

Project Access: California

Project Access: Improving Access to Care for Children/Youth with Epilepsy

Project Access is a three-year grant funded by the Maternal and Child Health Bureau, a branch of the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services.

The project aims to improve access to health care for children and youth with epilepsy who live in rural and frontier communities in Alaska, California, Nevada, and Wyoming. The project seeks to assure access to an integrated system of health and related services by establishing State Teams that work toward improved systems of care. State Teams collaborate with Epilepsy Foundation affiliates to develop comprehensive models of care and to eradicate stigma by increasing public awareness and understanding of the disorder.

Project Access serves children with epilepsy, their families, and the primary and specialty care providers who serve them.



A Summary of Issues Facing Children with Epilepsy and their Families

What You Should Know about Epilepsy

What is Epilepsy?

Epilepsy is a neurological condition in which a sudden and brief excess surge of electrical activity occurs between nerve cells in the brain, resulting in a seizure.¹ Seizures can cause abnormal movements, a change in behavior, or a loss of consciousness. A seizure is a symptom of epilepsy. **A diagnosis of epilepsy is generally given after a person experiences two or more seizures.**¹

Epilepsy is the third most common neurological disorder in the U.S. after Alzheimer's disease and stroke.¹ **It is equal in prevalence to cerebral palsy, multiple sclerosis and Parkinson's disease combined.**¹ Epilepsy is most common among the very young and the very old. Of major chronic medical conditions, it is one of the least understood. Epilepsy remains a mystery to a large segment of the United States population.

Who has Seizures?

Epilepsy affects over 3 million Americans.² Each year in the U.S., over 150,000 children will seek medical attention for newly occurring seizures.³ **Over half of all epilepsy cases begin before the age of 25.**⁴ **In California, it is estimated that 93,730 children ages 0-17 live with epilepsy.**⁵

Why is it a Problem?

Epilepsy is a condition that is more easily treated with early diagnosis and intervention. However, many families affected by epilepsy experience significant barriers to accessing health care for their child. Many parents of children with epilepsy struggle to maintain employment while caring for children with unpredictable seizures. More children with epilepsy are uninsured than the general child population. Health care services such as primary and specialty care tend to be disjointed and difficult to access for families, especially those who reside in a rural community. Additionally, travel to and from weekly specialty care appointments places an enormous financial burden on families.

What Can Be Done?

This document will explore the health status of children with epilepsy in California and common barriers faced by families in accessing diagnostic and continuing care. Suggestions for improving access, quality, and coordination of services for children/youth with epilepsy will be identified. **With the proper steps, we can ensure better health and improved quality of life for children living with epilepsy in California.**



The Current Situation

Challenges Facing Families of Children with Epilepsy Living in Rural Communities

Disparities Exist Between Children with Epilepsy and Other Children with Special Health Care Needs

- Only 36% of children with epilepsy have a medical home, compared to nearly half of all children with special health care needs.⁸
- Children with epilepsy miss more days of school, on average, than other children with special health care needs.⁸
- Almost 40% of families affected by epilepsy report major financial strain caused by the condition, compared to just 17% of families of children with special health care needs, generally.⁸

BOTTOM LINE: Additional outreach and services are needed to close the gap in care received by children with epilepsy and other children with special health care needs. Community support is needed to enroll children with epilepsy in the Medi-Cal and Title V plans to reduce financial barriers to accessing services.

Health Insurance Coverage for Children with Epilepsy

- Nationally, only 55% of children with epilepsy have adequate insurance coverage.⁸
- Children with epilepsy are likely to have lower coverage rates than other children, thus increasing the health care disparity.
- Though the number of children uninsured in California dropped by 25% from 2001 to 2005, roughly 6% of children (560,000) are still uninsured.^{7,9}
- Of children without insurance, over half are eligible to receive Medi-Cal or Healthy Families.⁷
- If a low-cost health insurance plan for families, such as Healthy Kids, were available in all counties, California could reduce hospitalizations by 4,300 and save \$24.3 million annually.⁷

BOTTOM LINE: The state should focus on a different strategy in advertising, marketing, and promoting the existence of programs like SCHIP. Electronic applications for Medi-Cal and Healthy Families should be adopted by all counties to increase ease of enrollment.⁷

California Family Needs

The greatest barriers identified in a needs assessment conducted by Project Access¹⁴ included:

- Long travel times for rural families to reach specialists.¹⁴
- Lack of public transportation in rural areas, making it difficult to travel to distant appointments.¹⁴
- Insurance coverage that is not continuous due to seasonal work or inadequate insurance coverage for necessary medical expenses relating to a child's chronic condition.¹⁴
- Shortage of primary care providers and neurologists in rural counties of California.¹⁴
- Primary care providers are not always up to date on new treatments for epilepsy.¹⁴

BOTTOM LINE: Parents expressed greatest concern with overall access to, and quality of, health or medical services for children with epilepsy.

