ABSTRACT

Delivering High Quality Care to Children and Youth with Epilepsy in Urban and Rural Settings

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Boston Medical Center’s (BMC), Delivering High Quality Care to Children and Youth with Epilepsy in Urban and Rural Settings program, will utilize strategic approaches to expand access to high quality primary and specialty care in underserved populations of children and youth with epilepsy and related disorders (CYE) seeking epilepsy specialty care at BMC. As the largest safety net hospital in New England, BMC provides a continuum of primary and specialty care and serves as a local and regional referral center for children in need of pediatric subspecialty care. Our program will reach a minimum of 1,000 CYE, more than 20% of whom live in communities that are medically underserved and experiencing health disparities.

Our Comprehensive Epilepsy Center (CEC) and Section of Pediatric Neurology will lead the program and provide multidisciplinary assessments, coordinated treatment planning, seizure action plans, and transition plans for CYE. Our specialty physicians work closely with multidisciplinary teams on diagnostic evaluations and the development and implementation of treatment plans that empower families and primary care providers (PCPs) to manage the medical, social and emotional challenges that accompany a seizure-related diagnosis.

We will enhance the ability of local providers in community health centers (CHCs) to identify signs of seizures in infants, children, and adolescents. We will provide PCPs with a highly sensitive (98%) seizure screen for populations that have a high risk of seizures. Once a child is identified as having signs of seizures, we will interview the family using Part 2 of the seizure screen with a 94% negative predictive value. The CEC physicians will review seizure screen results and triage positive screens for evaluation at the CEC within two weeks. We will utilize video-conferencing with the PCP, the CYE and family when possible. Persons with epilepsy who face health disparities or geographic challenges are less able to access specialized epilepsy care; this strategy will address this problem for CYE with health disparities and isolated from a specialized epilepsy center.

Our second strategy will enhance care provided locally for CYE. After a comprehensive, multidisciplinary assessment at BMC, we will work with their specialty and primary care teams to design, implement and monitor mhealth care plans and seizure action plans for all patients, revising and updating them as needed. Telemedical encounters will be integrated into this strategy, so that patients and families will not need to travel to BMC for pediatric neurology and other specialty care. In addition, we will provide automated mHealth reminders to parents and CYE to take their medicines and follow-up with their appointments. We will coordinate with local care teams to ensure that required enabling and support services are in place to ensure that parents are able to attend their telemedical appointments.

Our third strategy is our CYE Quality Improvement Learning Collaborative, which will meet monthly via web-based conferencing facilitated by BMC staff. Members of the Learning Collaborative will receive updates on treatment best practices, will have access to a library of electronic learning materials and participate in quality improvement efforts. They will also help to develop a new Transition Framework for CYE based on the Got Six Transition Model.