

Objective 2: Access to Care	Action Steps	Accountability	Timeframe	Measure
Improve access to care across Maryland.	Conduct a tele-health pilot project with a community-based Eastern Shore hospital.	Vice President, Training; Sr. Vice President, Clinical Services and Programs	Fall/Winter 2013	Record the number of patient visits conducted. Record the patients', providers', and referring physicians' satisfaction with project.
	Submit a grant proposal to build capacity on the Eastern Shore for educators and families • Grant includes Technical Assistance training to manage challenging behaviors in the classrooms and at home	Director, MCDD and Staff	November 2013	Award of grant—refer to grant evaluation, if funded.
	Resource Finder—the MCDD and Kennedy Krieger will continue to fund the operations of the Resource Finder to serve Maryland communities, to assist in locating resources related to care.	Kennedy Krieger Administration	Fiscal Years 2014, 2015, 2016	Record performance measure, to include number of inquiries (calls, emails, walk-ins), website hits, type of inquirer, reasons for inquiry, satisfaction.
Objective 3: Transportation	Action Steps	Accountability	Timeframe	Measure
Assist with transportation for persons with disabilities to access health services.	To increase public awareness of transportation options in each county via the Resource Finder.	Maryland Center for Developmental Disabilities: Resource Finder	FY 2014	Record the number of inquiries received requesting transportation resources.
	Kennedy Krieger will provide transportation resources to access the Specialized Transition, Child and Family Support, Family Center, and Social Work programs.	Kennedy Krieger Administration	FY 2014, 2015	The number of patients who utilize the transportation resources provided by the program.
Objective 4: Advocacy	Action Steps	Accountability	Timeframe	Measure
To increase parents/caregivers' and professionals' knowledge of rights on special education laws and services.	Accept intakes and provide legal representation to patients who access Kennedy Krieger services related to special education law, primarily from underrepresented groups.	Project HEAL	FY 2014	Record intake demographics and case disposition.
	Provide training to educational providers on topics related to special education law and options to provide services in the public school system.	Project HEAL	FY 2014	Training evaluations.
To assist in enhancing self-advocacy amongst families, caregivers, and self-advocates.	Kennedy Krieger Institute will support the following family-run organizations by providing resources such as space, financial support, staff, public relations consultation, etc.: • Cerebral Palsy Kinetic Connections • Chesapeake-Potomac Spina Bifida Association, Inc.	Kennedy Krieger Administration	FY 2014, 2015, 2016	Record the group membership annually, number, and type of events.
	The MCDD supports People on the Go, a statewide group of advocates with intellectual and developmental challenges who use our voices to advocate for common issues.	MCDD and People on the Go	FY 2014, 2015	Record community meetings with local self-advocacy groups, presentations statewide, and visits to legislatures.
	The MCDD and Maggie's Light Foundation will offer a Family Perspective Experience to selected Trainees throughout the year.	MCDD and Maggie's Light Directors	FY 2014, 2015	Reflective Essays from each trainee and training evaluations from trainees and families involved.

Kennedy Krieger Institute 2013 Implementation Action Plan

Objective 5: Youth Healthcare Transition to Adulthood	Action Steps	Accountability	Timeframe	Measure
To improve the healthcare transition of youth to adulthood.	Conduct the Adolescent Transition Lecture Series.	Maryland Center for Developmental Disabilities: Resource Finder	FY 2014, 2015 (October through May)	Record the number of lectures, number and type of participants, and satisfaction information.
	Provide resources on healthcare transition for families, healthcare and educational professionals.	Maryland Center for Developmental Disabilities: Resource Finder	FY 2014, 2015	Record dissemination information, to include type of information, number and type of persons, follow-up, and satisfaction with usefulness of information.
Record dissemination information, to include type of information, number and type of persons, follow-up, and satisfaction with usefulness of information.	Provide information to families, youth, and educators regarding transition in schools through Project HEAL contacts in the community statewide.	Maryland Center for Developmental Disabilities: Resource Finder and Project HEAL	FY 2014	Record dissemination information, to include type of information, number and type of persons, follow-up, and satisfaction with usefulness of information.