Children with Epilepsy in California: Rural Health Care Access Challenges

- Rural California makes up 80% of the land mass and 15% of the population – five million people.¹⁴
- Families living in Central California often drive to the Bay Area or Los Angeles for services; northern California families may drive as far as Nevada or Oregon.¹⁴
- Many rural counties have no pediatricians.¹⁴
- Cultural and language barriers further complicate the process for families trying to access care for a child with epilepsy.¹⁴
- Providers may relocate outside of California due to the high cost of living and low Medi-Cal reimbursement rates, increasing the shortage of providers and specialists.¹⁴

BOTTOM LINE: Improved accessibility to neurological and pediatric services is needed. Loan forgiveness and stipends should be used to encourage new specialists to practice in rural areas. Technologies such as telehealth and telemedicine are promising solutions to rural health care access and should be more heavily funded and implemented in California.



Epilepsy-Related Hospitalizations

- Since 2000, hospitalizations for epilepsy have increased by 50%.¹²
- Epilepsy-related hospitalizations for children are most expensive, with an average daily cost of \$2,200, compared to \$1,800 for adults.¹²
- While children make up only 18% of all hospital admissions, they account for 31% of epilepsy-related hospitalizations.¹²
- The national estimated annual cost of epilepsy-related hospitalizations for children is \$5.6 million.¹²
- With the high rate of uninsured children with epilepsy, over 45% of emergency room and hospitalization costs fall on the state.

BOTTOM LINE: Without accessible, effective, and continued care to treat seizures in children with epilepsy, emergency room visits will continue to be necessary to treat uncontrolled seizures. Services must be created to ensure regular, continued care for children in order to control seizures and reduce the need for emergency room visits.

Mental Health

- Children with epilepsy are five times more likely than other children to develop a mental health or behavioral problem.¹⁴
- Seizures may influence brain functioning in key areas, such as those that regulate emotion or impulses.¹⁴
- Bullying and strained peer relationships are commonly experienced by children with epilepsy.
- Stress due to the unpredictability of seizures can increase the likelihood of depression or anxiety disorders.¹⁴

BOTTOM LINE: Early identification and treatment of mental health conditions are key to healthy development. More services are needed to provide emotional support, help children work through the fear of seizures, and teach kids to talk about their epilepsy.¹⁴

Early Diagnosis and Treatment

- With proper treatment and control of seizures, epilepsy-related hospitalizations can be reduced.
- The highest treatment costs for epilepsy occur in the first year following diagnosis, with costs declining drastically in subsequent years.¹³
- With seizures under control, anti-epileptic drugs and routine preventive care appointments account for the only continued costs.
- Without treatment to manage seizures, however, continued emergency room visits and hospital stays are likely.
- School nurses, when available, can aid in early diagnosis of epilepsy and other chronic conditions in the school setting, but are in short supply, especially in rural areas.

BOTTOM LINE: Primary care providers and school personnel should be trained to recognize seizures and make the necessary referrals. School nurses are qualified to manage students with epilepsy and train school personnel, but are often overloaded in the current system. The state should support rural school nurses and recognize the integral role they play in connecting children with epilepsy with diagnostic and (routine/emergency) treatment services. All schools should have school nurses that can support care.

Seizure Action Plans (SAPs) in Schools

Treatment for children with epilepsy in the school setting continues to be a challenge. Parents may need to leave work and lose income when they are called in response to a child's seizure. In some cases, multiple calls from a child's school make it difficult for parents to maintain employment.

Emergency seizure preparedness in schools is essential both to the child's classroom performance and parents' productivity. A Seizure Action Plan (SAP) allows parents, physicians, and school personnel to create a response and treatment plan in the event of a seizure. A SAP, when followed and maintained by school personnel, can allow children to continue school activities after recovering from a seizure. Everyone can benefit from a SAP. Students are more likely to receive an appropriate response, school teachers and school nurses have the necessary information to respond and provide first aid, parents are more at ease knowing that a written plan is in place, and emergency responders are not called in unnecessarily.



http://98.129.194.75/docs/Seizure-Action-Plan_v1.pdf

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Project Access: Improving Care for Children with Epilepsy, is a national initiative funded by the federal Maternal and Child Health Bureau, Health Resources and Services Administration. One of five grants awarded in August 2007 was to The USC University Center for Excellence in Developmental Disabilities, Childrens Hospital Los Angeles, grant #H98MCO8579. Two other partners in Project Access also provide support: The National Initiative for Children's Healthcare Quality (NICHQ) and the Epilepsy Foundation of America. The USC UCEDD, CHLA has subcontracted with UCEDDs in Alaska and Wyoming, as well as, Family TIES of Nevada, and the Epilepsy Foundation of Northern California to carry out Project Access. The Epilepsy Foundation Northwest and the Epilepsy Foundation of Colorado also provide support.

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