Kennedy Krieger Institute

2019 Community Health Needs Assessment

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KennedyKrieger.org

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June 24, 2019

Dear Maryland community,

We are both so very pleased and proud to have assumed new leadership positions at Kennedy Krieger Institute this past year—Brad as president and CEO, and Nancy as chair of Kennedy Krieger's board of directors. We're honored to be part of a vibrant, vital, mission-driven organization staffed by more than 2,800 dedicated colleagues who serve in more than 80 clinical, school and community programs and hundreds of research investigations.

The Institute's mission is to improve the lives of individuals with brain, nervous system and neuromuscular disorders, diseases and injuries. We are grateful for the trust you put in us, and in Kennedy Krieger as a whole, as our goal is to partner with you to achieve the very best outcomes for our patients. Since 1937, the Institute has dedicated itself to collaborating, partnering and building capacity with the community to enhance the health and wellness of Maryland's children and young adults, and their families.

We are happy to present to you Kennedy Krieger's third community health needs assessment (CHNA), and to report that the Institute has met the goals and objectives associated with the 2016 priorities. Currently, with 15 clinical and community sites, Kennedy Krieger continues to explore how it can expand its reach and develop stronger partnerships across the state and within its immediate physical community of East Baltimore.

Institute staff and faculty members worked with the Maryland Center for Developmental Disabilities at Kennedy Krieger—the state's University Center of Excellence in Developmental Disabilities—to conduct an assessment of the needs of the Institute's target populations. As part of this CHNA, and through the collection of this data, we have identified potential new partners with whom Kennedy Krieger can jointly address opportunities to improve outcomes for individuals with emotional, behavioral and developmental disorders and injuries.

The Institute will continue to provide its much-needed services for children, adolescents and young adults as it strives to meet requests from Baltimore City and surrounding communities through partnership opportunities.

Please feel free to send an email to **CommunityBenefit@KennedyKrieger.org** with any questions or comments related to this report.

Sincerely,

Bradley L. Schlaggar, MD, PhD
President and CEO

Nancy S. Grasmick, PhD
Chair, Board of Directors

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Executive Summary

Located in Baltimore, Maryland, Kennedy Krieger Institute is an internationally recognized, comprehensive resource dedicated to improving the lives of children with disorders of the brain, spinal cord and musculoskeletal system, and of children at the greatest risk for acquiring disorders of the developing nervous system, through innovative treatments, life-changing education, groundbreaking research, professional training, powerful community outreach and enlightened advocacy. Kennedy Krieger Institute meets this challenge by serving patients and students throughout childhood and adolescence, starting with evidence-based early recognition and intervention, and continuing through the transition to adulthood.

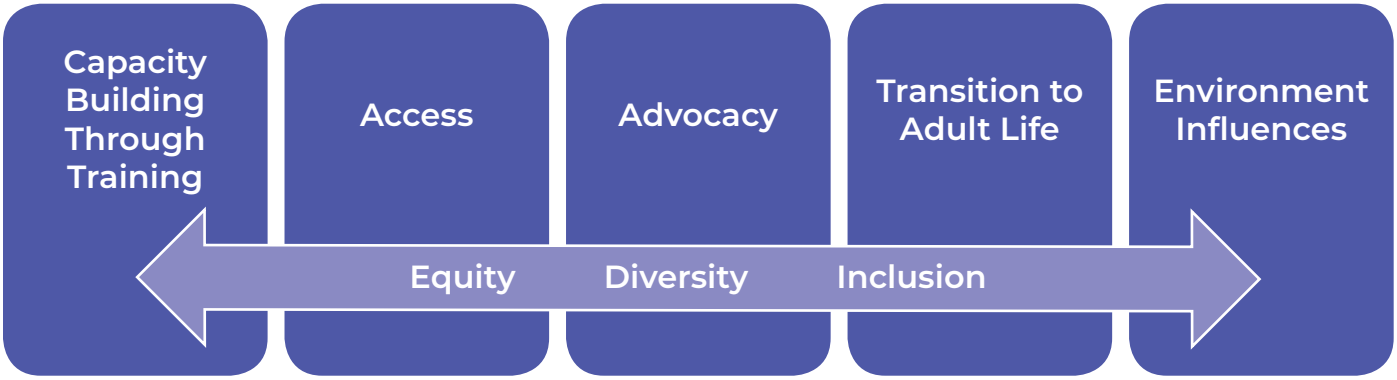
For more than 80 years, Kennedy Krieger Children's Hospital, Inc. (Kennedy Krieger), an affiliate of Kennedy Krieger Institute, has served as Maryland's hidden treasure in providing unique services of the highest quality to individuals with developmental and related disorders and their families.

Kennedy Krieger conducted this most recent community health needs assessment (CHNA) based on data and community information collected and shared by multiple partners. Because the majority of patients and students served by Kennedy Krieger are Maryland residents, with every Maryland county represented, Kennedy Krieger views the state of Maryland as the community it serves, with our anchor in East Baltimore, adjacent to the campus of Johns Hopkins Medicine.

This CHNA focuses on the needs of children and young adults with developmental disabilities, and on those at the greatest risk for acquiring disorders of the nervous system resulting from the social determinants of health. It also focuses on the families of these children and young adults, and on the community of providers who may have an impact on the lives of those whom we serve.

The graphic below identifies the top priority areas of need identified through conducting this CHNA. Solutions to address these areas of need will be implemented through new and existing community partnerships.

Addressing Community Priorities for Individuals With Disabilities Through Partnerships



Introduction

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.

We recruit the most talented and compassionate clinicians, scientists and educators to provide the best care and family support. Our approach is child- and family-centered and interdisciplinary, to ensure that children with conditions affecting the nervous system have access to all the resources—treatments, education and community programs—they need 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 $258 million, and the hospital's budget is $166 million. A financial audit was performed for fiscal year 2018, and the resulting report was issued on September 27, 2018, by PricewaterhouseCoopers, LLP.

The Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger is Maryland's University Center for Excellence in Developmental Disabilities (UCEDD), one of 67 UCEDDs across the country. MCDD serves as the statewide community agent for pre-service and continuing education training, community service and technical assistance, research and evaluation, and information dissemination to the community. MCDD determines its focus by assessing strengths and gaps, to assist in addressing priorities with Maryland stakeholders. Kennedy Krieger works with MCDD and other community stakeholders to conduct a comprehensive community health needs assessment (CHNA) focusing on the population served. People On the Go Maryland, a citizens-with-disabilities self-advocacy group, is a project of MCDD that partners with other developmental disability organizations in Maryland to support specific state legislation that enhances the lives of individuals with disabilities.

Kennedy Krieger Institute offers more than 50 different outpatient clinics, three inpatient units, several home and community programs, and clinical laboratories, all addressing hundreds of conditions and diseases, ranging from autism spectrum disorder (ASD) and attention deficit hyperactivity disorder to more rare diseases like adrenoleukodystrophy and Duchenne muscular dystrophy. The hospital serves patients and families from our immediate neighborhood as well as communities across the state, country and world. Through research, the Institute addresses new approaches in neuroscience and technology to address the immediate needs of the Maryland community and enhance the services and curriculum provided. We educate and support more than 500 Maryland school students with unique needs every year, from elementary through high school. Our Maryland community programs include not only MCDD, but also day care services for medically fragile children, prekindergarten classes, a therapeutic nursery embedded in a family shelter in Baltimore City, and training workshops covering topics such as child care, advocacy and legal issues, reaching parents, caregivers and professionals across Maryland.

Our Structure

A Maryland treasure, Kennedy Krieger Institute, Inc. (the parent organization) comprises several sub-entities: (1) Kennedy Krieger Children's Hospital, Inc.; (2) Kennedy Krieger Education and Community Services, Inc.; (3) Hugo W. Moser Research Institute at Kennedy Krieger, Inc.; and (4) PACT Helping Children with Special Needs, Inc.

Since our beginning in 1937, Dr. Winthrop Phelps, the organization's founder, and his colleagues understood that by bringing together the disciplines of medicine, therapy, research 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 interact with individuals with disabilities; and helping to foster interdisciplinary understanding of developmental disabilities in the medical school, the university and the community.

While the CHNA is conducted as a requirement of Kennedy Krieger Children's Hospital, Inc.'s tax-exempt status under the Patient Protection and Affordable Care Act (ACA), all of our entities are uniquely integrated. Kennedy Krieger Institute affiliates support one another to accomplish the mission of transforming the lives of children and young adults with disorders of the nervous system through groundbreaking research, innovative treatments and life-changing education. Although the original mission sought to transform that environment by developing new treatments and therapies and new approaches to integrating

children with special needs into the community, we continue this journey today, in 2019, through a refreshed lens, as part of our upcoming strategic plan and our 2019 CHNA Implementation and Action Plan.

The healthcare sector of our organization provides services by well-qualified professional staff members through an established interdisciplinary model. We offer inpatient, day treatment and outpatient programs across multiple service delivery models. The organization serves persons with a variety of developmental disorders and injuries. Our most frequent outpatient diagnoses for the last fiscal year (2018) included attention deficit hyperactivity disorder, conduct disorder, mixed receptive-expressive language disorder and ASD. During the last three fiscal years (2016–2018), Kennedy Krieger averaged 350 inpatient admissions. Inpatients and outpatients served are predominantly between the ages of 5 and 12 years old. The racial and ethnic composition of Kennedy Krieger's patients closely resembles Maryland's population, according to the 2017 population estimates of the U.S. Census.

Table 1. Kennedy Krieger Outpatient Demographics (Source: Kennedy Krieger Institute)

	Unique Outpatients at Kennedy Krieger Institute			Maryland Population	
	Fiscal Year 2016	Fiscal Year 2017	Fiscal Year 2018	All Marylanders (Source: U.S. Census, 2017 Population Estimates)	Marylanders Under 18 Years Old (Source: U.S. Census, 2017 Population Estimates)
Total	22,597	23,895	24,348	5,996,079	1,347,613 (22.5%)
Age					
0–2	8%	7%	8%		
3–5	17%	16%	16%		
6–8	19%	19%	19%		
9–11	17%	18%	18%		
12–14	15%	14%	14%		
15–17	10%	11%	11%		
18–20	5%	5%	5%		
21+	9%	9%	9%		
Race					
White, not Hispanic or Latino	48%	48%	47%	51.9%	43.2%
Black	32%	30%	30%	29.3%	31.5%
Hispanic	4%	5%	5%	9.6%	14.1%
Native Hawaiian/ Pacific Islander	0.3%	0.5%	0.3%	0%	0%
Asian	3%	4%	4%	6.2%	5.7%
Two or More Races/Other	7%	7%	8%	2.9%	12.5%
American Indian or Alaska Native	0.15%	0.2%	0.15%	0.2%	0.2%
Unknown	5%	5%	6%		
Sex					
Male	64%	64%	64%		52%
Female	35%	36%	36%		48%

Compared to the 2016 CHNA, the age distribution of unique Kennedy Krieger patients has remained essentially unchanged, as has the racial and sex composition. Kennedy Krieger outpatient programs have seen approximately 1,750 more unique patients in 2018, as compared to 2016 data trends (Table 1). While the Maryland sex distribution of persons less than 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 data found in the literature.[1]

The Intellectual and Developmental Disabilities Research Center (IDDRC) at Kennedy Krieger Institute and The Johns Hopkins University supports research to help children, adolescents and adults with intellectual and developmental disorders achieve their potential and participate as fully as possible in family, school, work and community life. One of 14 IDDRCs funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) throughout the U.S., our center has been central to a scientific enterprise involving hundreds of investigators working to understand and address the problems of developmental disabilities. Since 1987, the IDDRC has been the nucleus of a larger program of research supported through the Hugo Moser Research Institute established within Kennedy Krieger Institute, in collaboration with affiliated programs throughout The Johns Hopkins University's academic community. The strengths of this community provide enormous opportunities for translational research relevant to developmental disorders, with internationally recognized expertise and infrastructure well-suited to the task of moving knowledge along the continuum, from labs to clinics to the community. Kennedy Krieger Institute, which is dedicated to research, clinical care, training and education in support of individuals with disorders of the brain, spinal cord and musculoskeletal system, is uniquely situated to house this IDDRC, leveraging active collaboration with the Institute's University Center for Excellence in Developmental Disabilities (UCEDD) and the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs.

As a training institution, Kennedy Krieger provides extensive interdisciplinary training opportunities for families, students and professionals from all educational levels and multiple disciplines. Kennedy Krieger is home to one of 52 LEND programs across the U.S. and its territories. Through fellowships and internships, we dedicate resources to training the next generation of diverse healthcare professionals, researchers and educators in the fields of neurological and developmental disabilities. Annually, we train more than 1,000 individuals, for time periods ranging from three months to four years. In addition to offering training opportunities and experiences, Kennedy Krieger sponsors and conducts local, regional and national training events, both in person and through live webcasts and webinars. In 2019, the Institute will hold its ninth annual "Room to Grow: Journey to Cultural and Linguistic Competency" conference, which is open to the public and webcast live on the internet.

Kennedy Krieger School Programs offers special education and related services to students ages 3 to 21 in multiple day-school settings: (1) kindergarten–eighth grade, (2) high school, (3) an intensive 12-month special education program serving students ages 5 to 21 with a primary diagnosis of ASD or other related disorder, and (4) public school partnership settings. Our high school educational programming prepares our high school students to transition back to their communities and into adulthood. During the 2017–2018 school year, Kennedy Krieger School Programs enrolled 501 students and delivered more than 64,000 clinical, direct-service sessions of speech-language pathology, occupational therapy, counseling, physical therapy, expressive therapy and case management contacts. Disorders served include ASD, learning disabilities, speech-language disorders, orthopedic disabilities, traumatic brain injury and intellectual disabilities. Many of the students served have other and/or multiple disabilities.

