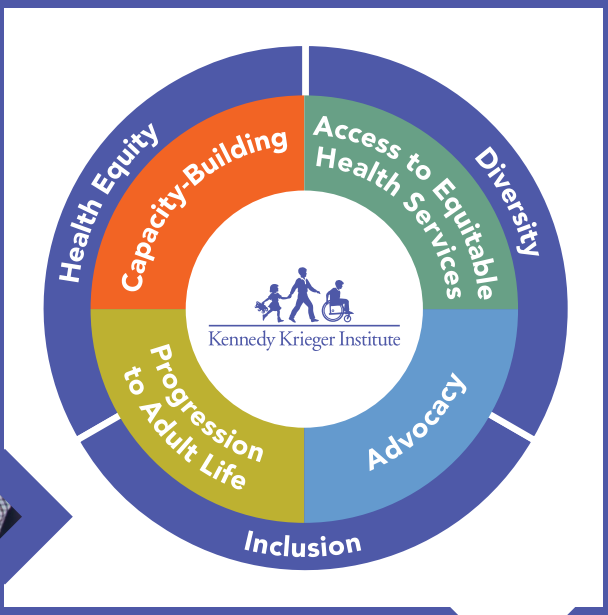
Kennedy Krieger Institute

2022 Community Health Needs Assessment



Kennedy Krieger Institute
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Kennedy Krieger Institute
2022 Community Health Needs Assessment

Table of Contents

Kennedy Krieger Institute

June 27, 2022

Dear Maryland community,

We are happy to present to you Kennedy Krieger's fourth Community Health Needs Assessment (CHNA), approved by the Board of Directors on June 8, 2022, and to report that the Institute met the goals and objectives associated with the 2019 priorities.

We're honored to be part of a vibrant, vital, mission-driven organization of nearly 2,800 dedicated staff members who serve more than 25,000 patients and students each year through 80 clinical, school and community programs and hundreds of research investigations.

The Institute's mission is to improve the lives of individuals with, or at risk for, nervous system diseases, disorders or injuries. We are grateful for the trust you put in us, and in Kennedy Krieger as a whole. Our goal is to partner with you to achieve the very best outcomes for our patients and students. 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.

Kennedy Krieger continued to expand its reach and developed stronger partnerships across the state and within its immediate physical community of East Baltimore.

Building on our experience with telehealth, we significantly expanded our delivery of telehealth and tele-education services, while continuing to serve patients in person in our hospital and outpatient centers. The expanded use of tele-education has offered enhanced access across Maryland.

To address the growing need for mental and behavioral health services for children and teens, and specifically for those with developmental or other disabilities, we expanded our behavioral health services across multiple programs, including serving families who have been impacted by traumatic stress.

Through our free vaccination clinics, we delivered COVID-19 vaccination to hundreds of individuals and families who may not have otherwise received the vaccine. And with our newly formed Pediatric Post COVID-19 Rehabilitation Clinic, we've served children, teens and young adults who continue to experience lingering symptoms and deficits after recovering from acute stage COVID-19 infection.

Kennedy Krieger will continue to expand its reach and develop stronger partnerships across the state and with our neighbors from the East Baltimore communities. We look forward to working with all of you to operationalize this plan to improve the health of Maryland's community for children, youth and adults with disabilities.

Bradley L. Schlaggar, MD, PhD
President and CEO

Nancy S. Grasmick, PhD
Chair, Board of Directors

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Executive Summary

Kennedy Krieger Institute, headquartered in Baltimore, Maryland, shared its last community health needs assessment (CHNA) in 2019, six months before the start of the COVID-19 pandemic. While our main campus is an anchor organization in East Baltimore, adjacent to the Johns Hopkins Medical Institutions campus, we embrace the entire state of Maryland as our community.

Kennedy Krieger Children's Hospital, Inc., an entity within Kennedy Krieger Institute, delivers unparalleled value to Maryland by providing the highest quality of care to individuals with developmental and related disorders and their families.

The Kennedy Krieger Institute 2019 CHNA focused on addressing the needs of Maryland's children and young adults with developmental disabilities, and those at the greatest risk for acquiring disorders of the nervous system. Top-priority areas noted in the report included capacity building through training, access, advocacy, transition to adult life and environmental influences—all rooted in equity, diversity and inclusion. After more than 2.5 years of witnessing health disparities brought into sharp focus by the lens of the COVID-19 pandemic, we must strive to eliminate disparities for individuals with disabilities through health equity practices and policies.

While work toward the 2019 priorities continued throughout the pandemic, we made innovative adjustments while cultivating and building new partnerships. With limited opportunities for in-person engagements to conduct our work, the Institute and its partners were able to successfully achieve the objectives of the implementation plan by providing services through multiple service-delivery models during the pandemic: inpatient, outpatient, telehealth, tele-education and community.

This current CHNA is based on data and community information collected and shared by partners from July 1, 2019, through most of 2021. The graphic 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.

While the pandemic presented multiple tragedies, it also offered opportunities and insight for alternative healthcare models. Additionally, the Institute relaunched its strategic planning process, which incorporated insights learned from our COVID-19 experiences. We envision a future in which health equity will drive how we implement the knowledge from our research activities to provide equitable access to evidence-informed clinical care and education; how we engage with our patients, students, families and the community to address needs; and how we support inclusivity in all aspects of our work.

Kennedy Krieger Institute
Community Health Needs Assessment:
Community Priorities

Introduction

Overview of Kennedy Krieger Institute

Kennedy Krieger Institute is a comprehensive nonprofit, Maryland-licensed pediatric rehabilitation and specialty hospital, school program and research center located in Baltimore, Maryland. Kennedy Krieger Institute's mission is to transform the lives of children, youth and adults with, and those at risk for, disorders of the developing nervous system, through innovative, equity-based and culturally relevant clinical care, research, education, community partnership, advocacy and training. Diversity, cultural and linguistic competency, and inclusion are foundational in services the Institute provides.

We envision a world where Kennedy Krieger will continue to lead with intention, through innovation, to provide equitable, relevant and effective clinical care, research, educational interventions, training and advocacy services in partnership with the community to improve the lives of all individuals who have or are at risk for disorders of the nervous system. Our approach is child- and family-centered and interdisciplinary, ensuring that children and young adults from diverse backgrounds have access to the highest-quality treatments, education and community programs they need to achieve the best possible outcomes.

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 President Kennedy's administration produced the first federally-funded grant, which allowed Kennedy Krieger to focus on the following three program areas of greatest concern: recruiting 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. The original mission sought to transform the environment by developing new treatments, therapies and approaches to integrating children with special needs into the community. We continue this journey today, in 2022, through a refreshed lens, as part of our upcoming strategic plan and our 2022 CHNA Implementation and Action Plan.

As important is the need for our Institution to understand what drives health, as an anchor organization in our community, how we contribute to the health and well-being of the population we support and the general community is vitally important as we strive to achieve health equity.

Our Structure

A Maryland asset, 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. 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 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 developing nervous system through groundbreaking research, innovative treatments and life-changing education. The wide range of services offered under the Institute allows us to serve the whole individual at many stages of their lives. We serve patients and families from all over Maryland, the mid-Atlantic region, across the country and the world.

The consolidated annual operating budget for Kennedy Krieger Institute, Inc, across all of its sub-entities, was $275.5 million and the Kennedy Krieger Children's Hospital's annual budget was $194.6 million for the fiscal year ended June 30, 2021. A financial audit was performed for fiscal year 2021 and an unmodified opinion was expressed by PricewaterhouseCoopers, LLP, dated October 4th, 2021.

Through research, across all affiliates, Kennedy Krieger employs new approaches in neuroscience and technology that contribute to the needs of the Maryland community and enhance the services and educational curriculum.

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 citizens. Kennedy Krieger works with the MCDD and other community partners to conduct a comprehensive community health needs assessment (CHNA) focusing on the population served. People On the Go Maryland

(POG), 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. POG is currently a partnership between the Maryland Developmental Disabilities Council and the MCDD at Kennedy Krieger Institute.

Serving as the core foundation of the Institute's community programs, the 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 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 15 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. The 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 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 close to 1,000 individuals for time periods ranging from several months to two 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 2022, the Institute will hold its twelfth annual "Room to Grow: Journey to Cultural and Linguistic Competency" conference, which is open to the public and webcast live on the internet.

The School Programs at Kennedy Krieger offer special education and related services to students ages 3 to 21 in multiple day-school settings: (1) kindergarten–eighth grade; (2) high school; and (3) an intensive 12-month special education program serving students ages 5 to 21 with a primary diagnosis of autism spectrum disorder (ASD). Pre-pandemic, we educated and supported approximately 500+ Maryland school students with unique needs every year from elementary through high school across three school campuses in Maryland, currently located in Baltimore City and Prince George's County.

Our high school educational programming prepares our high school students to transition back to their communities and into adulthood. During the 2021-2022 school year, enrollment for the School Programs at Kennedy Krieger ranged from 492 (FY2021) to 468 (YTD April 2022) and delivered more than 60,000 clinical, direct-service sessions of speech-language pathology, occupational therapy, counseling, physical therapy and expressive therapy sessions. 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.

The healthcare sector of our organization provides services by highly qualified professional staff members through a longstanding, 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. The patient population presents an array of conditions and diseases ranging from ASD and attention deficit hyperactivity disorder (ADHD) to more rare diseases like adrenoleukodystrophy and acute flaccid myelitis. During the last three fiscal years (2019 through 2021), Kennedy Krieger averaged approximately 500 inpatient admissions. Inpatients and outpatients served are predominantly between the ages of 3 and 12 years old. The racial and ethnic composition of Kennedy Krieger's patients closely resembles Maryland's population, according to the 2020 population estimates of the U.S. Census.[1]

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

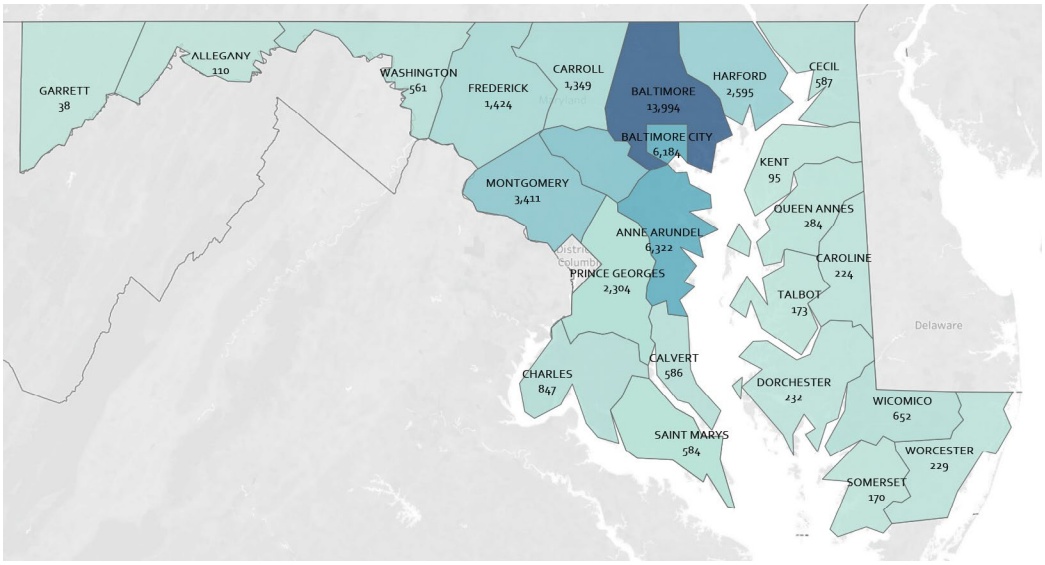
	Unique Outpatients at Kennedy Krieger Institute			Maryland Population	
	Fiscal Year 2019	**Fiscal Year 2020**	**Fiscal Year 2021**	**All Marylanders (Source: U.S. Census, 2020 Population Estimates)**	**Marylanders Under 18 Years Old (Source: U.S. Census, 2020 Population Estimates)**
Total	24,730	24,634	24,502	6,037,624	1,340,766 (22.2%)
Age					
0–2	11.4%	8.4%	8.6%		
3–5	19.1%	19.1%	18.7%		
6–8	20.3%	20.5%	20.2%		
9–11	18.7%	20.1%	19.2%		
12–14	15.7%	16.7%	16.8%		
15–17	11.8%	12.9%	13.5%		
18–20	4.8%	6.6%	7.2%		
21+	8.7%	9.4%	10.6%		
Race					
White, not Hispanic or Latino	46.8%	46.2%	45.5%	50.2%	41.2%
Black	29.2%	29.4%	27.8%	29.4%	30.8%
Hispanic	4%	6.6%	7.0%	10.3%	15.5%
Native Hawaiian/Pacific Islander	5.3%	0.1%	0.1%	0%	0%
Asian	4.2%	2.3%	2.7%	6.3%	5.9%
Two or More Races/Other	7.4%	5.8%	6.2%	3.3%	8.9%
American Indian or Alaska Native	0.2%	0.2%	0.2%	0.2%	0.2%
Unknown	6.2%	14.5%	14.5%		
Sex					
Male	64.4%	63.7%	62.0%		51%
Female	35.4%	36.2%	38.0%		49%

Compared to the 2019 CHNA, the age distribution of unique Kennedy Krieger patients has remained essentially unchanged, as has the racial and sex composition. However, trends show a slight rise in Hispanic patients and a gradual decrease in Asian patients served, mirroring the population changes in Maryland. Kennedy Krieger outpatient volumes varied during fiscal years 2019, 2020 and 2021. The pandemic resulted in programs seeing an increase in patient visits as opposed to seeing more unique patients. We saw more patients who were able to receive services using telehealth as a service modality. The distribution of patients seen at Kennedy Krieger is weighted more towards males—similar to data found in the literature.[2]

The Community We Serve

Kennedy Krieger serves children, adolescents and adults from Maryland, across the U.S. and internationally. Data analyzed during the last three fiscal years—2019, 2020 and 2021—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 (represented in Figure 1). While who we serve has expanded, we continue to provide services and advocate for the same population that started Children's Rehabilitation Institute, the precursor to Kennedy Krieger Institute. By continuing our investment in Maryland, and in our immediate neighborhoods where we are located, we seek opportunities through partnerships to achieve equitable health care for our communities.