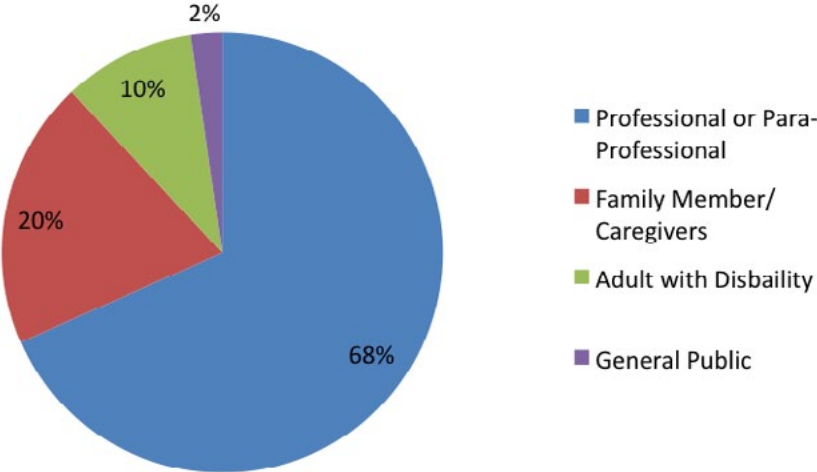
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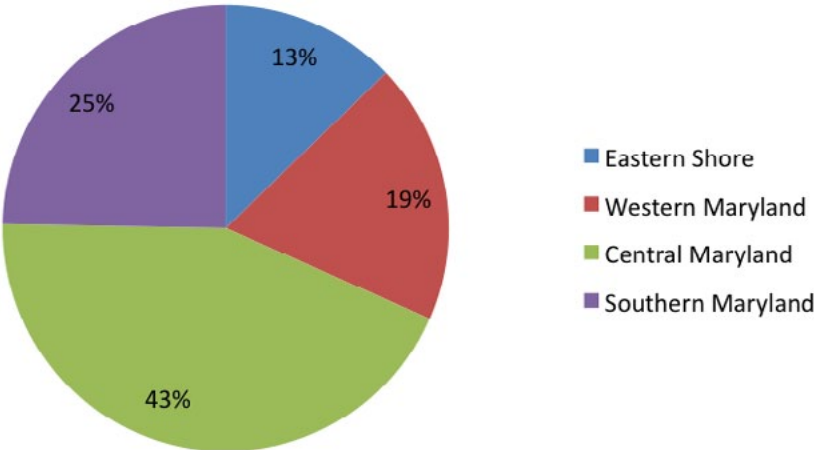
Appendix A. Community Forum Attendees

Total Participants: 236

Percentage of Community Forum Attendees by Self-Identified Role



Percentage of Community Forum Attendees by Region



Appendix B. MCDD Statewide Summary of 18 Community Forums (MCDD, 2011)

Strengths (Q: What is working well?)	<ul style="list-style-type: none"> • Development of community advocacy groups • Recreational activities through community collaboration • Services for infants and children • The development of a more collaborative transitioning process
Weaknesses (Q: What is not working well?)	<ul style="list-style-type: none"> • Inadequacies in access to primary and specialty healthcare services • Lack of reliable transportation that is affordable and accessible • Lack of affordable and accessible housing • Ineffective dissemination of reliable information • Inadequate training among professionals working with the DD population
Solutions (Q: What solutions do you recommend for the future?)	<ul style="list-style-type: none"> • Improve and develop reliable networks of information that can be disseminated to professionals/para-professionals, service providers, consumers, family members/caregivers, and the community at large • Strengthen communication and information sharing. To accomplish this, there must be a financial and technological investment that will allow systems to “talk” to each other and develop a network between agencies, community partners, and service providers that are accessible • Develop an accessible system that will also improve the ability of service providers to deliver care, particularly within the realm of tele-healthcare and using other forms of technology to reach consumers during crisis or due to distance • Recruit younger advocates and develop DD citizens advisory committees, which will increase the reach of the DD population • Undertake additional capacity building with local businesses, advocacy groups, faith-based institutions, and academic institutions