Kennedy Krieger engages in community initiatives that enhance the lives of children, and their families, within Baltimore and in communities across the state of Maryland, who are at the greatest risk for acquiring disorders of the nervous system. PACT, an affiliated program of Kennedy Krieger, offers young children and their families hope when they have nowhere else to turn. Ensuring that all children get the proper start in life is the goal that has been driving PACT since 1981. PACT's mission is to ensure all children have a good start in life. PACT offered services to 210 children and parents in fiscal year 2018 through two specialized programs: the World of Care medical child care center, which serves as the only child care center in Central Maryland for young children with complex healthcare needs requiring daily nursing interventions, and the Therapeutic Nursery, for children and families living in family shelters in Baltimore City. PACT has worked extensively in seeking ways in which to replicate its child care and parenting models through community partnerships, as summarized in Table 2.

Table 2. PACT Community Partners and Projects (Source: PACT Project Partnerships)

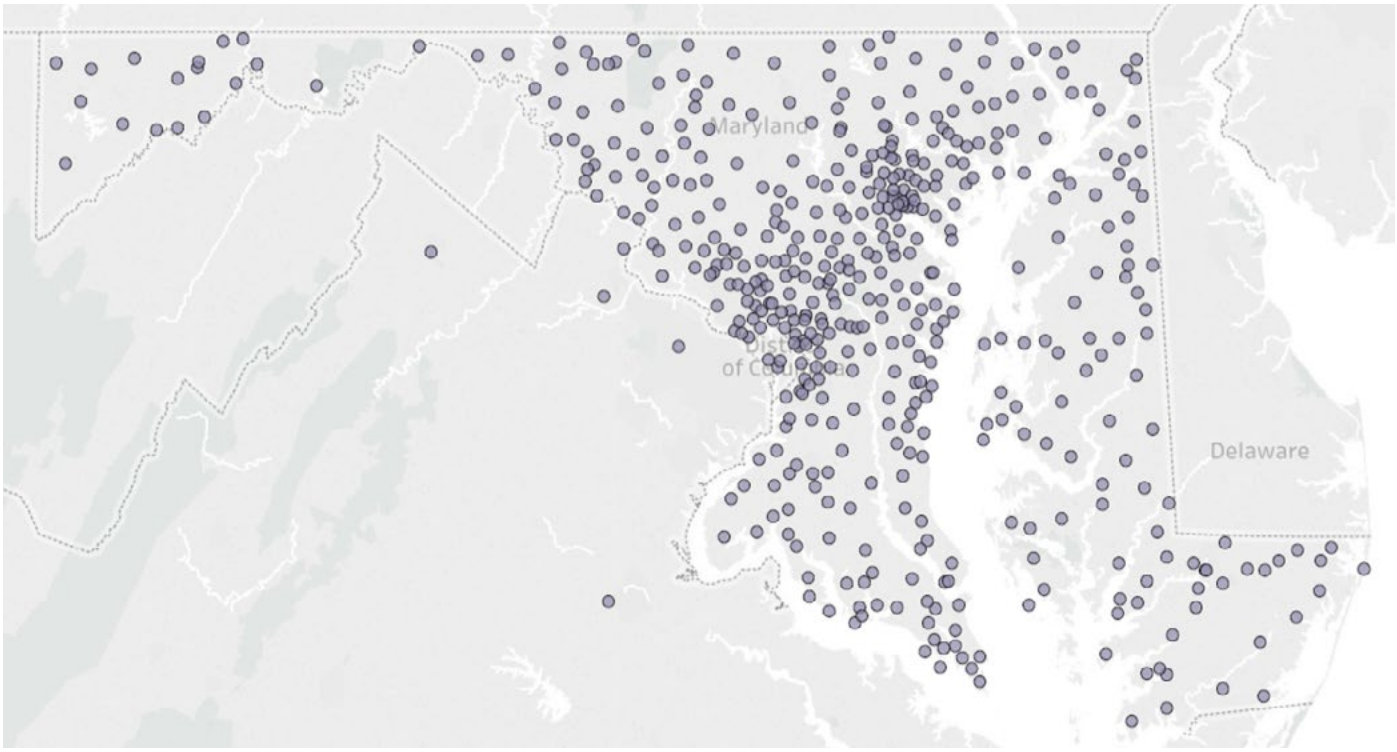
Partnership Agency	Project
Maryland Family Network	Therapeutic Nursery Early Head Start
Bon Secours Early Head Start	Child Care Replication Project
University of Maryland	B-More Succeeds
Developmental Disabilities Council of Maryland	Expanding Daycare Inclusion through Coaching
United Way	Ben Franklin Family Center

Serving as the core foundation of the Institute's community programs, MCDD assists in linking the needs of the population served with advocacy and policy. Today, creation of new programs serves 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 leadership and all staff members as they meet the opportunities and needs of the Maryland community.

The Community We Serve

Kennedy Krieger Institute serves children, adolescents and adults from Maryland, across the U.S., and internationally. Data analyzed during the last three fiscal years—2016, 2017 and 2018—indicate that an average of 60% of all inpatients and an average of 87% of 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. Under new leadership in 2018, while Kennedy Krieger will continue to serve individuals with various types of disorders of the brain, we understand the environment impacts brain development of many children across Maryland. By continuing our investment in Maryland, and particularly with our immediate neighbors, we seek opportunities through partnerships to improve the health of our community.

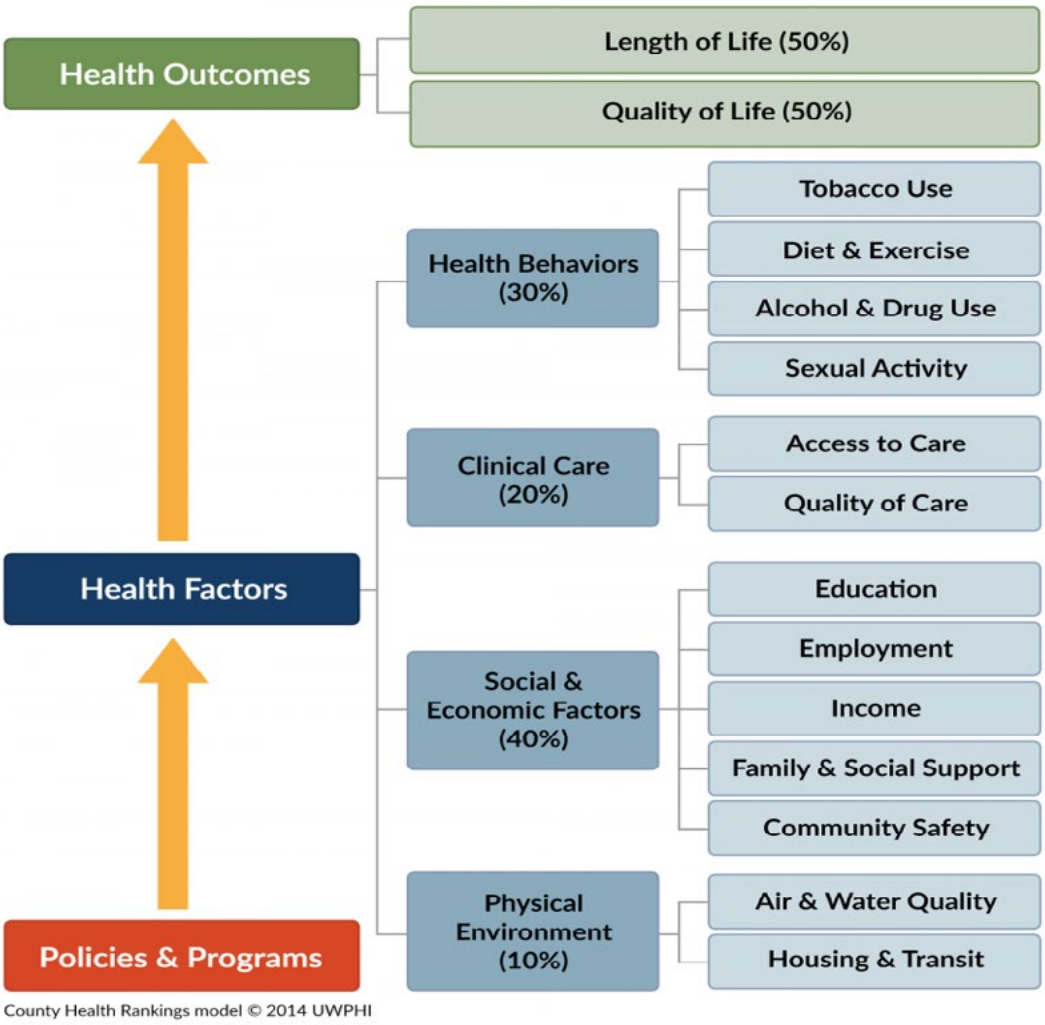
Figure 1. Outpatient Population Distribution by ZIP Code, Fiscal Years 2016, 2017 and 2018 (Source: Kennedy Krieger Institute)



Map based on ZIP code. Density represents number of records.

Knowing what affects the health of the population we serve means understanding the needs and opportunities essential to achieving health equity for individuals with disabilities. Health disparities emerge among people with disabilities because of less access to opportunities and resources over a lifetime and across generations, and are even more exacerbated by adding race/ethnicity, gender and social determinants of health. The differences often result from policies and practices at many levels that create barriers to good health.[2] Approaches such as universal design and maximizing opportunities offered by technology like telemedicine are solutions that can help us move toward health equity.[3]

Figure 2. County Health Rankings Model, 2014 (Source: University of Wisconsin Population Health Institute)



Target Population

Our target population includes children, adolescents and adults with disabilities and those at the highest risk for disorders of the nervous system. In Maryland, 19.2% of children 0 to 17 years of age have a special healthcare need, as adopted by the Health Resources and Services Administration.[4] These include children and youth who, along with their families, often need services from multiple systems—healthcare, public health, education, mental health and social services. Narrowing the focus, we know that approximately 12 to 15% of U.S. children experience developmental delays or disabilities, which range in severity and scope from isolated delays in achieving certain developmental milestones to functional impairments in hearing or vision, as well as diagnosable learning, emotional and behavioral disorders.[1] In exploring community needs, the focus is on those served across all entities of Kennedy Krieger Institute.

As a comprehensive specialized healthcare institution, we strive to impact health outcomes through many of the categories identified in the County Health Rankings model. The category areas include health factors, and policies and programs. Specific health factors addressed through this assessment include (1) health behaviors, (2) clinical care—access to care and quality of care, and (3) social and economic factors of special education services, or access to special education information, employment opportunities for those with neurodiverse profiles and those who reside in our immediate neighborhood, and the provision of family and social supports embedded in our services.

Approach/Methodology

Because multiple organizations within Maryland and across the U.S. are mandated to conduct their own CHNA, in an effort to streamline the data-collection process for our CHNA and collaborate with community partners, Kennedy Krieger used existing data sources and participated in community meetings in which 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 nonstandardized qualitative input from participation in public community meetings. Approaches and collection of information differ across Maryland's regions, given the diversity of stakeholders and communities involved.

Description of Selected Resources Used in Collecting Data

For the 2019 CHNA, some of the data used to derive the priority areas are noted below. For a comprehensive listing of data sources, reference Appendix 1: Data Sources and Resources.

1. U.S. Census Data
2. 2017 Maryland Parent Survey, conducted by the Maryland Department of Health Office for Genetics and People with Special Health Care Needs and Parents' Place of Maryland
3. Maryland Report on Part B Indicator 8 of the Individuals with Disabilities Education Act 2016–2017, conducted by ICF International for the Maryland State Department of Education Division of Special Education/Early Intervention Services
4. 2017 Maryland Transitioning Youth Survey, conducted by the Maryland Developmental Disabilities Council and Parents' Place of Maryland
5. Maryland Department of Disabilities' State Disabilities Plan 2016–2019
6. County Health Rankings and Roadmaps 2019
7. Participation in the Maryland Statewide and Maryland Eastern Shore Consortium of Care Quarterly Meetings
8. Kennedy Krieger Institute Patient/Student Demographic Statistics 2016–2018
9. Healthy People 2020
10. The Annual Disability Statistics Compendium 2018
11. American Board of Medical Specialties (ABMS) 2017–2018 Board Certification Report
12. Data Resource Center for Child & Adolescent Health: National Survey for Children's Health 2016–2017

Data Gaps

While the sources of data related to children and youth with special healthcare needs (CYSHCN), and specifically to those with disabilities, appear vast, actual organized data are limited. Inclusion of the most relevant, up-to-date data for analysis of a comprehensive needs assessment of the Maryland community occurred, although the following data gaps and limitations exist across data sets: inconsistent definitions of conditions, age groupings and geographic boundaries among different indicators; data for some indicators are available only for national and/or state levels; and information about access to and awareness of resources continues to be a topic of many meetings across communities. While there are multiple information resource programs serving Maryland and certain counties, not one fulfills the need of any one community.

