

2017 Kennedy Krieger Institute

Community Health Needs Assessment Update



I. Introduction

In 2016, Kennedy Krieger Children’s Hospital, Inc. conducted its second Community Health Needs Assessment (CHNA). The 2016 CHNA identified four priority community health needs in Maryland: training, access to care, advocacy and youth transition. This report shares where we are, to date, in working toward addressing these community needs across Maryland, with a focus on individuals with disorders of the brain, and their families and caregivers.

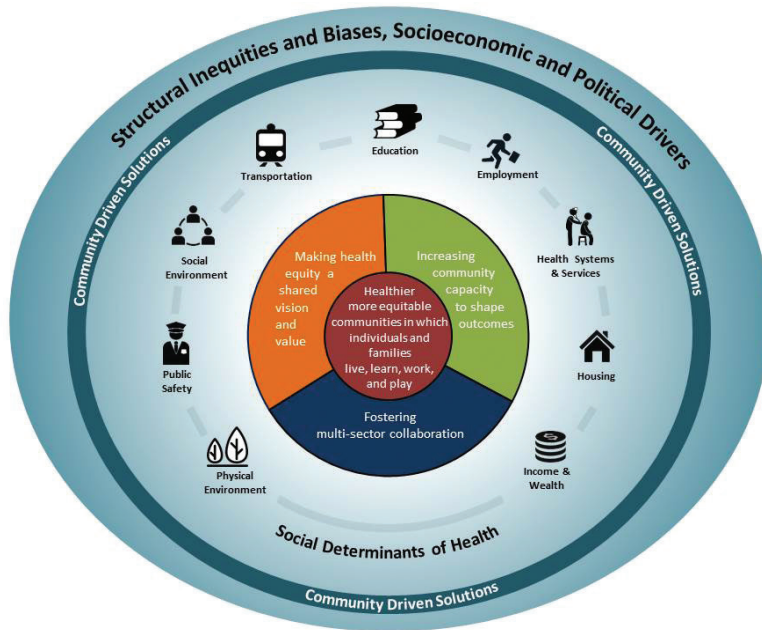
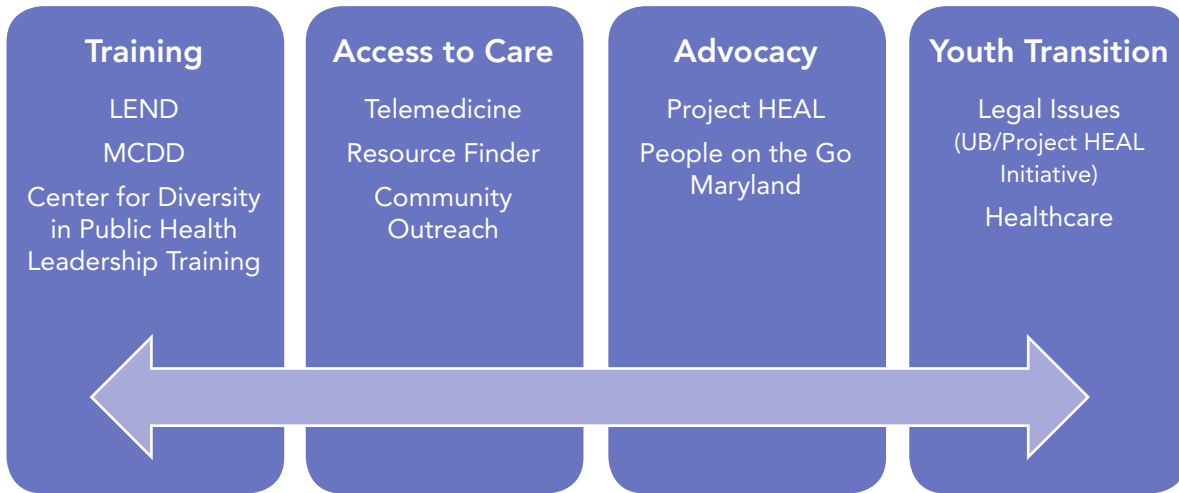


Figure 1: A conceptual model for community-based solutions to promote health equity.

The action plan for the 2016 CHNA calls for achieving health equity and, in particular, for including people with disabilities in population health equity initiatives. Community participation in advancing health equity is essential to all populations. The elements of the conceptual model presented by the National Academies Press, which is informed by the Robert Wood Johnson Foundation Culture of Health Action Framework and the Prevention Institute’s Systems Framework to Achieve an Equitable Culture of Health, are critically important to all populations, including individuals with disabilities (The National Academies of Sciences, Communities in action: Pathways to health equity, 2017).

