Epilepsy Foundation and Project Access

Janice M. Buelow, RN, PhD, FAAN
Vice President of Programs and Research
Epilepsy Foundation
Disclosure

- I am employed by the Epilepsy Foundation
- I have no other disclosures
Learning Objectives

- Participants will
  - Understand the purpose of Project Access
  - Discuss the Programs implemented in Project Access
  - Be able to access deliverables of Project Access
What is Project Access?

- A national initiative that has 2 independent components
- National Center for Project Access
- Funds demonstration grants to State agencies and organizations
Component 1

- Establish the National Center for Project Access (NCPA) through a cooperative agreement with the Epilepsy Foundation and HRSA
- The NCPA provides
  - Support and technical assistance to PA grantees,
  - Raises awareness about epilepsy
  - Newsletters, tool kits
  - Promotes PA nationwide through social marketing and public outreach.
Component 2

- Provides grants to states and community agencies and organizations
- to support demonstration projects in medically underserved areas
- aimed at improving access to comprehensive, coordinated seizure-related health care, and other services with emphasis on early detection and treatment.
Addressing Care Through Community Based Programs

- The NCPA provided the following
  - National leadership to improve access to coordinated care services and achieve early detection and treatment for children with epilepsy
  - Technical assistant to all grantees
  - Forums to stimulate discussion about strategies to improve access
  - Information clearinghouse
Phase 1 -- 2004-2007

- Raise awareness and increase education surrounding epilepsy and seizures
  - informational toolkits, brochures, fact sheets, and resource manuals.
  - Resources were targeted to health care professionals, families, and the community and translated into non-English versions

- States held in-person educational and training seminars
  - geared towards health care professionals
  - focused on increasing knowledge related to the diagnosis and treatment of epilepsy and seizures
  - Created a continuum of care between primary care providers, specialists, and families.
Phase 2—2007-2010

- Conducted a community wide needs assessments
- Established learning collaboratives which engaged providers, school personnel, parents, youth, Title V representatives and educational campaigns.
Phase 3 -- 2010 - 2013

- Focused on utilizing an Innovative Strategy and Promising Practice (IS/IP)
  - Telehealth
  - Care Coordination
  - Mental Health
  - Provider Education
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Project Highlights

- Montana's Pediatric Epilepsy Telehealth (PET) Project has
  - Established telemedicine capabilities in 3 Pediatric Specialty Care Clinics
  - Developed personal health records to assist patients & their families in recording PHI, clinical improvements, and care coordination.
- Kansas University Center for Telemedicine and Telehealth has integrated distance education and pediatric epilepsy telemedicine services.
- Michigan Depart of Community Health (MDCH) built an interoperable telemedicine network to provide access to epilepsy care.
- University of Nebraska Medical Center Munroe-Meyer Institute is working to
  - Improve access to specialized epilepsy services
  - Expand the use of tele-health technologies to improve health care, including behavioral health care interventions.
- Cleveland Clinic’s Project COPE is improving access to mental health care.
- The EF of Western/Central PA is working to create a system of care
  - Replicable co-management practice guidelines
  - A process of identifying early cognitive effects of seizures and anti-epileptic medications.
  - Videos to improve seizure education for primary care providers, address behavioral health comorbidities, and manage seizures in school.
- The EF of Florida is improving access to comprehensive services, including:
  - Online resource materials, flash drives containing portable health records, seizure first aid training for school personnel and nurses.
- The national EF partnered with
  - The National Association of Community Health Centers to train care coordinators
  - EF affiliates in four states to conduct educational networking forums for health professionals, parents, and families.
Results

- Nebraska created 4 telehealth subsites.
- Each telehealth medical consultation saves 14.3 hours, 373 miles, and $450.00 per family.
- Lessons learned from this were used to develop distance learning modules, state-based websites, social media support groups for isolated children and their families.
Results

- Cleveland Clinic
  - Conducted a needs assessment
  - Developed a psychosocial intervention “Collaboration for Outreach and Prevention Education for Children/Adolescents with Epilepsy” (COPE)

- The COPE survey (359 parents, 6 specialists, 37 school nurses, 7 key informants, 12 primary care physicians), indicated that psychosocial care is provided but not accessed by families because of stigma

- 2200 youths have completed mental health screening; 720 - completed follow up; 200 comprehensive psychiatric evaluation; 44 families have completed COPE
List of Projects

• For a complete list of projects
  http://www.epilepsyfoundation.org/projectaccess

This is the project access clearing house.
Deliverables from the Coordinating Center

- The EF developed a Toolkit for parents of children with newly diagnosed epilepsy. (one example)
  It can be found and used at
  To date 3194 toolkits in English and 920 toolkits in Spanish have been distributed.
Care Coordination

- The Epilepsy Foundation was not only the coordinating center but also was a recipient of a small grant.

- The Care Coordination Program was designed to for care coordinators and offers experienced based principles to facilitate care coordination.

- To date 5 programs were delivered.

- The training will be available on line.
Lessons Learned

- Partnerships and Collaborations provide invaluable sources of input, diversity and opportunity to make a positive impact on affected families
- Family involvement is critical
- Realistic budgeting includes incentives for collaborative partners
Lessons learned

- Sustainability and dissemination of information need to be addressed from the onset of the project.
- A national center is needed to:
  - provide technical assistance,
  - enhance information sharing among state demonstration projects, and
  - to make available lessons learned and strategies developed by individual grantees to encourage a wide impact.
Conclusion

- The NCPA is an excellent mechanism for creating collaborations that improve access to care for children with epilepsy.
Reference

Impact on Clinical Care and Practice

• Using programs like PA will improve children’s access to care through innovative mechanisms such as care coordination and telehealth.