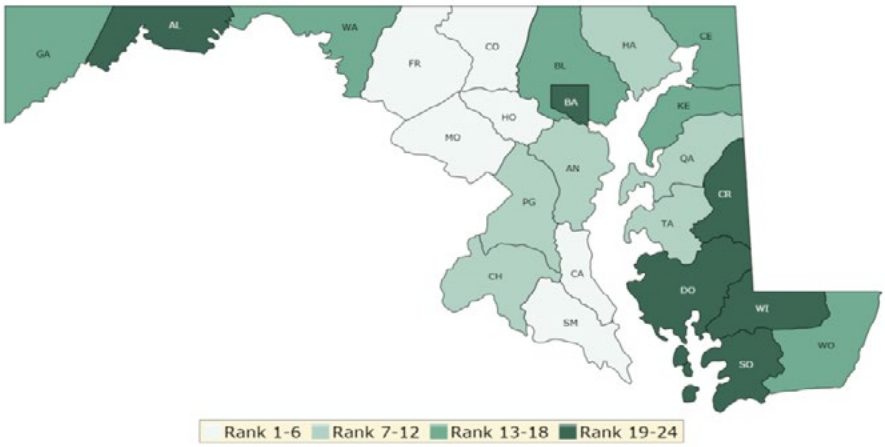
What the Data Tell Us

Health Outcomes: Maryland Health Outcomes and Factors

County Health Rankings and Roadmaps[2] is a partnership between the Robert Wood Johnson Foundation (RWJF) and the University of Wisconsin. The County Health Rankings are influenced by policies and programs, and measure health factors that drive health outcomes. The County Health Rankings provide us with an overview of the health of the communities in which our target population resides in order to 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 data provide a starting point for communities as they work to improve the health and wellness of their citizens. Most importantly, the County Health Rankings offer strategies that guide communities toward action to improve health by working together.

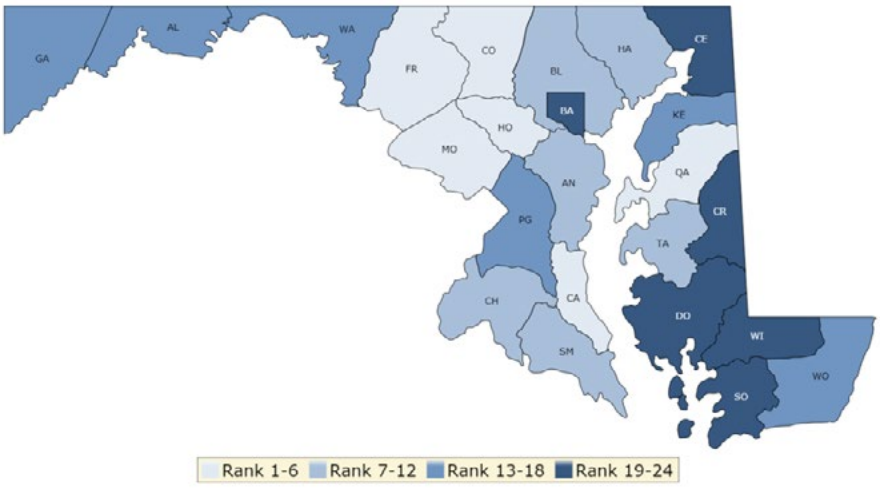
For counties presenting with the worst health status, individuals with disabilities may experience the worst health outcomes. Baltimore City ranks as the lowest jurisdiction for health outcomes in the state (Figure 3). Health outcomes measure how long people live and their quality of life. Factors influencing health include individual characteristics and behaviors, family, community, health, service delivery and other sectors, including education, social assistance, housing and labor.

Figure 3. Maryland Health Outcomes, County Health Rankings, 2019 (Source: University of Wisconsin Population Health Institute)



Maryland's Eastern Shore counties and Baltimore City have the lowest health factor measures compared to other Maryland counties. Somerset County, located on the far Eastern Shore of Maryland, ranks the lowest for health factors that measure how long and how well we live. Those factors are health behaviors (tobacco use, diet and exercise, alcohol and drug use, sexual activity), clinical care (access to care, quality of care), social and economic factors (education, employment, income, family and social support, community safety), and the physical environment (air and water quality, housing, transit) (Figure 4).

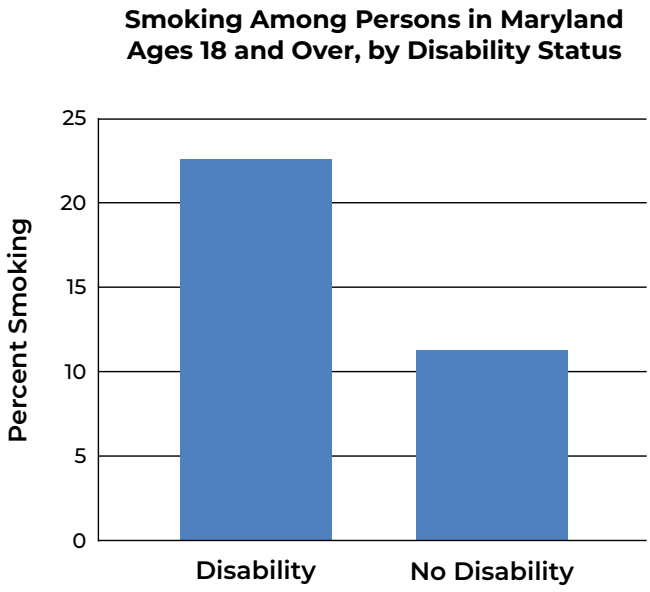
Figure 4. Maryland Health Factors, County Health Rankings, 2019 (Source: University of Wisconsin Population Health Institute)



Health Factors: Health Behaviors

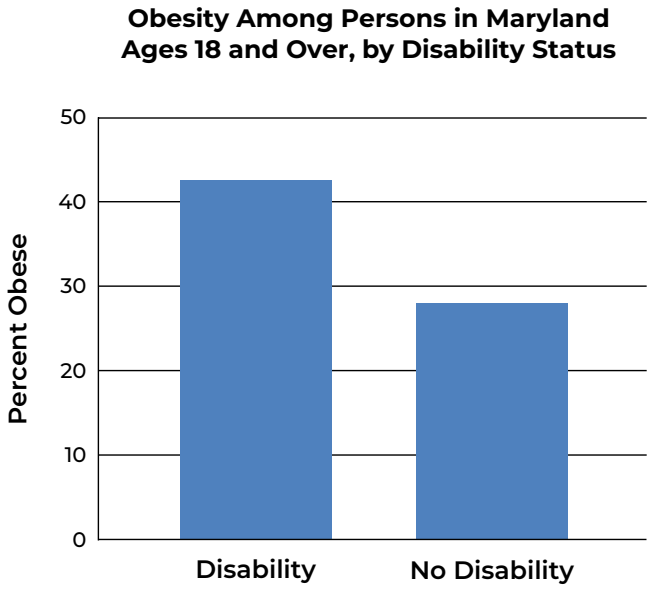
The Annual Disability Statistics Compendium for 2018[5] measured several health behaviors specific to individuals with disabilities. Health behaviors contribute to 30% of an individual's health outcomes. The health behaviors measured in this compendium include smoking (tobacco use), obesity (diet and exercise) and binge behaviors (alcohol and drug use). Individuals over 18 years old with disabilities are more likely to smoke (24.3%) than adults without disabilities (13.5%) (Figure 5).

Figure 5. Health Behavior: Smoking Among Persons in Maryland Ages 18 and Over, by Disability Status, 2017 (Source: Annual Disability Statistics Compendium, 2018)



Obesity, a major public health crisis and a Centers for Disease Control and Prevention (CDC) "winnable battle," is disproportionately high among individuals with disabilities.[6,7] Individuals over 18 years old with disabilities are more likely to be obese (42.6%) than adults without disabilities (28.0%) (Figure 6). Prevention of excessive weight gain and obesity should be a focus for health professionals serving people both with and without disabilities.

Figure 6. Health Behavior: Obesity Among Persons in Maryland Ages 18 and Over, by Disability Status, 2017 (Source: Annual Disability Statistics Compendium, 2018)

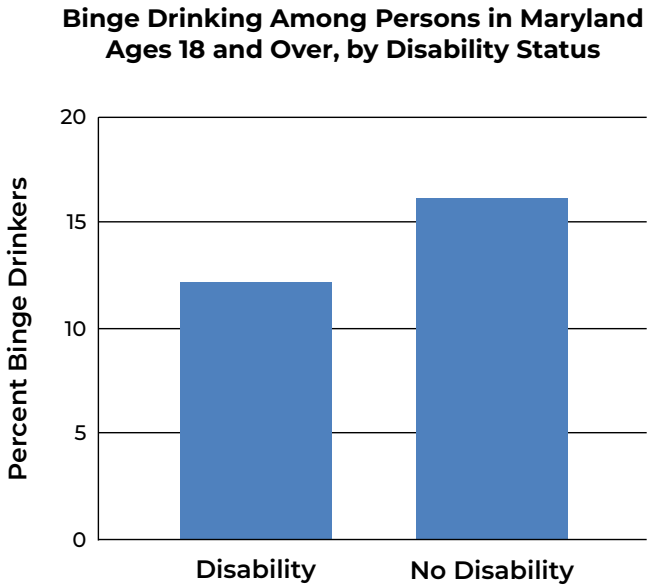


Typically, our assumptions about binge drinking and drug use are not associated with individuals with developmental disabilities. The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) issued a request for information in 2018 on people with disabilities and opioid use disorders. While the information sought did not specifically inquire about binge drinking, the information retrieved indicated that little is known about the prevalence of binge drinking and/

or drug/opioid use among those with disabilities. In a recent study, an association was identified between frequency of prescription medication use, sensation seeking and binge drinking with unintentional death due to drug poisoning and overdose.[8] A significant portion of these preventable deaths was directly related to opioid use. Maryland ranks in the top five states for opioid-related overdose death rates, with the largest increase attributed to cases involving synthetic opioids in Maryland. While the opioid-prescribing rate is declining, the overdose death rate involving prescription opioids is increasing, with Maryland's low-income rural communities, i.e., communities in western Maryland, being the hardest hit.[9]

Several devastating consequences of Maryland's rising opioid use are the effects it can have on infants born to women with substance abuse disorders, including opioid use disorders, and on adolescents who are increasingly experiencing injuries and stressors that are more frequently resulting in interventions that manage pain with opioids. The importance of our Healthy People 2020 objectives for maternal, infant and child health will be discussed in this assessment. The current opioid crisis further compounds the health status of mothers and infants, thus placing these infants and children at a greater risk for acquiring neurodevelopmental disorders. Attention to young adults engaging in alcohol or opioid use and mothers' use of opioids is of concern. Our expertise is in the effects opioid use has on the developing brain, and this is an area of public health in which we are very committed. Kennedy Krieger's alternative approach to pain management, only one method to prevent the abuse of opioids, starts during childhood and adolescence, with the goal of reducing adult addiction and associated mental health issues.

Figure 7. Health Behavior: Binge Drinking Among Persons in Maryland Ages 18 and Over, by Disability Status, 2017 (Source: Annual Disability Statistics Compendium, 2018)



Health Factors: Clinical Care

Clinical care contributes to approximately 20% of our health outcomes. The County Health Rankings model includes access to care and the quality of care rendered. Healthy People (HP) 2020,[10] however, made two points quite clear: (1) the health of people with disabilities is often perceived inaccurately, and (2) the promotion of health and well-being of people with disabilities is an objective requiring attention. Disparities and/or barriers to access and quality of care contribute to the health disparities experienced by persons with disabilities.

The objectives identified by Healthy People 2020 guide the focus of our nation's health priorities. The Healthy People 2020 objectives determined to have a significant influence on our target population include disability and health (DH) objectives and maternal infant and child health (MICH) goals and objectives. Sufficient data collected in the area of disability and health is lacking, possibly resulting from limited inclusion of individuals with disabilities into all areas of public health and research. Over all, about 56.7 million people in the U.S. present with a disability as defined by the World Health Organization (WHO) model of social determinants of health.[11] Research focused on disability and health objectives has uncovered a need for: (1) better disability health data to inform policy and program development; (2) the development of improved, evidence-based, health- and wellness-integrated community programming; and (3) environmental designs and public infrastructure, such as universal designs and improved access to technology.[12]

The well-being of mothers, infants and children determines the health of the next generation and can help predict future public health challenges for families, communities and the healthcare system.[13] The importance of this topic drives much of the health and public health focus in the pediatric arena. Noted below are relevant data for the following maternal, infant and child health objectives:

- Objective MICH-29: Increase the proportion of young children with ASD and other developmental delays who 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% (U.S.) HP 2020: 2011–2012 = 40.9% (Maryland)
HP 2020: Target = 24.9% (TARGET MET)

Progress in screening children for ASD and other development delays is moving in the right direction. Maryland has exceeded the U.S. score of screening children 10 to 35 months old, as reported in 2011–2012. Maryland's overall screening score surpassed that of the nation. Data on screening by race and ethnicity in Maryland are not available through the Healthy People 2020 portal, although the National Survey of Children's Health 2016–2017[14] collected data on children 9 to 35 months old who received a developmental screening using a parent-completed screening tool. Again, Maryland's screening exceeded that of the nation. As for screening data from the 2016–2017 National Survey on Children's Health by race/ethnicity, insufficient data were collected from underrepresented populations to determine if there were any differences. Early data sets collected targeting children with special healthcare needs (2015) did identify disparities in access to care and quality of care between parents of African-American and Latino children, as compared to parents of white children.[15]

The CDC's 2014 Maryland estimates, from the Autism and Developmental Disabilities Monitoring (ADDM) Network 2018 Report,[16] noted that about one in 50 white, non-Hispanic 8-year-olds were identified as having ASD. The prevalence among boys was higher, as boys were four and a half times more likely to be identified as having ASD than girls. The estimated prevalence of ASD for white 8-year-olds was 7% greater than among black 8-year-olds, while the estimated prevalence of ASD was 22% greater among Hispanic 8-year-olds than among white 8-year-olds. In Maryland, the estimated prevalence ratio by race/ethnicity was not significant between white and black children, white and Hispanic children, and black and Hispanic children. Also in Maryland, an intelligence quotient was available for 78.4% of children, and of those, 34.6% had intellectual disability. Most importantly for the Maryland community is that of children identified as having ASD, about 92% displayed developmental concerns by 3 years of age, but only 56% received a comprehensive developmental evaluation by that age. (Note: ADDM Network data for Maryland are collected on 8-year-olds living in Baltimore County, Maryland.)

