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## California Learning Collaborative Team

### Replicable Models, Tools and Learning Collaborative Outcomes

#### Background

As the most populous state in the nation, California (CA) is home to more than 9.5 million children between the ages of birth and 18 years<sup>1</sup>. Using a prevalence estimate for active epilepsy<sup>2</sup> of 4-9 children per 1,000 it is estimated that over 85,000 children in CA in 2004 had epilepsy and/or a seizure disorder<sup>3</sup>. Epilepsy is defined as any of a group of syndromes characterized by paroxysmal transient disturbances of brain function that may be manifested as episodic impairment or loss of consciousness, abnormal motor phenomena, psychic or sensory disturbances, or perturbation of the autonomic nervous system; symptoms are due to disturbance of the electrical activity of the brain<sup>4</sup>. The goal of eliminating seizures while preventing side effects is potentially achievable for many children and youth. However, organized systems of services are not in place to uniformly provide timely access to care that could improve quality of life for children and youth with epilepsy. CA as well as the rest of the US is impacted by the current shortage of pediatric neurologists, with even fewer neurologists or epileptologists who are experts in diagnosing and treating epilepsy<sup>5,6</sup>. Obtaining an accurate diagnosis and finding the appropriate medication to assist children with epilepsy so that they can achieve seizure control is a major barrier to optimum quality of life and participation in everyday activities including school. For families of children with epilepsy having to “wait” for the medical diagnosis and optimum medications may have a significant impact on the entire family as well as their ability to take care of everyday activities including gainful employment.

In April 2004 the Maternal and Child Health Bureau (MCHB), Division of Services for Children with Special Health Care Needs (DSCSHCN) US Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), released a request for proposals soliciting applicants to work toward improving access to comprehensive, coordinated health care and related services for children and youth with epilepsy residing in medically underserved areas (MUAs) and rural areas. The purpose of the initiative, Improving Care for Children and Youth with Epilepsy: Project Access, under Priority Area 1, was for *states* to develop and implement a plan to improve community-based systems of services for children and youth with special health care needs who have epilepsy and/or seizure disorders as defined by the following components.

1. Partnership between professionals and families of children/youth with epilepsy;

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<sup>1</sup> US Census Bureau, State and County Quick Facts, <http://quickfacts.census.gov/qfd/states/06000.html>, February 2008.

<sup>2</sup> Occurrence of a seizure within the previous 5 years or control of seizures with medications.

<sup>3</sup> Murphy, CC, Trevathan, E., Yeargin-Allsopp, M. (1995) Prevalence of Epilepsy and Epileptic Seizures in 10-Year-Old Children: Results from the Metropolitan Atlanta Developmental Disabilities Study, *Epilepsia*, 36(9):866-872.

<sup>4</sup> Dorland, WA Newman (2003) Dorland's Medical Dictionary for Health Consumers, 30<sup>th</sup> Edition, WB Saunders, an imprint of Elsevier, Inc.

<sup>5</sup> -Laureta E, Moshe SL. (2004) State of training in child neurology 1997-2002. *Neurology*; 62; 864-869.

<sup>6</sup> -Werner RM, Polsky D. (2005) Comparing the Supply of Pediatric Subspecialists and Child Neurologists, *J Pediatr* 2005; 146:20-5.

2. Access to culturally competent family-centered medical home which coordinates care to pediatric subspecialties;
3. Access to adequate health insurance and financing of services;
4. Early and continuous screening for epilepsy and seizure disorders;
5. Organized community services for easy use by families;
6. Transition to adult health care.

The University of Southern California (USC) University Center for Excellence in Developmental Disabilities (UCEDD) at Childrens Hospital Los Angeles (CHLA) was one of eight states that received funding beginning in September 2004. Over the past 3 years the CA Grantee has worked closely in CA with California Children's Services (CCS), the Family Resource Center Network of CA (FRCNCA), three affiliate offices of the National Epilepsy Foundation (Northern CA; Los Angeles, including Orange San Bernardino and Ventura Counties; San Diego County), Pediatric Neurologists, four community-based Medical Home Coalition and several Pediatric Neurology Programs, affiliated with California Universities and Children's Hospitals.