Figure 1. Outpatient Visit Distribution by Maryland County FY19-FY21



Knowing what affects health means understanding the needs and opportunities essential to achieving health equity for all, to include 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 the intersectionality of age, 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.[3] Approaches such as universal design and maximizing opportunities offered by technology like telemedicine are solutions that can help us move toward health equity.[4]

Target Population

Our target population includes children, adolescents and adults with disabilities and injury, and those at the highest risk for disorders of the nervous system. In Maryland, 23.21% of children 0 to 17 years of age have a special healthcare need.[5] Children and youth with multiple and complex healthcare needs require coordination of services from multiple systems—healthcare, public health, education, mental health and social services. Narrowing the focus, we know that approximately 17.3% 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.[5] In exploring community needs, the focus is on the population served across all entities of Kennedy Krieger, residing in Maryland.

As a comprehensive specialty institution, to support equity in health for those at risk or having an impairment, it is important to integrate their needs and leverage existing resources to ensure comprehensive access. Viewing needs and resources through a universally designed lens will support achieving health outcomes identified in the County Health Rankings (CHR) model for all populations.

Specific health factors addressed through this assessment include: (1) health behaviors; (2) clinical care—access to care and quality of care; (3) social and economic factors to include education, employment, income, family and social supports and community safety, especially for those with neurodiverse profiles; and (4) the physical environment.

Approach/Methodology

A Kennedy Krieger CHNA team collected and analyzed data with community partners to develop the 2022 priority areas and implementation plan. Simultaneously, the Institute launched a strategic planning process in which the work and data from the CHNA was used to assess needs, prioritize needs, and develop plans to provide services to the population we serve. We continue to rely on partnerships that allow us to access and share data metrics over the years that assist all corporate entities in identifying community needs. Partnerships have allowed internal and external leveraging of resources to provide and advocate with the same population: children, adolescents and adults with disabilities and their families. Data sharing has been seamless between entities. Several organizations that shared data included: (1) Kennedy Krieger's MCDD; (2) Developmental Disabilities Council; (3) Disability Rights Maryland; and (4) Maryland Eastern Shore Consortium of Care Quarterly Meetings, among others (Appendix 2). Many data sources are publicly available on the internet for access. Appendix 1 represents key data sources used for this CHNA.

Description of Selected Resources Used in Collecting Data

For the 2022 CHNA, selected data sources 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. Maryland Report on Part B Indicator 8 of the Individuals with Disabilities Education Act 2018–2019, conducted by ICF International for the Maryland State Department of Education Division of Special Education/Early Intervention Services
3. Maryland Department of Disabilities' State Disabilities Plan 2020–2023
4. County Health Rankings and Roadmaps 2021
5. Participation in the Maryland Statewide and Maryland Eastern Shore Consortium of Care Quarterly Meetings
6. Kennedy Krieger Institute Patient/Student Demographic Statistics 2019–2021
7. Healthy People 2020 and 2030
8. The Annual Disability Statistics Compendium 2021
9. American Board of Medical Specialties (ABMS) 2017–2018 Board Certification Report
10. Data Resource Center for Child & Adolescent Health: National Survey for Children's Health 2019–2020
11. Voice of the Caregiver Survey, Maryland Center for Developmental Disabilities, 2021
12. Maryland Center for Developmental Disabilities External Needs Assessment Survey, 2021

Data Gaps

According to the CDC, 7.4 million people in the U.S. have an intellectual disability, the most common developmental disability.[6] The prevalence of developmental disability in the U.S. for ages 3 to 17 years increased between 2009 and 2017.[2] The prevalence of ADHD, ASD and intellectual disabilities (ID) increased, but also there was an associated reduction in other developmental disabilities. Research supports greater health disparities, specifically poor health outcomes, for people with intellectual and developmental disabilities, as compared to those without. COVID-19 has amplified the need to view and measure health equity across diverse population groups by (1) adding populations typically not included in survey data; (2) further delineating the population by age, race ethnicity, gender, etc.; and (3) identifying geographic boundaries among different indicators. Data for some indicators are available only for national and/or state levels. Information about access to and awareness of resources continues to be a topic of many meetings across communities.

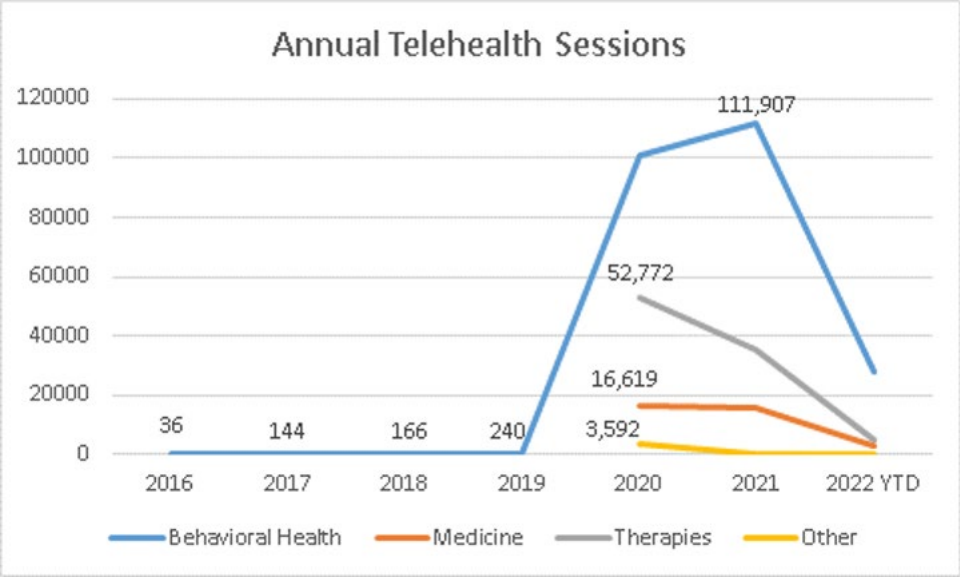
While there are multiple information resource programs serving Maryland and certain counties, not one fulfills the complete need of any one community.

Kennedy Krieger during COVID-19: 2020 to Present

On March 5, 2020, COVID-19 (SARS-CoV-2) hit our Maryland community, and Governor Larry Hogan proclaimed a state of emergency. Governor Hogan also issued an early 2020 executive order that 1) limited gatherings to no more than 250 people, 2) closed senior centers and parts of the Port of Baltimore, 3) required hospitals to implement new visitor policies, and 4) closed public schools for two weeks. This was only the beginning.

Normal operations at the Institute and all healthcare entities statewide were immediately impacted by these events. Knowing what we knew about SARS-CoV-2 at the time, it became clear we needed to protect our patients, students and their families, and our Kennedy Krieger staff and their families. We implemented an immediate but dynamic response to shift our delivery model of services—clinical care (inpatient, outpatient, community), training, education, research and advocacy—to virtual platforms (Figure 2). The messaging to our program leaders was: Think outside the box and create processes that will allow continued provision of care in a safe matter for the patient, family and staff member. A state of emergency had been declared, and we needed to respond using all means or tools necessary: telephone, telehealth, tele-education, new screening processes, limiting outpatients at facilities, implementing strict screening—"Whatever It Takes"—using clinical judgment and providing meaningful and effective care to patients and students and their families.

Figure 2. Kennedy Krieger Telehealth Sessions (annual)



What the Data Tell Us

Healthy People

In reviewing Healthy People 2030, our country's blueprint for improving health for all populations, specific objectives have been identified that align with data collected for this assessment.

Table 2. Selected Aligned Healthy People 2030 Objectives with the 2022 CHNA Needs

Healthy People 2030 Objectives[9] Aligned with Kennedy Krieger's 2022 CHNA Needs	
HP 2030 Objectives	**CHNA Priorities**
AH-D01: Increase the proportion of elementary and secondary schools and early childcare settings that are trauma-informed	Access to Equitable Health; Advocacy
AH-09: Reduce the proportion of adolescents and young adults who aren't in school or working	Progression to Adult Life
SDOH-02: Increase employment in working-age people*	Progression to Adult Life
EMC-D03: Increase the proportion of children who participate in high-quality early childhood education programs	Access to Equitable Health
DH-05: Increase the proportion of students with disabilities who are usually in regular education programs	Progression to Adult Life; Advocacy
AHS-04: Reduce the proportion of people who can't get medical care when they need it	Progression to Adult Life
AHS-R01: Increase the ability of primary care and behavioral health professionals to provide more high-quality care to patients who need it	Capacity Building

**Leading Health Indicators: Leading Health Indicators (LHIs) are a small subset of high-priority objectives selected to drive action toward improving health and well-being.[9]*

Core – Orange: Core objectives have valid, reliable, nationally representative data, including baseline data from no earlier than 2015.[9]

Developmental – Purple: Developmental objectives represent high-priority public health issues that are associated with evidence-based interventions but don't yet have reliable baseline data.[9]

Research – Green: Research objectives represent public health issues with high health or economic burden or significant disparities between population groups — but they aren't yet associated with evidence-based interventions.[9]

Table 2 presents the objectives that correspond with needs identified. The Healthy People 2030 (HP 2030) Health Behavior topic includes child and adolescent development. The goal is to promote health development for children and adolescents. As a community, we support development through supportive care, providing education, taking care of our children physically, and as health providers, track development, through screenings and evaluations. The pandemic has demonstrated that trauma-informed approaches to care, communication and more are essential in influencing development. The HP 2030 objective AH-D01 to increase the proportion of trauma-informed early childcare settings and elementary and secondary schools is a developmental high-priority public health issue, but no data has been collected to support this objective to date. This objective is in a developmental stage, meaning it is not a core HP 2030 objective (no reliable baseline data to measure and track), it does represent a major public health issue with evidence-based interventions.

The Social Determinants of Health (SDOH) objective areas that will be tracked for this assessment include Economic Stability, Education Access and Quality, and Health Care Access and Quality. SDOH are conditions within our environments where we are born, live, learn, work, play, worship and age. All domains within the SDOH are areas that impact our health and life outcomes.

While healthcare organizations do not frequently consider economic stability as an objective in the health arena, we know that economic instability, i.e. poverty, influences health outcomes especially related to the growth and development of children. For families, also impacting children, the ability to obtain healthy foods and finding and retaining employment impacts the level in which one can care for their family members. One specific objective that aligns with the needs identified in the Maryland community is HP 2030 objective AH-09, Reduce the proportion of adolescents and young adults who aren't in school or working; and HP 2030 objective SDOH-02, Increase employment in working-age people but including persons with disabilities in the target achievement. AH-09 will gauge how successful we are as a state in facilitating transition to adulthood for our youth with developmental concerns.

Education is a core component of health. We know that persons with higher levels of education are typically healthier and live longer.[7] This makes objectives related to education access and quality extremely important as we work to improve equitable access and quality in childhood development programs. The overarching goal for education access and quality is to increase educational opportunities and help children and adolescents do well in school. The goal of EMC-D03 is to Increase the proportion of children who participate in high-quality early childhood education programs. This objective has a developmental status, which means that while there are evidence-based interventions to address it, there is no baseline data. DH-05 is to Increase the proportion of students with disabilities who are usually in regular education programs. Based on current data (2019-2020), the objective is at a baseline of 63.5%.

Major barriers in the U.S. healthcare system include access and quality, which continue to present as a major barrier within the U.S. healthcare system, meaning many that live in this country do not get the services they need at all, in a timely fashion, or high-quality services that are available to some. Access for some also continues to be related to health insurance coverage, and without insurance coverage, having a primary care provider is less likely. Persons with disabilities experience barriers for some of the reasons listed, but in addition, providers who are trained to provide care in such specialized areas are limited. Objectives that support increased access include AHS-04, Reduce the proportion of people who can't get medical care when they need it and AHS-R01, Increase the ability of primary care and behavioral health professionals to provide more high-quality care to patients who need it.

The 2019 assessment focused on Healthy People 2020 (HP 2020) maternal child health objectives. 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.[13] The final results of the HP 2020 maternal child health objectives identified are as follows:

- 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)
HP 2030: Baseline Year 2016-2017 = 31.1%
HP 2030: Target = 35.8%

  - MICH-29.2 Increase the proportion of children with ASD having a first evaluation by 36 months of age.
  - MICH-29.3 Increase the proportion of children with ASD enrolled in special services by 48 months of age.

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: 2014 = 48.5% (U.S.)
HP 2020: Target = 57.6% (NOT MET)
HP 2030: Baseline Year 2016-2017 = 43.3%
HP 2030: Target = 53.3%

- 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)

As a country, we met the HP 2020 target in two of the three objectives selected as aligning with the 2019 priority needs. In the U.S. and Maryland, we met the objective that sought to increase the proportion of children (aged 10–35 months) who have been screened for ASD and other developmental delays.

HP 2030 resulted in fewer objectives, less overlap of topic areas, and topics and objectives that address major public health concerns. The core principles that guide decisions about HP 2030 address the health and well-being of all people, achieving health equity and literacy while eliminating health disparities, and addressing the social determinants that strengthen individuals' health and well-being. The HP 2030 plan will establish measurable objectives, generate interventions that are evidence-based or of promising practices, and create a system to move forward. HP 2030 lays the foundation of policy for the development of programs to improve the health and wellness of our nation.

2022 County Health Rankings

The County Health Rankings (CHR) Model displays all factors that contribute to health in the broadest sense.[3] Health includes more than healthcare. It includes where we live, the safety of our neighbors that allows outside exercise and play, access to good education, the food we eat, and how easy it is to obtain adequate food. It shows how policies and programs play a significant role in influencing health factors that in turn shape the community's health outcomes. That means not just how long we live, but how well we live. Being able to see all the factors that impact health allows us to understand where we can take action to improve the health of the population we serve. Health outcomes are broken down into length of life or measuring how long people in a community live, and telling us whether people are dying too early and why, and quality of life or how healthy people feel while alive. Health factors are broken down into health behaviors, clinical care, social and economic factors, and physical environment. An important note is the contribution to clinical care, which health care providers have traditionally focused on in rendering service and developing programs in our institutions. Research supports that health behaviors and social and economic factors like social responsibilities play a larger role in health outcomes than clinical care alone.[8] Health outcomes represent the physical and mental well-being of our Maryland community. This report will show the disparities across our state, but more importantly, provide strategies to achieve greater health equity for children, youth and adults at risk for disorders of the developing nervous system.

