EPILEPSY COMPENDIUM:
A COMPILATION OF RESOURCES FOR PROVIDING CARE TO CHILDREN AND YOUTH WITH EPILEPSY (CYE)

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®
EPILEPSY COMPRENDIUM: A COMPILATION OF RESOURCES FOR PROVIDING CARE TO CHILDREN AND YOUTH WITH EPILEPSY (CYE)

INTRODUCTION

Since 2013, the American Academy of Pediatrics (AAP) has been serving as the Coordinating Center for Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy (Center) under Health Resources and Services Administration (HRSA) Maternal Child Health Bureau (MCHB). The overarching vision of the Center 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.

The purpose of this compendium of resources is to create a centralized location for individuals, practices, community, state-based, and national organizations interested in increasing access to care for CYE. It was designed with support from the Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy 2013 – 2016 cycle grantees and is continually updated as new resources and best practices emerge.

A special thank you to –

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Health Resources and Services Administration
Maternal and Child Health Bureau

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Epilepsy Foundation of New Jersey
Epilepsy Foundation of Texas
Epilepsy Foundation of Western/Central Pennsylvania
Michigan Department of Community Health
New Hampshire Department of Health and Human Services
The Cleveland Clinic Foundation.
The Parents Place of Maryland

For more information, contact the AAP Coordinating Center on Epilepsy Staff at shueneke@aap.org.
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SECTION SIX: APPROACHES AND RESOURCES TO IMPROVING ACCESS TO SERVICES FOR CYE: FOR FAMILIES

Build A Strong Support Team

Diagnosis and Treatment

HealthyChildren.org

Maintaining a Healthy Lifestyle

Making the Most of Every Office Visit

Mental Health and Bullying

Safety and Injury Prevention

Seizure First Aid

Tracking Seizures and Medical Information

Videos and Webinars

Videos and Webinars (For Youth)

Appendix A: Pre-recorded ECHO Didactics

Appendix B: References and Resources
SECTION ONE: EPILEPSY OVERVIEW

EPIDEMIOLOGY

Children and youth represent one of the fastest growing populations affected by epilepsy, the most common childhood neurologic condition in the United States. Epilepsy is a condition of recurrent, unprovoked seizures that occurs more frequently in children, youth, and the elderly. There are approximately 470,000 children aged birth to 17 years with epilepsy (CDC, 2017).

Despite ongoing research and treatment advances, approximately one-third of individuals with epilepsy “continue to have difficult-to-control seizures”. (Greenlund) Authors Greenlund, Croft and Kobau used the Centers for Disease Control and Prevention (CDC) Wide-ranging Online Data for Epidemiological Research (WONDER; Wonder.cdc.gov) to study epilepsy deaths from 2005 through 2014. Their research revealed that although despite great strides in epilepsy care, age-adjusted epilepsy mortality rates have increased especially among non-Hispanic whites, across male and female gender, and those aged ≤ 24 and ≥ 85 years.

The clinical spectrum of CYE varies as some forms of epilepsy can have dramatic effects on brain development in early childhood and lead to poor functioning later in life. There are many etiologies for the disease that range from genetic and metabolic conditions to infections, trauma, and developmental brain disorders.
Resources for Epilepsy Diagnosis and Treatment

- **Differential Diagnoses of Episodic Events and Febrile Seizures, Johns Hopkins Hospital** – A presentation about the differential diagnoses of episodic events and febrile seizures and identifying next steps.

- **Epilepsy 101, Epilepsy Foundation**
  - Identify common types of childhood seizure types presenting to primary care settings.
  - Screen and monitor children with epilepsy for anti-seizure medication related side effects and associated behavior and learning issues.
  - Provide anticipatory guidance to children with epilepsy and their families about safety and transition to adult care.

Additional resources are available at the Epilepsy Foundation at [http://www.epilepsy.com/](http://www.epilepsy.com/).

