Kennedy Krieger Institute

Community Health Needs Assessment

2016

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Kennedy Krieger Institute

UNLOCKING POTENTIAL

June 9, 2016

Dear Maryland Community,

Kennedy Krieger Institute is proud to be a leader in providing clinical care for children and young adults with developmental disabilities and injuries. As leaders of the Institute, we have continued to support the depth and breadth of services initiated by our founder, Dr. Winthrop Phelps, in 1937. More than 75 years later, we continue to dedicate ourselves 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.

We are happy to present to you our second community health needs assessment (CHNA). A lot has happened in Maryland over the last three years since our first CHNA. We are happy to report that we have met our goals and objectives associated with the 2013 priorities. Kennedy Krieger has expanded its reach into the Eastern Shore through new partnerships and telemedicine services, and we anticipate working with the Western Maryland community to continue addressing access to care.

As part of this CHNA, we collaborated with community organizations to share and collect data on the needs of the targeted population we serve in Maryland: individuals with developmental and related disabilities. Kennedy Krieger worked with the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute—a University Center of Excellence in Developmental Disabilities—to conduct focus groups and attend public meetings focused on the needs of our target population.

We have learned that partnerships have been critical to addressing all priority areas that were identified in 2013. We look forward to strengthening those partnerships and establishing new relationships to respond to the priority areas within this report.

If you have comments or questions related to this report, please email **CommunityBenefit@KennedyKrieger.org**.

Sincerely,

Gary W. Goldstein, MD   Howard B. Miller
President   Board of Directors Chair

Executive Summary

Located in Baltimore, Maryland, Kennedy Krieger Institute is an internationally recognized institute dedicated to improving the lives of children and young adults with developmental disorders and injuries through patient care, special education, research, professional training, and community initiatives. Our mission is to transform the lives of children with disorders of the brain through groundbreaking research, innovative treatments, and life-changing education. For more than 75 years, Kennedy Krieger Children's Hospital, Inc. (Kennedy Krieger), an affiliate of Kennedy Krieger Institute, has served as a "niche" provider because of our unique services for individuals with developmental and related disorders and their families.

Kennedy Krieger conducted a community health needs assessment (CHNA) based on data and community information collected and shared by multiple partners. Because the majority of patients served by Kennedy Krieger are Maryland residents, with patients representing every Maryland county, Kennedy Krieger views the State of Maryland as the community it serves. This CHNA targets the needs of children and young adults with developmental disabilities and other disorders in Maryland, as well as their families.

The top four priority areas of need identified through this CHNA are:

- **Training** needs of education 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 geography/distance and shortage of providers

- **Advocacy** for families and self-advocates through stronger inter-agency, cross-regional partnerships and collaborations

- **Youth transition:** Legal planning and healthcare

Training	Access to Care	Advocacy	Youth Transition
LEND	Telemedicine	Project HEAL	Legal Issues (UB/Project HEAL Initiative)
MCDD	Resource Finder	People on the Go Maryland	
Center for Diversity in Public Health	Community Outreach		Healthcare
Leadership Training			
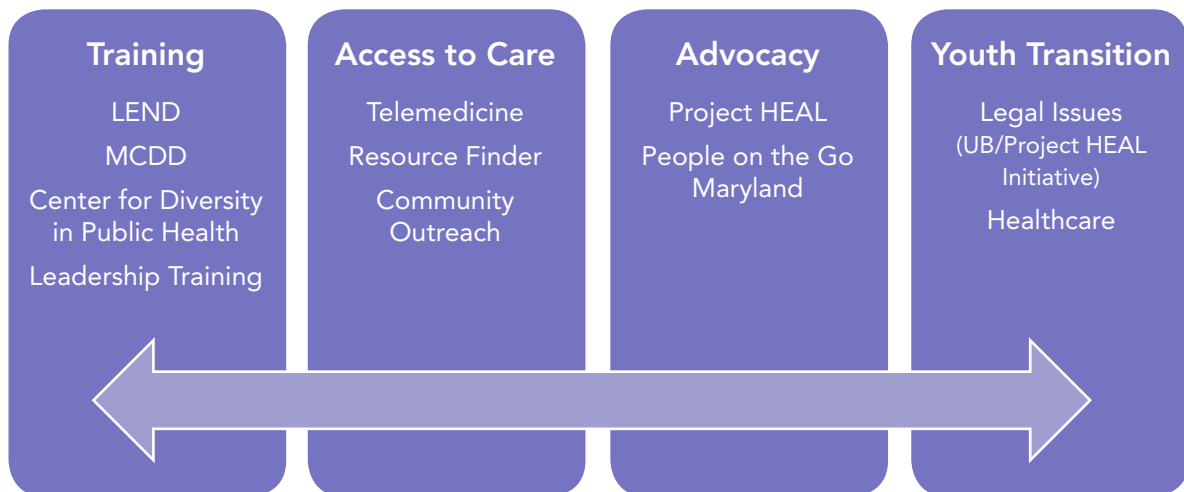
I. Introduction

a. Overview of Kennedy Krieger Institute

Kennedy Krieger Institute is a nonprofit, Maryland-licensed pediatric rehabilitation and specialty hospital, school, and research center located in Baltimore, Maryland. Kennedy Krieger Institute's mission is 'To transform the lives of children with disorders of the brain through groundbreaking research, innovative treatments, and life-changing education.'

Our values: We recruit the most talented and compassionate clinicians, scientists, and educators to provide the best care and family support. Our approach is child-family centered and interdisciplinary, to ensure that children with conditions affecting the nervous system have access to all the resources they need—treatments, education, and community programs to achieve ever better outcomes.

Kennedy Krieger Children's Hospital, Inc. (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. Kennedy Krieger Institute's annual operating budget is $228 million, and the hospital's budget is $138 million. A financial audit was performed for fiscal year 2015, and the resulting report was issued on October 16, 2015, by PricewaterhouseCoopers, LLP.

The Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger, a University Center for Excellence in Developmental Disabilities and part of a national network, 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. Kennedy Krieger worked with the MCDD and other community stakeholders to conduct a comprehensive community health needs assessment (CHNA) focused 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.

Kennedy Krieger was also a place where physicians, therapists, and researchers interested in helping children with disabilities could come to train and conduct research. By 1938, Kennedy Krieger had started training professionals in medicine, physical therapy, nursing, occupational therapy, and education about cerebral palsy, which was then the leading diagnosis at the Institute. 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. Kennedy Krieger's innovative model of care—known as interdisciplinary 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 relocated 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 administration produced the first federally funded grant, which allowed the Institute to focus on the following three program areas of greatest concern: recruitment of high caliber students and personnel from all disciplines to the field of intellectual disability; providing broader training and concepts for all Johns Hopkins medical, nursing, and professional personnel who interacted with individuals with disabilities; and helping to foster interdisciplinary understanding of developmental disabilities in the medical school, the university, and the community.

Today, new programs continue to open to meet the needs of the community. 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—2013, 2014, and 2015—indicate that 87 percent of all inpatients and outpatients served by Kennedy Krieger are Maryland residents, with patients from every Maryland county, as represented in Figure 1. Thus, the hospital views the State of Maryland as the community it serves.

Figure 1. Patient Population Distribution by Zip Code (Fiscal Year 2015)
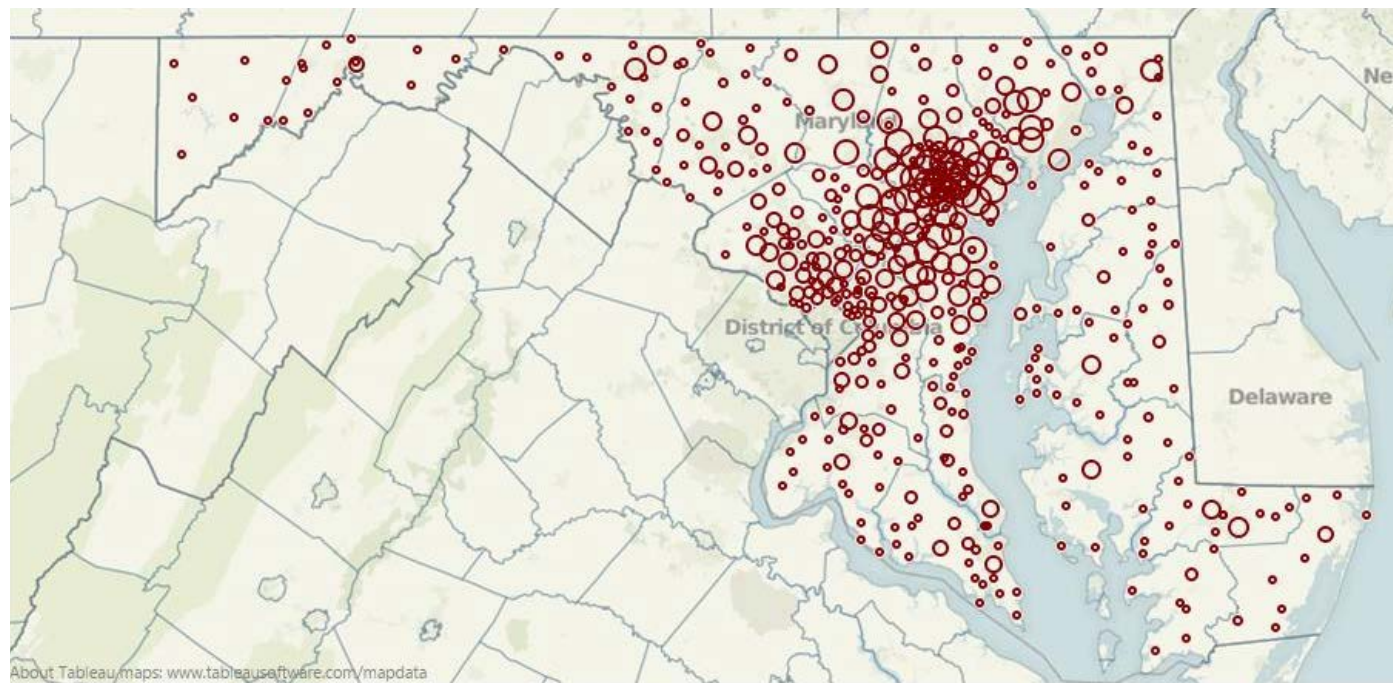
Map based on Zip Code. Size shows details about total count of Number of Records.

d. Target Population

The organization serves persons with a variety of developmental disorders and injuries. Our top outpatient diagnoses for the last fiscal year (2015) included conduct disturbance, attention-deficit hyperactivity disorder, autism spectrum disorder, and language disorder. During the last three fiscal years (2013-2015), Kennedy Krieger averaged 345 inpatient admissions, with the majority of patients between 3 and 14 years of age.

The racial and ethnic composition of Kennedy Krieger's patients closely resembles Maryland's population, according to the 2014 population estimates of the U.S. Census (Table 1). Compared to the 2013 CHNA, the age distribution of Kennedy Krieger unique patients has remained essentially unchanged, as have the racial and gender composition. While the Maryland gender distribution of persons under 18 years is close to a 50/50 split, the distribution of patients seen at Kennedy Krieger, representing children across Maryland with developmental disabilities, is weighted toward males—comparable to what is found in the literature (Boyle et al., 2011).