  - 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: 2008 = 45.9% (U.S.) HP 2020: 2010 = 43.8% (U.S.) HP 2020: 2012 = 42.8% (U.S.)
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 2012 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. In the 2012 update, the best group rate for this objective, 44.9%, was attained by children identified as white—not by children identified as being part of the Hispanic or Latino population. The Hispanic or Latino population attained the worst group rate, 32.9%, for this objective.

  - 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: 2008 = 51.5% (U.S.) HP 2020: 2010 = 52.0% (U.S.) HP 2020: 2012 = 46.4% (U.S.)
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 continues to present greater disparities for specific groups when adjusted for race and ethnicity. In 2012, the best group rate for this objective, 50.9%, was attained by the black or African-American, not Hispanic or Latino, population. The Hispanic or Latino population attained the worst group rate, 35.7%, for this objective in 2012.

- 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: 2009–2010 = 43.0% (U.S.) HP 2020: 2009–2010 = 44.2% (Maryland)
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. In the 2009–2010 update, the best group rate for this objective, 52.8%, was attained only by those identified as white, not by those identified as being part of the Hispanic or Latino population. The Hispanic or Latino population attained the worst group rate for this objective, 32.2%, followed by the black or African-American population (36.0%) at baseline.

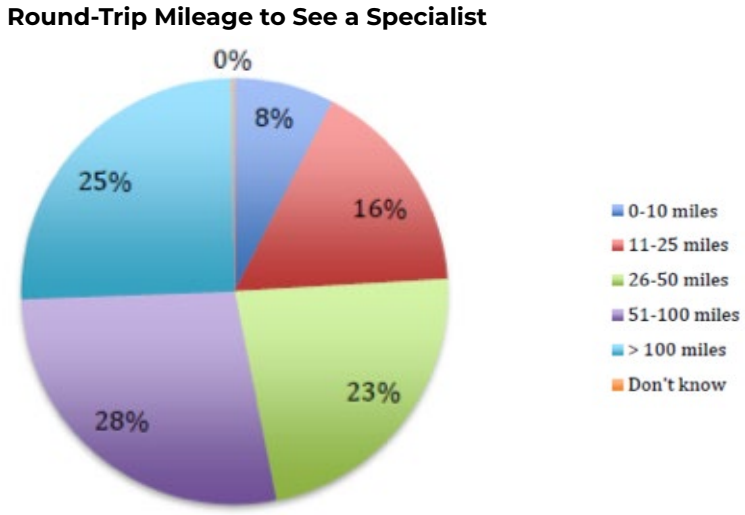
Healthy People 2030 planning is underway. Upon the finalization of Healthy People 2030, a review will occur, with community partners to identify goals and objectives relevant to their target populations.

Ensuring access to care means making sure those who need care receive it when needed. Access to specialty care for CYSHCN is challenging, due to current and anticipated health profession shortages and the geographic distribution of specialty providers. These causes result in waiting lists for specialties and longer drives to receive care. While many of the insurance coverage issues have been addressed through the ACA, adequacy of insurance to cover the necessary services has impacted many children seeing a specialty provider. Access to specialists is increasingly being addressed through alternative service delivery models, such as telemedicine.

Access to speciality care is challenging overall, but when the dimension of developmental/intellectual disability is added, the disparity increases. In a systematic review, it was found that the prevalence of epilepsy for the general population is about 0.6% to 1%.[17] While the rates of epilepsy for people with intellectual disabilities varied more than in the general population, epilepsy in those with intellectual disabilities is more common than in the general population. Epilepsy care for those with intellectual disability is often poorly coordinated and not equitably available due to the types of specialists needed to provide the care.[18] While addressing increased provider capacity across Maryland communities, Kennedy Krieger will, simultaneously, continue to develop specialized programs, especially for complex issues.

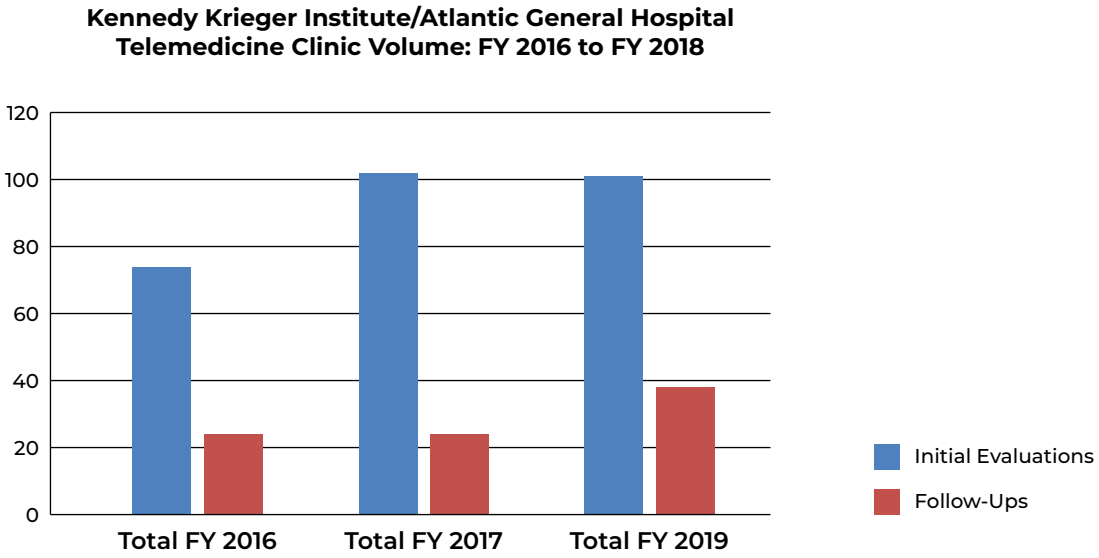
Parents' Place of Maryland (PPMD) launched a Maryland Parent Survey in 2017, resulting in 839 parent respondents. The survey was conducted online and via paper and pencil. The survey results provide data on the impact of ASD, developmental disabilities and epilepsy/seizure disorder on families, and on their unmet needs. Several questions asked about the distance traveled to obtain and receive specialty care for families with children with developmental and other disabilities. About 36% of families drove more than 25 miles to access behavior services and mental health counseling; 7% drove more than 100 miles to access those services. About 76% drove more than 25 miles to access unspecified other therapy services for their child, with 25% of these parents driving more than 100 miles. Findings noted that the majority of families (53%) who participated in this survey traveled more than 50 miles to have their child see a specialist (Figure 8).

Figure 8. Round-Trip Mileage to See a Specialist (Source: 2017 Maryland Parent Survey Summary, Parents' Place of Maryland and Office for Genetics and People with Special Health Care Needs)



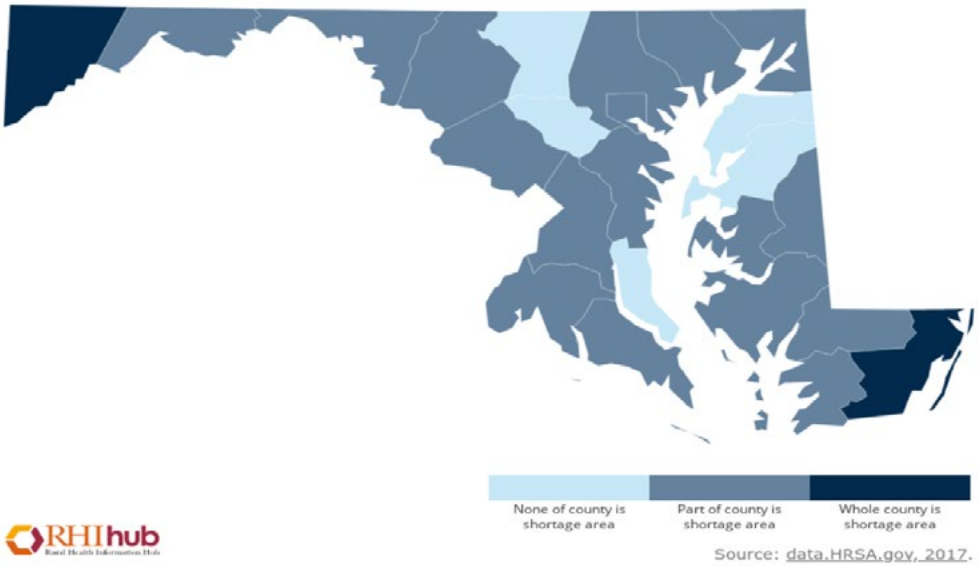
Kennedy Krieger's telemedicine service is growing. Kennedy Krieger engages in telemedicine partnerships with Atlantic General Hospital (in Berlin, on Maryland's Eastern Shore) and with Garrett Regional Medical Center (in Oakland, in western Maryland). Figure 9 shows the volume of patients seen across fiscal years 2016, 2017 and 2018 at Atlantic General Hospital.

Figure 9. Kennedy Krieger Institute Telemedicine Clinic Visit Volume (Source: Kennedy Krieger/Atlantic General Hospital)



Telemedicine has been one strategy used to address the shortage of health professionals in Maryland's Eastern Shore region and in western Maryland, the two areas of the state with the most pronounced shortage of health professionals. The County Health Rankings identified health professional shortage areas for the state, and ways in which to facilitate professional recruitment and placement in these identified shortage areas. Figure 10 shows that western Maryland, southern Maryland and the Eastern Shore counties experience shortages of health professionals, thus affecting access and health outcomes for children and youth. The American Academy of Pediatrics' Committee on Pediatric Workforce supports the use of telemedicine through the medical home to address professional shortages as a means to address barriers to access.

Figure 10. Health Professional Shortage Areas: Primary Care, 2017 (Source: Maryland Rural Health Information Hub)



In addition to the County Health Rankings, the Rural Health Information Hub 2017 reports the need for mental health providers in Maryland based on the ratio of people to mental health providers[19] (Figure 11). The majority of the state is impacted by a poor ratio of mental health providers to patients. Clearly, our Eastern Shore counties, far western Maryland counties and lower southern Maryland counties are the most influenced. The data maps do not represent individuals with compounded developmental disabilities who are in need of mental health providers. This comorbidity adds complexity to the skills needed to render service, thus creating an even greater shortage based on expertise.

Figure 11. Health Professional Shortage Areas: Mental Health, 2017 (Source: Maryland Rural Health Information Hub)

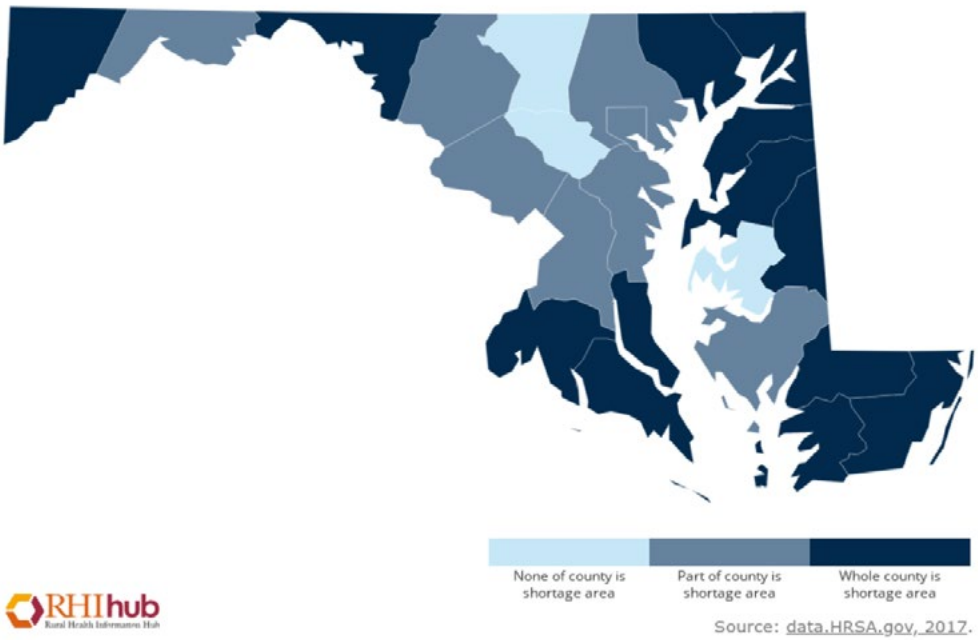


Table 3. Total Number of Active Certificates by Specialty/Subspecialty in Maryland, 2013 Compared to 2018 (Source: 2017–2018 ABMS Board Certification Report)

Specialty	MD—2013	MD—2018	U.S.—2013	U.S.—2018
Family Medicine—All Areas	1,274	1,294	85,751	87,705
Pediatrics—All Areas	2,604	2,856	84,387	97,362
Developmental Behavioral Pediatrics	18	19	633	695
Pediatrics, Psychiatry and Neurology: Neurodevelopmental Disabilities	21	18	266	214
Psychiatry and Neurology: Child and Adolescent Psychiatry	246	361	5,890	8,995

While there has been some growth in the number of active certificates issued to specialty and subspecialty providers between 2013 and 2018 (Table 3), the data identify neither the specific region of the state where the certificates are held nor whether an active certificate is associated with a practicing provider. In 2017, the American Board of Medical Specialties developed a focused practice designation. Focused practice is an added designation to a certification recognizing additional expertise or focus gained through clinical experience. Unfortunately, the only applicable specialty area for the population served that currently has this designation is family medicine.

Expansion of slots in academic medical programs will not increase sufficiently to address or be able to meet the demand for services, especially in behavioral/mental health. Using alternative service and training delivery models will be essential in addressing the increasing need and gap in services. Enhancement and continuation of the training programs at Kennedy Krieger Institute focused on building the capacity of specialty providers in developmental disabilities, integrating caring for individuals with disabilities into community public health practices, and providing continuing education—on topics such as health promotion, wellness, disease prevention, policy, education and other areas related to developmental disabilities—are essential to increase health knowledge and awareness in the community. These actions are critical to improving the culture of health.