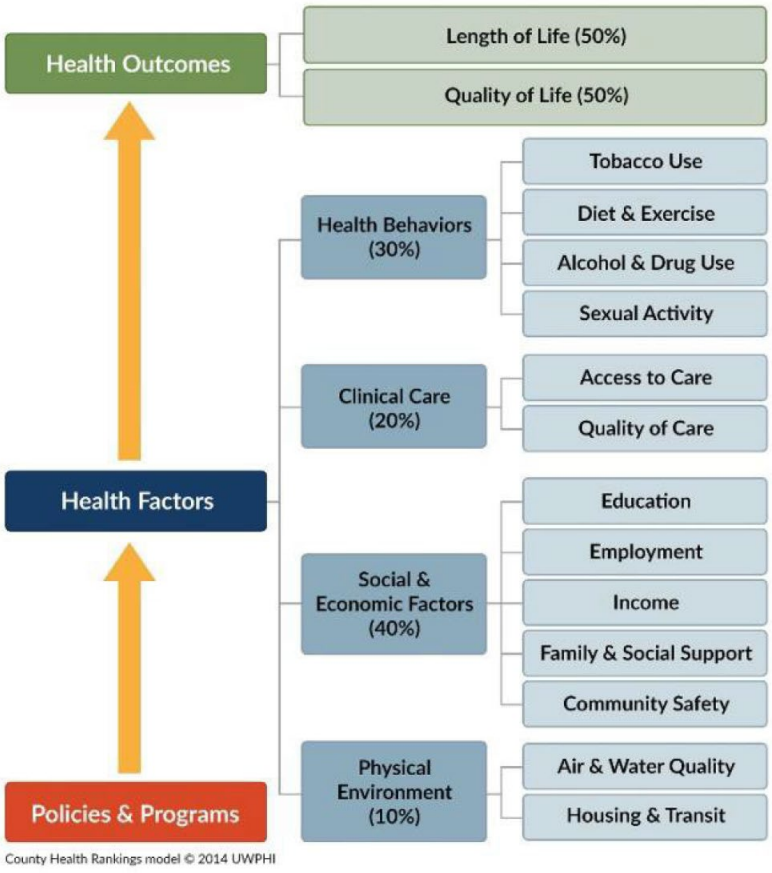
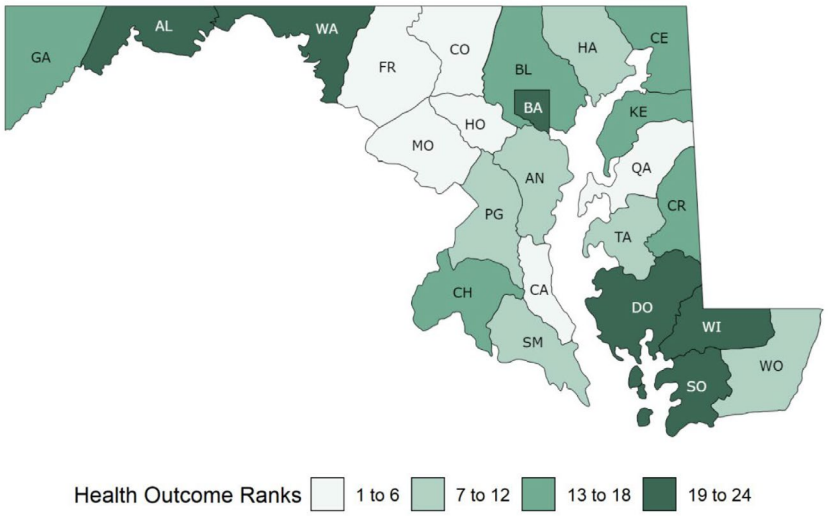


Figure 3. County Health Rankings Model, 2016 (Source: The University of Wisconsin Population Health Institute. County Health Rankings & Roadmaps, 2022. www.countyhealthrankings.org)

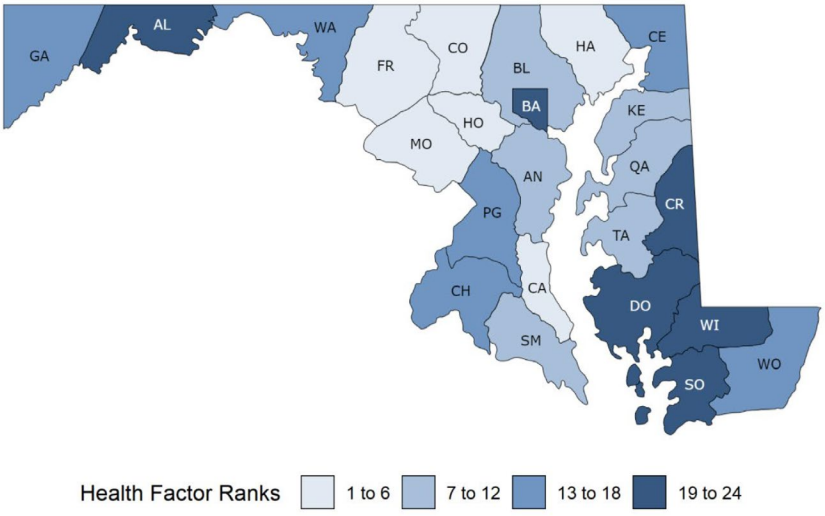
With funding from the Robert Wood Johnson Foundation (RWJF), the University of Wisconsin Population Health Institute created a roadmap for states and their communities across the country. For each state, every county is ranked for health outcomes, factors and other measures that influence health. County rankings provide evidence-informed strategies that guide communities toward action to improve health equity. 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. For counties presenting with the worst health status, individuals with disabilities may experience the worst health outcomes. Baltimore City ranks among the lowest jurisdictions for health outcomes in the state (Figure 4).

Figure 4. Maryland Health Outcomes, County Health Rankings, 2022(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 5).

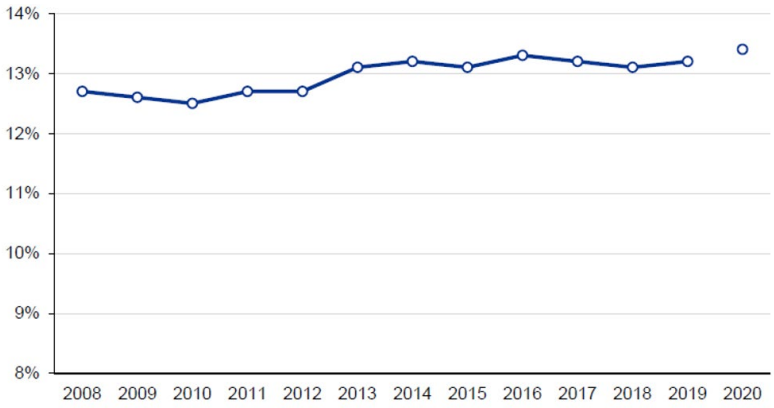
Figure 5. Maryland Health Factors, County Health Rankings, 2022 (Source: University of Wisconsin Population Health Institute)



Much of the data has not changed since 2019. What do we need to do differently to influence the health of all, which will then impact the health of the specific population served by Kennedy Krieger? In reviewing the data collected that identifies the needs of Maryland's community, especially those at risk and with disorders of the nervous system, we will utilize evidence that supports what has influenced community change while ensuring the specific needs shared are included.

According to the U.S. Census, in 2020, the percentage of persons with disabilities was 13.4% (Figure 6). For those ages 25–34 years living in community settings, those with disabilities were less likely to have a high school diploma (14.6% vs. 6.6%) and even more so when looking at the same population having attained a bachelor's degree (19% of persons with disabilities vs. 41.9% of persons without a disability).

Figure 6. U.S. Census Percentage of People with Disabilities

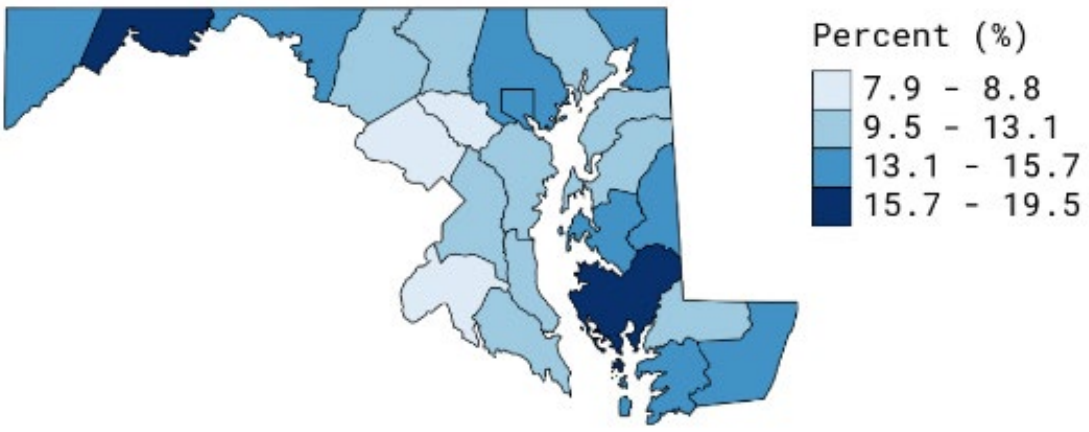


The Annual Disability Statistics Compendium 5 annually tracks the progress of persons with disabilities using social and economic metrics, which allows us to determine improvement in any one area, such as education, employment, earnings, poverty, transportation and independent living. Health behaviors 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 drinking behaviors (alcohol and drug use), all measured by the Behavioral Risk Factor Surveillance Survey. The statistics collected for 2021 demonstrate, as in prior years, that adults with disabilities are more likely to smoke (21.7%) than those without disabilities (11.7%). Adults with disabilities are more likely to be obese (40.4%) than adults without disabilities (29.0%).

The Rehabilitation Research and Training Center on Disability Statistics and Demographics (StatsRRTC) and the Rehabilitation Research and Training Center on Employment Policy and Measurement (EPM-RRTC), both funded by National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), produced a 2019 state report for county-level data on the prevalence of (the proportion of) people with disabilities across each county. The data for this report is generated by the American Community Survey (ACS), developed by the U.S. Census Bureau to collect information about the social, economic and demographic characteristics of the U.S. population. Disability in U.S. Census data is determined by replies to six questions. As we work to ensure individuals with disabilities are fully integrated into all aspects of our society, a core and significant component is health and wellness. Collecting data to measure health outcomes is critical for all. While the six questions used by the ACS are a start (difficulties with vision, hearing, ambulation, cognition, self-care and independent living),[1] there are additional metrics we need to collect and analyze, as we do for other populations, that will allow improved strategies for improved outcomes.

While the count of people per county (Figure 7) with disabilities presents at a higher frequency in central Maryland counties (Carroll, Baltimore City and County, Anne Arundel, Montgomery and Prince George's), the percentages of persons with disabilities are highest in Allegany and Dorchester counties (15.7% to 19.5%). These two counties also are representative of counties where the health professional workforce shortages exist, and health outcomes are among the lowest. One takeaway from this data is that persons with disabilities are also experiencing poorer health outcomes in these counties. Additionally, data indicate the challenges in providing specialized services when there is minimal mass to justify such a specialty service. A capacity-building model that builds greater knowledge is beneficial in these situations.

Figure 7. Percent of People with Disabilities for Maryland, by County: 2019, The Annual Disability Statistics Compendium 2021



Policies and Programs

CHR have shown for years that the areas with the worst outcomes are not necessarily aligned with the counties with the most health professional resources. Certainly, access to these resources is important, but it does not constitute the only component that contributes to one's health outcome.

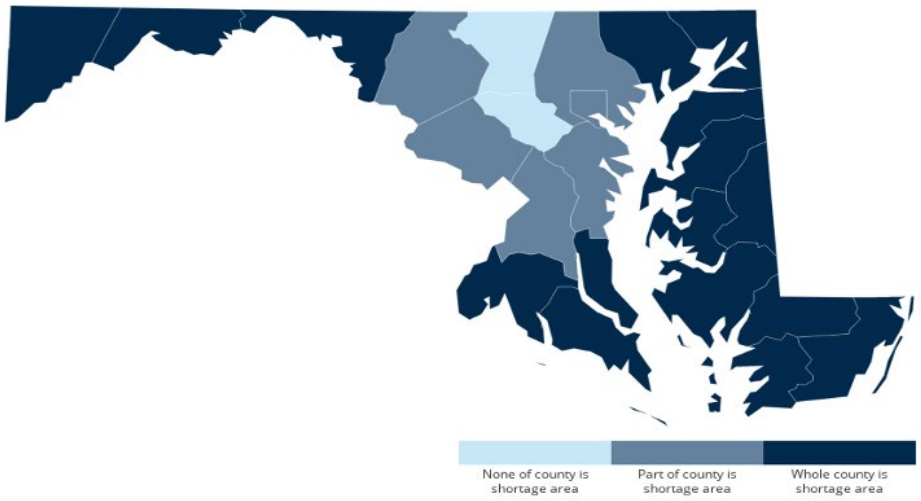
As health professionals, we view clinical care as a primary focus of the care we render to our patients, although it only contributes to 20% of our health outcomes. The nation's health blueprint, HP 2030, the 5th version of the Healthy People initiative, drives health for all Americans to include those with disabilities.[9] We know through studies that persons with disabilities receive less preventative healthcare, required to stay healthy and contribute to improving health outcomes.[10] HP 2030 contributes significantly to the CHR framing of health outcomes, meaning it is not all about healthcare in a hospital or practice, but in our social environment and activities. We also often speak of access to health, but access must include work, education, community engagement and more.

The objectives and measures identified by HP 2030 help us track the health and well-being of the nation's health. While all of the HP 2030 objectives contribute to the health of persons with disabilities, the topics we will address and connect to the health outcomes for persons with disabilities include health behaviors and social determinants of health. The HP 2030 objectives align with promoting physical, mental, emotional and behavioral development in children and adolescents.

Health Factors

CHR health outcomes are areas that influence how well and how long we live. This includes multiple areas that impact our lives, for example, our education, our environment and more. Health Factors are categorized in Figure 5.