This report also summarizes the community investments Kennedy Krieger Children’s Hospital, Inc. made in 2017.

I. Introduction *(Continued)*

a. Organizational Description

Kennedy Krieger Institute is an internationally recognized institution dedicated to improving the lives of children and young adults with pediatric developmental disabilities and disorders of the brain, spinal cord and musculoskeletal system, through patient care, special education, research and professional training. About 87 percent of individuals served by the Institute are Maryland residents, and they come from every county in the state.

b. Our Mission

To transform the lives of children with disorders of the brain through groundbreaking research, innovative treatments and life-changing education.

c. Our Vision

Discoveries of how the brain develops and functions are occurring at an accelerating pace. Kennedy Krieger Institute leads the way in translating these scientific advances into new therapies and educational interventions, while providing an inspirational environment for training tomorrow's leaders in the field. These successes benefit millions of children and families around the world.

d. Our Values

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



Kennedy Krieger Institute Community Health Needs Assessment

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II. Priority 1: Impact on Training

Training professionals as well as community service providers addresses the need to increase provider knowledge, across Maryland, about how to serve individuals with developmental and related disorders. The training programs at Kennedy Krieger focus on building capacity for subspecialty providers in developmental disabilities, integrating disability into community public health practices, and providing community continuing education to increase knowledge and awareness of health, in areas such as health promotion, wellness, disease prevention, health policy and education, and other areas related to developmental and related disorders. While health is often viewed as a separate component, its contribution to all other aspects of life—education, work, school, recreation and more—is critical.

a. Kennedy Krieger Training Programs

	FY2016	FY2017
Total Number of Trainees	525	505
Total Number Employed¹	99	N/A ²
Total Number in School³	18	40

b. Programs Included

- LEND (Leadership Education in Neurodevelopmental Disabilities Program)
- MCDD (Maryland Center for Developmental Disabilities)
- Center for Diversity in Public Health Leadership Training
 - o MCHC/RISE-UP (Maternal Child Health Careers/Research Initiatives for Student Enhancement - Undergraduate Program)
 - o MCH-LEARN (Maternal Child Health-Leadership Education, Advocacy, and Research Network)
 - o PLLUSS (Public Health Leadership and Learning Undergraduate Student Success Program)
 - o FERGUSON-RISE (Dr. James A. Ferguson Emerging Infectious Diseases Research Initiatives for Student Enhancement Fellowship Program)

¹Trainees employed trained under LEND, MCHC/RISE-UP and PLLUSS.

²2017 was not a data collection year.

³Data on trainees in school derived from MCHC/RISE-UP and PLUSSS.

III. Priority 2: Impact on Access to Care

It is especially important to improve access to care in areas we serve where there is a shortage of providers. The programs Kennedy Krieger offers in communities with less access to care include technical outreach visits in Eastern Shore schools, telemedicine services in western Maryland and on the Eastern Shore, and information to community stakeholders about resources through the Institute’s Resource Finder.

a. Telemedicine Outreach

	FY2016	FY2017
Total Patient Visits	115	142
Total Evaluation Visits	73	114
Total Follow-Up Visits	42	28

b. Eastern Shore Technical Assistance Project

Technical assistance and coaching grants in Maryland schools

	FY2016	FY2017
Eastern Shore Schools⁴	225	289

c. Resource Finder

Assisting stakeholders in locating resources in their communities

	FY2016	FY2017
Number/Method of Inquiries	998	978
Calls	595	513
Emails	214	212
Walk-Ins	184	153
Drop Box Card	5	11
U.S. Mail	N/A	1
Website Hits	21,804	11,562 ⁵

⁴Some schools received assistance only in either FY2016 or FY2017.

⁵Website reconstruction occurred during this time period.