The 2017 Maryland Parent Survey (MDPS) asked parents if certain healthcare-related services for CYSHCN were delayed or not received in the past 12 months. As seen below, 41% of respondents have children between the ages of 6 and 11 years old; 63% of the respondents' children were male, and 71% were non-Hispanic white. The data also indicate that more than half of the respondents' children had private health insurance. Surveys were unable to be analyzed by county due to large amounts of invalid responses to the questions in the survey.

Table 4. 2017 Maryland Parent Survey Child Demographics (Source: Parents' Place of Maryland and the Office for Genetics and People with Special Health Care Needs)

Child Characteristics	Sample n	%
Age		
0–5	107	12.8%
6–11	342	40.8%
12–17	332	39.6%
18–22	57	6.9%
Gender		
Male	531	63.3%
Female	302	36%
Transgender	5	0.6%
Does not identify as male, female or transgender	<5	NR
Race/Ethnicity		
Non-Hispanic white	597	71.2%
Non-Hispanic black	100	11.9%
Hispanic	34	4.1%
Asian	16	1.9%
American Indian/Hawaiian	<5	NR
Multiple Race	90	10.7%
Insurance Type		
Private insurance only	494	59.5%
Public insurance only	288	34.7%
Private and public insurance	46	5.5%
No insurance	<5	NR

Numbers may not add up to N=839 due to missing responses; missing responses were for health insurance (n=8). Percentages calculated from responses per question. If cell is <5, then number and percentage are not reported (NR).

Anecdotally, we have heard that behavioral health is a major issue related to ineffective educational strategies in the classroom and access to behavioral health services. The 2017 MDPS quantified these barriers by asking parents about any behavioral needs during the last 12 months. Slightly more than six in 10 parents (61%) reported their children having anxiety problems during the past year. Other frequently reported behavioral issues included anger/conflict management, depression and an increase in problem behaviors. For each behavior cited, parents sought help between 67–96% of the time, yet the majority of parents reported accessing the help they needed was either somewhat or very difficult. The 2017 MDPS unmet needs findings were rated as follows: "mostly easy", "somewhat easy", "somewhat difficult", "very difficult" and "didn't get help with this". The issues and highest response groupings are noted in Table 5.

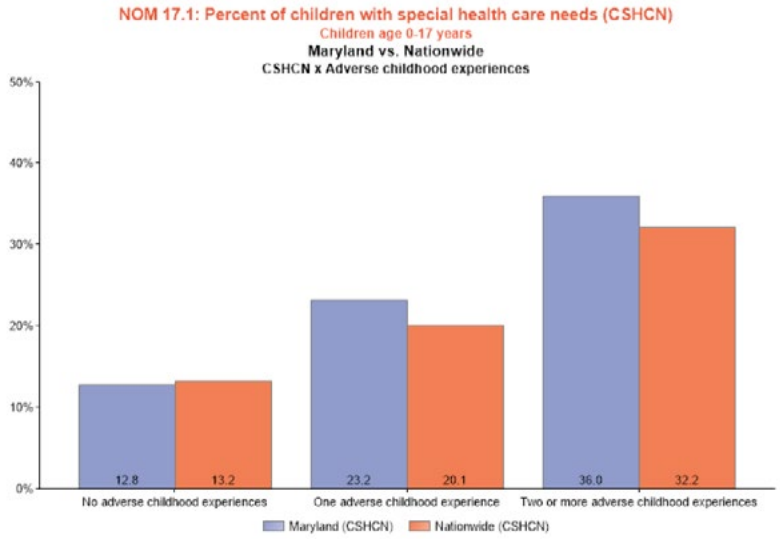
Table 5. Unmet Needs Based on Child Behavioral Health Issue (Source: 2017 Maryland Parent Survey)

Behavioral Health Issue	% Reporting Difficulty in Getting Help
Anxiety	60.6%
Suicidal Thoughts/Behaviors	44.7%
Increase in Problem Behaviors	51.2%
Depression	50.5%
Anger/Conflict Management	50.4%
Bullying	40.4%
Drug/Alcohol Abuse	35.7%

Health Factors: Social and Economic Factors

Disparities in the social determinants of health for children place them at greater risk of acquiring disorders of the developing nervous system. Children with special healthcare needs in Maryland are more likely to experience at least one adverse childhood experience than children in Maryland without special healthcare needs.[20] The words "adverse childhood experiences" (ACEs) are used to describe types of abuse, neglect, reduced opportunities, environmental experiences and other potentially traumatic experiences that occur to people under the age of 18 and can be strongly related to the development and prevalence of a wide range of health problems throughout a person's lifespan, such as risky health behaviors, chronic health conditions, acquired disorders of the nervous system and a reduced life expectancy. As the number of ACEs increases, so does the risk for these outcomes.

Figure 12. Children With Special Healthcare Needs, by Number of Adverse Childhood Experiences (Source: Child and Adolescent Health Measurement Initiative: 2016–2017 National Survey of Children's Health)

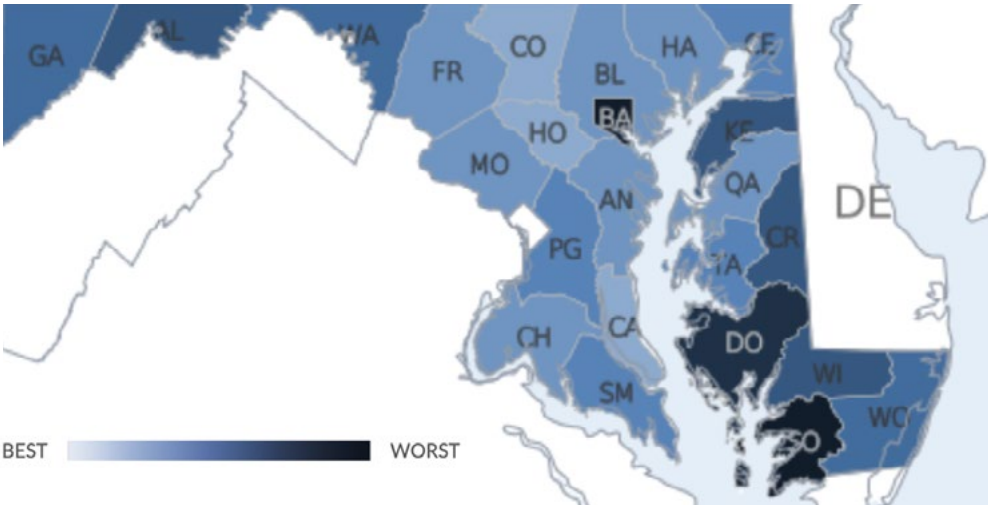


Poverty

While effects resulting from poverty are present for all ages and races, children living in poverty may experience lasting effects on academic achievement, health and income into adulthood resulting from the influence an environment of poverty has or can have on the developing brain. Children from low-income households have an increased risk of injuries from accidents and physical abuse and are susceptible to more frequent and severe chronic conditions—and complications such as asthma, obesity, diabetes, ADHD, behavior disorders and anxiety—than children living in high-income households.[20] In Maryland, our most challenging areas of the state include Maryland's Eastern Shore, western Maryland and Baltimore City, our immediate neighborhood (Community Commons).[21] Children living in poverty are also faced with higher levels of environmental stress and trauma, thus resulting in higher ACEs among children in those areas.[20]

The goals of a community common indicator report are to identify and prioritize the significant needs of a community and to identify services that would address those needs. A community indicator report measures vulnerability using an area of deprivation index (ADI). Vulnerability includes the social determinants of health, i.e., measures of social vulnerability such as housing, education, employment and income. Our neighborhood's ADI is 131.1, placing us at the end of the continuum—the end that is identified as most deprived. Cultivation of relationships is key to all community work; as relationship development evolves, community partnership and interventions can proceed to address the community common indicator report.

Figure 13. Children in Poverty, 2019 (Source: County Health Rankings, 2019)



Education

Reduced opportunities in education for children with disabilities may include inappropriate services rendered through their individualized education program, reduced resources available in their school setting, a disproportionate number of school suspensions and punishments, reduced access to transition programs that facilitate successful entry into adult life, and disparities in all of the above by race/ethnicity, geographic location and bias. Collectively as a community, our efforts in addressing the disparities in education are multifaceted and may include training for early interventionists, teachers and medical providers; caregiver support and partnership development; early childhood access to programming; and enhanced integration across systems.

Our partner in working to reduce these inequities, the Maryland State Department of Education (MSDE), conducts an annual survey to determine if parent involvement could be used as a means of improving services and results for students with disabilities. As noted, a family-professional partnership is one key to overall health and wellness for the child and family. Figuring out how to ensure shared decision-making; addressing family priorities; connecting families to needed services; tailoring recommendations to the family from a social, educational and cultural perspective; and most importantly, acknowledging the family as the key support in the child's, youth's and young adult's life are of the utmost importance.[22]

Parents/guardians of children who received special education services during the 2017–2018 school year were invited by MSDE to complete a preschool survey for children between the ages of 3 and 5 as of September 30, 2016, and a school-age survey for children who were at least 6 years of age as of September 30, 2016. Both surveys included 24 core questions, demographic questions and open-ended comments.

A total of 103,701 surveys were mailed, 13,475 to parents/guardians of preschool children, and 90,226 to parents of school-age children. Of the 13,475 surveys mailed to parents/guardians of preschool children, 1,651 were completed, 1,069 on paper and 582 online, yielding an adjusted response rate of 13%. Of the 90,226 surveys mailed to parents/guardians of school-age children, 8,564 were completed, 5,738 on paper and 2,826 online, yielding an adjusted response rate of 10%. The racial and ethnic distribution presented with representation across multiple groups for both survey groups. The disabilities with higher frequencies for the preschool children included ASD (16%), developmental delay (33%) and speech-language impairment (32%).

In the preschool survey, the areas in which parents agreed with statements less frequently, thus presenting opportunities for improvement, included situations in which people from preschool special education programs, including teachers and other service providers:

1. …connect me with other families for mutual support. (Q24)
2. …provide me with information on how to get other services (e.g., childcare, parent support, respite, regular preschool program, WIC, food stamps). (Q8)
3. …offer me information regarding parent training. (Q21)

In the school-age survey, the three disabilities appearing the most frequently included specific learning disabilities (22%), ASD (18%) and multiple disabilities (15%). The areas in which parents agreed with statements less frequently, thus presenting opportunities for improvement, included situations in which their school and/or school system:

1. …offers me training about special education issues. (Q22)
2. …provides information on agencies that can assist my child in the transition from school. (Q23)
3. …gives information about organizations that offer support for parents of students with disabilities. (Q7)
4. …explains what options I have if I disagree with a decision of the school. (Q24)

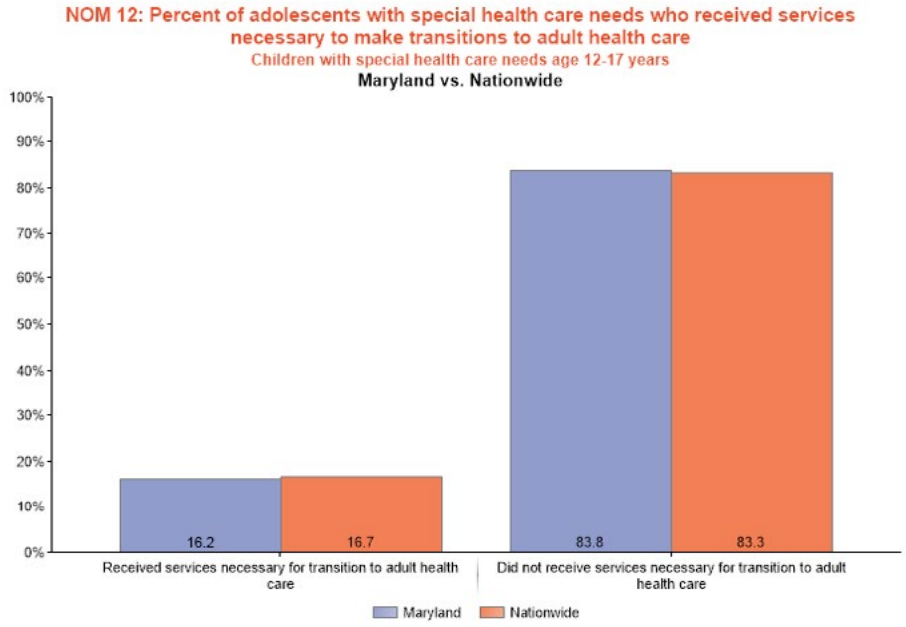
These findings offer opportunities for partnerships between MSDE, Kennedy Krieger Institute and families to improve how training and communication through information dissemination are offered across the state, not only for families but also for non-educational entities that have linkages with education.

Transition

Maryland engages multiple mechanisms and systems that attempt to organize efforts for youth transitioning to adulthood across the state. Unfortunately, there is no public or private consensus on what activities have been most beneficial for families and youth, or guide on how families get started or enter the process. The National Survey on Children's Health (Figure 14) found that the number of children with special healthcare needs in Maryland who did not receive the services they and/or their parents/guardians felt were necessary to make the transition to adult healthcare (83%) was higher than that of those who did receive the necessary services; this is a similar finding nationally.