Figure 8. Health Professional Shortage Areas: Mental Health, 2022 (Source: Maryland Rural Health Information Hub)



Clinical Care

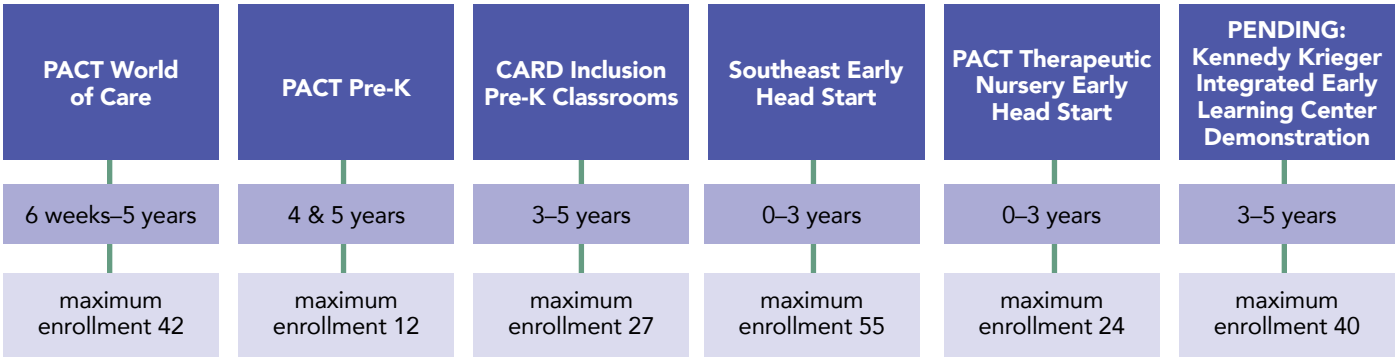
The CHR and the Rural Health Information Hub 2022 report the need for mental health providers in Maryland based on the ratio of people to mental health providers[19] (Figure 8). The majority of Maryland is impacted by a poor ratio of mental health providers to patients. Clearly, our Eastern Shore counties, far western Maryland counties and lower southern Maryland counties are the most influenced. What is not represented, nor can it be extracted, are providers who have confidence and skills to serve individuals with developmental disabilities. Factoring in competency of skills to service a specialty population could contribute to an even greater health professional shortage.

While the data confirms that the population needing mental health services is increasing and access to mental health services presents with barriers, we also see that geographic disparities in health professional shortages also contribute to access. In Maryland, using the latest data from HRSA, 2022 reveals little to no changes in areas of shortage compared to 2019. While the mapping represents mental health providers overall, if we were able to adjust for pediatric providers, the areas of shortage may be even greater.

Early Childhood Education

Early childhood development programs address the development of children. Children with complex medical and special healthcare needs need equitable access to early childhood education. Starting early to address social determinants of health that influence one's later health and well-being is the investment in quality early childhood education we have to make. It is the upstream approaches to addressing root causes of poor health as opposed to symptoms that will generate improved outcomes.

Figure 9. Kennedy Krieger Institute Early Childhood Programs



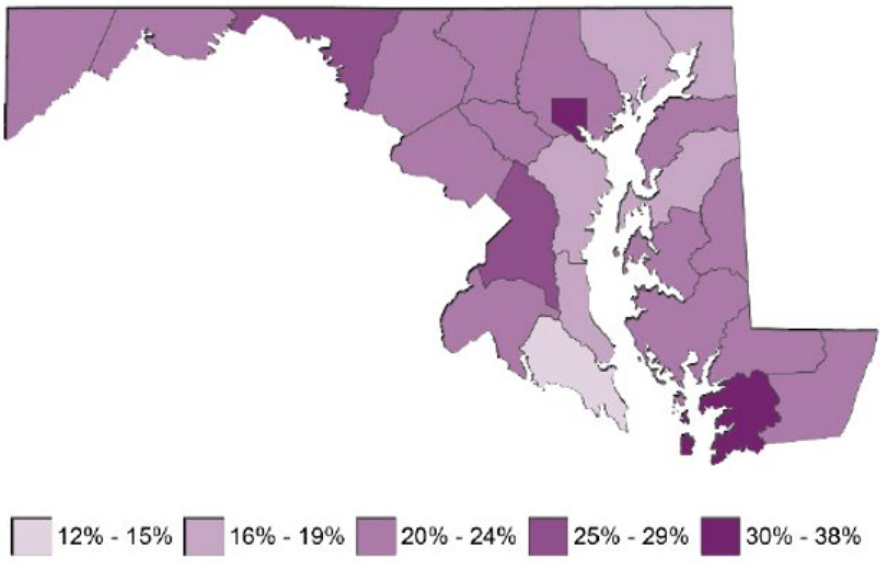
Kennedy Krieger engages in community initiatives that enhance the lives of children and their families within Baltimore and in communities across Maryland who are at the greatest risk for acquiring disorders of the nervous system. Kennedy Krieger aims to intervene early in a child's development. Through early childhood education and development programs, we are a part of the solution towards eliminating barriers to development and learning. One of our original early childhood programs is PACT: Helping Children with Special Needs, Inc. PACT's mission is to ensure all children have a good start in life. PACT has three programs: PACT World of Care (WOC), a medical childcare center; PACT Pre-K program, for those with special needs; and PACT Therapeutic Nursery's Early Head Start program, for infants and children residing in a family shelter. PACT WOC serves children up to age 5 and is the only medical childcare center in central Maryland with nurses, developmental therapists and experienced childcare teachers on staff to meet the needs of children who are medically fragile and/or developmentally disabled and their families. PACT Pre-K classroom is a free program serving twelve 4-year-old children with and without special healthcare needs and living in central Maryland. Both programs are in Northwest Baltimore County. PACT Therapeutic Nursery offers Early Head Start services for children under 3 who are currently without a permanent home or experience housing insecurity. The program promotes parent-child attachment and enhances family stability through attachment-based, trauma-informed mental health interventions.

Our Southeast Early Head Start (SEEHS) is a comprehensive program that serves low-income families and children up to age 3 by promoting emotional security, health and safety, and the enjoyment of learning. SEEHS achieves these goals by emphasizing the importance of nurturing and advocating for children, building parents' skills and confidence, increasing awareness of and access to community resources, and developing life skills that help families to pursue personal and professional growth. Finally, Kennedy Krieger offers another Pre-K program embedded in our Center for Autism and Related Disorders (CARD). CARD Inclusive Pre-K is a free, full-day program serving children ages 3 to 5. CARD Pre-K uses the Connect 4 Learning Pre-K curriculum, a National Science Foundation–supported curriculum that encourages child development and learning across developmental domains. The Pre-K program provides a social-emotionally-enriched comprehensive learning environment with a low student-to-

staff ratio to meet the learning and emotional needs of each child. The program is in Northwest Baltimore City on the Kennedy Krieger Greenspring Campus. All our programs voluntarily participate in the Maryland Excels program, the quality rating and improvement system for childcare and early education programs.

We see in regions of Maryland, in particular Baltimore City and Somerset County on the Eastern Shore, that the childcare cost burden is high (Figure 10), in addition to significant high levels of poverty, poor health outcomes and factors, workforce shortages and more. Additionally, reports show limited ECE centers that offer equitable environments for children that learn differently.[11]

Figure 10. Childcare cost burden in Maryland by county

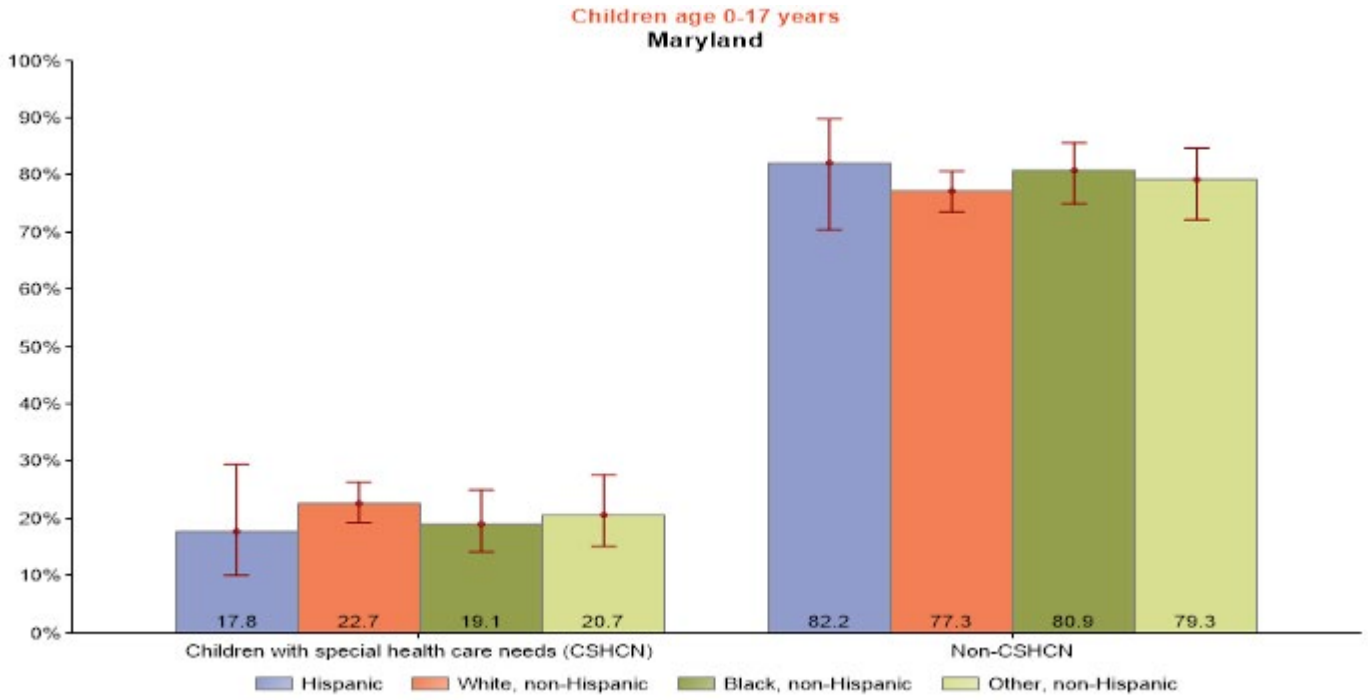


National Survey of Children's Health

The National Survey of Children's Health (NSCH) is an important source of data on a vast amount of elements about children's lives: physical and mental health; access to quality healthcare; and the child's family, neighborhood, school and social context.[12] Content maps display data collected for children ages 3 to 17 in the areas of Child and Family Health Measures and Title V Maternal Child Health Services Block Grant Measures. The NSCH provides national and state-level data on measures related to needs identified by other Maryland community members: (1.11) Children with special health care needs; (2.10) Mental, emotional, developmental or behavioral problems, 3 to 17 years; (4.4) Received mental health care, 3 to 17 years; (4.4a) Difficulties obtaining mental health care, 3 to 17 years; (4.15) Transition to adult health care, 12 to 17 years among CSHCN and Non-CSHCN; (5.1) Special education or early intervention plan (EIP), 1 to 17 years; (6.13) Adverse childhood experiences; (6.20a) Time spent coordinating health care; and (6.26) Food insufficiency.

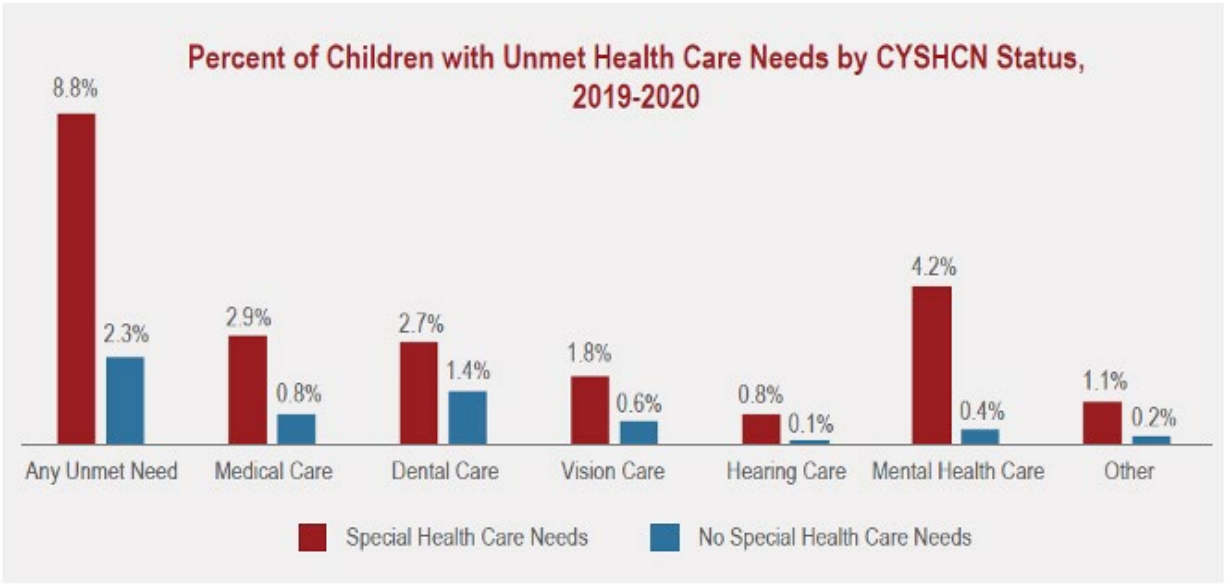
Maryland has 273,531 children with special healthcare needs, representing about 21% of the 0- to 17-year-old population in the state.[12] Of the children identified with a special healthcare need, almost 9% use a language other than English as their primary language. Approximately 11% did not have insurance at the time of the survey. Slightly over 20% had only public health insurance. In looking at children in Maryland with special healthcare needs by race/ethnicity, we see white children are more prevalent, followed by other, non-Hispanic (Figure 11).

Figure 11. Children with special health care needs



In assessing the population of children in Maryland having one special healthcare criterion, we see the numbers increase, especially as we look at those requiring prescription medications, increased use of health services and, to a lesser degree, those with functional limitations as compared to national data.

Figure 12. Unmet Health Needs by CYSHCN Status

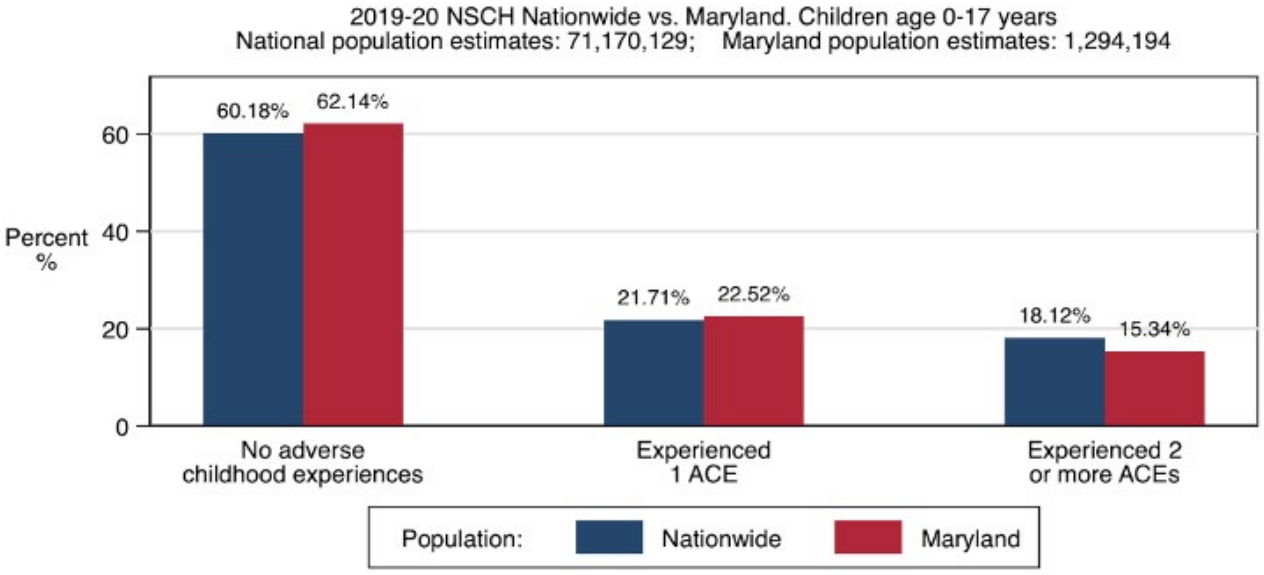


CSHCN are more likely to not receive specific healthcare needs, i.e., medical, dental, vision, hearing and mental health (Figure 12). Data also reports that the reason for most of the unmet healthcare needs in this population is due to cost (48.9%) and access, specifically appointment availability (53.9%). The data clearly identifies access as a continued barrier to equitable health services.