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

	Kennedy Krieger unique patients Fiscal Year 2013	Kennedy Krieger unique patients Fiscal Year 2014	Kennedy Krieger unique patients Fiscal Year 2015	MD (U.S. Census, 2014 population estimates)	MD (U.S. Census, 2014 population estimates) < 18yrs.
TOTAL	20,010	20,648	22,046	5,976,407	1,350,668 (22.6%)
AGE					
0-2	8%	8%	8%		
3-5	17%	17%	17%		
6-8	19%	20%	19%		
9-11	18%	17%	17%		
12-14	14%	13%	14%		
15-17	10%	10%	11%		
18-20	4%	4%	4%		
21+	10%	11%	10%		
RACE					
White alone, not Hispanic or Latino	48%	49%	49%	52.6%	42.6%
Black	33%	33%	33%	30.3%	30.3%
Hispanic	4%	4%	4%	9.3%	11.5%
AI/Pacific Islander	0.3%	0.3%	0.2%	0.1%	0.2%
Asian	3%	3%	3%	6.4%	5.2%
Multi-Racial/ Other	5%	6%	7%	2.6%	10.2%
GENDER					
Male	64%	64%	64%		51%
Female	35%	35%	35%		49%

II. Approach/Methodology

Expectations vary for diverse stakeholders across Maryland's regions. Because multiple organizations within Maryland and across the United States are mandated to conduct CHNA, in an effort to streamline the data collection process for our community needs assessment and collaborate with community partners, Kennedy Krieger utilized existing data sources and participated in community meetings where organizations convene with community members to discuss community assets, needs, and services. At the time of Kennedy Krieger's first CHNA in 2013, we initiated discussions with community organizations to establish a collaborative data-sharing consortium. While a formal agreement between these entities does not exist to date, the organizations that expressed interest have readily collected and shared de-identified data to help assess community assets and needs for children and youth with disabilities and their families. While the process for this CHNA differs slightly from 2013, the outcomes reflect a richer integration of data elements, to include standardized/government databases, surveys distributed to the community by our community and local and state government entities, and non-standardized qualitative input from participation in public community meetings.

For the 2016 CHNA, we used predominantly the following methodologies to derive the priority areas:

1. Review of U.S. Census Data

2. MCDD Needs Assessment: Pathfinders Community Forums on Adolescent Transition[i]

3. Participation in Maryland Consortium of Care Quarterly Meetings[ii]

4. Participation in Eastern Shore Consortium of Care Quarterly Meetings[iv]

5. Review of data collected by multiple partner organizations[i-v]

6. Attendance at Maryland Community Health Resources Commission Regional Meetings: Sustaining Community-Hospital Partnerships to Improve Population Health[vi]

7. Attendance at other community and group meetings across the state focused on specific communities and populations

8. Input from the Maryland Center for Developmental Disabilities Consumer Advisory Council

a. Description of Selected Resources Used in Collecting Data

i. MCDD Needs Assessment: Pathfinders Community Forums on Adolescent Transition
The MCDD entered into a formal partnership with Pathfinders for Autism to conduct four community forums in each Maryland region (Western, Eastern, Southern, Capital, and Central) to gain insight into parent perspectives about transitioning for children and youth on the autism spectrum. Topics discussed at each forum include school-based transition, healthcare transition, adult services, and other topics as identified.

ii. Maryland Title V Agency 2015 Needs Assessment
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 Office for Genetics and People with Special Health Care Needs (OGPSHCN) administers the Title V Children and Youth with Special Health Care Needs (CYSHCN) Program. From fall 2013 through spring 2015, OGPSHCN worked with multiple stakeholders in Maryland to compile data via surveys, interviews, and participation in public meetings to identify priority issues for the CYSHCN in Maryland.

iii. PPMD/Maryland Parent Survey 2014/Maryland Consortium of Care
The Parents' Place of Maryland (PPMD) is a nonprofit, 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 healthcare needs (CYSHCN) and their families. PPMD, with the OGPSHCN, leads the Maryland Consortium of Care. Meetings occur quarterly and include stakeholders from across the state interested in issues targeting CYSHCN. In 2014, PPMD and OGPSHCN conducted the Maryland Parent Survey, resulting in 1,090 parent respondents. The survey was conducted online and via paper and pencil. Participants were recruited through PPMD, MCDD, local health departments, Pathfinders for Autism, Abilities Network, and other community stakeholders. The survey results provide data on the impact of autism spectrum disorder, developmental disabilities, and epilepsy/seizure disorder on families, and their unmet needs.

iv. Eastern Shore Consortium of Care
The Eastern Shore Consortium of Care for CYSHCN meets quarterly in Talbot County, Maryland, and is facilitated by a county health department nurse. The participants are diverse and include families of CYSHCN, health and educational providers, community providers, and general stakeholders. The meetings provide opportunities for networking and information sharing about services, events, potential collaborations, and knowledge-based learning. A representative from Kennedy Krieger attends the meetings.

v. Maryland State Department of Education Parent Survey
The Maryland State Department of Education conducted a survey to discover the "percentage of parents with a child receiving special education who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities." Parents/guardians of children who received special education services during the 2014-2015 school years were invited to complete a Preschool Survey and a School-Age Survey.

vi. Maryland Resource Health Commission (MRHC) Hospital Community Forums Summary
The Maryland General Assembly created MRHC in 2005 to expand access to healthcare services in underserved communities in Maryland. In 2015, the MRHC conducted regional forums across Maryland to discuss promising community collaborative practices focused on promoting the capacity and sustainability of Maryland's health system for the underserved. While the population focus was not specific to developmental disabilities, the population health issues influence all groups across Maryland communities and rely on community resources for ongoing healthcare. The findings from these MRHC community forums contribute to the State Health Improvement Process (SHIP). The SHIP framework provides accountability, local action, and public engagement in order to advance the health of Maryland residents (http://dhmh.maryland.gov/ship/Pages/home.aspx). The measures are aligned with *Healthy People 2020*. Kennedy Krieger's participation in these regional forums was beneficial in linking with community resources across Maryland, especially for the communities in Western, Southern, and Eastern Shore regions.

vii. Kennedy Krieger Planning Hackathon Sessions

Hackathons are venues that bring together a group of people with technical backgrounds to form teams around a problem or development of an idea. Kennedy Krieger held three internal hackathons in 2015 and 2016 to generate ideas related to the development of products for individuals with disabilities. The forums included providers, families, and self-advocates, and provided an opportunity to brainstorm ideas in preparation for the Abilities Hackathon—a collaborative effort to enable the Baltimore community to solve and address problems that those with disabilities face—held in Baltimore in April, 2016.

viii. Other Community Meetings

Kennedy Krieger Institute participated in the LEAH Adolescent Medicine Grand Rounds: Transition Symposium and the J-Train (Johns Hopkins Transition Independence Network) Symposium on Healthcare Transition in Maryland. Got Transition (www.gottransition.org) directors provided an overview of the project and facilitated discussions on engaging adolescent groups and families into the transition process. The symposiums convened healthcare providers and state representatives to share and discuss barriers and intervention strategies for diverse patient groups. The MCDD Consumer Advisory Council, the majority of whose members include people with developmental and related disabilities and their family members, meets quarterly. The council's role is to consult with and advise the University Centers for Excellence in Developmental Disabilities (UCEDD) in the development, review, and revisions of the center's five-year plan for the State. The MCDD's focus has been establishing community partnerships and collaborating to address needs across the state in various communities. This focus aligns well with the goals of Kennedy Krieger's CHNA for Maryland.

ix. What is Healthy People 2020 Telling Us in 2016?

Since 2010, the objectives identified by *Healthy People 2020* have guided the focus of our nation's health priorities. The *Healthy People 2020* objectives most relevant to our target population include Disability and Health (DH) objectives and Maternal Infant and Child Health (MICH) goals and objectives. Data updates in these areas inform our nation and state communities how well we are doing overall in certain areas as identified by the objectives.

Disability and Health Objectives *(no data reported for objectives marked with an asterisk)*

- *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 health care needs whose healthcare provider has discussed transition planning from pediatric to adult healthcare (DH-5).

- *Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs (DH-8).

- *Reduce the proportion of people with disabilities who encounter barriers to participating in home, school, work, or community activities (DH-9).

- *Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree that they wish (DH-13).

- Objective MICH-29: Increase the proportion of young children with autism spectrum disorder (ASD) and other developmental delays that are screened, evaluated, and enrolled in early intervention services in a timely manner.

  - MICH-29.1 Increase the proportion of children (aged 10-35 months) who have been screened for ASD and other developmental delays.

  - MICH-29.2 Increase the proportion of children with ASD having a first evaluation by 36 months of age.

  - MICH-29.3 Increase the proportion of children with ASD enrolled in special services by 48 months of age.

- Objective MICH-30: Increase the proportion of children, including those with special health care needs, who have access to a medical home.

  - MICH-30.2 Increase the proportion of children with special health care needs who have access to a medical home.

x. County Rankings

County Health Rankings and Roadmaps is a partnership between the Robert Wood Johnson Foundation (RWJF) and the University of Wisconsin. Based on the RWJF priority to build a culture of health, this program helps communities:

- Build awareness of the multiple factors that influence health,

- Provide a reliable, sustainable source of local data to communities to help them identify opportunities to improve their health,

- Engage and activate local leaders from many sectors in creating sustainable community change, and

- Connect and empower community leaders working to improve health.

The County Rankings are influenced by policies and programs, and measure health factors that drive health outcomes. The data provide a starting point for communities as they work to improve health and wellness of their citizens.

xi. Other Available Data

Other data collected through community meetings, reports, and survey findings by partner organizations provided a holistic view of the needs of the population. These data, available at different levels—local, state, and national—were analyzed and synthesized. Appendices I and J list major sources of data reviewed and used for this CHNA.

b. Data Gaps

Data from children and youth with special healthcare needs, particularly those with developmental disabilities, are limited. Although every attempt was made to include the most relevant, up-to-date data for a comprehensive needs assessment of the community, the following data gaps and limitations exist:

- CHNA data were collected from varying data sets, with inconsistent definitions of conditions, age groupings, and geographic boundaries among different indicators. Data for some indicators are available only at national and/or state levels.

- The Annual Disability Statistics Compendium, compiled by the Institute on Disability at the University of New Hampshire, has the most consistent data trended across populations, although it lacks data specific to children and youth.

- Access to and awareness of resources continues to be a topic of many meetings across communities. While there are multiple resource programs serving Maryland and certain counties, not one can fulfill the need of any one community.

III. What the Data Tell Us

a. Summary Characteristics

Figure 2. Children with Special Health Care Needs (National KIDS COUNT, 2011-2012)
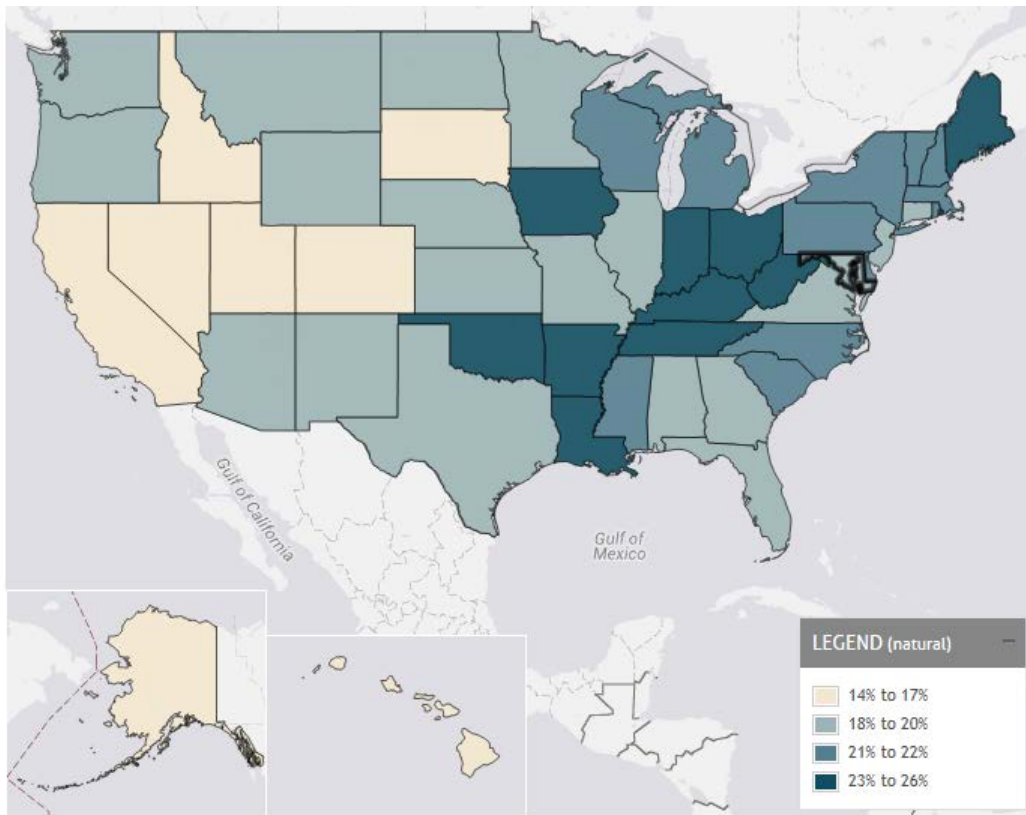
CHILDREN WITH SPECIAL HEALTH CARE NEEDS (PERCENT) - 2011-2012

National KIDS COUNT
KIDS COUNT Data Center, datacenter.kidscount.org
A project of the Annie E. Casey Foundation

The 2011-2012 National KIDS COUNT Data Center reports that 20 percent of the population under 17 years in Maryland had special healthcare needs, similar to the national average (Figure 2). Statistics on children's disability status and type of children and youth are not routinely collected by government surveys. Much of the Centers for Disease Control and Prevention (CDC) activities have focused on developmental disabilities monitoring to include autism spectrum disorder (ASD). The CDC's most recent estimates, from the 2016 national report, are that about 1 in 68 children has been identified with ASD. There are differences across groups for children on the spectrum. As in prior years, the prevalence among boys was higher than among girls. In the 2016 report, the prevalence in boys was 1 in 42, compared to 1 in 189 for girls. White children were more likely to be identified with ASD than black or Hispanic children. Black children were more likely to be identified with ASD than Hispanic children. Additional data on ASDs are presented in the *Healthy People 2020* findings.

