Coordinating Center on Epilepsy

The American Academy of Pediatrics (AAP) is proud to have been selected to serve as the 2016-2019 Coordinating Center for Strategic to Improving Access to Quality Health Care for Children and Youth with Epilepsy (Center) through a Cooperative Agreement, Grant # U23MC26252, with the Health Resources and Services Administration Maternal Child Health Bureau.

Between 2013-2016, the AAP served in this role and is delighted to have the opportunity to build upon the work from the previous cycle to improve access to sustainable, coordinated and comprehensive quality care for CYE, with an emphasis on those experiencing health disparities and/or residing in rural or medically underserved communities.

In this role, the AAP and its partners (Got Transition, National Institute for Children’s Health Quality (NICHQ), and the Parents’ Place of Maryland) will support the grantees in developing quality improvement learning collaboratives, conducting project evaluation, and by providing guidance on evidence-based models, best practices, and strategies regarding the patient/family-centered medical home model, youth transition using the Got Transition Six Core Elements of Health Care Transition, and telehealth/telemedicine/mobile health. For additional resources on the previous grant cycle, please visit www.aap.org/epilepsy.

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Current 2016-2019 Grantees

- **Boston Medical Center**
- **Children’s Hospital of Philadelphia**
- **Cleveland Clinic of Ohio**
- **Epilepsy Foundation of Texas**
- **Epilepsy Foundation of Western/Central Pennsylvania**
- **Michigan Department of Health and Human Services**
- **University of Michigan**
The Michigan Department of Health and Human Services (MDHHS) held its first Pediatric Epilepsy Learning Collaborative Meeting in Novi, Michigan on December 1, 2016. Twenty-six participants attended the meeting in person (one via Skype) representing five primary care clinics and four epilepsy centers, Children’s Special Health Care Services, the Family Center, Michigan AAP, Epilepsy Foundation of Michigan, and Child Health Evaluation and Research (CHEAR) Unit (University of Michigan). Clinic teams were comprised of primary care physicians, pediatric neurologists, parents of children and youth with epilepsy (CYE), nurses, physician assistants, nurse practitioners, and practice managers. One team traveled nearly 500 miles to attend the meeting.

The 5-hour meeting enabled clinic teams to meet and become familiar with the project’s history and goals for the next three years. Daniel Arndt, MD, the project Epileptologist Consultant, helped to kick-off the meeting by leading introductions and sharing his excitement for the project’s anticipated impact on statewide systems. A Parent Involvement Panel allowed parents of CYE to share personal experiences parenting a child with epilepsy, successes, challenges, and expectations for the project.

Participants also heard presentations on quality improvement, current epilepsy education efforts, the project share site, and evaluation activities. The evaluation discussion focused on key findings from the state’s 2016 CYE Parent Survey, timelines for project data collection, and an evaluation exercise for clinic teams (Got Transition’s Assessment of Health Care Transition Activities). Preliminary feedback indicated the meeting content was well-received, useful, and teams are eager to participate in future activities.
Although there has been a growing effort to prepare youth, families and pediatric primary care providers to support youth to transition to adult primary care, it can often be a struggle to find adult primary care practices willing to accept an emerging young adult with special health care needs. In fact, adult providers are often not prepared or interested in welcoming or accepting youth with more severe disabilities or chronic health conditions. To better understand this, the Epilepsy Foundation Western/Central Pennsylvania (EFWCPA) has partnered with the Pennsylvania Medical Home Initiative to conduct telephone interviews and hold a focus group of adult primary care providers. To date, two telephone interviews have been conducted and a focus group was held at the Pennsylvania Academy of Family Physicians and Foundation conference. The focus group resulted in a rigorous discussion with the following questions being considered:

- **Challenges/Barriers:**
  - What are some of the unique challenges or barriers (medical, social service related, cultural, linguistic, etc.) that adult primary care providers experience in meeting the special health care needs of youth with epilepsy?

- **Knowledge Gaps:**
  - When you think of the type of training that primary care providers typically receive and the broad range of patients that a practice might serve, what types of knowledge gaps, if any, might adult primary care providers have regarding the special health care needs of patients with epilepsy?

- **Records Information:**
  - What information do you need to know when accepting a patient with epilepsy?
  - What records, documents, information would facilitate transition of patients with epilepsy?
  - What information should a patient bring or be able to self-report?

- **Resources for Adult Primary Care Providers:**
  - What information would assist adult primary care providers to overcome challenges, barriers, and knowledge gaps?
  - What information and resources would facilitate role-coordination between adult and pediatric primary care providers?
  - What information would facilitate role-coordination between the adult primary care provider and specialists?

Results from this effort will inform a video to assist and support adult primary care providers which will be housed on the Medical Home Initiative website learning library and be utilized for future trainings and programs. EFWCPA has utilized the Got Transition platform when developing this transition learning collaborative.
The AAP National Office and the AAP Section on Neurology (SONu) are partnering with Child Neurology Foundation, Child Neurology Society, American College of Emergency Physicians, American Epilepsy Society, CURE, Tuberous Sclerosis Alliance, Global Genes, and others to promote Infantile Spasms Awareness.