- **Guidance on Defining Seizure Disorders versus Epilepsy** – A presentation by Dr. Richard Morse, pediatric neurologist and epileptologist
- **Pediatric Nonepileptic Seizures** – A set of leading experts discuss three emerging ethical challenges in treating pediatric and adolescent patients with Nonepileptic Seizures
- **The Role of the Developmental Pediatrician** – Discusses the role of the developmental pediatrician in the care of children with special health care needs

**COMORBIDITIES**

Negative effects on cognition and physical development, as well as social stigmatization and poor quality of life, are commonly observed in CYE and these children are at higher risk for developmental, intellectual, and mental health comorbidities with 80% of CYE with cognitive impairment and/or at least one DSM-IV-TR disorder according to [Neurobehavioral Comorbidities in Children With Active Epilepsy: A Population-Based Study](http://www.epilepsy.com/).

**Resources for Comorbidities**

- **Comorbidities and Epilepsy Health Didactic Session, Children’s National Medical Center** – A presentation meant to aid primary care providers in recognizing comorbidities.
- **Depression and Epilepsy in Children and Adolescents, Cleveland Clinic** – A presentation introducing the signs and symptoms of depression in relation to epilepsy.
- **Epilepsy and Autism, NH Family Voices** – A presentation by Dr. Richard Morse
- **Inattention as an Important Factor for Quality of Life in Youth with Epilepsy, Cleveland Clinic** – A poster presentation explaining a study which examined the relationship between quality of life ratings and the domains of the Impact of Childhood and Neurological Disability scale in youth with epilepsy.
- **Integration of Mental Health Screening May Prevent Suicide in Epilepsy, Neurology Advisor** – A news article announcing the research shared by Dr. Tatiana Falcone (Cleveland Clinic) during the 2015 American Epilepsy Society annual meeting.
• **Increased Suicidality in Children and Adolescents with Epilepsy and Depression, Cleveland Clinic** – A poster presentation explaining the results of a study which evaluated psychiatric disorder symptomatology comparing the Brief Psychiatric Rating Scale-children version (BPRS-C) scale between children and adolescents with depression and epilepsy with those with depression without epilepsy.

• **Pediatric Epilepsy and Depression, Cleveland Clinic** – An informational brief that includes symptoms, impact, and treatment options for depression among CYE.

• **Project COPE: Collaboration for Outreach and Prevention Education for youth with Epilepsy, Cleveland Clinic** – A presentation describing the associated comorbidities of epilepsy and a program to help increase access to mental health services for CYE

• **Stigma in Chronic Neurological Diseases, Cleveland Clinic** – A presentation from Dr. Tatiana Falcone explaining the misconceptions and stigma that surround epilepsy due to lack of the public’s understanding.
SECTION TWO: ACCESS TO CARE

Many CYE, particularly those in rural and medically underserved areas, do not have access to high-quality coordinated care provided by a medical home or pediatric neurologists. A national shortage of pediatric neurologists and a primary care workforce that may not have the requisite knowledge base and skill sets may exacerbate the difficulty in effectively diagnosing and treating epilepsy.

The 2009/2010 National Survey of Children with Special Health Care Needs illustrates that access to pediatric subspecialty care is a significant element of an effective medical home for children with special health care needs; however, access is a multi-faceted problem with many causes. These include:

- Insufficient number of pediatric subspecialists
- Dramatic increase in demand for pediatric care
- Fragmented and inefficient system of pediatric primary and specialty pediatric care
- Inadequate financing of medical education
- Poorly structured payment for clinical care

Often the evaluation of a child with seizures starts with a primary care physician (PCP) in a medical home or in an emergency room. Thereafter, the child is often referred to a neurologist for further diagnostic evaluation. Treatment and referral patterns for CYE are not uniform or standardized across the country. In some areas, pediatric epilepsy is treated by adult neurologists, even in regions where pediatric neurology care is available. Many families must travel for several hours from rural areas or wait weeks/months for clinic appointments. Diagnostic studies such as an electroencephalogram and neuroimaging studies often require additional travel, which is an added burden to the child (missing school) and parents (missing days at work). Consequences of decreased access to subspecialty care can include: adverse health outcomes as a result of lengthy wait times with delays in making diagnoses and intervention, increased family and child stress and anxiety, and reliance on emergency room services.

