EMERGING STRATEGIES FOR CHILDREN AND YOUTH WITH EPILEPSY IN TEXAS

EPILEPSY FOUNDATION OF TEXAS

PROGRAM OVERVIEW

From 2016-2019, the Emerging Strategies for Children and Youth with Epilepsy in Texas aimed to improve access and quality care for 1,000 children and youth with epilepsy (CYE) living in Texas including CYE experiencing health disparities or living in medically underserved/rural areas. The Epilepsy Foundation of Texas-Houston/Dallas-Fort Worth/West Texas (EFTX) accomplished this in three metropolitan areas: 1) Houston 2) Dallas 3) San Antonio.

PROGRAM UNIQUENESS

- Texas serves a large undocumented population.
- Hurricane Harvey was an unexpected event that shifted the focus of medical providers involved in the project.
- There are a limited number of providers that accept patients with Medicaid. Children with special health care needs are more likely to have Medicaid coverage than children without special health care needs.

STRATEGIES

LEARNING COLLABORATIVE

A learning collaborative (LC) brings together clinical team members to seek improvement on a specific area of care. Staff from seven clinics participated in the LC focused on improving policies, procedures, and access to telehealth/telemedicine services for all CYE. A second LC focused on increasing transition planning from pediatric to adult care. The LC led to improved collaboration and the opportunity to implement quality improvement tools to improve processes.

NATIONAL EPILEPSY AWARENESS MONTH PROJECTS

The “I am More than Epilepsy” campaign, in collaboration with EFTX and their clinical sites, displayed pictures of teens participating in the EFTX Summer Camp program. The EFTX camping programs provide children and youth with epilepsy a safe, structured, FUN and encouraging home away from home. The campaign also shared epilepsy education materials for the public and was disseminated within the clinical sites and on social media.

MOBILE HEALTH APP

With input from CYE and family members, a mobile health application has been developed. The app provides information on seizure action plans, care plans, accessing specialists and primary care physicians, links to information about Children's Health Insurance, updates on events and activities, tips for staying safe, medication adherence, seizure logs, and more. The app increases access to accurate and reliable information for CYE.

SUCCESSES

- The Texas Pediatric Neuroscience Conference in February 2019 gathered 134 attendees from 46 different organizations to exchange research, approaches, and treatment options for children and youth with epilepsy.
- EFTX education efforts that focused on advocacy and transitioning to self-management of care were successful.
- Transition classes during summer camps.

This project is part of the Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy, funded by the Health Resources and Services Administration and supported by the National Coordinating Center for Epilepsy.

The National Coordinating Center for Epilepsy is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U13MC26122, Awareness and Access to Care for Children and Youth with Epilepsy/ cooperative agreement. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

EFTX GOALS

TELEMEDICINE

7 clinics will have increased telemedicine services to CYE, including those CYE experiencing health disparities, and/or living in medically underserved areas.

TRANSITION

7 clinics will have a pediatric to adult transition infrastructure in place using Got Transition Six Core Elements of Health Care Transition Model.

CARE FOR CYE

Improve care to 1,000 CYE including 200 CYE experiencing health disparities/living in MUA/rural areas.