The Governor's Interagency Transition Council for Youth with Disabilities is a partnership of state and local government agencies. In Maryland, there are multiple nongovernmental organizations that have a stake in adolescent transition, given the investment in the population served. In fiscal year 2016, the Maryland Department of Health Office for Genetics and People with Special Health Care Needs (OGPSHCN) and Parents' Place of Maryland awarded approximately 15 grants addressing some form of healthcare transition. Kennedy Krieger was awarded a grant to create a systematic, orderly and family-centered evaluation of current healthcare needs for youth and young adults approaching transition age at the Center for Autism and Related Disorders by creating a portable healthcare document to aid in the coordination of services between pediatric and adult healthcare providers. This facilitated case-by-case personalization of care and healthcare management for young adults with ASD, and thus improved their quality of life.

Figure 14. Adolescents With Special Healthcare Needs Who Received Services Necessary for Transition to Adult Healthcare, by Race/Ethnicity (Source: Child and Adolescent Health Measurement Initiative: 2016–2017 National Survey of Children's Health)



In partnership, the Maryland Developmental Disabilities Council and Parents' Place of Maryland conducted a 2017 Maryland Parent Youth Transition Survey, a follow-up to the 2013 Maryland Parent Youth Transition Survey. The survey targeted families

of children with special healthcare needs. The total number of respondents to the survey was approximately 139, but with a significant number of incomplete responses to questions throughout the survey. Findings cannot be used to represent any groups of respondents or regions. From the limited responses to the 2017 Maryland Parent Youth Transition Survey, families received information on transition first from transition fairs (63%), followed by the Transition Planning Guide (47%), which is published by the Maryland State Department of Education. About half of the families who responded to the question asking where they received information to assist them when their child exits school said that information came from the state's Developmental Disabilities Administration and Maryland State Department of Education/Division of Rehabilitation Services (DORS). In response to the question asking how old their child was when transition planning began, more than 50% indicated their child was between 14 and 16 years of age.

Several important self-advocacy questions were asked in this survey, such as:

(1) Did your child participate in their own IEP meeting? If so, did your child participate in the transition planning?

(2) How did they participate in the IEP meeting?

(3) As a participant in the transition process, is your child learning how to self-advocate?

(4) As part of school and transition planning, did your child take advantage of opportunities for paid work experiences?

The focus on transition to adult life is important, as adults with disabilities are four times as likely as adults without disabilities to report having fair or poor health (40.3% versus 9.9%),[23] and adults with disabilities have a significantly higher rate of unemployment. Taking preventative measures can change future outcomes for this population in the years to come. While there are multiple systems and resources related to transition, individuals and families are in very different places with regard to recognizing needs, goals, objectives and supports. Therefore, creating a "no wrong door" system, with coaches to guide individuals, could be of benefit.

Employment

In 2017, there were a reported 20,444,249 individuals with disabilities, ages 18 to 64, living in the community, 37% of which were employed. Of the 177,320,890 individuals reported in 2017 without disabilities, ages 18 to 64, living in the community, 77.25% were employed. North Dakota had the highest percentage of individuals with disabilities employed (54.0%), whereas West Virginia had the lowest percentage of individuals employed (27.4%). Maryland rates are noted in Table 6.

Table 6. Employment: Civilians Ages 18 to 64 Years Old Living in the U.S. (Source: The Annual Disability Statistics Compendium, Institute on Disability, University of New Hampshire, 2017)

Region	Civilians Without Disabilities Percentage Employed	Civilians With Disabilities Percentage Employed
U.S.	77.25%	37%
Maryland	80.4%	42.3%

Efforts by the Maryland Department of Disabilities (MDOD) and an initiative launched by Kennedy Krieger Institute address the business case for inclusive employment. MDOD has engaged community partners to dismiss common myths and facts about hiring individuals with disabilities. Their campaign to ensure employment statewide for self-advocates has included partners from the private and public sectors learning together about the benefits and good business sense for expanding their employee talent pool. Kennedy Krieger's Neurodiversity Initiative encompasses staff member education, employment, community business partnerships providing education, and internship/employment opportunities. As an organization, we are addressing barriers to inclusive employment at the organizational, departmental and individual levels. A goal of Maryland's 2016–2019 State Disabilities Plan is that individuals with disabilities will have equal opportunity to improve their financial well-being. One pathway to financial independence is through employment, as individuals with disabilities have the right to meaningful employment. As a state, we have to support prevocational and career training programs that are accessible to individuals with disabilities.

Family

Caregiver well-being influences a child's functioning. Understanding caregiver needs and preferences can help reduce barriers and obstacles to a child's overall functioning. A starting point is to understand caregiver needs and perspectives, and to value family perspectives that differ from those of the provider. There is limited research and knowledge on the factors that impact the health, well-being and independence of children and young adults with intellectual and developmental disabilities. The majority of past studies examined and explored the impact different disabilities had on a child and their family members, but from a clinician's point of view, not from a caregiver's perspective.[24]

In 2018, the U.S. Health Resources and Services Administration convened a workgroup to revise the Maternal Child Health Leadership Competencies from 2009. The competency area for family-professional partnerships was revised. This area includes the integration of partnerships at all levels of care. These partnerships are about more than providing care or education for the individual; the partnerships recognize that family, self-advocate, faculty and personal expertise is a body of knowledge that constitutes a discipline.[22] PPMD serves an integral role in the design and implementation of services for CYSHCN and their families across Maryland.

PPMD, with the OGPSHCN, leads the Maryland Consortium of Care. This consortium reflects a true family-professional partnership in working to influence state services and policy. Meetings occur quarterly and include stakeholders from across the state interested in issues targeting CYSHCN. An offshoot of the Maryland Consortium of Care is the Eastern Shore Consortium of Care (ESCOC), which 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. The ESCOC conducted an assessment of needs in their area in winter/spring 2018 and identified the following top priorities for CYSHCN on the Eastern Shore, in order of ranking:

1. Specialty providers
2. Transportation
3. Parent education and support
4. Parent support/resources for addressing IEP concerns
5. Care coordination
6. Respite (especially for parents of children/youth with physical limitations who also have behavioral issues)
7. Access to behavioral health services, especially urgent/emergency services

Areas working well for CYSHCN on the Eastern Shore:

- Family support and education by some providers
- Having the ESCOC
- Community-based providers on the Eastern Shore

These priorities can be categorized into access, training and advocacy needs.

Advocacy

Through the work of People On the Go (POG) Maryland, a self-advocacy project of the Maryland Center for Developmental Disabilities, implementation of Project STIR (Steps Toward Independence and Responsibility) across the state will support further expansion of self-advocacy development. The training is delivered by individuals with and without disabilities, and is designed to empower people with developmental disabilities. It provides the practical, "how-to" tools necessary for anyone 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.

Advocacy also supports recognizing barriers to speaking for yourself, sharing of preferences, identifying areas of desired independence and determining how and when that is achieved, and taking on more responsibility for oneself.

Although progress has been made in creating a powerful advocacy and resource network in Maryland, recurring themes continue to be heard in public forums:

- Knowledge about available resources and services in communities
- Knowledge of service providers in communities
- Redundancies and lack of communication across systems
- Challenges (health, education and work) experienced by youth transitioning to adulthood, and their families, when accessing services for 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.

Policies and Programs

Community Training Program

The Maryland Center for Developmental Disabilities (MCDD) Training and Continuing Education program is committed to partnering with local and state agencies, national leaders, people with disabilities and their families, health and allied health professionals, and community members to provide evidence-based training across a broad spectrum of topics, technical assistance and evaluation to improve quality of life for people with disabilities and their families. The training mission of MCDD is to increase awareness, knowledge and competency in a wide range of settings and across a number of categories of content to support and enhance professional development opportunities for professionals and community members, and to expand their knowledge and skills to engage in effective advocacy in areas such as special education and law, human behavior and behavior supports, mental health, and disabilities.

Training evaluations from 2018 solicited input for future community trainings. The noted themes and topics that emerged were:

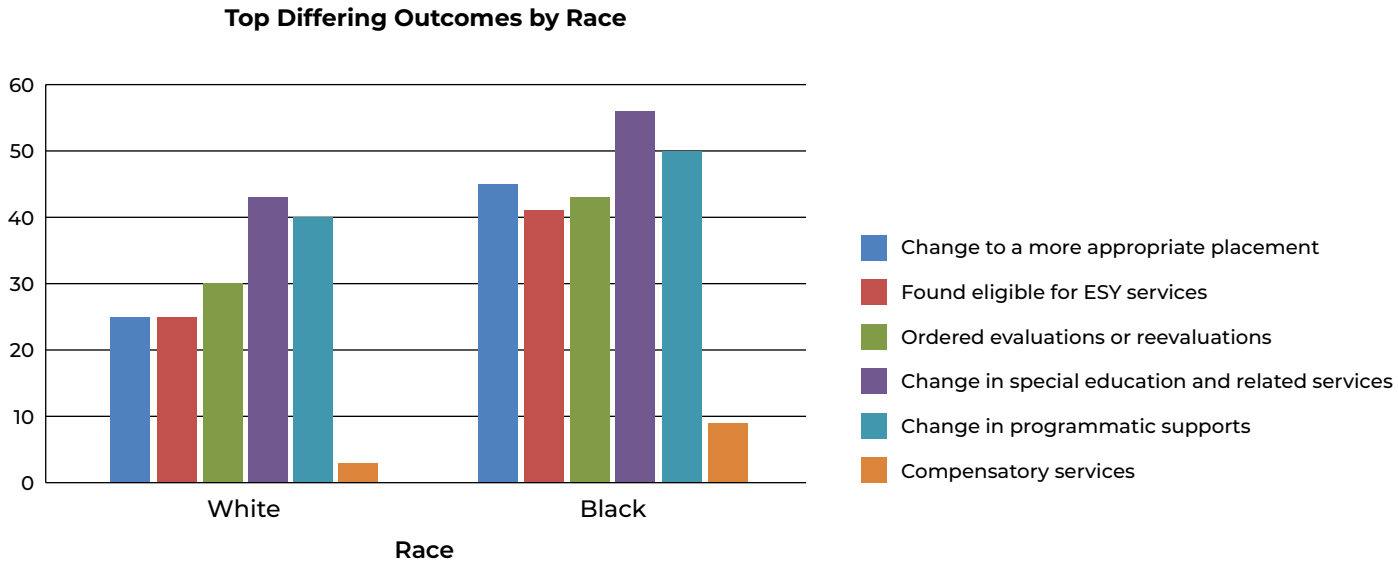
Youth Transitioning to Adulthood	Law	Interdisciplinary Training	Locating and Identifying Resources
Parent and caregiver role in sexuality exploration	Disability law	Trainings for healthcare professionals	Maternal and child health resources
Developing healthy relationships	Guardianship	Evidence-based intervention models	Support groups
Internet safety	Special education law	Crisis intervention	Resources by county and city
Adult relationships		Trauma-informed training	Agencies that provide services
		Applied behavioral analysis	

Law: Legal Planning Services Program

Having differing abilities with which to consent to healthcare services and procedures may present barriers to accessing those services. Understanding one's rights or being armed with adequate information for a caregiver to advocate for an individual may require legal documents in place, especially when one reaches adulthood, at age 18. According to the National Center for Medical-Legal Partnership, these same socioeconomic barriers require arduous effort for families to "successfully challenge the unlawful actions of a landlord, a governmental agency, or a school system, and therefore many unlawful—and unhealthy—situations persist" (Beeson, 2013). Project HEAL (Health, Education, Advocacy, and Law), a project of the Maryland Center for Developmental Disabilities, is a unique medical-legal partnership (MLP). It is the only MLP that resides in a UCEDD and focuses on advocacy and law for children with disabilities. Many of the 24,000 patients seen at Kennedy Krieger each year are children who are also faced with barriers to receiving appropriate educational services and supports to achieve academic success in their communities. Health systems and lawyers are beginning to work together to address the social determinants of health, and to make way for medical-legal partnerships to emerge as strategists in minimizing the effects of health disparities.

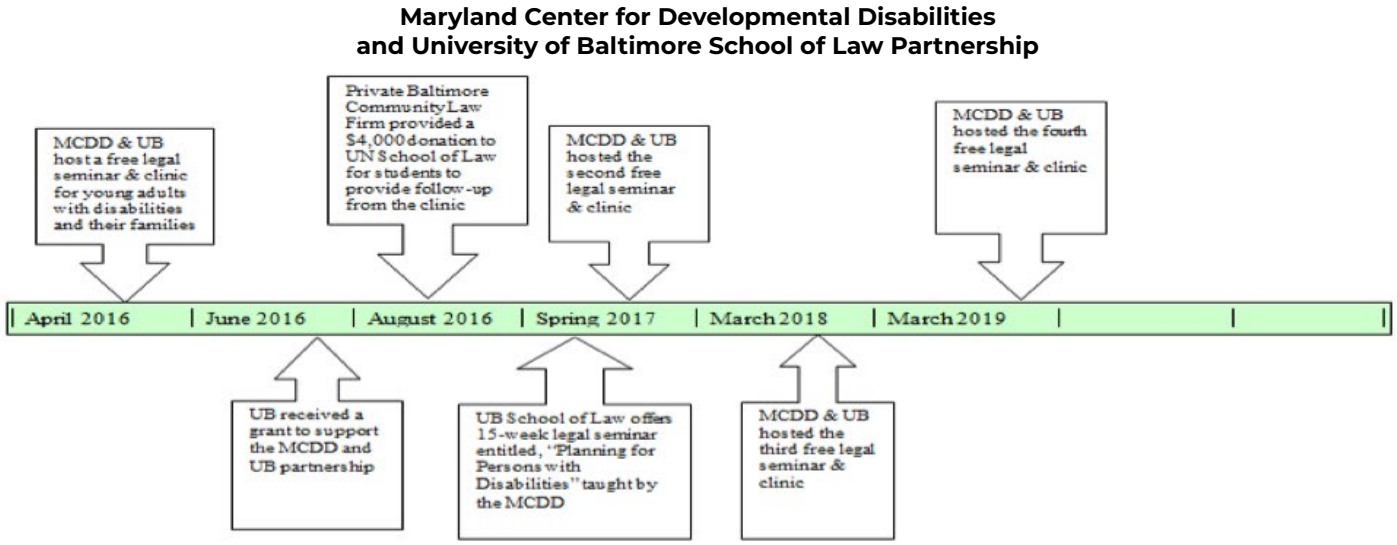
Project HEAL offers representation on special education matters, Supplemental Security Income appeals and simple family law matters; limited representation offering brief advice, document review, referrals, information and resources; case consultations to advise Kennedy Krieger faculty members, staff members and trainees; pro bono referrals to private and public entities; and professional and community trainings. Data collected were recently analyzed and showed racial disparities in appropriate educational placements, provision of services and eligibility for services. The proportion of black clients found eligible for extended school year (ESY) services was found to be statistically higher than that of white clients (p-value = .020). The same statistical trend was observed for clients requiring a change to a more appropriate placement (p-value = .045). These data points indicate many children with disabilities receive inadequate supports and services in special education matters, and thus, there is a need for expanded advocacy offered through MLP services.