The 2012 Institute of Medicine’s (IOM) report Epilepsy Across the Spectrum: Promoting Health and Understanding stated that access to high-quality health care for CYE and their families would require:

- Improved access to pediatric neurologists
- A collaborative, patient / family-centered, team-based approach to care
• A better informed primary care workforce
• Public education and awareness

The Future of Pediatric Education (FOPE) II Project was a 3-year grant-funded initiative of the AAP to assess the status and future trends of pediatric education. From the inception of the FOPE II Project, it was acknowledged that any discussion of pediatric education and needs must encompass a review of the pediatric workforce.

Methodology

To inform its work, the AAP surveyed 17 of its’ medical subspecialty and surgical specialty sections. The results were groundbreaking for many subspecialties, and even today, the data generated because of those surveys remains some of the only existing data regarding subspecialty workforce issues. A questionnaire was mailed to the members of the Section on Neurology (SONu), in addition to US physicians who were members of the Child Neurology Society (CNS), generating a sample size of approximately 900.

Results

Though this survey was conducted over 10 years ago, the following key findings continue to be relevant:

• Epilepsy was the most common diagnosis among pediatric neurologists’ patients, representing approximately one-third of their total pediatric patient panel.
• Eight out of ten pediatric neurologists said they had a special area of expertise within the field, with the most common area of special expertise being epilepsy.
• Two-thirds of those with special expertise in epilepsy said they acquired such expertise through experience.
• Among those pediatric neurologists who experienced a change in the volume or complexity of pediatric referrals, approximately 70% had seen an increase in the volume of referrals and just over one half had seen an increase in the complexity of referrals.
• Almost one half of pediatric neurologists anticipated their communities would need additional pediatric subspecialists in the next 3-5 years.
• Even in areas or states where there are enough pediatric neurologists for the need, access may still be an issue since for nearly one half of pediatric neurologists, their main practice setting was at a medical school and the primary practice site for three fourths of pediatric neurologists was in an urban area.
- Over 90% of pediatric neurologists received referrals for pediatric patients from pediatric generalists and family physicians.
- Over 80% received referrals from pediatric medical/surgical subspecialists.
- Approximately 60-70% received referrals from urgent care centers, community agencies, and school districts.

**Implications**

The FOPE II Project highlighted that in most urban and suburban settings, pediatric subspecialists care for the majority of CYE with complicated and advanced disease. Because there are few pediatric subspecialists in rural settings, clinical services for patients in these areas are usually provided by periodic outreach clinics, telephone and telemedicine consultation, or referral to local adult subspecialists.
SECTION THREE: MEDICAL HOME

The AAP believes the “medical home” is an important aspect of caring for children while delivering advanced “primary care with the goal of addressing and integrating high quality health promotion, acute care and chronic condition management in a planned, coordinated, and family-centered manner”. Thus, building access to medical homes and the medical home’s knowledge base and skill sets in diagnosing, treating, and supporting CYE is necessary and critical in ensuring patient access to ongoing, high-quality care.

Primary care health professionals and medical home teams must know, or have access to:

- Current knowledge about epilepsies including:
  - Seizure recognition and diagnosis
  - Prevention strategies
  - Treatment options
  - Understanding of comorbidities
- Necessary psychosocial services for patients
- Resources to help patients and their families counter stigma

The specific educational needs for primary care health professionals are significant including:

- Understanding how to make an accurate diagnosis
- Recognizing when referrals to subspecialists are necessary
- Understanding medication therapies and side effects
- Ensuring care coordination and co-management with the specialists

Additionally, coordination with schools, and when needed, early intervention, therapies, and other community resources and advocacy groups is another critical component of the medical home.

Resources for the Medical Home

- AAP National Center for Medical Home Implementation
- Coping and Resilience Medical Home Resources, Cleveland Clinic – An informational brief regarding resiliency and behavioral health care coordination in the medical home.
SECTION FOUR: FAMILIES AS PARTNERS

The comorbidities of pediatric epilepsy extend beyond the child or adolescent with epilepsy as it can affect the whole family. Some siblings of children with epilepsy have been shown to demonstrate negative feelings towards epilepsy, mostly anxiety or fear about seizures, and a feeling of responsibility towards their affected sibling. Mothers of CYE have also reported higher rates of depression, particularly among children with new-onset epilepsy.