Figure 3. Maryland Child Poverty Rate by County

CHILDREN IN POVERTY (PERCENT) - 2014

Advocates for Children and Youth
KIDS COUNT Data Center, datacenter.kidscount.org
A project of the Annie E. Casey Foundation

LEGEND (natural)

▢	7.1% to 10.9%
▢	11.0% to 14.8%
▢	14.9% to 23.7%
▢	23.8% to 32.6%
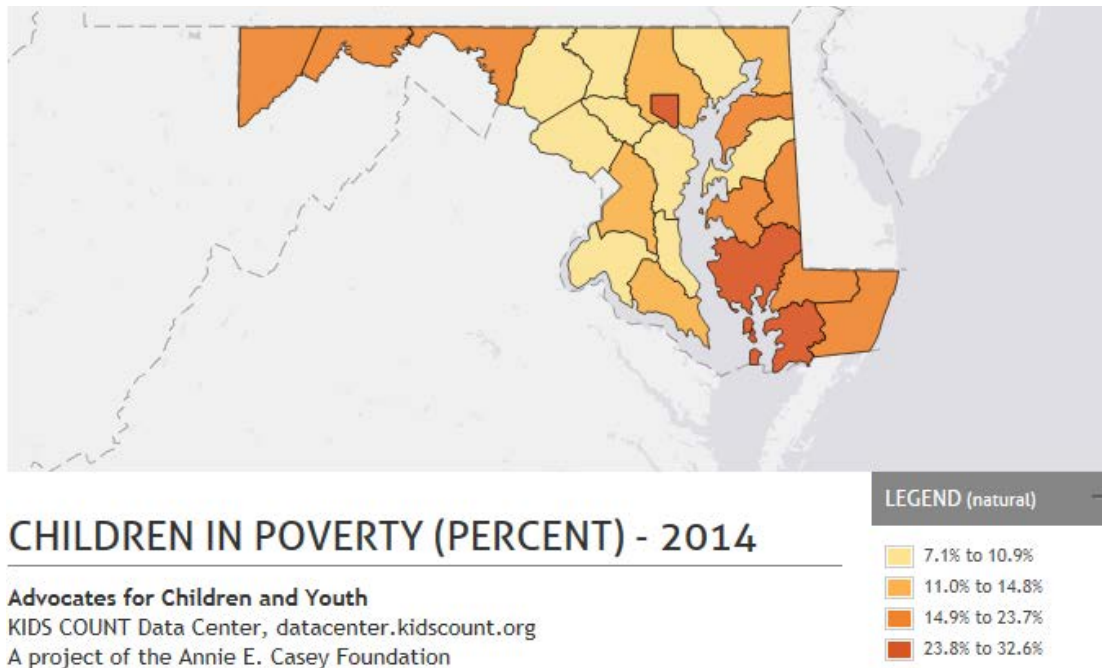
Maryland child poverty rates for children less than 18 years who live in families with income below the federal poverty level in 2014 by jurisdiction ranged from 7.1 percent (Howard) to 32.6 percent (Somerset). There are geographic disparities, with certain counties having vastly higher poverty rates, such as Somerset (32.6 percent), Baltimore City (32.2 percent), Dorchester (29.4 percent), Caroline (23.7 percent), Wicomico (23.5 percent), and Allegany (22.9 percent) (Figure 3). A greater number of children with intellectual/developmental disabilities live in poverty compared to those without intellectual/developmental disabilities (Segal et al., 2015; Emerson & Hatton, 2009).

b. *Healthy People 2020*

Data are available for the following *Healthy People 2020* (HP 2020) Disability and Health objectives:

- Objective DH-5: Increase the proportion of youth with special healthcare needs whose healthcare provider has discussed transition planning from pediatric to adult healthcare.

HP 2020 Baseline Year 2005-06 = 41.2%
HP 2020 2009-2010 = 40.0%
HP 2020 Target = 45.3%: NOT MET

Progress toward this objective continues to be addressed. This objective presents greater disparities when adjusted for race and ethnicity. At baseline, the best group rate for this objective, 46.5 percent, was attained by the White only, not Hispanic or Latino population. The Hispanic or Latino population attained the worst group rate for this objective, 26.3 percent, at baseline.

Data are available for the following Maternal, Infant, and Child Health objectives:

- Objective MICH-29: Increase the proportion of young children with autism spectrum disorder (ASD) and other developmental delays that are screened, evaluated, and enrolled in early intervention services in a timely manner.

  - MICH-29.1 Increase the proportion of children (aged 10-35 months) who have been screened for ASD and other developmental delays.

HP 2020 Baseline Year 2007 = 22.6%
HP 2020 2011-2012 = 38.0%
HP 2020 Target = 24.9%: MET

Progress in screening for ASD and other development delays is moving in the right direction.

- MICH-29.2 Increase the proportion of children with ASD having a first evaluation by 36 months of age.

HP 2020 Baseline Year 2006 = 42.7%
HP 2020 Year 2008 = 45.9%   HP 2020 2010 = 43.8%
HP 2020 Target = 47.0%: NOT MET

Progress toward the target level for MICH 29.2 was moving in the correct direction in 2008, but 2010 reflected a slight decline from the target goal. Increased programs and research have supported the need for early evaluation. This objective presents greater disparities when adjusted for race and ethnicity. At baseline the best group rate for this objective, 50.4 percent, was attained by the White only, not Hispanic or Latino population. The Hispanic or Latino population attained the worst group rate for this objective, 31.9 percent, at baseline.

- MICH-29.3 Increase the proportion of children with ASD enrolled in special services by 48 months of age.

HP 2020 Baseline Year 2006 = 52.4%
HP 2020 Year 2008 = 51.5%   HP 2020 2010 = 52.0%
HP 2020 Target = 57.6%: NOT MET

Progress toward the target level has decreased slightly since baseline. Research supports increased training across all groups—providers, caregivers, and childcare providers—for greater screening, leading to evaluation and needed services. This objective also presents greater disparities when adjusted for race and ethnicity. At baseline the best group rate for this objective, 56.6 percent, was attained by the White, not Hispanic or Latino population. The Black or African American population attained the worst group rate for this objective, 52.7 percent, at baseline. Data for other populations are statistically unreliable.

- Objective MICH-30: Increase the proportion of children, including those with special healthcare needs, who have access to a medical home.

  - MICH-30.2 Increase the proportion of children with special healthcare needs who have access to a medical home.

HP 2020 Baseline Year 2005-2006 = 47.1%	
HP 2020 Year 2009-2010 = 43.0%	
HP 2020 Target = 51.8%: NOT MET	

Progress toward the target level has decreased since baseline. Activities informing providers and caregivers of the importance of a medical home are needed. This objective presents greater disparities when adjusted for race and ethnicity. At baseline the best group rate for this objective, 52.8 percent, was attained by the White only, not Hispanic or Latino population. The Hispanic or Latino population attained the worst group rate for this objective, 32.2 percent, followed by Black or African American (36.0 percent) at baseline.

c. Maryland State Department of Education Parent Survey

Of the 12,048 Preschool Surveys mailed to parents, 1,914 were completed—1,316 on paper and 598 online, yielding a 13 percent response rate. Of the 62,461 School-Age Surveys mailed to parents, 8,895 were completed—6,215 on paper and 2,680 online, yielding a 10 percent response rate. The Preschool Survey findings indicated that the largest degree of discordance between teachers and parents (52 percent) was related to the way parents were connected to outside services, organizations, and individuals. The statement which received the lowest percentage of agreement on the School-Age Survey (60 percent) was related to training provided by the school and how well the school connects parents to other organizations for support: "The school and/or school system offers me training about special education issues."

d. 2014 Maryland Parent Survey

The 2014 Maryland Parent Survey (MDPS) conducted by PPMD and Title V resulted in 1,090 parent respondents. Although every county in Maryland was represented, the counties most represented in the sample were Baltimore County (14.8 percent), Frederick County (12.6 percent), and Montgomery County (10.8 percent).

Figure 4. 2014 Maryland Parent Survey Child Demographics

Child Characteristics	Sample n	%
Age		
0-5	204	18.7
6-11	395	36.2
12-17	349	32.0
18+	134	12.3
Sex		
Male	748	68.6
Female	341	31.3
Race/Ethnicity		
Non-Hispanic White	720	66.1
Non-Hispanic Black	194	17.8
Non-Hispanic Asian	29	2.7
Hispanic	72	6.6
Other, non-Hispanic	72	6.6
Health insurance		
Private insurance only	580	55.7
Public insurance only	339	32.6
Private and public insurance	117	11.2
No insurance	5	0.5

MDPS (2014) unmet needs findings were rated using a Likert scale as follows: needed help, easy to get help, difficult to get help, and didn't get help with the issue. The issues and highest response groupings are noted in Table 2. MDPS (2014) also asked parents if certain care related services for CYSHCN were delayed or not received. The responses were reported by region.
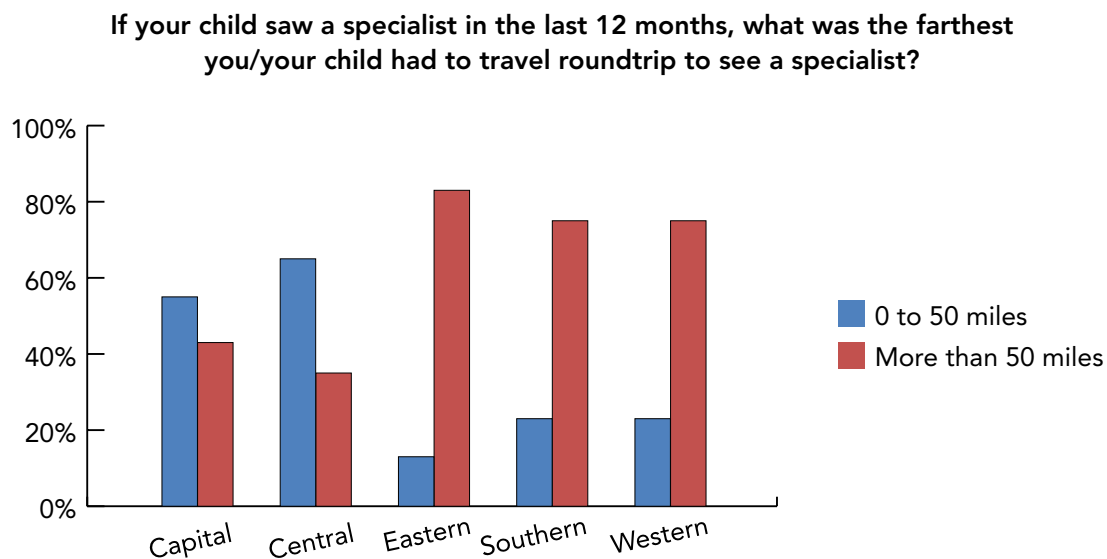
Table 2. Unmet Needs Based on Child Behavioral Health Issue *(Source: 2014 Maryland Parent Survey)*

Issue	% of highest response
Anxiety	65.9% needed help
Suicidal Thoughts/Behaviors	54.4% difficult to get help
Increase in Problem Behaviors	56.1% difficult to get help
Depression	47.8% difficult to get help
Anger/Conflict Management	46.3% difficult to get help
Bullying	44.4% difficult to get help
Drug/Alcohol Abuse	40.0% difficult to get help

The top three service groups identified included behavioral counseling/support, therapies, and mental health services. The region with the highest respondents indicating delayed or needed care not received was Southern Maryland, although this number may be skewed given the response rates from the specific counties.

