

PROJECT ABSTRACT

Title: “Epilepsia en Washington: Improving Access to Care for Children and Youth”
Applicant Name: Washington State Department of Health, CSHCN Program
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Needs: Epilepsy is a challenging condition that affects from 6100 to 15,000 children in Washington. It can seriously affect their lives by causing severe seizures, injuries, lifestyle restrictions, stigma, and depression, all contributing to a poor quality of life. Children with epilepsy who live in rural, under-served areas of Washington and who speak a language other than English have even more difficulty managing their epilepsy because they have less access to the range of needed health care services. There is a shortage of pediatric neurologists and experts who treat epilepsy which has resulted in diagnostic delays and lack of access to appropriate medical care. Children and youth with epilepsy repeatedly face barriers to appropriate and timely care including lack of insurance, gaps in health care coverage, lack of culturally competent, coordinated care, lack of information about community resources, lack of access to interpreters, transportation barriers, and lack of ability to partner with their provider for their own and their children’s health care.

Proposed services: Along with the Epilepsy Foundation Northwest and other partners, our grant activities will highlight children and youth with epilepsy and their families to find out how they are doing related to the components of a comprehensive system of care: (1) have access to care in a Medical Home, (2) are involved in decision-making for their own and their children’s care; (3) have adequate health insurance to pay for needed services, (4) know about and receive early and continuous screening to identify special health care needs, including epilepsy, (5) are able to easily find community based services for epilepsy, and (6) have the services necessary to transition to adult healthcare. Focusing on two rural, medically underserved communities, we will work with five groups to achieve the grant goals: (1) conduct a Needs Assessment of the communities, (2) create a Partnership Committee to develop and implement a Statewide Plan and Sustainability Plan for improving access to care for children and youth with epilepsy, (3) recruit and train parents and youth to increase their self-efficacy through a Family Leadership Training Program so they can better advocate for their child and for themselves and to effectively do community outreach activities to reduce stigma and improve public and professional awareness, and (4) develop co-management strategies between primary care providers and epilepsy specialist. We will also recruit and lead teams to participate in two National Learning Collaboratives through the National Center.

Population group to be served: Through this project, our population group will be (1) Hispanic parents and children with epilepsy, (2) youth with epilepsy, (3) primary care providers, (4) epilepsy specialists, and (5) community care coordinators in two medically underserved, rural communities with a significant Hispanic population.