Figure 15. Improving Outcomes for Low-Income Children with Disabilities, Fiscal Years 2016, 2017 and 2018 (Source: Project HEAL)



Project HEAL hosted its third legal planning seminar with the University of Baltimore (UB) School of Law in 2018. The 45-minute seminar was delivered by two UB School of Law alumni, both of whom took the "Planning for Persons with Disabilities" course. The attorneys covered topics such as advance directives, advance directives for mental health, statutory powers of attorney, guardianship, wills and special needs trusts. After the seminar, 20 attorneys and 20 UB law students met individually with clients/families regarding powers of attorney, advance directives and advance directives for mental health needs. Eleven statutory powers of attorney were executed by nine family members and two young adults, 11 advance directives were executed by nine family members and two young adults, and four advance directives for mental health were executed for three family members and one adult. Eight other young adults and families met with an attorney and law student to discuss their other unmet legal needs, including special needs trusts, wills and adult guardianships. Evaluation findings from families reflected that all were satisfied with the legal planning seminar for young adults, and they reported an increase in knowledge gained from attending the seminar and speaking with representatives about legal planning.

Figure 16. Maryland Center for Developmental Disabilities and University of Baltimore School of Law Partnership (Source: MCDD)



Finally, we know that policies can impact health through structural and systematic change. Policies can be applied at any level—at the level of the program or organization, or across the public sector (local, state and federal). Policies can influence many of the factors presented in this document. Kennedy Krieger Institute will not only integrate into its strategic initiatives the enhancement of our partnerships with local, state and federal representatives, but also explore alternative service delivery models that blend and/or integrate the approaches and knowledge of traditional healthcare with public health. Considering the treatment of individuals with disabilities as part of population health will ensure inclusion in general health initiatives. Given our multiprong approach to addressing the needs of our population, we have the ability to affect many policies that deal with health factors that influence health outcomes.

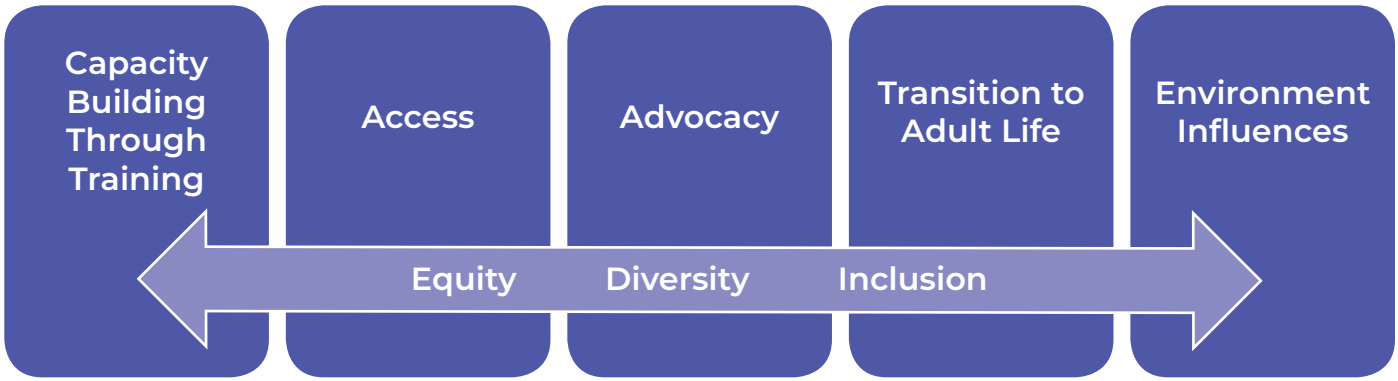
Prioritization of Needs

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

- Community Input ▸ National ▸ State Priorities: Does the identified need align with national and state priorities specific to our target population, such as the Healthy People 2020 objectives, the 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 its 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 and the target population? How do the data and indicators of the identified need compare to those of other states and the nation?

Through the process of prioritization described above, the following priority needs were selected:

Addressing Community Priorities for Individuals With Disabilities Through Partnerships



Taking direction from the areas of identified need, the focus will be to enhance and/or develop stronger partnerships and systematic collaborations across sectors and regions to address the areas of opportunity.

Capacity Building Through Training and Technical Assistance

Community providers, families and self-advocates are seeking usable and meaningful information to enhance care in their own communities. A focus on **capacity building through training and technical assistance** will foster community contributions through the development of new leadership in the neurodevelopmental arena. Through a multitude of training programs at Kennedy Krieger and continued enhancement of partnerships, we will contribute to the development of the next generation of diverse providers and to the dissemination of knowledge and evidence-based practices within the community. These vehicles include:

- Maternal and Child Health Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs at Kennedy Krieger Institute that provide short-, medium- and long-term undergraduate- and graduate-level interdisciplinary training
- University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) training programs that provide short-, medium- and long-term undergraduate- and graduate-level interdisciplinary experiences for students, parents, self-advocates and professionals
- Center for Diversity in Public Health Leadership Training, which focuses on increasing the diversity of providers and the population served from an integrated population health and healthcare perspective
- The use of Kennedy Krieger's tele-education platform to disseminate our expertise in developmental disabilities, advocacy, policy, special education and more

Access to Services

The community has identified **access to services** as a need. According to Healthy People 2020, a U.S. Department of Health and Human Services initiative, access includes entry into a healthcare system, accessing a geographic location where healthcare services are provided, finding a healthcare provider whom one can trust and with whom one can communicate, and timeliness of care. The Healthy People 2020 initiative also includes oral healthcare and access to essential prescription drugs. Barriers to access to healthcare services vary based on race, ethnicity, age, sex, ability status, sexual orientation, sex identification, socioeconomic status and residential location. While these barriers exist, the ACA of 2010 has resulted in fewer individuals not receiving healthcare services due solely to insurance coverage.

Mechanisms through which Kennedy Krieger will address access with community partners include:

- The use of tele-education to disseminate our expertise in developmental disabilities, advocacy, policy, special education and more
- Maximizing the use of our Resource Finder, a vehicle for disseminating information to professionals, caregivers and self-advocates in a variety of formats
- Engagement in community outreach activities through health fairs, one-on-one client trainings (i.e., technical assistance) and community trainings
- Telemedicine services offered internally and externally through established partnerships to expand access to healthcare services specific to the population served

Advocacy

Advocacy is essential in supporting individuals with disabilities and their families. Providing healthcare in isolation is not sufficient to improve the health and quality of life of individuals with disabilities. Throughout Kennedy Krieger's integrated research, special education, training and clinical service programs, we ensure that the development of self-advocacy skills is included in the care and services we provide to our patients and students and their families—this is critically important.

Typically developing children are taught to speak up for themselves, to have a voice and to stand up for what they believe in. The same must apply to individuals with disabilities across the lifespan. Kennedy Krieger emphasizes advocacy for—and self-advocacy by—the individuals it serves, and their families, by providing information about special education law and self-advocacy through Project HEAL (Health, Education, Advocacy, and Law), a medical-legal partnership, and by maximizing self-advocacy efforts through People On the Go Maryland (POG), a group of advocates with intellectual and developmental challenges who use their voices to be heard and recognized. POG is currently a partnership between the Maryland Developmental Disabilities Council and the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute.

Transition to Adulthood

Transition to adult life is, and has always been, a major barrier for adolescents with disabilities as they move from their later teen years into young adulthood. Transition planning can address—but is not limited to addressing—health, employment, self-advocacy, independent living and more. Integrated efforts to address transition planning remain fragmented, meaning that families have no entrance portal, require multiple stops to address identified needs, and receive different information from multiple sources. Assistance in creating a road map may help in navigating the complex landscape of transition. The important question is: What do young adults and their families need, and when do they need it?

Top barriers the community has identified as impeding the transition to adulthood include:

- Legal issues for young adults with disabilities—these issues can impact access to services through the complexity of verbal and signatory self-decision-making
- The need for self-advocacy development programs for youth
- The lack of meaningful employment avenues

Environmental Influences

Finally, this assessment process has identified **environmental influences** as not only barriers to achieving health equity but also opportunities to enhance Maryland's health outcomes. These environmental influences include adverse childhood experiences, a greater risk for suicide within the population we serve, opioid use by adolescents for chronic pain, education inequities and homelessness. Kennedy Krieger will continue to address several of these influences through its Center for Child and Family Traumatic Stress and Pediatric Rehabilitation Pain Program, and through community parenting programming by PACT, an affiliate of Kennedy Krieger Institute.

As an institution committed to enhancing the lives of those with—and at risk for—disabilities, we will continue to engage in continuous assessments with the community we serve. Status updates and revisions will occur annually to ensure we are addressing areas of value for those we serve, our professional colleagues and community stakeholders. Our emphasis will be to share a public focus on health inequity for those with disabilities across communities, and on sharing ways in which to improve health outcomes and achieve health equity. Communities are essential vehicles with which to partner to promote health equity, as it is in the community where one lives, works, learns and plays.

Implementation and Action Plan

Priority 1: Capacity Building Through Training and Technical Assistance				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships With Kennedy Krieger Institute**
Contribute to Maryland's recruitment of specialty providers	**Strategy 1:** Recruit and train trainees from multiple clinical professions through Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs	Record number of trainees by discipline Conduct follow-up upon graduation; if employment was sought, identify the location of employment	Fiscal years 2020 and 2021	Colleges and universities across the U.S. offering majors in specialty disciplines Minority-serving institutions
	Strategy 2: Recruit and train scholars from undergraduate and graduate programs in public health, with a focused recruitment from underrepresented populations through the Center for Diversity in Public Health Leadership Training	Record number of trainees by: · Maryland residency · Major · Race/ethnicity · Ability status · Anticipated profession sought · Employment follow-up (2021), as applicable	Fiscal years 2020 and 2021	Minority-serving institutions—embrace collaborative opportunities between Maryland schools and other Kennedy Krieger programs Colleges and universities across the U.S. offering majors in public health and healthcare professions
	Strategy 3: Recruit and train students from interdisciplinary undergraduate and graduate programs through the Maryland Center for Developmental Disabilities (MCDD) internship program	Record number of trainees by: · Maryland residency · Major · Race/ethnicity · Ability status · Anticipated profession sought · Employment follow-up (2021), as applicable	Fiscal years 2020 and 2021	Local colleges and universities in Maryland Johns Hopkins Bloomberg School of Public Health
Enhance the capacity of Maryland primary care providers and school health nurses to care for children with behavioral, emotional and developmental disorders in their own communities	**Strategy 1:** Create/develop a Kennedy Krieger tele-education platform to disseminate learning, provide coaching and offer professional technical assistance to providers		Fiscal years 2020, 2021 and 2022	Kennedy Krieger Institute tele-education platform Baltimore City Health Department Maryland stakeholders in health and education
	Strategy 2: Launch a Kennedy Krieger tele-education platform to disseminate learning, provide coaching and offer professional technical assistance to providers	Number of participants Identify first three curriculum modules to launch statewide Develop and complete platform	Fiscal years 2020, 2021 and 2022	Maryland community providers and general stakeholders

Priority 1: Capacity Building Through Training and Technical Assistance (continued)				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships With Kennedy Krieger Institute**
Increase the business community's awareness and knowledge of neurodiversity and the application of inclusion in the workforce	**Strategy 1:** Conduct a national conference	Number of participants and unique companies Increase awareness and/or knowledge about neurodiversity in the workplace	Fiscal year 2020	Neurodiversity Task Force MCDD Corporate business leaders
Expand neurodiversity program through replication	**Strategy 1:** Explore feasibility of development of a neurodiversity train-the-trainer model via the Kennedy Krieger tele-education platform	Track number of inquiries requesting assistance with developing a program	Fiscal years 2020 and 2021	Neurodiversity Task Force MCDD Corporate business leaders
	Strategy 2: Launch a Kennedy Krieger tele-education platform to disseminate learning, provide coaching and offer professional technical assistance to providers	Number of participants Identify first three curriculum modules to launch statewide Develop and complete platform	Fiscal years 2020, 2021 and 2022	Maryland community providers and general stakeholders
Expand awareness of environmental influences, such as adverse childhood experiences, in the disability population	**Strategy 1:** Disseminate information about the prevalence of suicide in the community of individuals with disabilities and ASD to health and educational providers, legislators, self-advocates, families and the general Maryland stakeholder community	Number of presentations—date, location and audience	Fiscal years 2020, 2021 and 2022	MCDD Parents' Place of Maryland Maryland Department of Health Maryland State Department of Education
	Strategy 2: Share information about non-opioid management of pain in children and adolescents in Maryland with health and educational providers, legislators, youth, families, and the general Maryland stakeholder community	Number of presentations and community events—date, location and audience	Fiscal years 2020, 2021 and 2022	MCDD Parents' Place of Maryland Maryland Department of Health Maryland State Department of Education