MDPS (2014) documented the distance traveled to obtain and receive specialty care. Findings reflected that families in Southern, Western, and Eastern Maryland typically travel more than 50 miles to have their child see a specialist (Figure 5). In addition to data collected from MDPS on distance traveled for specialty care, Kennedy Krieger gathered data from its telemedicine initiative on the Eastern Shore. Kennedy Krieger launched a pilot telemedicine project with Atlantic General Hospital in 2013. For each referral, we have computed the number of miles saved using the telemedicine clinic versus driving over the Bay Bridge to Kennedy Krieger from the patient's home. During fiscal years 2015 and 2016, respectively, families saved an average of 226 miles and 246 miles by using the telemedicine clinic.

Figure 5. Distance Traveled Roundtrip to See a Specialist

If your child saw a specialist in the last 12 months, what was the farthest you/your child had to travel roundtrip to see a specialist?

Kennedy Krieger's telemedicine service is growing. Figure 6 shows the growth in patients seen between FY 2014 and 2015. The majority of families scheduled indicated this was their first time using telemedicine (98 percent). In fiscal year 2015, over eighty percent of patients were satisfied with the service and felt they had their questions answered through the telemedicine encounter with the physician.

Figure 6. Kennedy Krieger/Atlantic General Hospital Telemedicine Clinic Visit Growth

Kennedy Krieger/Atlantic General Hospital Telemedicine Clinic Growth: FY 2014 to FY 2015
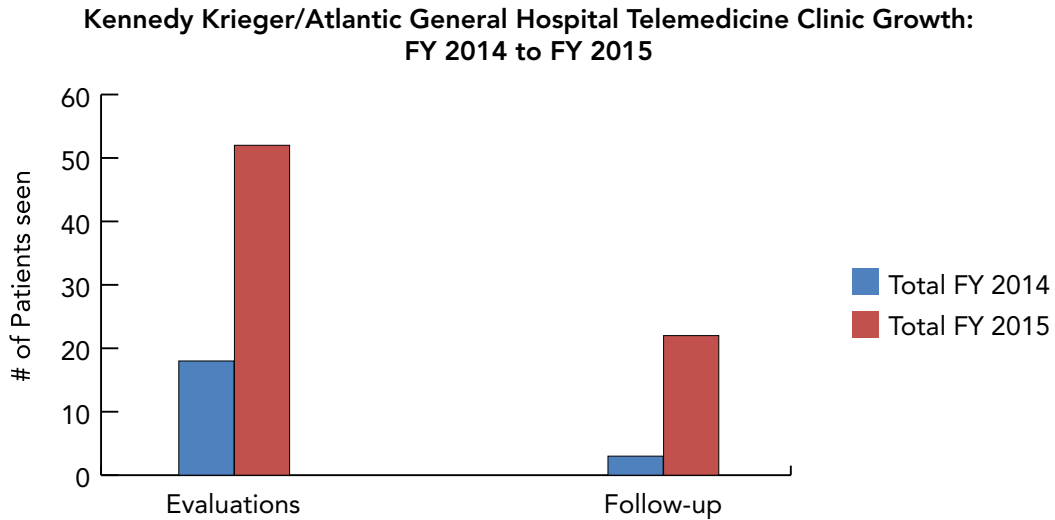
e. Youth Healthcare Transition

The MCDD engaged Pathfinders of Maryland to conduct several community forums on adolescent transition needs for youth on the autism spectrum. As of mid-April 2016, two forums have been conducted: one on the Eastern Shore and the second in Southern Maryland (Figure 7). The age of the children represented by the parents ranged from 14 to 21 years on the Eastern Shore and 14 to 24 years in Southern Maryland.

Figure 7. Pathfinders Community Forum Participants by County *(Source: Pathfinders Community Forums on Adolescent Transition, 2016)*

Pathfinders Community Forum: Eastern Shore Participants

Wicomico — 1
Worcester — 8
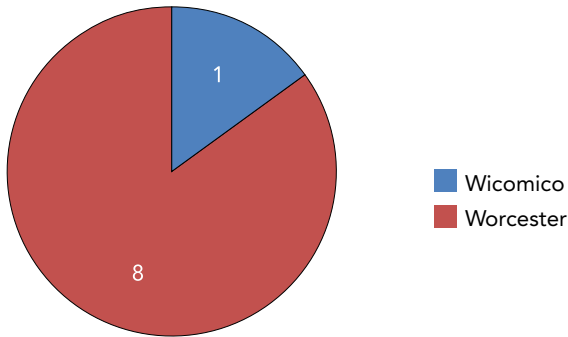
Pathfinders Community Forum: Southern Md. Participants

Charles County — 2
St. Mary's County — 8

Figure 7 *(Continued)*

**Pathfinders Community Forums:
Race/Ethnicity of Capital Region Participants**

- Capital White Caucasian
- Capital Bi-Racial

**Pathfinders Community Forum:
Race/Ethnicity of Eastern Shore Participants**

- Eastern unknown
- Eastern White/Caucasian

**Pathfinders Community Forums
Race/Ethnicity of Southern MD Participants**

- Southern White/Caucasian
- Southern African American/Black

**Pathfinders Community Forums:
Race/Ethnicity of Western MD Participants**

- Western White/Caucas
- Western African American/Black

The findings will be validated with all participants upon completion of the forums. Each group was asked to list what is going well, what is not going well, and ways to improve services for each topic category: school-based transition, healthcare transition, adult services, and other. Post-secondary activities, including college and employment, were a major concern for many. Suggestions for improvement focused on preparatory knowledge, skills, and experiences for college or work.

When Maryland families were asked how often their youth's doctor encouraged him/her to take age-appropriate responsibility for his/her health needs, 78.8 percent indicated the doctor does provide encouragement (NS-CSHCN 2009/10). When the respondents are further divided by emotional, behavioral, or developmental issues, more children with developmental issues did not receive encouragement from their doctor to take appropriate responsibility for their health needs. And when the same group of respondents was subdivided by race and ethnicity, black children had the highest rate of not receiving encouragement from their doctor to take appropriate responsibility for their health needs.

OGPSHCN and PPMD conducted a 2013 Maryland Parent Youth Transition Survey, a follow-up to the 2011 Transition Survey, which included similar questions to those asked on the NS-CSHCN. The Maryland survey targeted families of children with special healthcare needs, and the findings were not divided by race/ethnicity. From the 2013 Transitioning Youth Survey, only 12 percent of respondents reported having received any information on healthcare transition planning from their healthcare provider (Figure 8).

Figure 8. Doctor/Healthcare Professional Provided Transition-related Information in Maryland *(MD 2013 Transition Survey)*

Doctor/healthcare provider provided information on:
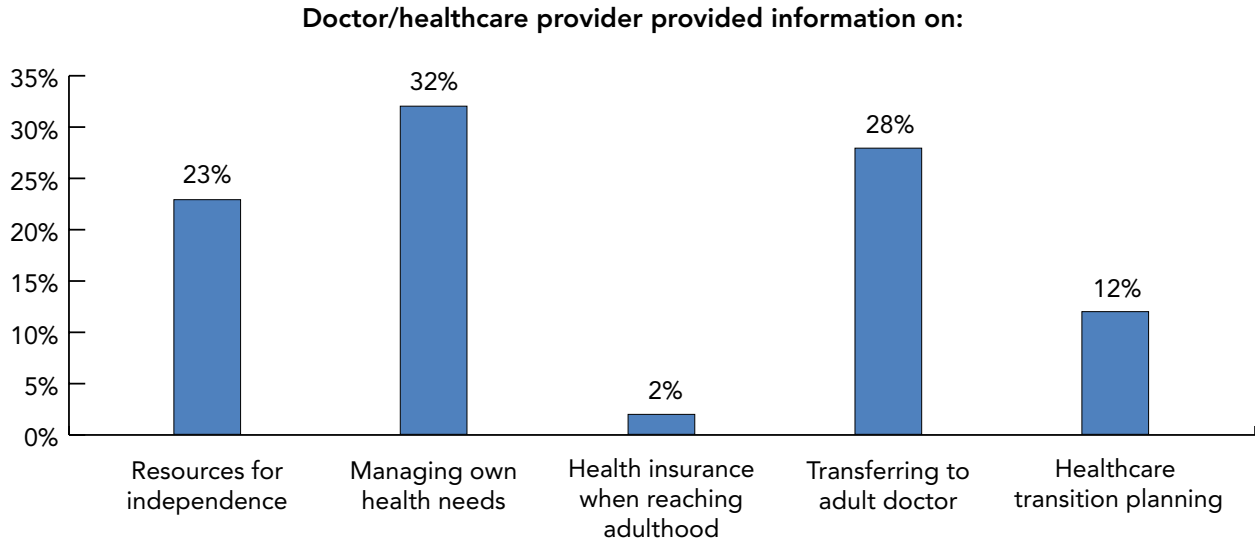
f. Legal Planning Services

Project HEAL (Health, Education, Advocacy, and Law), a project of the Maryland Center for Developmental Disabilities, launched a pilot initiative with University of Baltimore (UB) School of Law. Our first pilot session was conducted on April 11, 2016. The partnership pilot provided UB School of Law professors to speak with Kennedy Krieger's young adult patients, students, and their families about estate planning considerations and decision-making. After the seminar, Project HEAL attorneys and UB law students met individually with attendees regarding their power of attorney, advance directive, and advance directive for mental health. In addition, participants were able to participate in a needs assessment for other legal needs. Evaluation findings from families reflected that all were satisfied with the legal planning seminar for young adults, and reported an increase in knowledge gained from attending the seminar and speaking with representatives about legal planning. Anecdotal feedback from families indicated the importance of initiating legal paperwork to start the process with their youth. Law student evaluations provided information about their interest in providing a needed service for young adults with disabilities and their families. Most felt they were prepared to work with families, and all provided suggestions which will be incorporated into future sessions, such as providing frequently asked questions documents and pre-screening tools for families.

g. Prioritization of Needs

Based on the data reviewed and the meetings attended in the communities, prioritization of identified needs included several considerations. Each priority was considered by the following criteria:

• Community Input ⟶ National ⟶ State Priorities: Does the identified need align with national and state priorities, such as *Healthy People 2020* objectives, Maternal and Child Health Bureau performance measures, and community input from public meetings?

• Responsibility/Capacity: Does the identified need fit within the mission and capacity of Kennedy Krieger?

• Availability of Resources/Feasibility: Do Kennedy Krieger and our partner agencies have adequate resources available and knowledge to address the identified need?

• Magnitude/Severity: By addressing the identified need, is there an impact on the well-being of the community? How do the data and indicators of the identified need compare to those of the nation and other states?

