PROJECT ABSTRACT

Project Title: Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy

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Problem: Rural areas present numerous obstacles for families who need to access medical and community services. Barriers include: transportation, lack of medical/human services, child neurologists, unemployment, language, poverty and lack of adequate health insurance. Pennsylvania lacks systems of coordinated care for children and youth with epilepsy (CYE) who reside in rural communities across the state. Specialty care and subspecialty care providers are located in urban centers. Approximately 27% of the Commonwealth’s residents live in these rural counties. Over 2,000 CYE are of transition age but upwards of 34% have not had discussions about changes in healthcare needs with providers and only 24% have sometimes had discussion with their healthcare provider about taking increased responsibility for their care.

GOAL(S) AND OBJECTIVES: The goal of this initiative is to utilize quality improvement methods and measure outcomes to improve access to coordinated and comprehensive quality care for CYE, with an emphasis on populations experiencing health disparities and CYE residing in underserved and/or rural communities. The EFWCP will work to 1) Increase the capacity of medical home and pediatric practices to support CYE; 2) Establish primary care clinical sites to conduct telemedicine appointments; 3) Establish and implement epilepsy pediatric to adult transition models in clinical sites based on the Got Transition Six Core Elements Framework; 4) Establish and implement a program of education to increase awareness and knowledge of epilepsy and, 5) Implement quality improvement initiatives for the use of telehealth technologies to educate CYE and pediatric practitioners using telehealth/ehealth and mhealth.

METHODOLOGY: The vision of this proposal is to significantly enhance, through a variety of quality improvement methods, access to medical and community supports and services to CYE and their families. This will be accomplished by developing a Quality Improvement Leadership Team and local, site-based learning collaboratives as foundational, on-going structures to guide, evaluate and support specific quality improvement activities to achieve project goals. Project activities will be organized into 3 different levels with information and resource exchange occurring within and across levels.

COORDINATION: Partners include: National Coordinating Center for Access To Services for CYE, EFWCP, Children’s Hospital of Philadelphia, Penn State Hershey Medical Center, PA Medical Home Initiative, PA Department of Health, Bureau of Family Health (Special Kids Network), Epilepsy Foundation Eastern PA.

EVALUATION: The project will develop a two-prong plan to measure activity. Project evaluation will utilize both qualitative and quantitative methodologies.

ANNOTATION: This project will improve access to care and support for CYE in rural areas of PA by utilizing telemedicine, telehealth and education in coordinated approach of quality improvement initiatives for transitional services and education for youth with epilepsy using telehealth/ehealth and mhealth technologies.