Education of family members, teachers, and caregivers to recognize seizures and to intervene appropriately when needed is also necessary. CYE need to have a seizure safety plan or a seizure action plan at school that should be updated annually. Often, support through mental health services is also needed for CYE, particularly to manage co-morbidities such as ADHD, depression, and anxiety. CYE may need pharmacotherapy for these conditions, further emphasizing the importance for specialists to be familiar with these agents and the potential interactions with seizure medications.

Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership, honoring the strengths, cultures, traditions, and expertise that everyone - but particularly the family - brings to the relationship. To be most effective, the provision of healthcare for CYE must engage all stakeholders in concert. The patient and family have a role in understanding the importance of a child’s diagnosis of epilepsy.

Resources for Providers

- Family Voices YouTube Channel
- Primary Care Enhancement for Children and Youth with Epilepsy and Seizure Disorders: Comorbidities and Epilepsy Health (Pre- and Post-test Questions), Parents Place of Maryland – A set of evaluation questions used in CME to evaluate knowledge of patient-centered care.

Resources for Families (For additional resources for families, please see Section Six.)

- Healthychildren.org, American Academy of Pediatrics – A compilation of resources for seizure and associated concerns for families.
SECTION FIVE: APPROACHES AND RESOURCES TO IMPROVING ACCESS TO SERVICES FOR CYE: FOR MEDICAL PROVIDERS

BILLING AND CODING

Please note that fee schedules, relative value units, conversion factors and/or related components are subject to change and may vary by state and insurer.

Resources for Billing and Coding

- Coding Fact Sheets
- Private Payer Advocacy

COMMUNITY PROGRAMS

ESSENTIAL STEPS TO PROGRAM SUCCESS:

- Develop a Logic Model to track program activities and outcomes
- Engage parents and families by seeking their input and integrating it to ensure that programs are meeting their needs.
- Build a successful team that includes professionals, parent/family representatives, and CYE. Teams should be engaged and part of the program development. Each member should have a defined role/responsibility
  - Sample Parent Partner job announcement
- Create a Memorandum of Understanding for partnering with other organizations to provide each organization with agreed-upon responsibilities.
- Provide incentives for participation (such as CME or MOC credits for physicians and gift cards for parents)
- Engage in social media
- Establish clear expectations and share the benefits to participation
- Start thinking about sustainability at the beginning of your program

MANAGEMENT AND TREATMENT

- Seizure Disorders (Point-of-Care)
- Status Epilepticus
- Sleep Disturbances
- Prenatal Drug Abuse and Neonatal Drug Withdrawal Syndrome
- Head Injuries (Point-of-Care)
• Evaluation
• Management
• When to Refer
• When to Admit

PATIENT HANDBOOKS/RESOURCES

• Seizure Medications for Children & Teens (Audio)
• Practical Tips for Parents of Children who Take Seizure Medication (Audio)
• Talking About Epilepsy with Children, Family and Friends (Audio)
• Seizures and Epilepsy in Children (Spanish) (Audio)
• Seizures (Spanish) (Audio)
• Epilepsy and Children: Diagnosis and Treatment (Spanish) (Audio)
• How to Support a Child with Epilepsy (Spanish) (Audio)
• Children and Epilepsy at School (Audio)
• Seizure Safety: Tips for Parents (Spanish) (Audio)
• Febrile Seizures (Spanish) (Audio)
• What is a Child Neurologist? (Audio)

DIETARY THERAPIES

• Ketogenic Diet
• Modified Atkins Diet
• Low Glycemic Index Treatment

MEDICATION MANAGEMENT

Carbamazepine  Lacosamide  Phenobarbital
Clobazam  Lamotrigine  Phenytoin
Clonazepam  Levetiracetam  Rufinamide
Diazepam  Lorazepam  Topiramate
Eslicarbazepine  Oxcarbazepine  Valproate
Ethosuximide  Perampanel  Vigabatrin
Felbamate

• Adverse Effects Associated With Psychiatric Medications

• Anti-Epileptic Medication Guide
QUALITY IMPROVEMENT

Quality improvement is comprised of systematic and continuous actions that result in measurable improvement in health care services and patient’s health status. The Institute of Medicine (IOM) defines quality in health care as a direct correlation between the level of improved health services and the desired health outcomes of individuals and populations.