ACEs measured by a parent report on the 2019-2020 NSCH survey include the following: hard to cover basics on family's income; parent or guardian divorced or separated; parent or guardian died; parent or guardian served time in jail; saw or heard parents or adults slap, hit, kick or punch one another in the home; was a victim of violence or witnessed violence in their neighborhood; lived with anyone who was mentally ill, suicidal or severely depressed; lived with anyone who had a problem with

alcohol or drugs; treated or judged unfairly due to race/ethnicity; and treated or judged unfairly due to sexual orientation or gender identity. As we improve infant and childhood mental health assessments, we can identify children who experience ACEs that may impact their developmental trajectory (Figure 13).

Figure 13. Children experienced one or more ACEs from the list of 10 ACEs

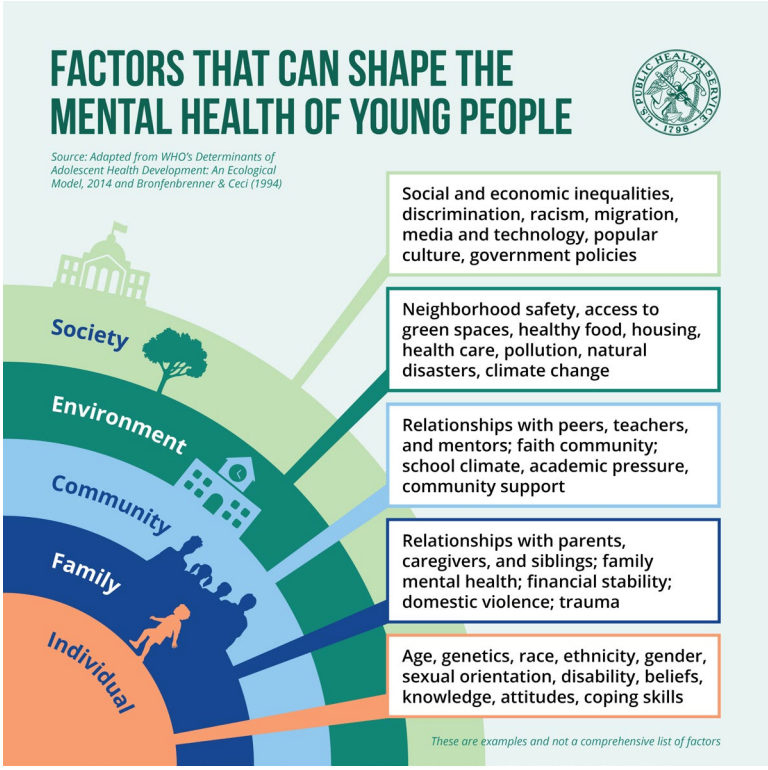


Mental Health

Mental disorders in children are described as critical changes in the way children typically learn, behave or handle their emotions, which causes distress and problems getting through the day (https://www.cdc.gov/childrensmentalhealth/basics.html). These issues, left unattended and untreated, result in school and social challenges influencing development and education.

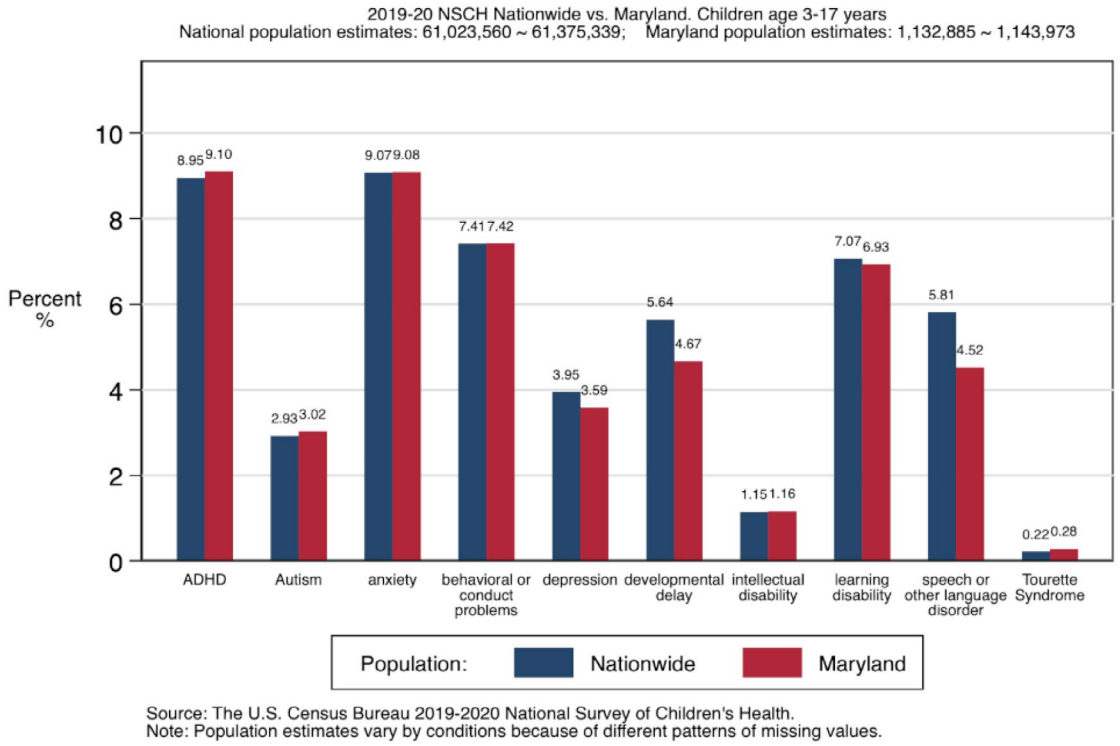
Since the start of the pandemic, we have seen increasing rates of mental health issues impacting children, youth and young adults across the U.S.[13] Recently, experiences influencing mental health challenges have stemmed from the stressors presented by the COVID-19 experiences of children and their families; structural racism amplified over the last two-plus years experienced by families and young children; inflation trending upward mid- to post-pandemic; and other inequities where children and persons of color are disproportionately affected. Addressing health factors and behaviors in early childhood development and education have been proven to significantly influence health outcomes. We need no additional information or data to validate that our children of all abilities are experiencing extensive mental and behavioral health challenges. This has been substantiated by the American Academy of Child & Adolescent Psychiatry and the Children's Hospital Association declaring a National State of Emergency in Children's Mental Health (2021); the Surgeon General's Advisory producing a public health statement calling for Protecting Youth Mental Health (2021); the American Academy of Pediatrics policy statement; The Impact of Racism on Child and Adolescent Health (2019); the JAMA Pediatrics article investigating the Five-Year Trends in U.S. Children's Health and Well-being, 2016-2020; and data from the National Survey of Children's Health, 2020, exploring mental and behavioral health among children with and without special healthcare needs.[12, 14–16]

Figure 14. Factors that can shape the mental health of young people (Sources: Protecting Youth Mental Health: The U.S. Surgeon General's Advisory and WHO's Determinants of Adolescent Health Development: An Ecological Model, 2014 and Bronfenbrenner & Ceci (1994))



The graphic (Figure 14) helps share how the individual, families, policies and programs, and health factors contribute to health outcomes—all of which are captured in the CHR Model.[17] The factors displayed do not represent an inclusive list of factors that impact mental health outcomes for children and youth, but we do know that these factors contribute at least 50% to 80% of the factors that influence health outcomes.

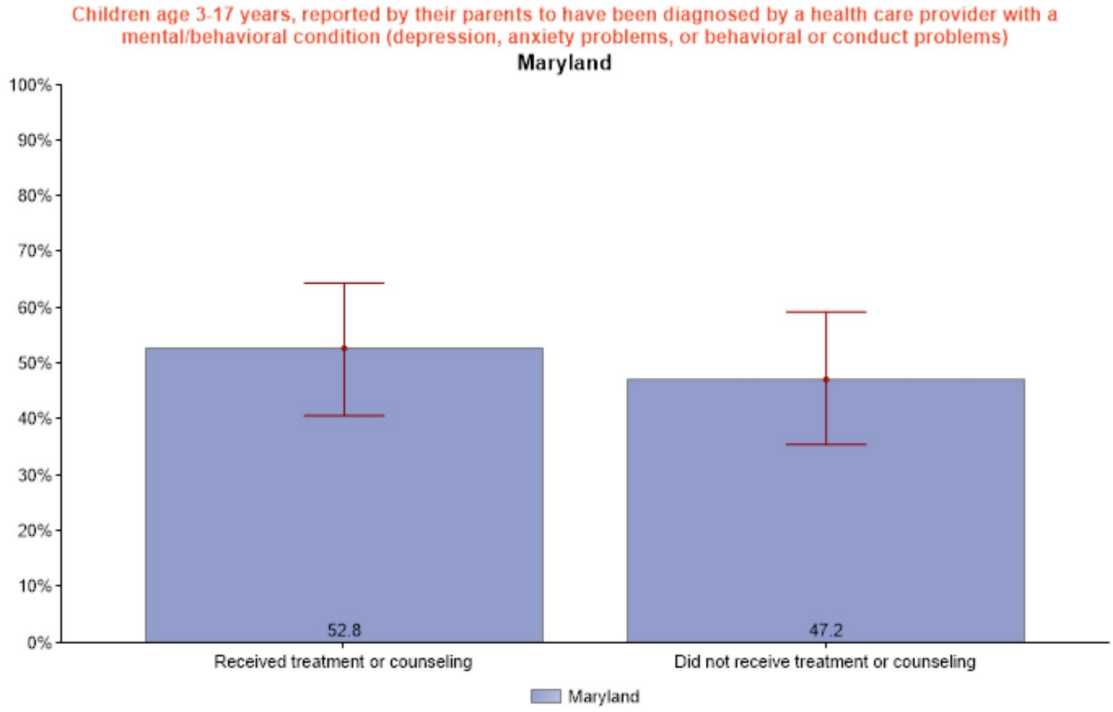
Figure 15. Children who currently have mental, emotional, developmental or behavioral conditions



Source: The U.S. Census Bureau 2019-2020 National Survey of Children's Health.
Note: Population estimates vary by conditions because of different patterns of missing values.

The NSCH 2019–2020 (Figure 15) presents the array of mental, emotional, developmental and behavioral concerns seen in children nationally and in Maryland. While the graph compares the prevalence of conditions geographically, the actual takeaway is the array and number of children who experience these conditions and the most prevalent conditions do fall within the mental health continuum—ADHD, anxiety, behavioral or conduct problems.

Figure 16. Percent of children with a mental/behavioral condition who receive treatment or counseling



The data in Figure 16 is based on the number of children whose parents report they have been diagnosed by a healthcare provider with a mental/behavioral health condition and did (55.7%) and did not (44.3%) receive treatment or counseling; this latter group represents, again, a significant barrier to access to care.

Voice of the Caregiver Survey

The lives of individuals with disabilities and their families face a remarkable number of challenges and hardship. Having an individual with disabilities sets a heavy burden on the caregiver/parent and on the family system financially, economically, physically and mentally. To promote the health, well-being and independence of individuals with developmental disabilities and their families, their personal, family and social experiences must be documented and understood. Previous studies have examined these factors from a clinical viewpoint, but have not focused specifically from a caregiver/parent viewpoint. Understanding these factors from a caregiver/parent perspective will give more of an insight into what individuals with disabilities face on a day-to-day basis. The MCDD initiated the development of the Voice of the Caregiver Survey in 2018 using a qualitative approach in which a 60-minute, semi-structured focus group interview with five open-ended guiding questions was used to capture the subjective experience of the participants. The purpose of the survey was to explore factors that impact the health, well-being and independence of children and young adults with disabilities from a caregiver/parent perspective. The survey was further refined and submitted to the Johns Hopkins Institutional Review Board as a quality improvement project to improve resources, support and health programs developed for individuals with disorders of the nervous system and their families across Maryland.

The survey results analyzed included 209 valid responses collected during the last quarter of calendar year 2021 and the first quarter of calendar year 2022. Table 2 presents the demographic information of the caregivers who completed the survey and the individuals with disorders of the nervous system they were caring for at that time.