### **The Learning Collaborative**

One of the grant-required objectives under Project Access was that grantees identify an interdisciplinary and interagency team to participate in a Learning Collaborative that could develop and implement change strategies to support quality improvement for children with epilepsy, ultimately leading to improved access to, and quality of, care for children with Epilepsy. The aim of the Epilepsy Learning Collaborative was that children with epilepsy would equitably receive timely, safe, effective, coordinated, family-centered care. Improvements in care delivery and timely access go hand in hand, as one affects the other. Therefore, the mission of the collaborative was to address both care delivery and access simultaneously. A second aim was to develop the capacity of state and local programs to sustain and spread these improvements across their regions, and serve as the basis for replication across the nation.

The Learning Collaborative was a time-limited effort (18 months), bringing together nationally, multiple organizations to learn about and create improved processes in specific topic areas. The expectation was that the teams would share expertise and data with each other, learning from each other. The Learning Collaborative was followed with an additional year of support from the National Initiative for Children's Healthcare Quality (NICHQ) to disseminate the lessons and tools from the Learning Collaborative and spread successful changes within states and regions.

In early 2005 the USC UCEDD approached the Neurology Institute at Children's Hospital Orange County, upon the recommendation of the Southern CA Regional Medical Director, CCS, and asked for their participation in the Learning Collaborative. The Neuroscience Center at CHOC is an innovative, comprehensive resource center that takes a multidisciplinary approach to the diagnosis and treatment of epilepsy - offering families the full range of services in one setting. The Center is dedicated to helping children whose seizures are unresponsive to therapy, as well as those with routine seizure disorders with a goal of providing a Program that offers individually tailored, advanced treatment alternatives including several new medications and the latest therapeutic approaches such as vagus nerve stimulation. The Center and its pediatric specialists provide a full range of dedicated services including a 24-bed neuroscience unit, 24- bed pediatric intensive care unit (PICU),

42- bed neonatal intensive care unit ( NICU), Long-term video EEG lab, Outpatient Epilepsy and Neurology Center.

Learning Collaborative Team Members included Tara Dilliaine, Parent, Kristie Freeman, RN, Clinic Manager, Jill Trice, MD, Pediatric Neurologist, Maria Tupas, MD, Pediatrician, Director CHOC Ambulatory Clinics, Kathie McCall, RN, Case Manager, CHOC Ambulatory Clinics, Cary Kreutzer, MPH, CA Project Access Director, Laura Schweers, CA Project Access Coordinator, Neva Hirshkorn, Executive Director, Epilepsy Foundation Northern CA and William Stack, Assistant Director, Epilepsy Foundation Northern CA. The majority of team members participated in three national NICHQ-sponsored Learning Collaborative Meetings (Houston-1/06, Boston-5/06, Denver, 10/06), local meetings at CHOC and telephone conference calls. The goal for the learning collaborative was that the CHOC Epilepsy Center would partner with CHOC's primary care clinics to increase and improve access to specialty care and care coordination for new and existing patients with epilepsy. The team worked in concert with families to assure that the care provided was family-centered and culturally appropriate. Specific objectives include:

- Parents will feel that they are a valued and integral part of the care team.
- Children/youth who present in CHOC's Emergency Department with epilepsy will have a documented Medical Home.
- Families will have a home medication list and a Parent Notebook.
- CHOC primary care providers will receive quarterly in-service training from PSF Neurology on seizures, assessments, referral guidelines and updates on new medications and other therapies.
- The CHOC Epilepsy Center will offer comprehensive and appropriate community resource information and referrals for accessing therapies, intervention services, and parent support to 100% of its patients.

## **Outcomes**

Parent data, collected monthly, were extremely informative in revealing areas of the Epilepsy Clinic that were in need of improvement; and, providing the Team with feedback on Piloted strategies or tools implemented in hopes of improving practice. Products that were implemented, evaluated and adopted are described below under Products. Because the barriers and obstacles encountered in the Pediatric Epilepsy Clinic are not dissimilar to other specialty clinics at CHOC the CHOC Clinic Manager strongly supported the replicable models discussed below and felt that a number of the strategies for improving access, productivity and assuring family satisfaction could be replicated even within the CHOC Specialty Clinics. While a number of the Learning Collaborative strategies were not well received, and some have yet to be implemented, the 1 ½ year period was enough time to raise awareness, think outside the box and recognize that to improve access to care for children with epilepsy, in the wake of decreasing numbers of pediatric neurologists, practices will need to think outside the box and embrace new clinical models. New models of specialty care must be tested and those that are effective implemented and parent input when re-designing systems is critical to success.