Using the process of prioritization described above, the following priority needs were selected.

h. Priority Needs

i. Healthcare Provider Shortages and Accessibility $\longrightarrow$ *Training*

The Department of Health and Mental Hygiene, Office of Primary Care Access, identifies health professional shortage areas for the state and facilitates professional recruitment and placement in these identified shortage areas. Figure 9 shows that Western Maryland (Garrett and Allegany counties), Southern Maryland (Charles, Calvert, and a portion of St. Mary's counties), and the Eastern Shore experience shortages of health professionals.

Figure 9. Maryland Primary Care Health Professional Shortage Area Designations
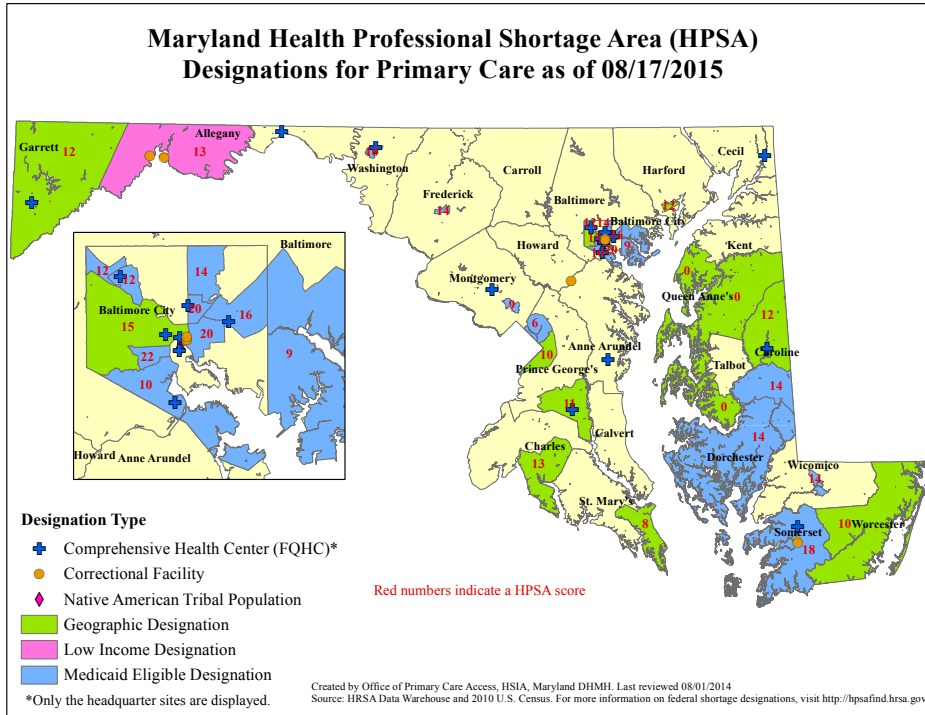
i.b. Training Future Providers – Pre-Service Training

While Maryland has several large academic healthcare entities in the state, including the University of Maryland Medical System and Johns Hopkins Medical Institutions, there are areas of the state with a poor ratio of primary care physicians to population (Figure 10). The top five counties with the highest ratio of patients to primary care physicians include Caroline (3,272:1), Somerset (2,917:1), Cecil (2,825:1), St. Mary's (2,725:1), and Queen Anne's (2,558:1) (County Rankings, 2015).

Figure 10. Primary Care Physicians in Maryland (ratio of provider to client: darker $\longrightarrow$ worst; lighter $\longrightarrow$ best) (Source: County Rankings, 2015)
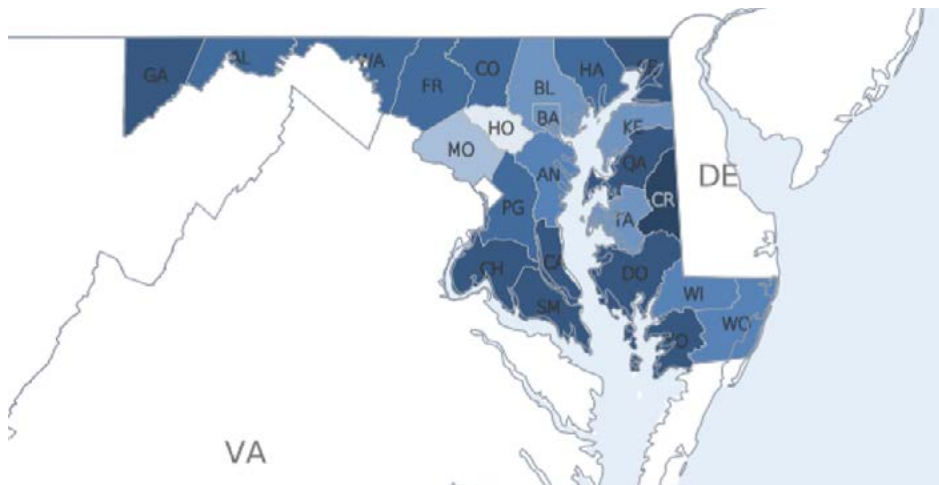
County Rankings (2015) reports the need for mental health providers in Maryland based on the ratio of provider to client (Figure 11). Caroline County (Eastern Shore) and Garrett County (Western Maryland) are the counties most impacted by the poor ratio of mental health providers to patients. As seen in the 2014 MDPS question asking about needed care, mental health and behavioral counseling/support were among the most needed services.

Figure 11. Mental Health Providers in Maryland (ratio of provider to client: darker ⟶ worst; lighter ⟶ best)
(Source: County Rankings, 2015)

Table 3 summarizes the number of active certificates of specialty/subspecialties issued in Maryland through the American Board of Medical Specialties (ABMS). The numbers represent the number of active certificates issued; providers often receive more than one certificate.
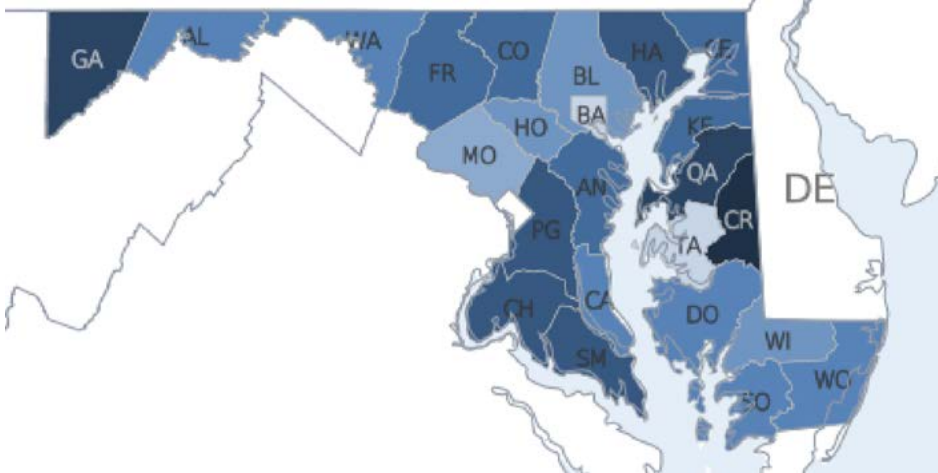
Table 3. Total Number of Active Certificates by Specialty/Subspecialty in Maryland: 2011 Compared to 2013 *(2013-2014 ABMS Board Certification Report)*

Specialty	MD-2011	MD-2013	U.S.-2011	U.S.-2013
Family Medicine – All Areas	1,190	1,274	80,837	85,751
Pediatrics – All Areas	2,476	2,604	79,709	84,387
– Developmental Behavioral Pediatrics	19	18	613	633
– Neurodevelopmental Disabilities	22	18	248	207
Psychiatry: Child and Adolescent Psychiatry	196	246	4,592	2,017

While there has been some growth in the number of active certificates issued between 2011 and 2013, the data do not identify the specific region of the state where the certificates are held nor if a clinically practicing provider uses the active certificate. Thus, using the numbers to trend the number of available providers is not warranted. While other disciplines, such as allied health professions, also represent shortages in our state, data specific to developmental disability specialties are not readily available.

The training programs at Kennedy Krieger focus on building capacity of subspecialty providers in developmental disabilities, integrating disability into community public health practices, and providing community continuing education to increase the knowledge and awareness of health, such as health promotion, wellness, prevention, policy, education, and other areas related to developmental disabilities.

The data on primary care and mental health provider shortages do not indicate provider capacity to serve children, youth, or adults with developmental disabilities. Capacity includes ability and willingness of a provider to serve this population. Prior and current projects have inquired about providers' willingness to learn about and serve persons with behavioral, learning, and other developmental disabilities (Community Resource Mapping Project, funded by Maryland Title V, 2013).

ii. Access to Healthcare

A frequent theme that surfaced at the Maryland Statewide Consortium of Care and Eastern Shore Consortium of Care meetings, through outreach visits to Western Maryland, and from inquiries through the Resource Finder at Kennedy Krieger was the gap in services in rural areas of Maryland and specific specialty service providers. Stakeholders at the statewide and Eastern Shore meetings—both providers and families—expressed needs for specialty services not available in their communities.

Data from local health departments were important to include in this CHNA. Our patients reside in all counties across the state. Basic medical needs, most importantly the social determinants of health, are typically provided in one's own community, where citizens are best served. While the many local health departments receive some level of funding from the state's Title V Agency, OGPSHCN, inclusion of persons with disabilities is not clearly stated in the CHNA Reports of Maryland local health departments. For this report, the assumption is full inclusion for all populations.

Access to care and provider shortage is a priority need reflected in over 50 percent of the CHNA reports reviewed for reference. Based on information gathered from meetings with community stakeholders at the Maryland Consortium of Care and the Eastern Shore Consortium of Care, as well as with a western Maryland health system with which we are exploring telemedicine opportunities, access to services continues to be a barrier and need. The 2014 Maryland Parent Survey also viewed access to care as one of the highest priorities. During the 2011 Priority Poll by OGPSHCN, "access to needed therapies" and "adequate health insurance and financing" were ranked the first and fifth 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.

iii. Advocacy

The work of People on the Go (POG) Maryland and the UB/Kennedy Krieger Initiative on Legal Planning reflect beginning work in Maryland to support greater advocacy for youth and adults with disabilities. Self-advocacy training is beginning with POG through Project STIR (Steps Towards Independence and Responsibility). The training is delivered by persons with and without disabilities, and is designed to empower people with developmental disabilities. It provides the practical, "how to" tools necessary for anyone who is interested in being a self-advocate and leader in making choices and decisions about how they live their lives. The model supports the development and strengthening of local self-advocacy groups through leadership training.

iv. Youth Transition to Adulthood

There remains much work to be done in the area of adolescent healthcare transition. Data from the National Survey of Children with Special Health Care Needs (NS-CSHCN) 2009/10 compares Maryland to national outcomes in transition (Appendix A through Appendix H). In addition, the outcomes become more disproportionate when first adjusted for the presence of emotional, behavioral, or developmental issues, and when adjusted for race/ethnicity. The outcomes are significantly lowered for each variable—youth with emotional, behavioral, or developmental issues and youth of underrepresented populations.