Table 3. Caregiver and child/youth demographic information from Voice of the Caregiver Survey (MCDD 2021)

Overall (N=209)

Caregiver Demographic Information

Caregiver age (years)	
Less than 18	1 (0.5%)
18–24	2 (1.0%)
25–38	35 (16.7%)
39–50	55 (26.3%)
51–62	71 (34.0%)
63–72	36 (17.2%)
73 and over	8 (3.8%)
Prefer not to respond	1 (0.5%)
Caregiver gender	
Women	192 (91.9%)
Men	13 (6.2%)
Gender Non-binary	1 (0.5%)
Prefer not to respond	3 (1.4%)
Caregiver race	
American Indian/ Alaska Native	2 (1.0%)
Asian	6 (2.9%)
Black or African American	42 (20.1%)
Caucasian/White	140 (67.0%)
Multiracial	4 (1.9%)
Prefer not to respond	13 (6.2%)
Missing	2 (1.0%)
Caregiver ethnicity (Hispanic/Latinx)	
No	185 (88.5%)
Yes	12 (5.7%)
Prefer not to respond	12 (5.7%)

Caregiver Demographic Information

Relationship of child/young adult to caregiver	
Mother	169 (80.9%)
Father	9 (4.3%)
Grandmother	2 (1.0%)
Adoptive parent	6 (2.9%)
Legal guardian	4 (1.9%)
Other relative	4 (1.9%)
Other non-relative	11 (5.3%)
Prefer not to respond	4 (1.9%)
Caregiver highest level of education	
Less than high school education	1 (0.5%)
High school diploma	44 (21.1%)
Certificate of program completion	8 (3.8%)
Associate degree	22 (10.5%)
Bachelor's degree	53 (25.4%)
Master's degree	52 (24.9%)
Doctorate/professional degree	19 (9.1%)
Other	5 (2.4%)
Prefer not to respond	5 (2.4%)
Caregiver employment status	
No, not seeking employment	25 (12.0%)
No, seeking employment	7 (3.3%)
Yes – part-time (less than 40 hours/week)	35 (16.7%)
Yes – full-time (40 hours/week)	108 (51.7%)
Retired	26 (12.4%)
Prefer not to respond	8 (3.8%)

Child/Youth Demographic Information

Child/young adult's age (years)	
0–5	22 (10.5%)
6–12	32 (15.3%)
13–17	37 (17.7%)
18–21	25 (12.0%)
21–25	25 (12.0%)
26–29	17 (8.1%)
30–39	35 (16.7%)
40 and above	15 (7.2%)
Prefer not to respond	1 (0.5%)
Length of time child/young adult has been cared for by caregiver	
Since birth	149 (71.3%)
Less than 1 year	6 (2.9%)
1-5 years	10 (4.8%)
6-10 years	4 (1.9%)
11-20 years	15 (7.2%)
21+ years	21 (10.0%)
Prefer not to respond	4 (1.9%)
Child/youth insurance	
No insurance	5 (2.4%)
Medicaid/Medical Assistance	34 (16.3%)
Private/Commercial	152 (72.7%)
Self-pay	4 (1.9%)
Prefer not to respond	14 (6.7%)

A cross-tabulation of the caregiver's age and the child's age indicates most children were between the ages 13 to 25 years with caregivers who were older, between ages 51 years to 62 years. Older survey participants (ages 62 to 73) had the higher number of older children and youth ranging from 26 years to 40 and above.

Key questions and findings that contribute to other data findings include (Figures 17-21):

- Health and wellbeing of caregiver's mental health
- Health, wellbeing and independence of child/youth impacted by their mental health
- Health and wellbeing of caregivers related to future of child/youth approaching adulthood
- Health, wellbeing and independence of child/youth impacted by plans for progression to adulthood
- How family's health is influenced by systemic supports

Figure 17. How do you think your child/young adult's health, well-being and/or independence is limited by the following items within the last 12 months? – Mental Health Concerns (e.g., depression, anxiety) N=209

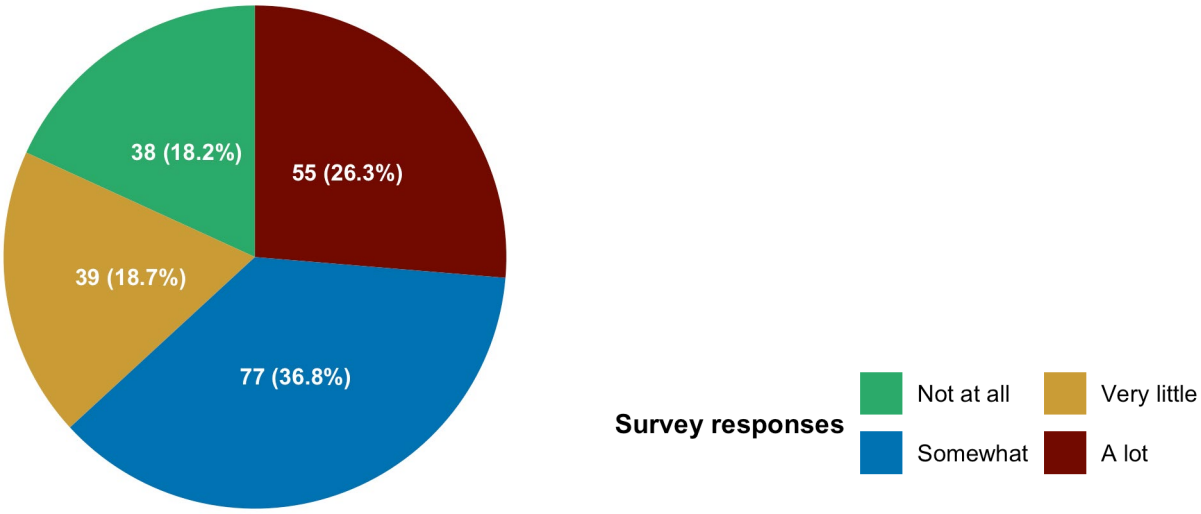


Figure 18. How do you think your child/young adult's health, well-being and/or independence is limited by the following items within the last 12 months? – Behavioral Concerns N=209

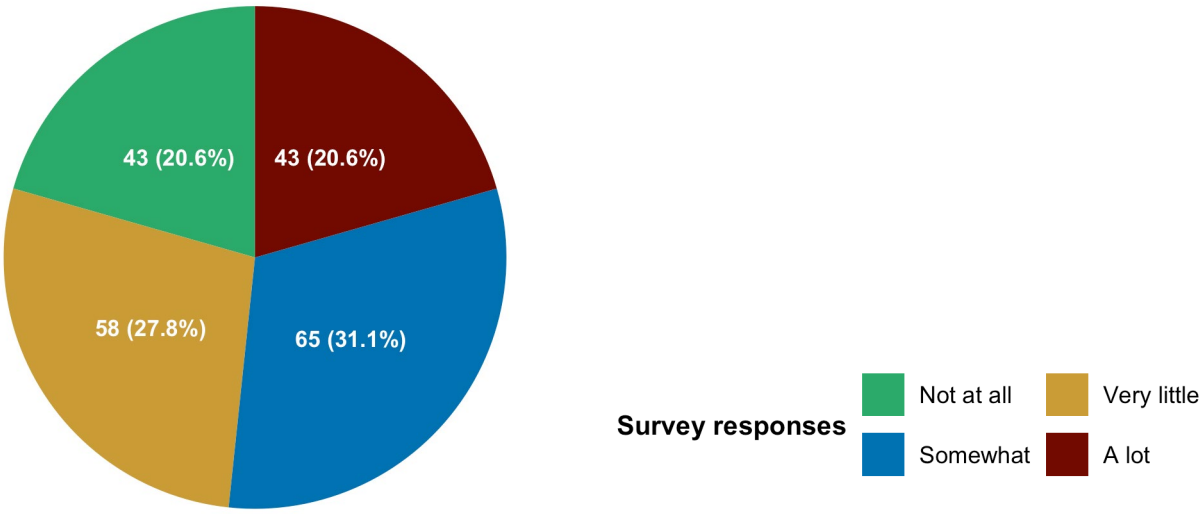


Figure 19. How do you think your child/young adult's health, well-being and/or independence is limited by the following items within the last 12 months? – Life Transition Concerns (e.g., service eligibility concerns as your child approaches adulthood) N=209

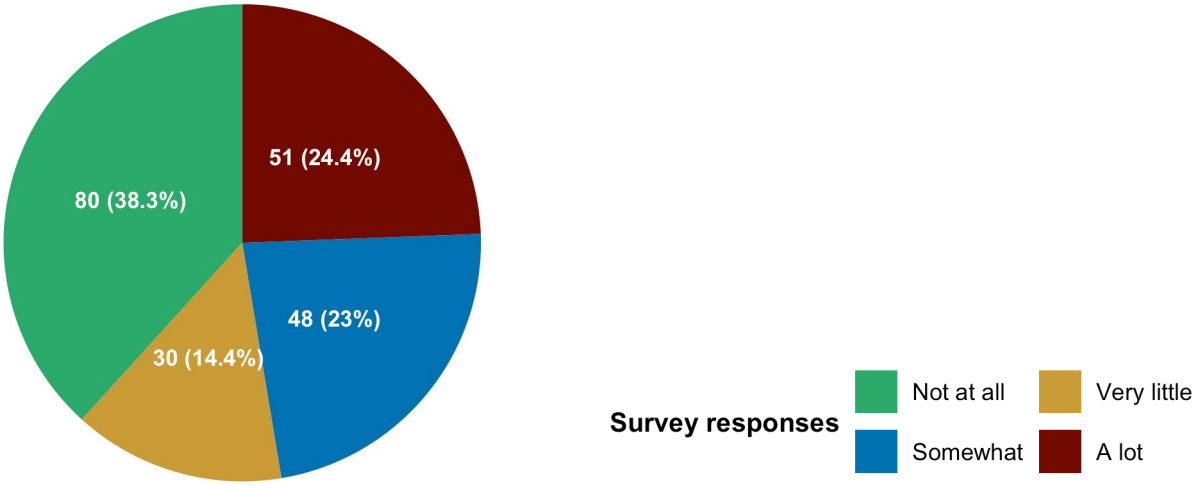


Figure 20. How do you think your child/young adult's health, well-being and/or independence is limited by the following items within the last 12 months? – Poor Support System (e.g., in-home healthcare, respite care, day/after-school care, community support, extended family) N=209

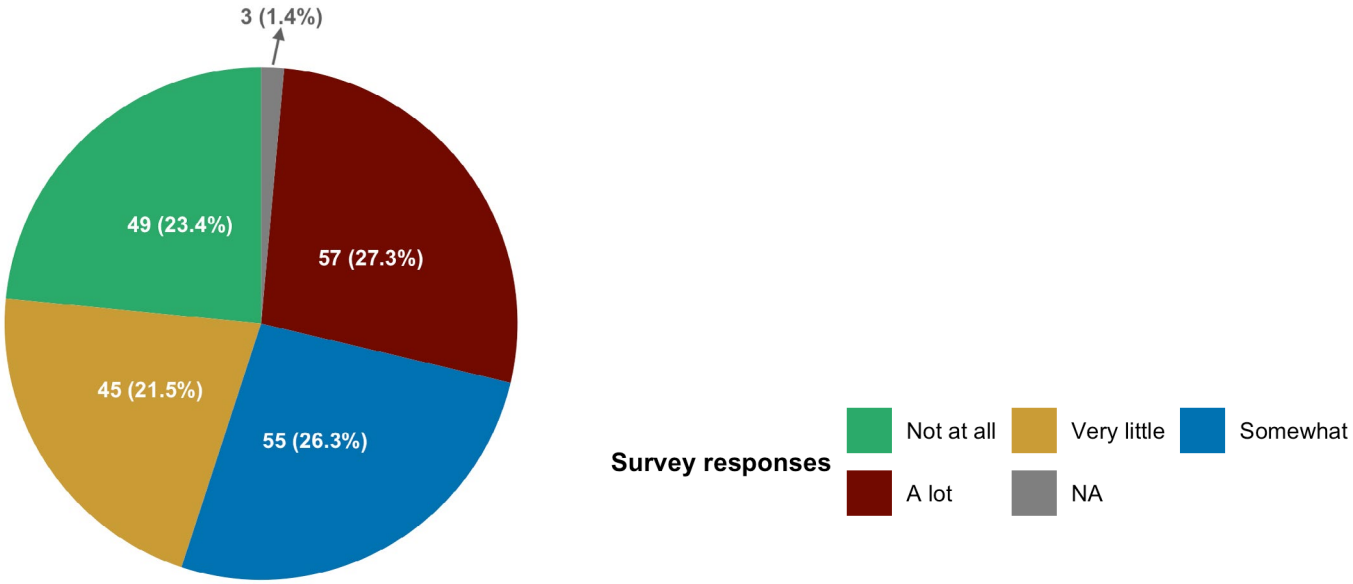
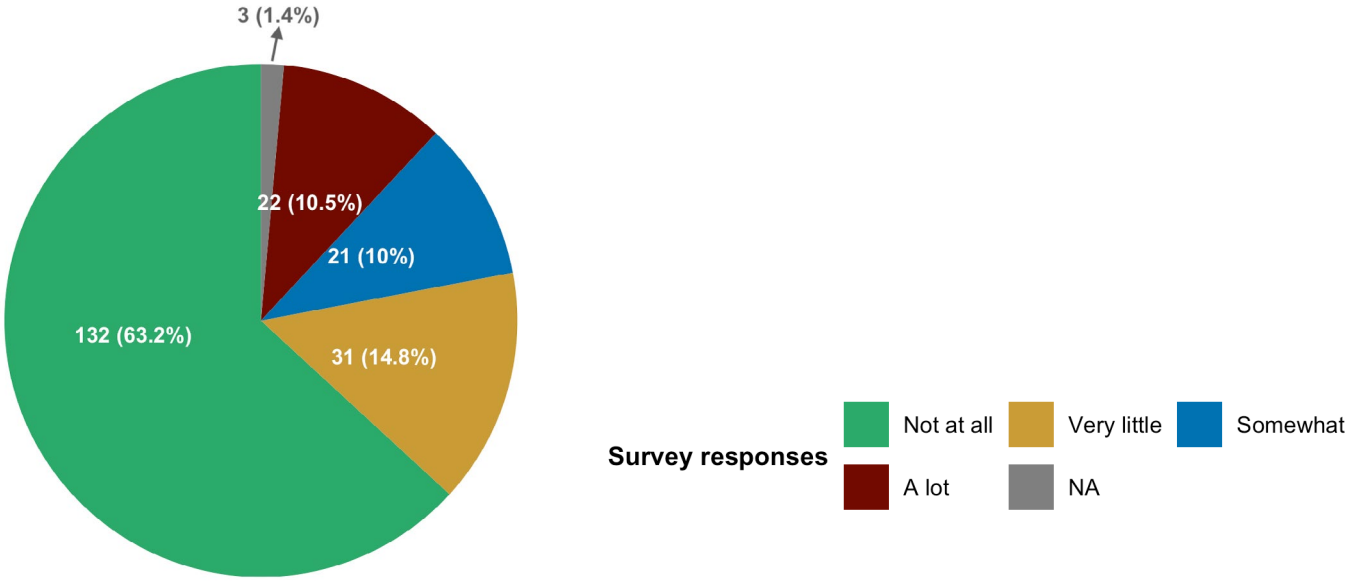


Figure 21. How do you think your child/young adult's health, well-being and/or independence is limited by the following items within the last 12 months? – Racial/ethnic differences concerns (e.g., lack of access to employment, good education, adequate housing, healthcare services, COVID-19 vaccine) N=209



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.

Caregiver participation in the development of programs, inclusion in training programs, and advocacy in policy areas are all key areas where it is essential for caregivers to play a partnership role.