## **Replicable Models**

The CHOC Epilepsy Center is not unlike other pediatric specialty centers in CA or across the country. All struggle with a shortage of pediatric neurologists to meet the appointment

scheduling needs to accommodate timely diagnosis and ongoing medical specialty care. The CHOC Epilepsy Center under the Learning Collaborative piloted and evaluated several strategies to decrease the wait list for appointments, defer work that is completed by the neurologist that could be taken care of by another member of the team, improve communication with primary care providers and most important, provide families with information and education enabling them to better understand their child's diagnosis and ongoing care. Strategies that were tested and evaluated included the following, not all have been fully implemented.

- Provide quarterly training to CHOC primary care providers to allow for improved communication and coordination of care and to equip the primary care providers with an improved understanding of treatment options, criteria for referral and medication management.
- Enter into a Service Agreement with CHOC Ambulatory Clinics and large community pediatric practice groups to define in writing, referral criteria, methods for assuring ongoing communication.
- Hire a Pediatric Nurse Practitioner (NP) to oversee follow-up appointments with return patients and to provide assistance to neurologists to decrease the time they are required to spend with new and/or returning patients. This was a good strategy but met with obstacles in re-defining roles and the NP was not in the Center long enough to test out her effectiveness.
- Hire a Health Educator, part-time, to provide education and training to families on keeping a notebook, understanding their child's condition. Parent evaluation data were critical to provide the justification for this position. Parents reported poor satisfaction with the level and amount of education/training they received.
- Social Worker will provide support to the families in accessing community services and supports, again helping to reduce the amount of time the neurologist is required to spend with families on non-medical issues.
- Extend visit intervals based on patient needs, not on a standard return policy, e.g. quarterly or semi-annual appointments. This was facilitated by updating the discharge form, adding a section, in which the neurologist can identify when the next visit is needed. Prior to this all visits were scheduled for the same intervals.
- Schedule return appointment prior to the patient/family departure from the clinic instead of waiting and scheduling 3 months prior to the appointment. Previous practice was only to schedule 3 months in advance, families were asked to call back for follow-up appointments 3 months prior to projected date.
- Implementation of the Patient Access Center at CHOC (Specialty Care, purpose was to track referrals from primary care to specialty care and provide follow-up to families) improved the Epilepsy Center's ability to follow-up with neurology referrals. The volume of referrals increased dramatically when implemented but settled to a more manageable amount. The Center improved the Epilepsy Center's ability to accurately assess the pool of new referrals waiting for a first appointment.

### **Tools Developed**

As one strategy for improving access to specialty and primary care services, the team developed a number of useful tools for the Epilepsy Center that can be adapted and used in other settings. A summary of each is presented below.

- **Parent Notebook** - These materials, designed to be printed and compiled in a notebook binder, consist of the following tools to help parents and caregivers of children with epilepsy organize and maintain their child's health information in a central location: binder cover, binder spine, and formatted divider tabs; care plan template; medical history template; home medication list with names of anti-seizure medications; seizure log; equipment log; provider list form; a template to record notes from a doctor's visit; and a resource section specific to services available in Orange County (this is meant to serve as an example of the information that could be included in a resources section). It is hoped that the notebook will also assist parents and caregivers in sharing their child's health information with members of the care team. (Available in English & Spanish).
- **Home Medication Sheet**- This tool was designed to help parents keep a history of their child's medications and to reconcile medications with their child's health care provider during an appointment. The second side of the sheet includes a small reference table of anti-epilepsy medications. (Available in English, Spanish, and Vietnamese).
- **Seizure Description Tool**- This tool was designed to assist parents and caregivers in describing their child's seizures and in reporting current anti-epilepsy medications taken by their child to the primary care physician or neurologist. The use of simple graphics was incorporated in an effort to facilitate communication between providers and parents/caregivers who may be monolingual in Spanish or Vietnamese, or who may have low literacy skills. (Available in English, Spanish, and Vietnamese).
- **Epilepsy and Seizure Disorders: A Resource Guide for Parents**- This guide was developed with partial support from the CHOC Learning Collaborative Team and incorporates many of the above referenced tools into the guide. Additional resources in the Guide include a description of seizure types, how epilepsy is diagnosed, treatment options, understanding service systems, federal laws that protect the rights of children with epilepsy in school, accessing parent resources, responding to a child's seizure, first aid for seizures, finding support, sample seizure action plan, preparing for visits to the doctor and logs for communications (Available in English, Spanish).

For additional information, please contact Project Access, USC University Center for Excellence in Developmental Disabilities at Childrens Hospital Los Angeles, 323-361-1877.

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