Top Five Priority Themes Emerged from Each Region and Statewide

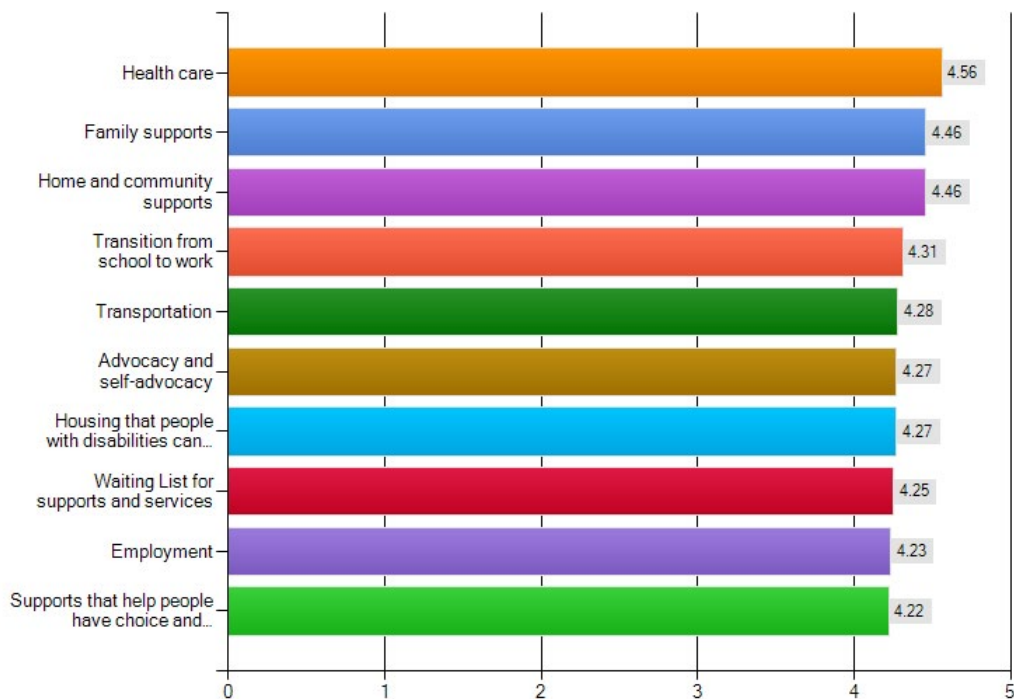
	Eastern	Western	Southern	Central	Statewide
1.	Knowledge Education Information Training	Knowledge Education Information Training	Knowledge Education Information Training	Knowledge Education Information Training	Knowledge Education Information Training
2.	Transportation	Healthcare Services	Transportation	Transitioning	Transportation
3.	Healthcare Services	Transportation	Transitioning	Housing	Healthcare Services
4.	Other (funding, leadership, accessibility)	Transitioning	Housing	Transportation	Transitioning
5.	Housing	Housing	Other (funding, leadership, accessibility)	Healthcare Services	Housing

Appendix C. Stakeholder Online Survey Results

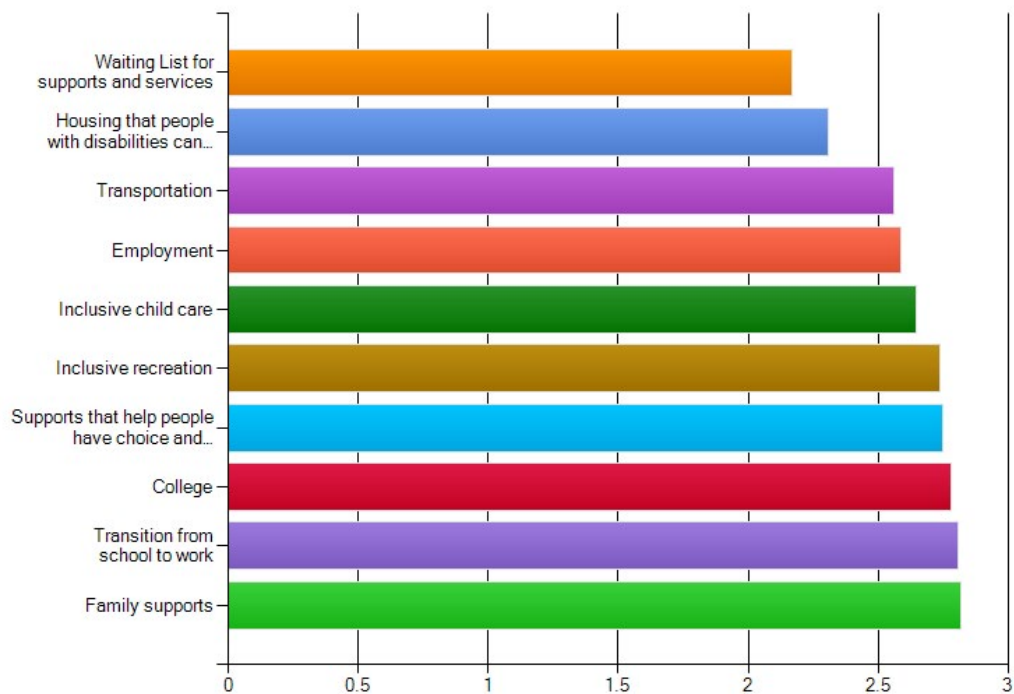
314 Surveys (84.5% completed)

Family Member:	52.2%
Service Provider:	32.3%
Advocate:	20.8%
Person with a Disability:	10.9%
Resource Coordinator:	10.9%
State Agency:	6.3%

How would you rate the importance of these issues?