December 1-7, 2016 marked Infantile Spasms Awareness Week, which served to raise awareness about a rare but often misdiagnosed neurological disorder. On behalf of the Section, child neurologist Dr. Mary Zupanc of Children’s Hospital of Orange County helped create a page on the AAP’s popular parent/family website, HealthyChildren.org and a Patient Care Online (PCO) webinar on this topic. Additional resources on this topic can be found on www.ISweek.org.

The Academy will continue working with these advocacy partners towards building awareness of Infantile Spasms in 2017. Future endeavors include development of a PediaLink® e-CME short course on screening at-risk patients, treatment, and referral.

For further information about SONu activities and initiatives, please visit the Section's website or contact Section Manager, Lynn Colegrove, with your questions related to SONu business or activities.
The use of telemedicine in health systems is changing how providers deliver healthcare today. Limited access, sub-optimal health outcomes, increasing complexity of chronic illness, escalating medical costs, medical provider shortages, and a shift to population health management have all played a role in demonstrating the need for expansion of healthcare services.

Traditional healthcare systems along with stand-alone, direct to consumer companies have opted to enter this growing industry. Yet despite the rapid growth and advances, telehealth remains in its infancy with many challenges to be overcome. Professional organizations and governmental agencies have joined the conversation, supporting the potential of telehealth but raising concerns regarding healthcare fragmentation, redundancy and quality (American Academy of Pediatrics, 2015; American Medical Association (2014); Kaiser Health News (2015). The (AAP) describes telehealth not as a new service but a tool, potentially able to address many of the current healthcare challenges and improve collaboration and communication, as long as it is delivered in support of the patient centered medical home model (AAP, 2015).

Discontinuity of care has been identified as a problem in healthcare since the Institute of Medicine’s To Err is Human report released in 1999, which outlined poor quality and patient harm events (Kohn, L. T., Corrigan, J., & Donaldson, M. S. (2000)). Efforts to minimize this challenge have been the focus of The Joint Commission, Agency for Healthcare Research and Quality, and Institute for Healthcare Improvement. Although focus has been predominantly in the inpatient arena, poor communication can occur at any transition point. Transition points can occur anywhere along the care continuum when there is a sharing of the patient’s information. Examples of error seen in transition points occur primarily between locations (inter-hospital, interdepartmental or home-going) or levels of care (caregiver, care team, the organization or political or economic agencies). These have been defined by the Centers for Medicare and Medicaid Services (CMS) as any transfer of a patient from one care setting to another (Centers for Medicare and Medicaid Services Transition of care summary. May, 2014; Mansukhani, R. P., Bridgeman, M. B., Candelario, D., & Eckert, L. J. (2015)). The potential for miscommunications and omissions during this critical time has been well documented in the literature, impacting quality and safety, along with a patient’s treatment adherence and health behaviors (Arora, V., Johnson, J., Lovinger, D., Humphrey, HJ and Meltzer, DO (2005); Riesenberg, L.A., Leitzsch, J., and Little, BW (2009); Riesenber, LA, Leisch, J. and Cunningham, JM (2010).
MAKING THE CONNECTION: SBAR HANDOFFS FACILITATE QUALITY IN TELEHEALTH (CONT’D)

Telehealth, depending upon the services provided, is a care transition point which has many parallel patterns that share the potential for communication breakdowns leading to patient harm and poor quality of care. Questions surrounding communication methods and how to coordinate with a patient’s healthcare team are legitimate and need to be addressed.

Handoff tools have been successfully used during intra-organizational inpatient transitions, transfers to other facilities and during provider sign outs by providing standardize processes and enhancing communication. SBAR (situation, background, assessment and recommendation), a handoff tool developed by the US Navy, was integrated into healthcare in the 1990’s. Providing a simple, clear and concise framework the use of SBAR, supported by The Joint Commission, identifies what information needs to be communicated and supports a culture of patient safety and teamwork. The tool uses an easy to remember pneumonic which frames the conversation or transfer of information, calling attention to pertinent details and highlights what are the anticipated courses of action. The SBAR tool has been successfully featured in Ohio’s statewide pediatric safety initiative, Solutions for Patient Safety. This initiative, launched in 2009, brought together healthcare providers and members of the business sector with the aim of making Ohio the safest place for children’s healthcare. Improving quality and reducing costs, the network implemented the SBAR tool as part of their improvement toolkit.

Telehealth transitions could use the handoff tool, SBAR, to facilitate patient care, address concerns of discontinuity and potentially minimize redundancy in care. Accomplished by completing a brief note at the end of a patient visit, the goal is to fill the transition gap using a standardized, template handoff. At the Cleveland Clinic, the on-demand urgent care telehealth service, Express Care Online (ECO), has incorporated SBAR into the provider workflow as part of their care delivery package. Initially implementing the tool internally, the ECO medical providers who deliver urgent care for minor acute illnesses, completed a template SBAR tool and sent a message through the electronic health record (EPIC) back to the primary care provider or patient centered medical home. Preliminary feedback has been excellent. The primary care providers appreciate the timely notification facilitating continuity of care and providing a feedback loop for quality monitoring.

