Improving Access to Care and Transition Services for Children and Youth with Epilepsy in Eastern Pennsylvania (I-ACT for Epilepsy)

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Total Funds Requested: $1,210,548 (Direct: $886,681; Indirect: $323,867)

Children and youth with epilepsy (CYE) living in medically underserved and rural areas as well as racial and ethnic minority populations are less likely to have access to coordinated and comprehensive quality health care, leading to poorer quality of life. As CYE approach adulthood, few receive the services and education needed to successfully transition from pediatric to adult healthcare services. Telehealth, telemedicine, and mobile health (mHealth) are promising approaches to improve access to specialty care among this population.

The overall goal of this project is to utilize quality improvement approaches and telemedicine to improve access to coordinated and comprehensive quality care for CYE and pediatric-to-adult healthcare transition services in the catchment area of The Children’s Hospital of Philadelphia (CHOP), with an emphasis on those living in medically underserved areas. CHOP will partner with the University of Pennsylvania Health System (PennMedicine) to create a learning collaborative with 7 different clinical sites: 2 pediatric neurology practices, 2 pediatric primary care practices, 1 adult neurology practice, and 2 adult primary care practices. CHOP will collaborate with the Child Neurology Foundation, the Epilepsy Foundation of Eastern Pennsylvania, and the Society of General Internal Medicine to develop outreach and education strategies and materials for CYE, their families, and their pediatric and adult providers. I-ACT for Epilepsy is expected to reach 1,000 CYE and accomplish the following specific outcome and process objectives by August 2019: (1) increase by 25% the number of CYE in the target population who receive care through a patient/family-centered medical home; (2) increase by 50% the number of CYE served by the clinical sites who have a youth transition plan in place; (3) increase by 25% the number of CYE in the target population who are from populations experiencing health disparities and/or residing in medically underserved and/or rural areas that have access to specialized epilepsy care; (4) increase by 25% the number of CYE in the target population reporting use of comprehensive and coordinated treatment and care plans; (5) increase by 25% the proportion of CYE served by the clinical sites receiving coordinated and comprehensive health care through telemedicine visits; (6) increase by 20% the number of CYE in the target population who are from populations experiencing health disparities and/or residing in medically underserved and/or rural areas receiving coordinated and comprehensive health care through telemedicine visits; (7) implement a pediatric to adult epilepsy transition infrastructure using the Got Transition Six Core Elements Framework across all clinical sites; and (8) increase by 50% the number of clinical sites with a plan in place to use telemedicine and mHealth to coordinate care for CYE from populations experiencing health disparities.

I-ACT for Epilepsy will develop and identify clinical pathways and strategies for the implementation of transition guidelines, telemedicine, and improved access to pediatric and adult medical homes for CYE, particularly those coming from populations experiencing health disparities and living in medically underserved areas. We will subsequently adapt and implement the pathways and strategies for children and youth with other special healthcare needs throughout our institution. Furthermore, these clinical pathways, strategies, and educational materials will be widely available for use by other pediatric healthcare institutions.