IV. Summary and Implementation Plan

The data presented have been collected, reviewed, and analyzed by multiple stakeholders. This process has been most meaningful in that not just one organization or group has collected the data, but the information has been provided from groups across the state in different forums. A representative from the Maryland State Department of Health and Mental Hygiene, Office for Genetics and People with Special Health Care Needs, has reviewed the needs assessment and provided input from a public health perspective. The top four 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 geography/distance and shortage of providers

- **Advocacy** for families and self-advocates through stronger inter-agency, cross-regional partnership and collaboration, with a special emphasis on the legal rights of transitioning youth

- **Youth transition:** Legal planning and healthcare

Figure 12: Kennedy Krieger Prioritized Needs for 2016 Implementation Plan

Training	Access to Care	Advocacy	Youth Transition
LEND	Telemedicine	Project HEAL	Legal Issues (UB/Project HEAL Initiative)
MCDD	Resource Finder	People on the Go Maryland	
Center for Diversity in Public Health	Community Outreach		Healthcare
Leadership Training			
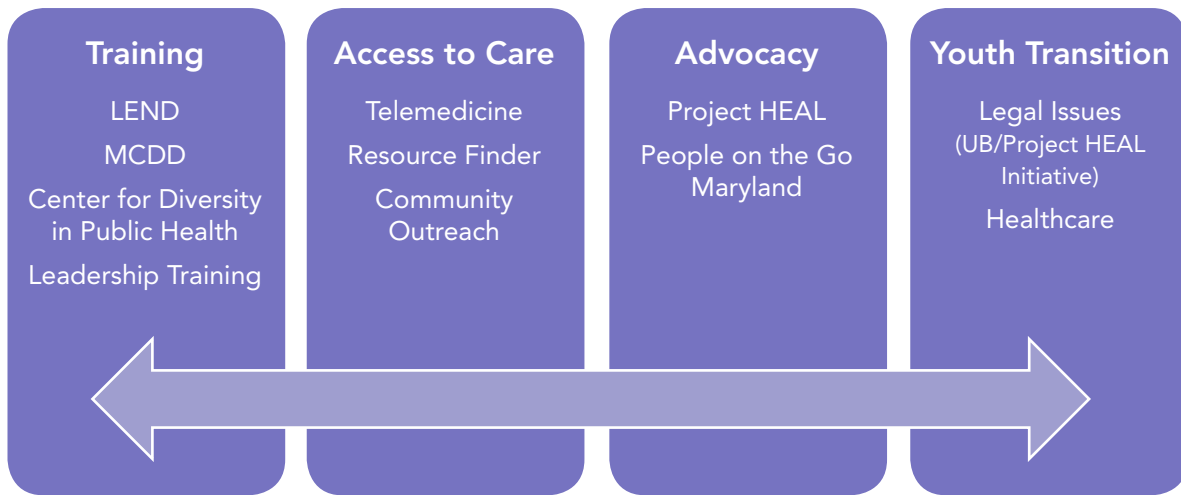
Although progress has been made in creating a powerful advocacy and resource network in Maryland, recurring themes continue to be expressed in public forum groups:

- Knowledge about available resources and services in communities

- Knowledge of providers in communities

- Redundancies in the system

- Challenges experienced by transitioning youth and families (health, education, and work) when accessing services with the youth involved

Stronger public-private partnerships and systematic collaboration across sectors and regions need to be established to maximize the use of existing assets and resources.

Kennedy Krieger Institute 2016 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.	Provide professional pre-service training and continuing education for healthcare professionals through the following programs: • Leadership Education in Neurodevelopmental Disabilities (LEND) Program • Maternal and Child Health Careers/Research Initiatives in Research Enhancements (RISE) Undergraduate Program • James A. Ferguson Fellowship Internship Program (RISE) • Maternal and Child Health Leadership Education, Advocacy, and Research Network (MCH-LEARN) • Maryland Center for Developmental Disabilities (MCDD) Internship Program	Vice President, Training/ Training and Administration Department; Director & Co-Director, Center for Diversity in Public Health Leadership Training Programs (CDPHLT); Director, Maryland Center for Developmental Disabilities	End of each Fiscal Year: 2016, 2017, 2018	Record the number of trainees per program. Conduct follow-up at periodic intervals for two years to assess their employed role in the community or level of progressive matriculation and field.
	Provide one presentation associated with the communities in which we provide telehealth.	Dr. Deepa Menon et al.	Each Fiscal Year: 2017, 2018, 2019	Presentation, documented method of delivery, satisfaction/ evaluations
Increase distance learning offerings	Utilize webinars and videoconferencing to share and disseminate trainings internal and external to the organization.	All applicable programs that offer trainings using distance modalities.	End of each Fiscal Year: 2016, 2017, 2018	Record number of trainings. Identify audience. Provide a link for community access to trainings, as applicable.

Kennedy Krieger Institute 2016 Implementation Action Plan

Objective 2: Access to Care	Action Steps	Accountability	Timeframe	Measure
Improve access to care across Maryland.	Continue and expand community-based telemedicine on the Eastern Shore.	Vice President, Training; Sr. Vice President, Clinical Services and Programs	End of each Fiscal Year: 2016, 2017, 2018	Record services provided through telemedicine: discipline service and type of service—evaluation or follow-up. Record the number of patient visits conducted. Record the patients', providers', and referring physicians' satisfaction with project. Record mileage saved.
	Continue technical assistance and coaching grants in Maryland schools.	Center for Autism and Related Disorders, Eastern Shore personnel	Over next three Fiscal Years: 2017, 2018, 2019	Schools where TA is provided. Number of hours spent in each school.
	Submit a grant proposal with community partners to build capacity of telemedicine services in Maryland rural regions (Southern, Eastern, and/or Western).	Clinical Providers, Kennedy Krieger, and community partners	FY 2017	Award of grant—refer to grant evaluation section of proposal, if funded.
	Resource Finder will serve Maryland communities, to assist in locating resources related to care in their communities.	Senior Director, Community Health Relations	End of each Fiscal Year: 2016, 2017, 2018	Record performance measure, to include number of inquiries (calls, emails, walk-ins), website hits, type of inquirer, reasons for inquiry, satisfaction, county served.
	Explore funding for targeted evaluation activities to determine the effectiveness of resources provided.	Senior Director, Community Health Relations	FY 2018	Award of grant, refer to grant evaluation of proposal, if funded.

Kennedy Krieger Institute 2016 Implementation Action Plan

Objective 3: Advocacy	Action Steps	Accountability	Timeframe	Measure
Increase self-advocacy amongst families, caregivers, and self-advocates (youth and adults).	POG Maryland will conduct train-the-trainer sessions for Project STIR.	Maryland Center for Developmental Disabilities/People on the Go Maryland	FY 2017	Record the number of train-the-trainer trainings. Record region of training. Record number of participants. Record satisfaction with training.
	POG will conduct voter trainings across the state. (Ends November 2016.)	Maryland Center for Developmental Disabilities/People on the Go Maryland	FY 2016 and FY 2017	Record the number of trainings. Record region of training. Record audience (youth, adult, family member, general stakeholder, professional, etc.). Record satisfaction of trainings.
	Provide training to community on topics related to special education law.	Project HEAL	End of each Fiscal Year: 2016, 2017, 2018	Record the number of trainings. Record region of training. Record audience (youth, adult, family member, general stakeholder, professional, etc.). Record satisfaction with training.
	Resource Finder will provide resources related to self-advocacy to self-advocates, families, and providers.	Senior Director, Community Health Relations	End of each Fiscal Year: 2016, 2017, 2018	Record performance measure, to include number of inquiries (calls, emails, walk-ins), website hits, type of inquirer, reasons for inquiry=self-advocacy/independence, resources related to transition, satisfaction with information, county served.

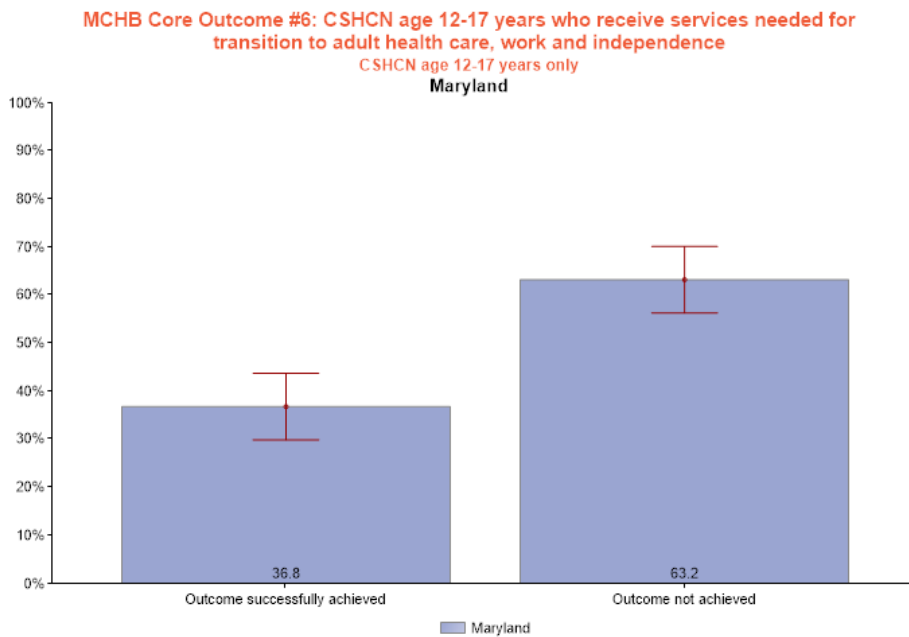## Kennedy Krieger Institute 2016 Implementation Action Plan

Objective 4: Youth Transition	Action Steps	Accountability	Timeframe	Measure
To improve the healthcare transition of youth to adulthood.	Provide resources on healthcare transition for families, healthcare and educational professionals.	Maryland Center for Developmental Disabilities: Resource Finder	End of each Fiscal Year: 2016, 2017, 2018	Record performance measure, to include number of inquiries (calls, emails, walk-ins), website hits, type of inquirer, reasons for inquiry=related to transition, satisfaction with information, county served.
	Project HEAL will provide information to families, youth, and educators regarding transition in Maryland school systems as part of the IEP process.	Maryland Center for Developmental Disabilities: Project HEAL	End of each Fiscal Year: 2016, 2017, 2018	School Transition: Record number of intakes. Record number of consults. Record number of representations.
	Develop pilot program to provide community assistance with legal planning and seek funding to implement.	Project HEAL with community partners	Fiscal Year: 2017	Formal program developed. Award of grant/ funding source (refer to evaluation of proposal, if funded).
	Develop an organizational process to inform and disseminate information to families who have youth approaching transition age.	Administration Senior Director, Community Health Relations	Fiscal Year: 2017, 2018	Develop core work group. Identify age in which to provide notification. Identify transition resources for dissemination. Staff training. Record number of families who are identified monthly. Record MD county of residence. Record number of information packets disseminated monthly.

References

The Annie E. Casey Foundation. Kids Count Data Center. Available at http://datacenter.kidscount.org.

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., ... & Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in U.S. children, 1997–2008. *Pediatrics*, 127(6), 1034-1042.

Catalyst Center. *State-at-a-Glance Coverage and Financing Charts – Maryland*. Available at http://chartbook.cahpp.org.

Dignity Health. *Community Need Index*. San Francisco, CA. Available at http://www.dignityhealth.org/Who_We_Are/Community_Health/212401.

Emerson, E., & Hatton, C. (2009). Socioeconomic position, poverty, and family research. International review of research in mental retardation, 37, 97-129.

Got Transition? Center for Health Care Transition Improvement National Alliance to Advance Adolescent Health. http://www.gottransition.org/

Maryland Department of Health and Mental Hygiene. Primary Care Office. (2011). *2010 Primary Care Needs Assessment*. Baltimore, MD. Available at http://phpa.dhmh.maryland.gov/IDEHASharedDocuments/PCO_Needs_Assessment_11_16_11.pdf

Maryland Local Government. *2010 Legislative Handbook Series*. Volume 6. Annapolis, MD. Available at http://mgaleg.maryland.gov/Pubs/LegisLegal/2010-local-government-handbook-vol-006.pdf

Mmari, Kristin, Dr. PH, MA. "Findings from the 2014 CoC Member Survey." Maryland Community of Care Consortium for Children with Special Health Care Needs. Columbia, MD. 23 Apr. 2014. Presentation.

Office of the Surgeon General (U.S.) (2005). Health and wellness for persons with disabilities today.

Rehabilitation Research and Training Center on Disability Statistics and Demographics (U.S.), National Institute on Disability and Rehabilitation Research (U.S.) & University of New Hampshire. (2015). Annual disability statistics compendium.

Segal, M., Eliasziw, M., Phillips, S., Bandini, L., Curtin, C., Kral, T., ... & Must, A. (2015). Intellectual disability is associated with increased risk for obesity in a nationally representative sample of U.S. children. *Disability and Health Journal*.