The Eastern Shore Consortium of Care (ES-COC) annually conducts an assessment of needs in their area. All respondents noted that the ES-COC was relevant to them and would recommend the consortium to others. In 2022, the ES-COC[18] identified areas that need improvement, suggestions to improve the ES-COC, and topics and expert speakers for the future. The identified priorities that align with data collected for this CHNA are as follows:

- Increase in specialty services (mental and behavioral health for those with developmental disabilities)
- Increase health workforce and family support
- Timely access to local diagnosis and referrals services
- Transportation access
- Parent support and training
- Local screening availability

These priorities can be categorized into capacity building in multiple arenas, equitable and timely access, and advocacy needs.

Adequacy in the number of specialty providers is a theme throughout the year as data is collected and discussions are engaged in with caregivers and other providers across Maryland, regardless of the region or specialty. Figure 8 shows the shortage in mental health providers in Maryland, Figure 24 reveals the primary care provider shortage areas, and Table 3 provides the number of active specialty/subspecialty providers in Maryland.

Table 4. Total number of active certificates by specialty/subspecialty in Maryland, 2013 Compared to 2020 (Source: 2018 – 2020 ABMS Board Certification Report)

Specialty	MD—2013	MD—2018	MD—2020	U.S.—2013	U.S.—2018	U.S.—2020
Family Medicine—All Areas	1,274	1,294	1,400	85,751	87,705	96,739
Pediatrics—All Areas	2,604	2,856	2,888	84,387	97,362	99,896
Developmental Behavioral Pediatrics	18	19	16	633	695	746
Pediatrics, Psychiatry and Neurology: Neurodevelopmental Disabilities	21	18	8	266	214	144
Psychiatry and Neurology: Child and Adolescent Psychiatry	246	361	319	5,890	8,995	8,566

While there has been some growth in the number of active certificates issued to specialty and subspecialty providers, between 2018 and 2020 (Table 3), the number of Family Medicine, Pediatrics and Developmental-Behavioral Pediatrics practitioner quantities do not reflect the geographic location or if the number of certificates are associated with a practicing provider.

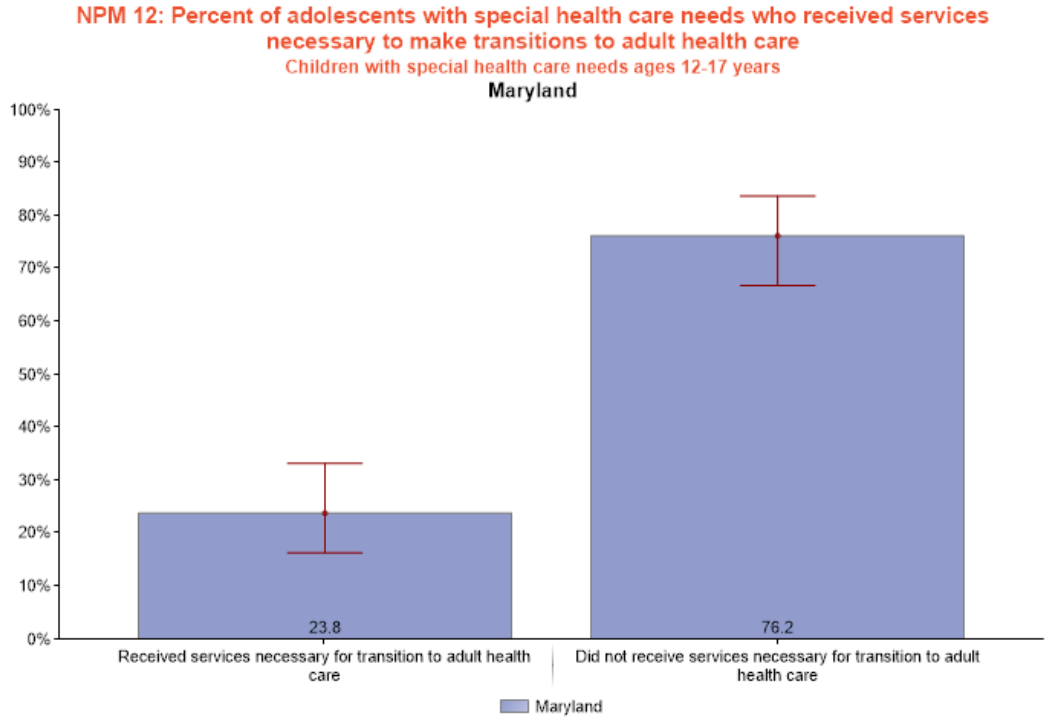
The Josiah Macy Jr. Foundation has produced multiple webinars and podcasts focused on reducing health disparities in patients with disabilities, improving access to medical education training and practices for trainees with disabilities, and improving policy and best practices. Expansion of slots in academic medical programs will not increase sufficiently to address or be able to meet the demand for services, especially in behavioral/mental health. Much of the disparities experienced by and toward persons with disabilities stem from attitudinal and unconscious biases deeply rooted in society.[19]

MCDD Survey Results/Maryland Developmental Disabilities Council

Transition

Caregivers and young adults continue to struggle with accessing programs and activities related to progression towards adulthood. This data shares the significant barrier that adolescents with special healthcare needs experience when trying to make transitions to adult healthcare. They cannot receive services to make the transition effectively. These services consist of the provider speaking with the youth individually during a preventative visit; working to gain understanding in changes in health; and proactively engaging in discussions related to health (Figure 22).

Figure 22. Percent of adolescents with special health care needs who received services necessary to make transition to adult health care



The MCDD community assessment survey disseminated across Maryland in 2021 asked about the greatest challenges or barriers for individuals with intellectual and developmental disabilities; two hundred eighteen persons responded to the MCDD needs survey. Sixty-seven percent were white and 16% Black. In conjunction with the MCDD external needs assessment survey, the Maryland Developmental Disability Council (MD DD Council) conducted a survey and disseminated it across Maryland using Survey Monkey in English and Spanish. Paper copies were also made available. Total participants completing the survey yielded 205 this year, during the pandemic, compared to 475 in 2015. Sixty percent of the respondents were family members of a person with a disability. The majority (31%) of respondents were Montgomery County residents, followed by Baltimore City (13.5%). Seventy percent were white and 13% Black.

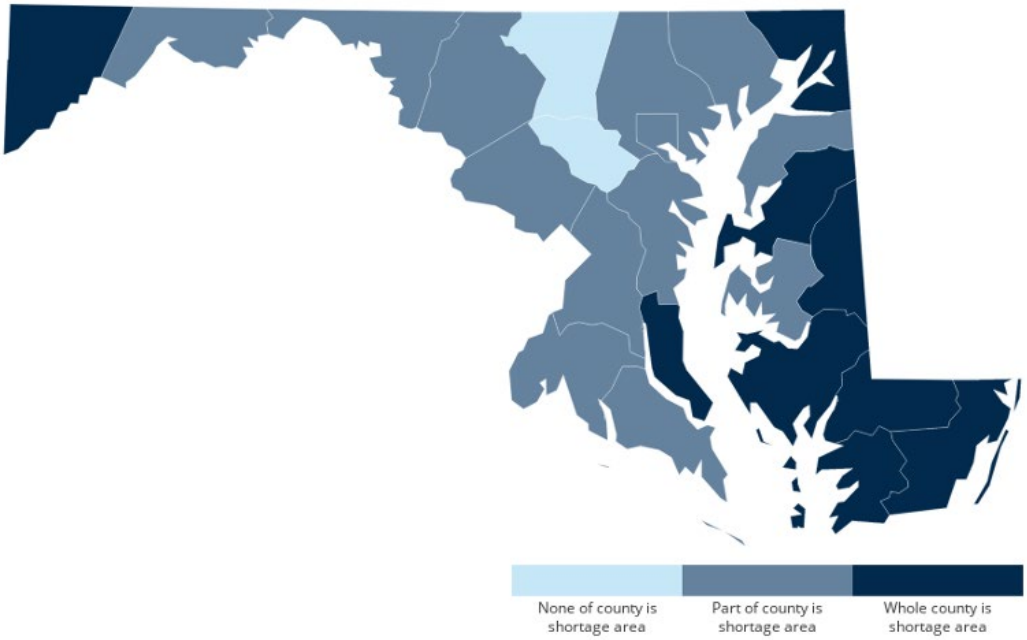
The MCDD survey respondents ranked transition services/supports as the 4th area for the MCDD to focus on over the next five years (identified by 38% of respondents). The MD DD Council Survey identified transition in the top five areas of most importance to improve upon for people with developmental disabilities (Improving transition from school to work or meaningful integrated community activities).

From the MD DD Council, qualitative focus groups recommended:

- Increasing the quality of pre-transition counseling to inform parents and students of all options available and to be able to give enough time to prepare a realistic transition plan
- Increasing community-based programs and supports for transitioning youth with a variety of tracks specific to the students' goals (e.g., life skills, secondary education, career and technical education)
- More opportunities during transition to explore vocational and trade opportunities, and
- Increased opportunities for post-secondary education for people with intellectual and developmental disabilities

Public comment from the MCDD Survey noted that transition supports in high school were more comprehensive than in college, indicating entitlement services vs. receipt of services based on eligibility. Other comments continued to expand on the theme that more responsibility was placed on the family to find services after a certain age, coupled with a significant shortage of providers and programs (Figures 8 and 23, respectively). Finally, and an important factor resulting from the Voice of the Caregiver Survey, children and youth are not ready to progress into adulthood and independent life.

Figure 23. Health professional shortage areas: Primary Care, 2022 (Source: Maryland Rural Health Information Hub)



RHIhub Rural Health Information Hub

Source: data.HRSA.gov, January 2022.

Employment

The MCDD External Needs Assessment survey and the MD DD Council Survey both support in the top tier, the need for increased employment and job training, and increased need for outreach to employers to educate and support them in hiring people with disabilities, respectively. The MD DD Council has identified quality consistent job coaching, work-site training and supports to maintain paid employment.

Kennedy Krieger initiated a Neurodiversity at Work initiative, launched at the direction of the Board of Directors, a multi-faceted effort to increase accessibility to employment within our own and external organizations. Additionally, the Human Resources Pathways Program is an accessible hiring program designed to minimize the barriers that often exist for individuals with neurodiverse conditions. The initiative includes strategic communications with departmental hiring managers and provides support to departments hiring employees or interns with neurodiverse conditions. Further, Kennedy Krieger has established on-going communication, outreach and relationships with regional businesses in a variety of industries and locations. The core component of this initiative, especially as related to capacity building, is the at-work collaborations and partnerships that have been and continue to be cultivated.

Through continued training locally and a national conference planned for 2023, the Neurodiversity at Work initiative will continue to:

- Engage in discussions focused on advancing disability policy on the local, state and national level
- Identify unified best practices for workforce development to drive national change for individuals with disabilities
- Engage in dynamic discussions around the complexity of communication and language when referring to individuals with disabilities
- Share innovative practices, policies and procedures that will focus on advancing service delivery for individuals with disabilities
- Engage in training, education and resource sharing that promotes the employment of individuals with disabilities as part of the workforce

In addition, in alignment with what we expect during progression to adulthood, employment and job training rank in the top five challenges and barriers for individuals with disabilities from both the MCDD external needs assessment and the MD DD Council surveys. Clearly, the data presents the significant disparity between employment for those without and those people with disabilities, with no movement toward or gains in the gap. Gainfully paid employment contributes to poverty, as we can see the wide gap in poverty experienced by people without and people with disabilities (Figures 24 and 25).

Figure 24. Employment to population ratio (Source: The Annual Disability Statistics Compendium, Institute on Disability, University of New Hampshire, 2021)

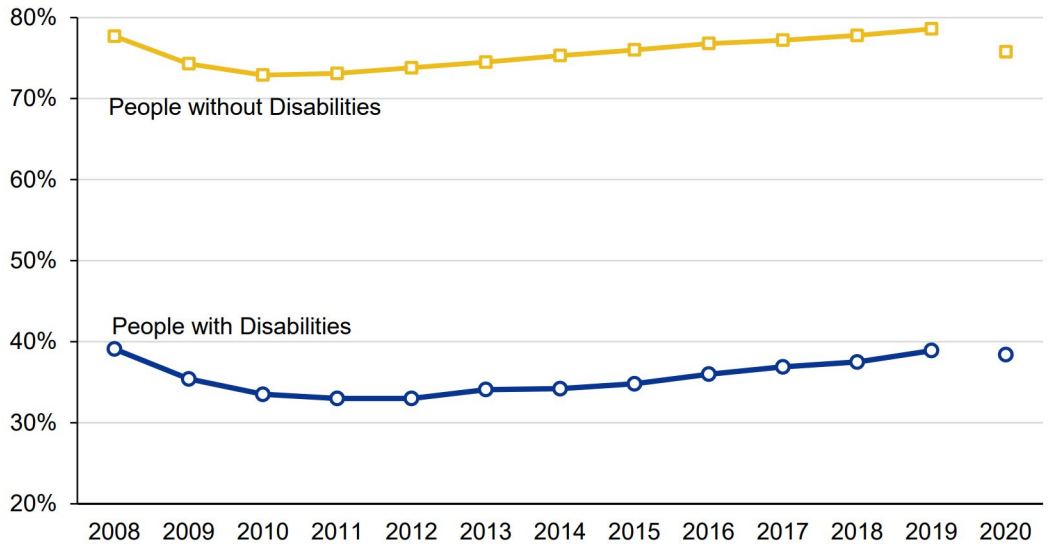
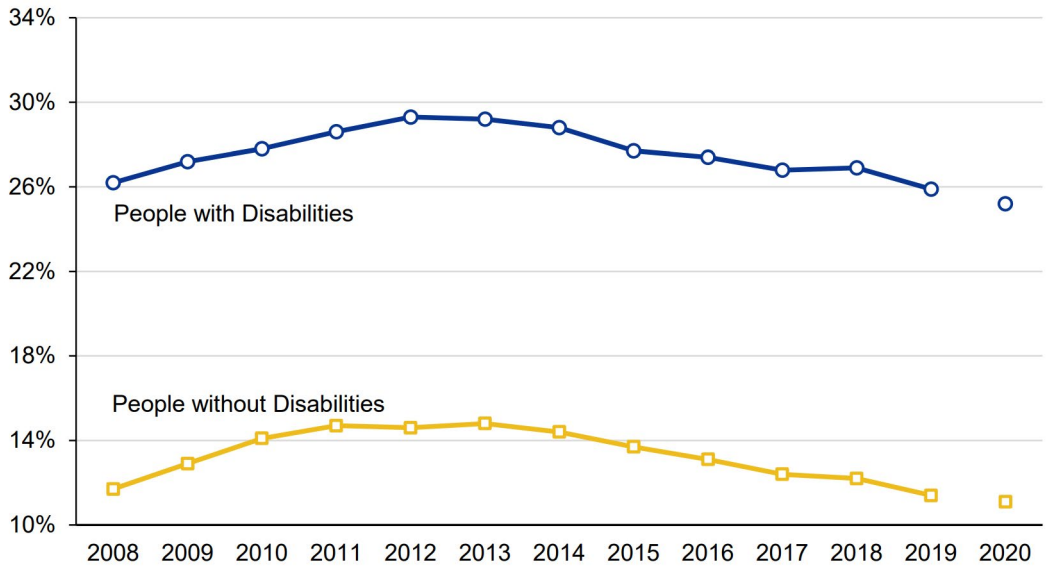


Figure 25. Poverty Rate



Advocacy

POG, a self-advocacy project of the MCDD, conducted a survey of self-advocates in Maryland and inquired about employment, counseling, access to health services, finding providers and transportation.