Priority 2: Access to Services				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships With Kennedy Krieger Institute**
Increase access to services	**Strategy 1:** Develop and launch a tele-education platform to disseminate learning, provide coaching and offer professional technical assistance to providers	Number of patients who were served in their communities (no visit to Kennedy Krieger) resulting from the health professional participating in Kennedy Krieger Institute's tele-education program	Fiscal years 2020, 2021 and 2022	Community primary care practices
	Strategy 2: Pilot use of outfacing telemedicine and online questionnaires to optimize triage and facilitate service identification	Time frame from referral for telemedicine triage to date of appointment Time frame from referral for determination review of online questionnaire to date of appointment Patient and family satisfaction with their clinic determination through this process	Fiscal year 2020	Community stakeholders who access services at Kennedy Krieger Institute
	Strategy 3: Explore sustainability of telemedicine services in specialty-provider-shortage areas of Maryland	Contract renewals Alternative service delivery model	Fiscal year 2020	Atlantic General Hospital (Eastern Shore) Garrett Regional Medical Center (Western Maryland)
	Strategy 4: Develop and launch a tele-education platform to disseminate learning	Increase awareness and knowledge of community providers—sufficient to provide services in their own communities	Fiscal year 2021	Department of Health School health personnel in Maryland Professional providers in Maryland
	Strategy 5: In all strategic planning and program development, consider the needs of, and access for, individuals with disabilities	Develop and open a specialized epilepsy monitoring unit for children diagnosed with epilepsy and other disorders of the nervous system	Fiscal Year 2020	Johns Hopkins Hospital State of Maryland
		Record improved access: type of service, if a geographic location is impacted, if a particular targeted group is impacted	Fiscal Years 2020, 2021 and 2022	To be determined

Priority 3: Advocacy				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships With Kennedy Krieger Institute**
Increase advocacy skills of persons with disabilities and their families	**Strategy 1:** Increase youth knowledge of sexual health **Strategy 1a:** Increase caregiver and provider knowledge of sexual health for those with a disability	Through qualitative and quantitative methods, assess knowledge before and after information-sharing sessions	Fiscal year 2020	MCDD Developmental Disabilities Administration Kennedy Krieger High School Project SEARCH CORE Foundations Parents' Place of Maryland Families/caregivers
	Strategy 2: Promote self-advocacy	Qualitative measures to assess speaking up for oneself, asking for what you need, knowing rights and responsibilities	Fiscal years 2020, 2021 and 2022	People On the Go Maryland MCDD Developmental Disabilities Administration Kennedy Krieger High School Project SEARCH CORE Foundations Parents' Place of Maryland Disability Rights Maryland Families/caregivers
	Strategy 3: Community outreach to facilitate community engagement (step 1)	Record number of community activities that include training and/or dissemination of specific data	Fiscal years 2020, 2021 and 2022	Community stakeholders
Expand understanding by individuals, families and staff members about the state legislative process and how involvement can influence policy	**Strategy 1:** For students and patients (and families/caregivers) approaching adulthood, share information about policy topics that could affect their independence—target topics identified at each legislative session with our community partners	Select focused area for each state legislative session	Fiscal years 2020, 2021 and 2022	Kennedy Krieger Institute Board of Directors MCDD People On the Go Maryland Developmental Disabilities Council Disabilities Rights Maryland Families/caregivers

Priority 4: Transition to Adulthood				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships With Kennedy Krieger Institute**
Increase awareness and knowledge about the challenges of transition to adulthood by families with a youth with a disability about to transition to adulthood	**Strategy 1:** Disseminate information—via webinars, websites and printed information—about the differences between eligibility (18 years old and up) and entitlement (under 18 years old)	Number of webinars Number of documents disseminated Number of website hits	Fiscal year 2020	MCDD Project SEARCH CORE Foundations Maryland State Department of Education Developmental Disabilities Administration Parents' Place of Maryland Maryland Title V Office
	Strategy 2: Conduct a legal seminar for youth transitioning to adulthood, and their families, and offer five to 10 community slots	Number of families in attendance Number of youth Number of volunteer attorneys Number of legal documents generated	Fiscal year 2020	MCDD University of Baltimore School of Law Volunteer attorneys and law firms in Maryland
	Strategy 3: Explore a funding source to conduct a legal seminar for youth transitioning to adulthood, and their families, open to the community	Number of families in attendance Number of youth Number of volunteer attorneys Number of legal documents generated	Fiscal years 2021 and 2022	MCDD Funding agent University of Baltimore School of Law Volunteer attorneys and law firms in Maryland

Priority 5: Environmental Influences				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships With Kennedy Krieger Institute**
Determine sustainability/expansion of PACT's Therapeutic Nursery	**Strategy 1:** Explore a funding source to address a new viable model to sustain the Therapeutic Nursery program	Improvement in childhood behavior and social emotional skills	Fiscal years 2020, 2121 and 2022	PACT's Therapeutic Nursery Funding agent Maryland Department of Housing and Community Development
Use Kennedy Krieger knowledge to effect positive changes in environmental influences through programs and training	**Strategy 1:** Pilot a take/send-your-child-to-school program—open to Kennedy Krieger employees and by invitation to community middle and high school students	Development of a product for community dissemination Number of Maryland schools represented by participants	Fiscal year 2020	East Baltimore middle and high schools Baltimore school partners Kennedy Krieger Institute employees
	Strategy 2: Development of Kennedy Krieger services/programs and/or engagement with community entities that may address areas such as trauma, pain, opioid use or suicide in the population served	To be developed with community partners		Local and/or statewide community organizations Families/caregivers
	Strategy 3: Share approaches used at Kennedy Krieger with statewide providers, groups and legislators through the Subcommittee on Children and Families for the Commission to Study Mental and Behavioral Health in Maryland	Kennedy Krieger appointment to the subcommittee Attendance at public Commission to Study Mental and Behavioral Health in Maryland meetings	Fiscal year 2020	State legislator Community organizations Local health departments Community stakeholders
	Strategy 4: Explore collaborations with Baltimore City Health Department (BCHD)	Kennedy Krieger will meet with BCHD twice during the fiscal year to continue discussions to identify potential collaborative efforts	Fiscal year 2020	Baltimore City Health Department Community Stakeholders Trainees

Endnotes

[1]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 US children, 1997–2008. *Pediatrics, 127*(6), 1034–1042.

[2]University of Wisconsin Population Health Institute. (2018). *County Health Rankings 2018*. Madison, WI.

[3]National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in Action*. doi.org/10.17226/24624

[4]McPherson, Merle, et al. (1998). A new definition of children with special health care needs. *Pediatrics, 102*(1), 137–139.

[5]Lauer, E. A., & Houtenville, A. J. (2019). *Annual Disability Statistics Compendium: 2018*. Retrieved on April 14, 2019, from iod.unh.edu.

[6]Charles Drum, M. P. A., McClain, M. R., Horner-Johnson, W., & Taitano, G. (2011). *Health Disparities Chart Book on Disability*.

[7]Iezzoni, L. I. (2009). Public health goals for persons with disabilities: Looking ahead to 2020. *Disability and Health Journal, 2*(3): 111–115.

[8]Hand, B. N., Krause, J. S., & Simpson, K. N. (2018). Dose and duration of opioid use in propensity score—Matched, privately insured opioid users with and without spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 99*(5), 855–861.

[9]Centers for Disease Control and Prevention. U.S. Opioid Prescribing Rate Maps. Updated on October 3, 2018. Retrieved on April 15, 2019, from www.cdc.gov/drugoverdose/maps/rxrate-maps.html.

[10]U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion. Healthy People 2020. Washington, DC: U.S. Department of Health and Human Services. Published in 2010. Retrieved on February 20, 2019, from www.healthypeople.gov/2020/data-search/midcourse-review/topic-areas.

[11]World Health Organization. What are social determinants of health? Updated in 2019. Retrieved on April 15, 2019, from www.who.int/social_determinants/en/.

[12]U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion. Healthy People 2020. Washington, DC: U.S. Department of Health and Human Services. Published in 2019. Retrieved on February 20, 2019, from www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health.

[13]U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion. Healthy People 2020. Washington, DC: U.S. Department of Health and Human Services. Published in 2010. Retrieved on February 20, 2019, from www.healthypeople.gov/2020/topics-objectives/topic/maternal-infant-and-child-health.

[14]Data Resource Center for Child and Adolescent Health, a project of the Child & Adolescent Health Measurement Initiative. (2019). National Survey of Children's Health 2016. Retrieved on March 15, 2019, from www.childhealthdata.org.

[15]Bishop-Fitzpatrick, L., & Kind, A. J. H. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(11), 3380–3391. doi.org/10.1007/s10803-017-3251-9

[16]Baio, J., Wiggins, L., Christensen, D., Maenner, M., Daniels, J., Warren, Z., ... Dowling, N. (April 27, 2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *Surveillance Summaries, 67*(6), 1–23.

[17]Robertson, J., Hatton, C., Emerson, E., & Baines, S. (2014). The impact of health checks for people with intellectual disabilities: An updated systematic review of evidence. *Research in Developmental Disabilities, 35*(10), 2450–2462.

[18]Kerr, M., Linehan, C., Thompson, R., Mula, M., Gil-Nagal, A., Zuberi, S. M., & Glynn, M. (2014). A white paper on the medical and social needs of people with epilepsy and intellectual disability: The Task Force on Intellectual Disabilities and Epilepsy of the International League Against Epilepsy. *Epilepsia, 55*(12), 1902–1906.

[19]Health Resources and Services Administration. Rural Health Information Hub. Updated in 2019. Retrieved on April 15, 2019, from www.ruralhealthinfo.org/data-explorer?id=204&state=MD.

[20]The Child & Adolescent Health Measurement Initiative. (2019). Childhood trauma and positive health. Retrieved on March 15, 2019, from www.cahmi.org/projects/adverse-childhood-experiences-aces/.

[21]McCarty, A. T. (2016). Child poverty in the United States: A tale of devastation and the promise of hope. *Sociology Compass, 10*(7), 623–639. doi.org/10.1111/soc4.12386

[22]U.S. Department of Health and Human Services, Health Resources and Services Administration, and Maternal and Child Health Bureau. (2018). Maternal and Child Health Leadership Competencies. Retrieved from mchb.hrsa.gov/training/documents/MCH_Leadership_Competencies_v4.pdf.

[23]Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health, 105*(S2), S198–S206.

[24]Jones, J. E., Kessler-Jones, A., Thompson, M. K., Young, K., Anderson, A. J., & Strand, D. M. (2014). Zoning in on parents' needs: Understanding parents' perspectives in order to provide person-centered care. *Epilepsy & Behavior, 37*, 191–197.

Appendix 1. Data Sources and Resources

Agency	Data Sources	Year
Advocates for Children and Youth	Maryland Kids Count Indicators	Various
American Board of Medical Specialties	2017–2018 ABMS Board Certification Report	2017–2018
Annual Room to Grow: Journey to Cultural and Linguistic Competency	https://www.kennedykrieger.org/training/programs/center-for-diversity-in-public-health-leadership-training/center-for-diversity-videos	2016, 2017 and 2018
Data Resource Center for Child and Adolescent Health	National Survey on Children's Health	2016–2017
Department of Health (DOH)—OGPSHCN	2015 Comprehensive Needs Assessment for Children and Youth with Special Health Care Needs	2015
Department of Health (DOH)—Office for Genetics and People with Special Health Care Needs and Parents' Place of Maryland	2017 Maryland Parent Survey	2017
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	2018
Kennedy Krieger Institute	Patient/Student Demographic Statistics	2016–2018
Maryland Department of Disabilities	2016–2019 State Disabilities Plan	2016–2019
Maryland Developmental Disabilities Council	Maryland Developmental Disabilities Five-Year State Plan	2016
Maryland Developmental Disabilities Council and Parents' Place of Maryland	Transitioning Youth Survey	2017
Maryland State Department of Education	Maryland Report on Part B Indicator 8 of the Individuals with Disabilities Education Act (2016–2017) —Parent Survey	2017
National Academies of Sciences, Engineering, and Medicine	Communities in Action: Pathways to Health Equity	2017
Robert Wood Johnson Foundation/University of Wisconsin Population Health Institute	2019 County Health Rankings	2019
U.S. Census Bureau	American Fact Finder	2017

Appendix 2. List of Major Community Programs, Partner Agencies and Advocacy Groups

DOH, Office for Genetics and People with Special Health Care Needs (Maryland Title V)

Eastern Shore Community of Care Consortium for Children with Special Health Care Needs

Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger

Maryland Community of Care Consortium for Children with Special Health Care Needs

Maryland Department of Disabilities

Maryland Developmental Disabilities Council

Maryland State Department of Education

Parents' Place of Maryland

People On The Go Maryland

Project HEAL (MCDD/Kennedy Krieger)

Resource Finder (MCDD/Kennedy Krieger)

Appendix 3. List of Acronyms

ACEs: adverse childhood experiences

ACA: Patient Protection and Affordable Care Act

CHNA: Community Health Needs Assessment

CNI: Community Needs Index

CYSHCN: children and youth with special healthcare needs

DD: developmental disabilities

DOH: Department of Health

HPSA: health provider shortage areas

MCDD: Maryland Center for Developmental Disabilities

MICH: maternal, infant and child health

NSCH: National Survey on Children's Health

OGPSHCN: Office for Genetics and People with Special Health Care Needs

PPMD: Parents' Place of Maryland

UCEDD: University Centers for Excellence in Developmental Disabilities

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