U.S. Department of Health and Human Services. Health Resources and Services Administration. (2005). *Core Outcomes: Key Measures of Performance*. Available at http://mchb.hrsa.gov/cshcn05/MI/cokmp.pdf

U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. *Healthy People 2020*. Washington, DC. Available at http://www.healthypeople.gov/2020/about/default.aspx.

U.S. Department of Transportation. Bureau of Transportation Statistics. (200). *Freedom to Travel*. Washington, DC. Available at http://www.rita.dot.gov/bts/sites/rita.dot.gov.bts/files/publications/freedom_to_travel/pdf/entire.pdf
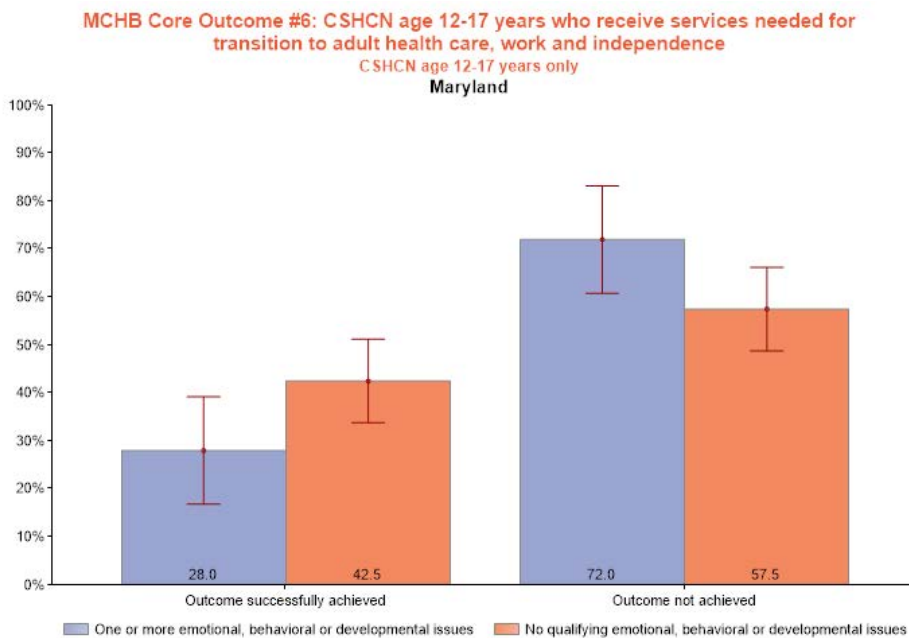
Appendix A.

Children and Youth with Special Health Care Needs Who Receive the Services Necessary to Make Appropriate Transitions to Adult Healthcare, Work, and Independence—Ages 12-17 Years *(Source: NS-CSHCN 2009/10)*

MCHB Core Outcome #6: CSHCN age 12-17 years who receive services needed for transition to adult health care, work and independence
CSHCN age 12-17 years only
Maryland

Outcome successfully achieved: 36.8
Outcome not achieved: 63.2

Legend: Maryland

Appendix B.

Children and Youth Who Receive Services Needed for Transition to Adult Healthcare, Work, and Independence—Ages 12-17, by Emotional, Behavioral, or Developmental Issue (Source: NS-CSHCN 2009/10)

MCHB Core Outcome #6: CSHCN age 12-17 years who receive services needed for transition to adult health care, work and independence
CSHCN age 12-17 years only
Maryland

Outcome successfully achieved: 28.0 / 42.5
Outcome not achieved: 72.0 / 57.5

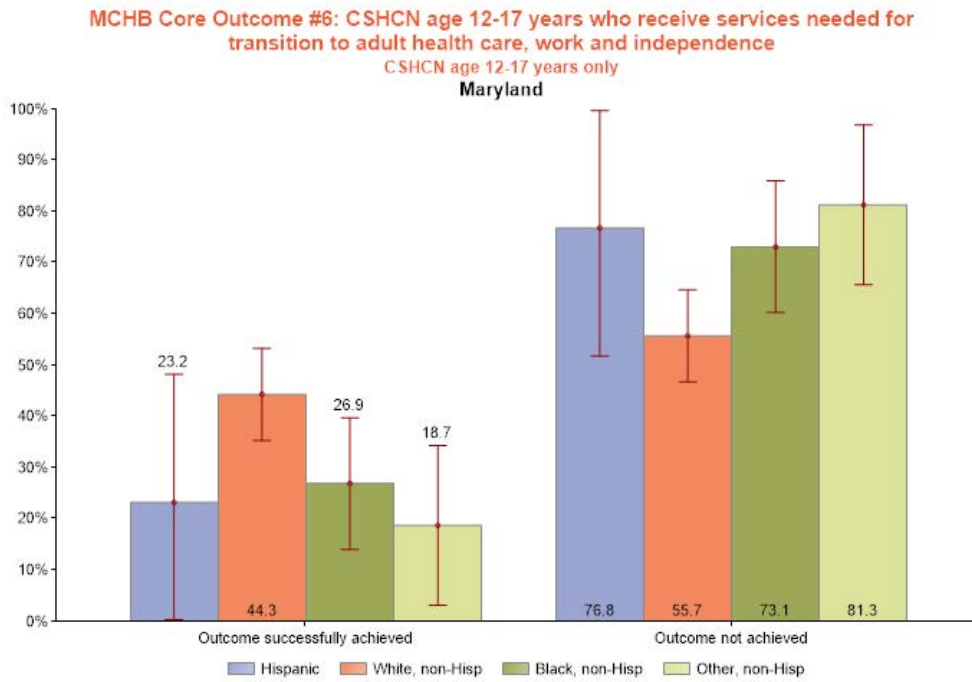Legend: One or more emotional, behavioral or developmental issues / No qualifying emotional, behavioral or developmental issues
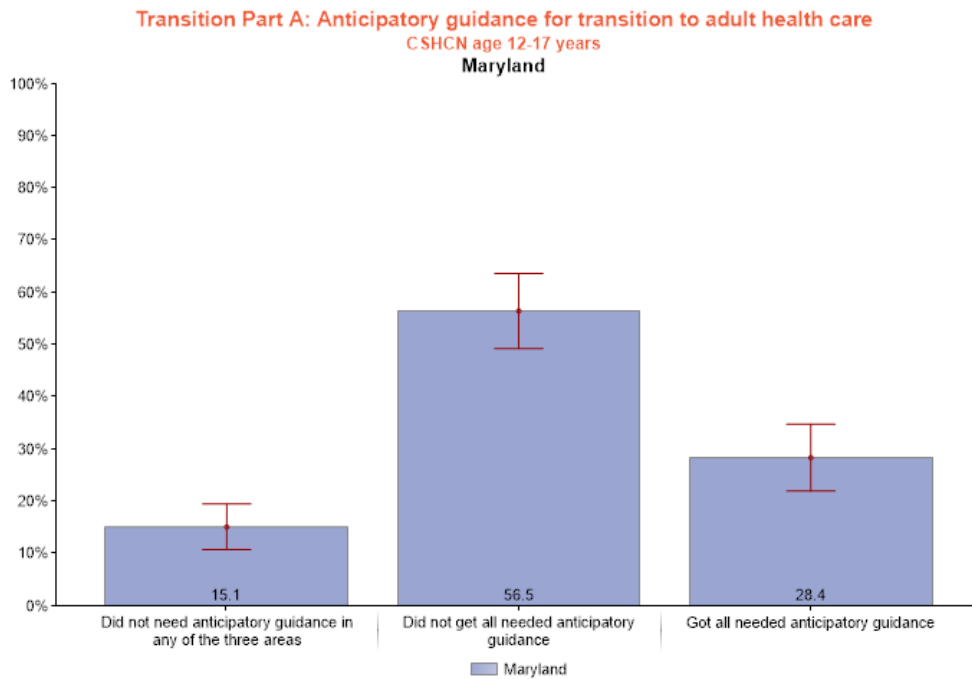
Appendix C.

Children and Youth Who Receive Services Needed for Transition to Adult Healthcare, Work, and Independence—Ages 12-17, by Race and Ethnicity *(Source: NS-CSHCN 2009/10)*
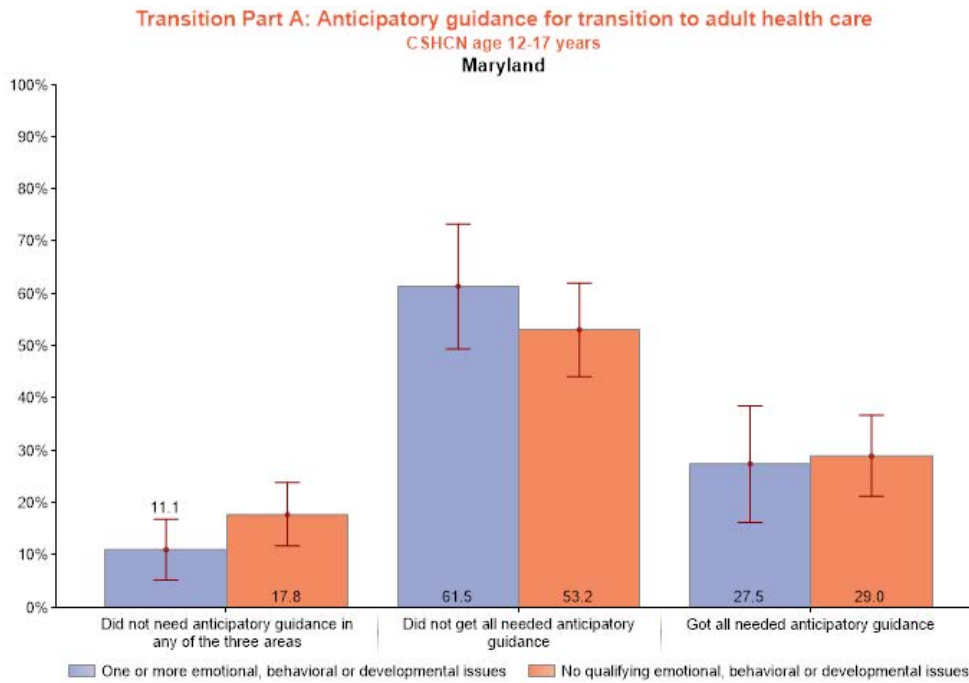

Appendix D.

Transition Part A: Anticipatory Guidance for Transition to Adult Healthcare, CSHCN Ages 12-17 *(Source: NS-CSHCN 2009/10)*

Transition Part A: Anticipatory Guidance for Transition to Adult Healthcare, CSHCN
Ages 12-17, by Emotional, Behavioral, or Developmental Issue *(Source: NS-CSHCN 2009/10)*

Transition Part A: Anticipatory guidance for transition to adult health care
CSHCN age 12-17 years
Maryland

Legend: One or more emotional, behavioral or developmental issues | No qualifying emotional, behavioral or developmental issues

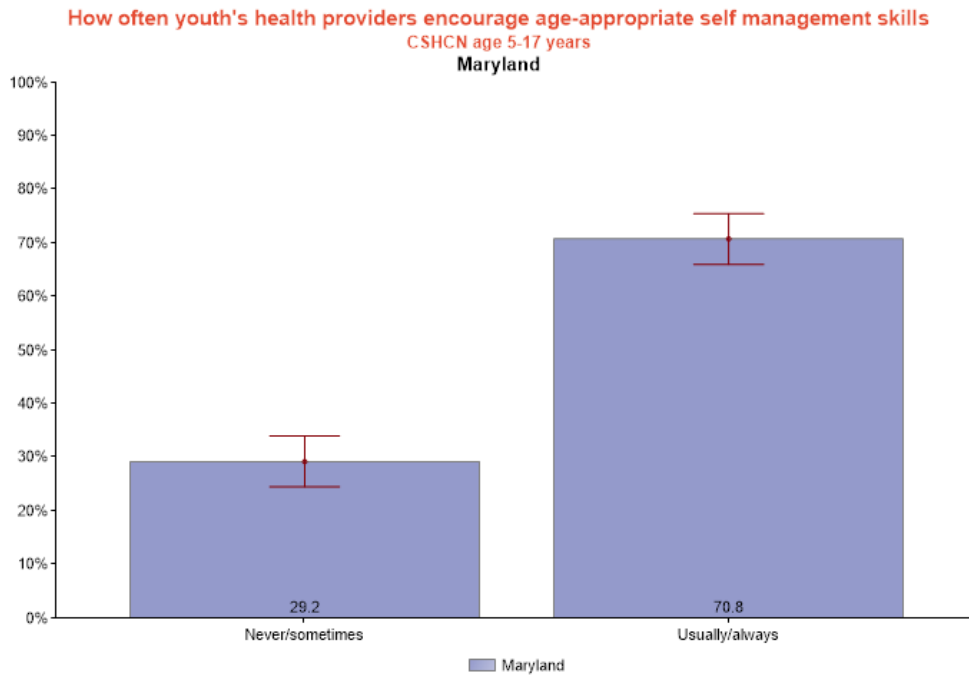**Appendix F.**

Transition Part A: Anticipatory Guidance for Transition to Adult Healthcare, CSHCN Ages 12-17, by Race and Ethnicity
(Source: NS-CSHCN 2009/10)