How well is Maryland doing in these areas?



Appendix D. Data Sources and Resources

Agency	Data Sources	Year
Advocates for Children and Youth	Maryland Kids Count Indicators	Various
American Association of Medical Education	Maryland Physician Workforce Profile	2011
American Board of Medical Specialties	2011 Certificate Statistics	2011
Catalyst Center	State-at-a-Glance Coverage and Financing Charts – Maryland	Various
Children’s Defense Fund	Children in Maryland	2013
Data Resource Center for Child and Adolescent Health	National Survey on Children with Special Healthcare Needs	2009-2010
Data Resource Center for Child and Adolescent Health	National Survey on Children’s Health	2011-2012
DHMH – OGPSHCN & PPMD	2012 Comprehensive Needs Assessment of Maryland Children with Autism Spectrum Disorders and other Developmental Disabilities	2012
DHMH – OGPSHCN	Maryland Priorities Poll for Children and Youth with Autism and Developmental Disabilities, 2011	2011
DHMH – OGPSHCN & PPMD	2010 Maryland Parent Survey	2010
DHMH – OGPSHCN & PPMD	Maryland Parent Survey on Youth Transition to Adulthood	2012
DHMH Primary Care Office	2010 Primary Care Needs Assessment	2011
Dignity Health	Community Health Needs Index	2012
Employment and Disability Institute at the Cornell University ILR School	2011 Disability Status Report Maryland	2011
Health Resources and Services Administration	Maryland Healthcare Professional Shortage Area / Medically Underserved Area / Population Data	2013
Kennedy Krieger Institute	Internal Patient Demographic Statistics	2013
Kennedy Krieger Institute: Maryland Center for Developmental Disabilities	Statewide Needs Assessment Forums and Online Survey	2011
Maryland Board of Education	Maryland Special Education / Early Intervention Services Census Data and Related Tables	2011
Maryland Commission on Autism	Final Commissions Report—Addressing the Needs of Individuals with Autism Spectrum Disorders in Maryland	2012
Maryland Developmental Disabilities Council	Maryland Developmental Disabilities Five-Year State Plan	2012
Maryland Department of Disabilities	2012-2015 State Disabilities Plan	2012
Maryland Title V Program	Title V MCH Block Grant and Needs Assessment	2010
National Association of State Directors of Developmental Disabilities Services (NASDDDS) / Human Services Research Institute (HSRI)	National Core Indicators	Various
Robert Wood Johnson Foundation / University of Wisconsin Population Health Institute	2013 County Health Rankings	2013
U.S. Census Bureau	American Community Survey	2011

Appendix E. List of Major Community Programs, Partner Agencies, and Advocacy Groups

Maryland Center for Developmental Disabilities (Kennedy Krieger)
Maryland Developmental Disabilities Council
Maryland Commission on Autism
Maryland Community of Care Consortium for Children with Special Health Care Needs
Maryland Department of DisabilitiesDHMH, Office of Genetics and People with Special Health Care Needs (MD Title V)
PACT: Helping Children with Special Needs (Kennedy Krieger)
Parents' Place of Maryland
Project HEAL (MCDD/Kennedy Krieger)
Resource Finder (MCDD/Kennedy Krieger)
Southeast Early Head Start (Kennedy Krieger)
Specialized Health Needs Interagency Collaboration (MSDE)

Appendix F. List of Acronyms

CHNA Community health needs assessment
CNI Community Needs Index
CYSHCN Children and Youth with Special Health Care Needs
DD Developmental Disabilities
DHMH Department of Health and Mental Hygiene
HPSA Health Provider Shortage Areas
MCDD Maryland Center for Developmental Disabilities
NSCH National Survey on Children's Health
NS-CSHCN National Survey on Children with Special Health Care Needs
OGPSHCN Office for Genetics and People with Special Health Care Needs
PPMD Parents' Place of Maryland
YTD Year-to-date