The ECO providers have commented that the template tool is easy to use and allows direct communication with the patient’s primary. Phase II of the project is projected to be launched this fall, connecting all ECO visits with primary care providers who share our EHR system (EPIC). Phase III, connecting with PCP’s outside of our networks reach is anticipated to be our biggest challenge. We are however hopeful that increased use of patient portals and secured messaging or advances in interoperability will prevail supporting the scalability of this project.
MAKING THE CONNECTION: SBAR HANDOFFS FACILITATE QUALITY IN TELEHEALTH (CONT’D)

How one might use the **SBAR template** can be viewed in the following example:

**S  Situation:**
This is an Express Care Online virtual visit, follow up note for (patient name/date of birth). The chief complaint for this visit was (cc).

**B  Background:**
Pertinent history (including PMH, medications, and allergies) and physical exam included …

**A  Assessment:**
This patient was diagnosed with…..

**R Recommendation:**
Recommendations for treatment and follow up included…. Please feel free to contact me at (phone number) with any questions.

References


Realistic access to consistent, high quality health care is a challenge for families caught in the nets of homelessness, unemployment and poverty. Whether they live in remote rural areas or blighted urban cities, millions of families face multiple barriers to accessing quality care and as a result, their children carry the burden of complex health challenges—from high rates of asthma to poor nutrition and stressful living conditions that challenge their emotional stability. Because these children need a level of health care and related services that often exceeds that which is typical for other children, Children’s Health Fund (CHF), a national non-profit targeting underserved children across the country, advocates for an enhanced medical home model of care. This model integrates intensive primary care, dental, and mental health services. This level of care also includes screening and managing acute and chronic conditions, as well as the provision of health education, case management and referral management services to ensure access to needed subspecialty care—most of which is not covered by insurance.

Despite broadening the reach of our National Network of pediatric programs through the use of mobile medical, dental, and mental health clinics, access remains a challenge for the children we serve, and for so many other across the country—especially those in poverty. We have recently started using telehealth on several of the mobile clinics in our Network to broaden our reach and scope of services. Dr. Lisa Gwynn is using telehealth to facilitate live consultations with specialists hours away at the University of Miami. Dr. Seth Ammerman is using telehealth equipment to improve the quality of patient engagement and education with teens in San Francisco, in partnership with our program at Stanford Health Care. Dr. Darlene Melk, a pediatrician at Chiricahua Community Health Centers, Inc. (CCHCI) is doing pediatric primary care consults with a CCHCI Nurse Practitioner several hours away in rural areas of Southern Arizona. Despite the challenges of using mobile clinics, especially in rural areas, these pilot programs are already laying the groundwork for broader rollout in our Network.

As part of our advocacy work, under the Samsung Innovation Center at Children’s Health Fund, CHF has written a white paper featuring case examples from many members of the AAP, highlighting the need, challenges, and solutions for utilizing of telehealth in their work. The paper shares stories from both rural and urban locations, and settings ranging from the Emergency Department and PICU to primary care in rural schools.

In late spring, Children’s Health Fund held a Congressional Briefing on pediatric telehealth, keynoted by Senator Roger F. Wicker (R-MS). The event served as a platform from which to launch the white paper and emphasized the ways that telehealth can overcome the access barriers to pediatric care, particularly for patients and families residing in Health Professional Shortage Areas (HPSAs). Special thanks to Dr. Aimee Grace, Dr. Steve North and Dr. Jim Marcin, who presented with us in the congressional briefing, and also to Dr. Robert Sapien and Dr. Ken McConochie who presented to CHF National Leadership as well. A big thank you to all of our contributing authors, and to the CHF Medical Directors and teams who distributed the paper in over 60 congressional visits that same day.

For more information, please access the paper here: https://ms01.childrenshealthfund.org/wp/
UPCOMING CONFERENCES

**Association of Maternal & Child Health Programs (AMCHP)**

March 4 - 7, 2017
Kansas City, Missouri

**American Telemedicine Association (ATA)**

Annual Conference
April 22 - 25, 2017
Orlando, Florida

**Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy**

Annual Project Grantee Conference
April 26 - 27, 2017
Location to be determined
MEDICAID MANAGED CARE: CHALLENGES AND OPPORTUNITIES FOR PEDIATRIC MEDICAL HOME IMPLEMENTATION AND CYSHCN

The National Center for Medical Home Implementation, in collaboration with the National Academy for State Health Policy, created a fact sheet that discusses challenges and opportunities to provision of care for children and youth with special health care needs (CYSHCN) enrolled in Medicaid managed care. The fact sheet identifies states that leverage Medicaid managed care to advance the pediatric medical home model through payment incentives, technical assistance, and care coordination services.

SHARED PLAN OF CARE: A TOOL TO SUPPORT CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES

Created by the National Center for Medical Home Implementation in partnership with the National Academy for State Health Policy, this fact sheet discusses key components of and the role of families in creating and maintaining a shared plan of care. Additionally, the fact sheet provides specific examples of how state programs and agencies are implementing and using shared plans of care for children and youth with special health care needs.