Transition Part A: Anticipatory guidance for transition to adult health care
CSHCN age 12-17 years
Maryland

Legend: Hispanic | White, non-Hisp | Black, non-Hisp | Other, non-Hisp
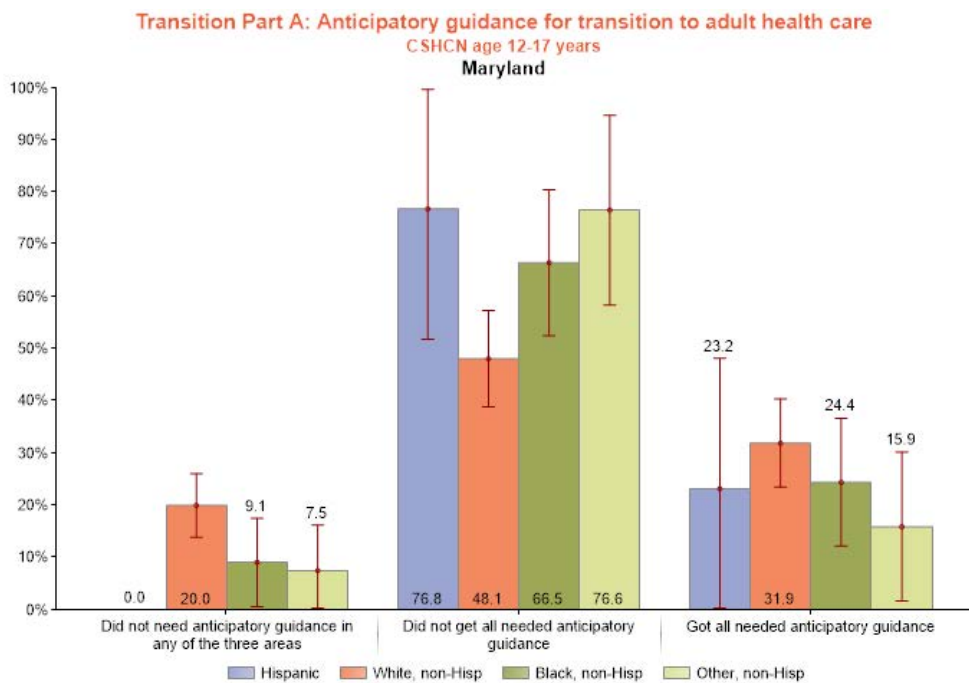
Appendix G.

How often do [child's name]'s doctors or other healthcare providers encourage [him/her] to take responsibility for [his/her] healthcare needs, such as taking medication, understanding [his/her] diagnosis, or following medical advice?
(Source: NS-CSHCN 2009/10)

How often youth's health providers encourage age-appropriate self management skills
CSHCN age 5-17 years
Maryland

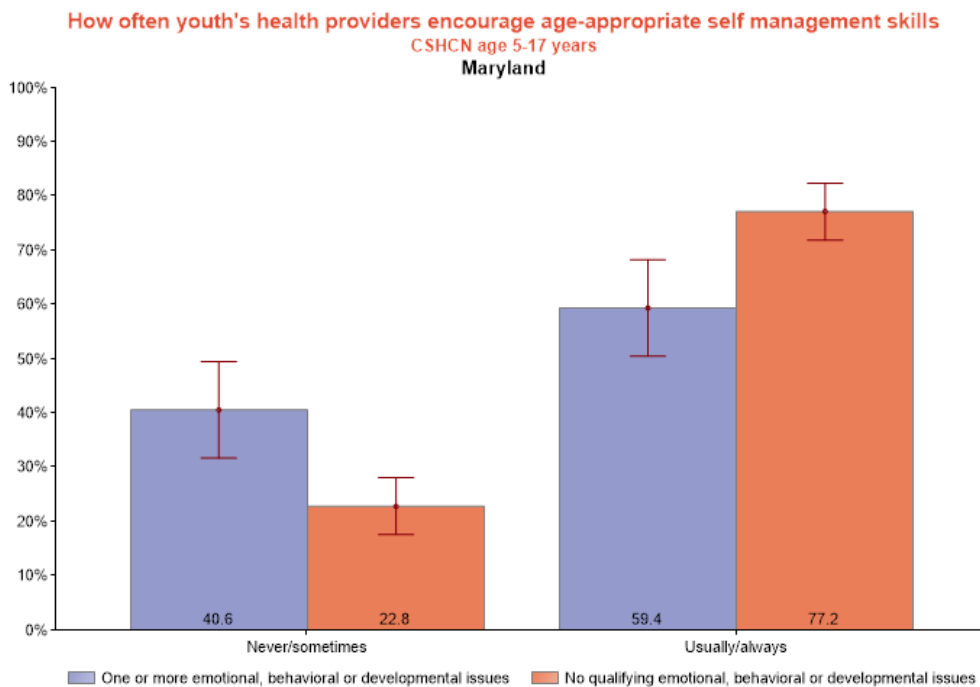|	Never/sometimes	Usually/always
Maryland	29.2	70.8

Appendix H.

How often do [child's name]'s doctors or other healthcare providers encourage [him/her] to take responsibility for [his/her] healthcare needs, such as taking medication, understanding [his/her] diagnosis, or following medical advice? (by emotional, behavioral, or developmental issue) *(Source: NS-CSHCN 2009/10)*

How often youth's health providers encourage age-appropriate self management skills
CSHCN age 5-17 years
Maryland

|	Never/sometimes	Usually/always
One or more emotional, behavioral or developmental issues	40.6	59.4
No qualifying emotional, behavioral or developmental issues	22.8	77.2

Appendix I.

How often do [child's name]'s doctors or other healthcare providers encourage [him/her] to take responsibility for [his/her] healthcare needs, such as taking medication, understanding [his/her] diagnosis, or following medical advice? (by race/ethnicity) *(Source: NS-CSHCN 2009/10)*

How often youth's doctor encourages [him/her] to take age-appropriate responsibility for [his/her] health needs
CSHCN age 12 - 17 years
Maryland

Legend: Hispanic | White, non-Hisp | Black, non-Hisp | Other, non-Hisp
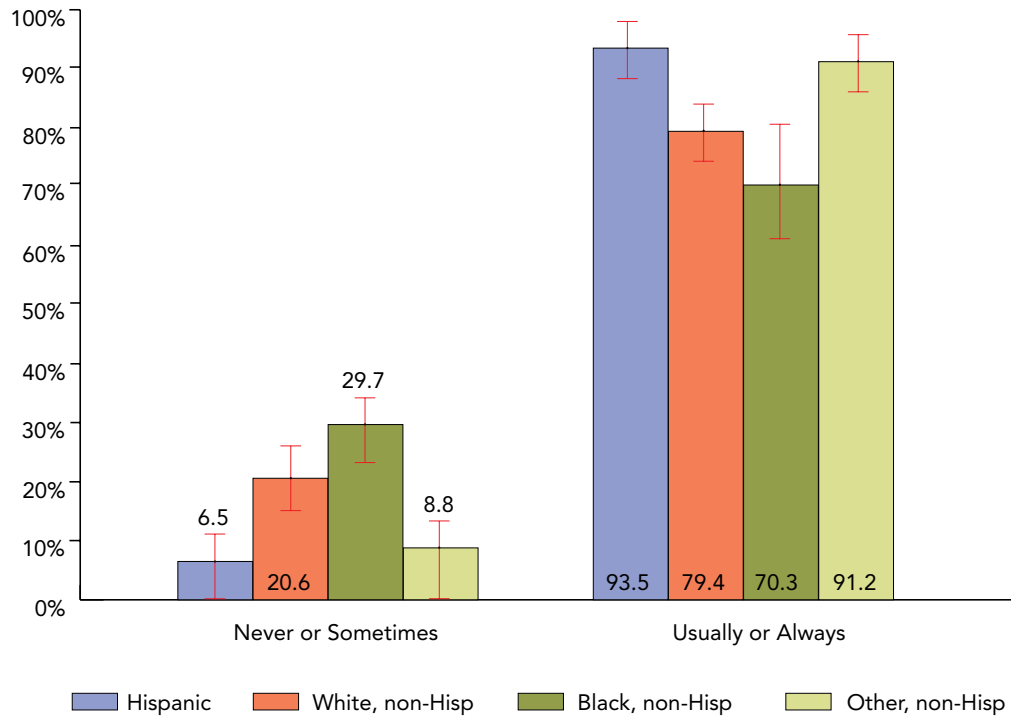
Appendix J. Data Sources and Resources

Agency	Data Sources	Year
Advocates for Children and Youth	Maryland Kids Count Indicators	Various
American Board of Medical Specialties	2012 Certificate Statistics	2013-2014
Data Resource Center for Child and Adolescent Health	National Survey on Children with Special Health Care Needs	2009-2010
Data Resource Center for Child and Adolescent Health	National Survey on Children's Health	2011-2012
Department of Health and Mental Hygiene (DHMH) – OGPSHCN	2015 Comprehensive Needs Assessment for Children and Youth with Special Health Care Needs	2015
DHMH – OGPSHCN & PPMD	2014 Maryland Parent Survey	2014
Health Resources and Services Administration/DHMH, Office of Primary Care Access	Maryland Healthcare Professional Shortage Area / Medically Underserved Area / Population Data	2014
Institute on Disability at the University of New Hampshire	Annual Disability Statistics Compendium	2015
Kennedy Krieger Institute	Internal Patient Demographic Statistics	2013-2015
Kennedy Krieger Institute: Maryland Center for Developmental Disabilities	Pathfinders for Autism Forums on Adolescent Transition	2016
Maryland State Department of Education	Maryland Report on Part B Indicator 8 of the Individuals with Disabilities Education Act (2014-2015)-Parent Survey	2014
Maryland Developmental Disabilities Council	Maryland Developmental Disabilities Five-Year State Plan	2016
Maryland Department of Disabilities	2012-2015 State Disabilities Plan	2012
Rehabilitation Research and Training Center on Disability Statistics and Demographics	Annual Disability Statistics Compendium	2015
Robert Wood Johnson Foundation / University of Wisconsin Population Health Institute	2013 County Health Rankings	2013-present
U.S. Census Bureau	American Community Survey	2011-2014

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

Eastern Shore Community of Care Consortium for Children with Special Health Care Needs
Maryland Center for Developmental Disabilities (Kennedy Krieger)
Maryland Developmental Disabilities Council
Maryland Community of Care Consortium for Children with Special Health Care Needs
Maryland Department of Disabilities
DHMH, Office of Genetics and People with Special Health Care Needs (MD Title V)
Parents' Place of Maryland
Pathfinders for Autism
Project HEAL (MCDD/Kennedy Krieger)
Resource Finder (MCDD/Kennedy Krieger)
Specialized Health Needs Interagency Collaboration (MSDE)

Appendix L. 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
UCEDD University Centers for Excellence in Developmental Disabilities
YTD Year-to-date