IV. Priority 3: Impact on Advocacy

Self-advocacy training conducted by People on the Go through Project STIR (Steps Toward Independence and Responsibility) is delivered by individuals with and without disabilities, and is designed to empower those with developmental and related disabilities. It provides the practical “how-to” tools necessary to anyone interested in becoming a self-advocate and in making their own choices and decisions about how they live their lives. Voter-training workshops, also administered by POG, teach self-advocates about voting.

a. People on the Go Maryland: Project STIR (Steps Toward Independence and Responsibility)

Self-advocacy training for self-advocates and their support persons on voter training

	FY2017
Number of Trainings	4
Number of Participants	36
Regions	Eastern, Southern, Southern Montgomery, Central

b. People on the Go Maryland: Voter Training

Self-advocacy training, with regard to voting, for self-advocates and their support persons

	FY2016 & FY2017
Number of Trainings	4
Number of Participants	44
Regions	Southern, Western, Eastern

i. Participant Satisfaction Questions–Voter Training

	Yes	No
I was treated with respect during the training.	32	2
Because of this project, I know my rights as a voter.	34	1
I learned new things from the presenters.	32	3
I voted before the workshop.	24	11
I plan to vote during the next election.	32	3

IV. Priority 3: Impact on Advocacy *(Continued)*

c. Project HEAL (Health, Education, Advocacy and Law)

Self-advocacy training for families, caregivers and adolescents on topics related to special education law

	FY2016	FY2017
Number of Trainings	11	6

d. Resource Finder

Provides resources related to self-advocacy support for families, caregivers and self-advocates

i. Inquiry Requests

	FY2016	FY2017
Financial Resources	82	91
Housing	61	37
Diagnosis Information	39	20
Kennedy Krieger Requests	281	190
Recreation	281	190
Respite	40	21
Reimbursement/Benefits	168	176
Schools/Education	124	78
Service Providers	568	578
Trainings	43	21
Transition	25	11
Transportation	18	24

V. Priority 4: Impact on Youth Transition

Health outcomes are significantly lower than average for youth with emotional, behavioral or developmental issues and youth of underrepresented populations. Kennedy Krieger programs offer resources to young adults with disabilities who are transitioning to adulthood, and their families, so they will be informed on how to make decisions as they approach adulthood. The University of Baltimore (UB) School of Law's partnership with Kennedy Krieger's MCDD brings together UB law students, volunteer attorneys, Kennedy Krieger students and family members of young adult patients who, due to neurodevelopmental conditions and other disorders of the brain, have unique legal needs related to appropriate legal documents, planning for the future or access to public benefits. Pro-bono services provided by UB may include powers of attorney, advance medical directives, advance directives for mental health and estate-planning matters, such as wills and special-needs trusts.

a. Resource Finder⁶

Helps improve healthcare for youth transitioning to adulthood by providing resources on healthcare transition for families and healthcare and education professionals.

b. University of Baltimore School of Law

University of Baltimore (UB) School of Law students work under the supervision of pro bono attorneys to execute advance directives, advance directives for mental health, and powers of attorney for young adults, and their families, who are attending UB and/or who are patients at Kennedy Krieger.

i. Participants Trained

	FY2016	FY2017
Number of Families	11	21
Number of Volunteer Attorneys	11	20
Number of Law Students	22	21

⁶See "Inquiry Requests" under the "Resource Finder" sub-section of "Priority 3: Impact on Advocacy."

VI. Conclusion

As Susan Havercamp, director of the Health Promotion and Healthcare Parity Program at the Ohio State University Nisonger Center, states, “The fact that disability is largely absent from public health training and practice leaves public health unprepared to address the health needs of this vulnerable population” (The National Academies of Sciences, 2017).

Kennedy Krieger strives to excel in collaborative partnerships designed to enhance the health of individuals we serve in communities across Maryland. While we see training as a critical component in reducing health disparities for individuals with disabilities, our other areas of focus—improving access to care, cultivating self-advocacy, and supporting youth transitioning to adulthood—are just as important, and can be accomplished through a variety of training avenues.

Kennedy Krieger Children’s Hospital, Inc. is continuously working to improve our partnerships and relationships with the communities we serve. We want to improve our programs and systems while addressing community-wide, within-our-reach gaps that impact individuals with disabilities. While the Affordable Care Act (ACA) mandated hospitals to engage in community health needs assessments (CHNA), the requirement forces us to intentionally look at how we serve and impact the community of individuals with disabilities. Engagement in this activity has broadened our vision of who our stakeholders are and what their needs are, and—most importantly—it has helped us identify potential partnerships that will improve the health and well-being of the population we serve and care about.

a. Community Investments

Community Health Improvement Services and Operations	\$3.5 Million
Employee Cash and In-Kind Contributions	\$400,000
Community Building Activities	\$260,000

References

The National Academies of Sciences, et al. (2017). *Communities in action: Pathways to health equity*. Washington, D.C.: The National Academies Press.

The National Academies of Sciences, et al. (2017). *People living with disabilities: Health equity, health disparities, and health literacy: Proceedings of a workshop*. Washington, D.C: The National Academies Press.