POG's implementation of Project STIR (Steps Toward Independence and Responsibility) across Maryland 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.

Policy

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 factors presented in this needs assessment, such as, but not limited to, access, transition, advocacy and education.

As we work to eliminate health disparities, policies that we develop should incorporate health considerations into all decision-making across all sectors and policy areas, i.e., health in all policies.[20]

A strategy for achieving a Health in All Policies society is helping our leaders across all sectors understand health in the broadest sense. While we typically equate policy to legislation, a policy is an agreement on issues or a course of action about a specific situation.

Summary

The ACA identified nonprofit hospital institutions, or anchor institutions, as the primary groups to engage with their communities, assess the needs of the community, and identify the benefits provided to the community based on the prioritized needs generated. Anchor institutions provide economic security for neighbors, as hospitals improve the health of the communities. While economic security is key to successful communities, there is limited discussion related to economic security among neighborhoods, communities and anchor organizations. Institutions can provide stability for a neighborhood and community, offer jobs to those living in the immediate area, and indirectly influence homeownership.

The last two to three years have presented multiple challenges as we have worked through an unprecedented global pandemic, COVID-19. Our last CHNA required innovation and significant effort to implement, as we were all focused on safety first, then figuring out alternative methods to provide basic service needs, then achieve goals. But during these experiences we have also found opportunities and insight for alternative healthcare models, models that support addressing health and well-being from a broader perspective than simply provision of healthcare visits. As we evaluated our accomplishments from the 2019 CHNA, the Institute relaunched its strategic planning process, which incorporated lessons learned from our COVID-19 experiences. Additionally, the information derived from the 2022 CHNA has informed the strategic planning process, the draft plan and recommendations, which, no doubt, will support and guide the implementation of not only the CHNA Implementation plan but the Institute's Strategic Plan. We envision a future in which health equity will drive: (1) how we implement the knowledge from our research activities to provide equitable access to evidence-informed clinical care and education; (2) how we engage with our patients, students, families and the community to address needs; and (3) how we support inclusivity in all aspects of our work.

Prioritization of Needs

After reviewing data and vast community input, prioritization of identified needs was based on several considerations. Each priority was considered according to the following criteria:

- National Priorities ➔ State Priorities ➔ Community Input: Does the identified need align with national and state priorities specific to our target population and identified in the community?
- Responsibility and Capacity: Does the identified need fit within the mission and capacity of Kennedy Krieger?
- Availability of Resources and Feasibility: Are resources and knowledge available for Kennedy Krieger and its partners to adequately address the need identified?
- Magnitude and Severity: Will there be 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:

Kennedy Krieger Institute
Community Health Needs Assessment:
Community Priorities

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

In addition to a workforce shortage in mental health, primary care and dentistry, there are not sufficient specialty providers in other areas available to care for children with special healthcare needs. 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, models of care provision and dissemination of information will foster that enhancement.

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 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, housed within the Office for Health, Equity, Inclusion and Diversity (OHEID), 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
- Project ECHO (KKI-NECT) Kennedy Krieger Institute Network for Early Childhood Telehealth (KKI-NECT): A Multidisciplinary Model of Integrated Care for Behavioral, Emotional, and Developmental Disorders in Children from Birth to Five Years of Age
- Exposure/training in legislative involvement and roles for advocates, providers and community members

Access to Equitable Health Services

The community has identified access to equitable health services as a need. According to the 2019-2020 National Survey on Children's Health (NSCH) Healthy People 2030, 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. 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:

- Telemedicine services offered internally and externally through established partnerships to expand access to healthcare services, including primary care and care coordination, specific to the population served
- Mental health
- 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 one-on-one client trainings (i.e., technical assistance) and community trainings

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 POG, a group of advocates with intellectual and developmental challenges who use their voices to be heard and recognized.

Progression to Adult Life

Progression 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 and employer training
- Approaching progression into adulthood from a public health perspective

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Implementation and Action Plan

Priority 1: Capacity Building				
Goal	**Strategies**	**Metrics**	**Time Frame**	**Potential External Partnerships with Kennedy Krieger Institute**
Contribute to Maryland's recruitment of specialty providers	**Strategy 1:** Recruit and train diverse trainees, professionals, learners and individuals from multiple disciplines **Strategy 2:** Room to Grow: Journey to Cultural and Linguistic Competency conference	Record number of trainees by: • Discipline • Major • Race/ethnicity • Gender • Ability status • Anticipated profession sought • Number of trainees/ scholars we are able to retain at Kennedy Krieger in the state of Maryland post training	Fiscal years 2023 and 2024	Colleges and universities across the U.S., to include intentional collaborations with: Historically Black Colleges and Universities Hispanic Serving Institutions Tribal Colleges and Universities Asian American and Pacific Islander Serving Institutions
Enhance the capacity of Maryland's early childhood education providers	**Strategy 1:** Launch the Kennedy Krieger tele-education platform to disseminate learning, provide coaching and offer professional technical assistance to providers	Number of cohorts Number of participants Participants by profession	Fiscal years 2023 and 2024	Maryland State Department of Education Maryland Department of Health, Behavioral Health Administration Early Childhood Education Centers and Providers Colleges and Universities
Enhance the capacity of Maryland's community providers to care for those with neurological concerns or those at risk for developing disorders	**Strategy 1:** Identify concepts to share with the Maryland community to increase inclusive practices **Strategy 2:** Create a brief video (1.5 minutes max) related to identifying children at risk for developing disorders of the nervous system	Number of hits from Kennedy Krieger website Number of inquiries resulting from viewing Number of community providers attending MCDD trainings	Fiscal years 2023 and 2024	Baltimore City Health Department Maryland Department of Health Maryland communities in health and education MD AAP Johns Hopkins/Sinai/UMMS Maryland General Assembly

Priority 1: Capacity Building (continued)				
Goal	**Strategies**	**Metrics**	**Time Frame**	**Potential External Partnerships with Kennedy Krieger Institute**
Inform elected officials of community and workforce needs	**Strategy 1:** Share knowledge related to the benefits of telehealth for those with developmental concerns and their families with Maryland elected officials	Number of legislative engagements related to telehealth Government relations metrics: Funding amount secured Number of meetings Number of testimonies Number of staff, faculty and trainees who participate in the legislative process Number of self-advocates Number of bills tracked related to health equity	Fiscal year 2023	State and local elected officials
	Strategy 2: Translate CHNA data into equity-based policy recommendations		Fiscal years 2023 and 2024	
Increase the business community's awareness and knowledge of neurodiversity in the workplace and the benefits of inclusive practices	**Strategy 1:** Conduct a national conference	Number of participants and unique companies Evaluation to assess an increased awareness and/or knowledge about neurodiversity in the workplace	Calendar year 2023	Neurodiversity Task Force MCDD Corporate business leaders Maryland Colleges and Universities
	Strategy 1: Increase training provided to employers, Adult Service Providers, and the community on enhancing employment opportunities and providing supports for a Neurodiverse Workforce	Development of one curriculum module related to one component of Neurodiversity@Work	Fiscal years 2023 and 2024	Neurodiversity Task Force MCDD Corporate business leaders

Priority 2: Access to Services				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships with Kennedy Krieger Institute**
Improve access to care for medically underserved and marginalized populations at risk for or presenting with neurological disorders	**Strategy 1:** Expand access to specialty services in healthcare shortage areas of Maryland	Number of patients who were served in their communities vs. a visit to Kennedy Krieger, resulting from the health professional participation in Kennedy Krieger's tele-education program	Fiscal years 2023 and 2024	Community Primary Care Providers Early Intervention Specialists Local Educational Agencies Infants and toddlers
Engage strategic community members	**Strategy 1:** Convene a group of community participants with a common interest in health equity for people with disabilities	Identify community assets	Between 1/1/2023 and 6/30/2024	To Be Determined
Use health equity outcomes to identify the most needed groups for increased access	**Strategy 1:** Expand, standardize collection and analyze health data, including race, ethnicity, preferred language, sexual orientation, gender identity, disability, income, geography, and other factors across our clinical programs to identify and address areas of health disparities	Integrate metrics into the electronic health record to access social drivers of health	Fiscal year 2023	Utilize standards and data from: The Joint Commission The Centers for Medicare and Medicaid Services Robert Wood Johnson Foundation
		Analyze clinical and operational data by sociodemographic factors	Fiscal year 2024	
	Strategy 2: Create a fact sheet focused on equitable access to share with families, self-advocates, legislators, and others about the benefits of telehealth services	Quantify barriers in telehealth use	Fiscal Year 2023	Caregivers Community Members Legislators

Priority 3: Advocacy				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships with Kennedy Krieger Institute**
Strengthen and support advocacy skills of people with disabilities and their families	**Strategy 1:** Identify elements necessary to enhance the transportation network in Maryland	Track Legislation Mechanism to track transportation complaints	Fiscal year 2023 and 2024	Transportation vendors by jurisdiction People On the Go Maryland MCDD Eastern Shore Consortium of Care
	Strategy 2: Share lived experiences, in terms of how policy/legislation has impacted their life and their role	Number of Family or Self-Advocate Testimonies		
	Strategy 3: Promote self-advocacy and increase advocacy awareness	Quality of life survey findings Qualitative measures to assess speaking up for oneself, asking for what you need, knowing rights and responsibilities Advocacy training during onboarding Trainings/coaching and mentorship to engage younger population with a focus on diversity and career path	Fiscal years 2023 and 2024	People On the Go Maryland MCDD Developmental Disabilities Administration – QIO contract – Liberty Healthcare LEND Parent Trainee Program Kennedy Krieger High School Project SEARCH CORE Foundations Parents' Place of Maryland Disability Rights Maryland Families/caregivers The Arc – self-advocates facilitate groups at Arc chapters MDD Council
	Strategy 4: Community outreach to facilitate community engagement (step 1)	Record number of community activities that include training and/or dissemination of specific data Utilize plain language and universal access when developing and disseminating information	Fiscal years 2023 and 2024	Maryland Community
Expand understanding by individuals, families and staff members about the state legislative process and how involvement can influence policy	**Strategy 1:** For students, patients, families and 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 Number of legislative trainings for self-advocates and caregivers	Fiscal years 2023 and 2024	Kennedy Krieger Institute Board of Directors MCDD People On the Go Maryland MD Developmental Disabilities Council Disabilities Rights Maryland Families/caregivers Self-advocates

Priority 4: Transition to Adulthood				
Goal	**Strategies**	**Measure**	**Time Frame**	**Potential Partnerships with Kennedy Krieger Institute**
Increase awareness, knowledge and actionable items related to the progression to adult life for youth with disabilities and their families	**Strategy 1:** Create a Transition Page on the website that shares data metrics on inequities and information resources related to: • Healthcare Access—finding providers • Employment • Education or training • Independent living • Housing • Wellness	Completion & Launch of a website to focus on Transition # of websites # of downloads Ranking of frequently most downloaded documents	Fiscal years 2023 and 2024	Project SEARCH CORE Foundations MCDD/Resource Finder Maryland State Department of Education Division of Early Intervention/Special Education Services Maryland Developmental Disabilities Administration Parents' Place of Maryland Maryland Title V Office
	Strategy 2: Develop a Transition Consultation Program	Launch pilot program # of web page hits # of consultations provided Categories of consultations Evaluation of helpfulness of consultation	Between Fiscal year 2023 and 2024	Project SEARCH CORE Foundations
	Strategy 3: Collect information on who is accessing guidance and information to target population in need	# of downloads Collection of emails Categories of those who access	Fiscal year 2024	Project SEARCH CORE Foundations
	Strategy 4: Explore a funding source to conduct a legal seminar for youth transitioning to adulthood, and their families	Secure funding source	Between Fiscal years 2023 and 2024	MCDD/ Project HEAL Pro bono law firm partner University of Baltimore School of Law
	Strategy 5: If funded, host a legal seminar for youth transitioning to adulthood, and their families	# of Attendees (by participant type) # of advance directive, advance directive for mental health and Maryland Statutory Powers of Attorney executes # of consultations provided	Between Fiscal years 2023 and 2024	Funding agent Kennedy Krieger Philanthropy

Appendix 1. Data Sources and Resources

Agency	Data Sources	Year
Advocates for Children and Youth	Maryland Kids Count Indicators	Up to 2019
American Board of Medical Specialties	2020-2021 ABMS Board Certified Report	2021
Data Resource Center for Child and Adolescent Health	National Survey on Children's Health	2019–2020
Health Resources and Services Administration/ DHMH, office of Primary Care Access	Maryland Healthcare Professional Shortage Area/Medically Underserved Area/Population Data	2021
Healthy People 2030	Healthy People 2030 – Baseline	2022
Institute on Disability at the University of New Hampshire	Annual Report on People with Disabilities in America	2020–2021
Kennedy Krieger Institute	Patient/Student Demographic Statistics	2019–2021
Maryland Center on Economic Progress	Kids Count Data Center	2021
Maryland Department of Disabilities	2020–2023 State Disabilities Plan	2020–2023
Maryland Developmental Disabilities Council	Maryland Developmental Disabilities Five-Year State Plan	2022–2026
Maryland State Department of Education	Maryland Report on Part B Indicator 8 of the Individuals with Disabilities Education Act	2021
Robert Wood Johnson Foundation/University of Wisconsin Population Health Institute	2021 County Health Rankings	2021
Rural Health Information Hub	Health Professional Shortage Areas	2022
U.S. Census Bureau	Explore Census Data	2020

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

ASD: autism spectrum disorder

CDC: Centers for Disease Control and Prevention

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

ID: intellectual disability

MCDD: Maryland Center for Developmental Disabilities

MD DDC: Maryland Developmental Disability Council

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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