As highlighted in IOM report *Crossing the Quality Chasm,* “Health care should be:

- **Safe** — Avoiding injuries to patients from the care that is intended to help them
- **Effective** — Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse, respectively)
- **Patient-centered** — Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions
- **Timely** — Reducing waits and sometimes harmful delays for both those who receive and those who give care
- **Efficient** — Avoiding waste, including waste of equipment, supplies, ideas, and energy, and
- **Equitable** — Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status” (IOM, 2001, pp. 5-6).

Resources for Quality Improvement

- **Developing Aim Statements**
- **Emerging Practices for CYE in Texas** – An example of a program in Texas implementing practice change
- **Quality Improvement and Pediatric Epilepsy** – A presentation by Ramesh Sachdeva, MD, PhD, JD, FAAP
- **Overview of QI Science and the Model for Improvement** – A presentation by Steven Kairys, MD, MPH, FAAP and C Eve Kimball, MD, FAAP
- **Quality Improvement in Epilepsy Provider Checklist**

POLICIES AND PUBLICATIONS

*American Academy of Pediatrics*

- **Behavioral and Emotional Problems in Children with Idiopathic Epilepsy and Well-Controlled Seizures**
- **Evaluation of Learning Difficulties in Epileptic Children with Idiopathic Generalized Epilepsy and Well-Controlled Seizures**
• Febrile Seizures: Guideline for the Neurodiagnostic Evaluation of the Child with a Simple Febrile Seizure, AAP Subcommittee on Febrile Seizures
• Febrile Seizures: Clinical Practice Guideline for the Long-term Management of the Child with Simple Febrile Seizures
• Immunization in Special Clinical Circumstances: Children with a Personal or Family History of Seizures
• Memory and Health-related Quality of Life in Severe Pediatric Epilepsy
• Mortality Risks in New-Onset Childhood Epilepsy
• Patient-and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems
• Prevention of Drowning
• Pediatric Care Coordination Curriculum – Online resource that helps practices implement the recommendations in this AAP policy statement
• Psychiatric and Medical Comorbidity and Quality of Life Outcomes in Childhood-Onset Epilepsy
• Rescue Medicine for Epilepsy in Education Settings
• Referral to Pediatric Surgical Specialists
• Spa-Drain Entrapment Complicated by Suspicions of Nonaccidental Trauma and Epilepsy Onset

American Academy of Neurology
• Evidence-based Guideline Update: Medical Treatment of Infantile Spasms, Endorsed by the AAP
• Practice Parameter: Diagnostic Assessment of the Child with Status Epilepticus (an evidence-based review), Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society, Endorsed by the AAP
• Treatment of the Child with a First Unprovoked Seizure, Endorsed by the AAP

Child Neurology Foundation
• Transitions Consensus Statement, Endorsed by the AAP

Additional Resources
• Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers
• The Patient Activation Measure (PAM): A Framework for Developing Patient Engagement
• Toward an Integrated Public Health Approach for Epilepsy in the 21st Century

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PROJECT ECHO

Project ECHO is a model of health care delivery and education, linking expert specialist teams at the academic “hub” with primary care clinicians in local communities “spokes”. It helps patients get the right care, in the right place, at the right time, and promotes medical home goals. Pioneered at the University of New Mexico, the ECHO model breaks down the walls between specialty and primary care and has been adopted in with a number of common chronic conditions.

Hub and Spoke Model

- Hub: Regional center at which multi-disciplinary team of subject matter experts is located
- Spoke: Primary care providers receiving the education

Hub identification

- Need to decide on disease/issue topic
- A multidisciplinary group of mentors in selected field of expertise comprised of different backgrounds.
  Please see video on “Strategies for Success” to assist in hub identification

Spoke recruitment

Successful recruitment of community participants or spokes is an important aspect of the ECHO model. It is essential that recruitment efforts focus on the learners and community providers. As a hub, you are helping spokes gain expertise outside their scope of practice and turning them into a “mini-specialist” in a topic area that is beneficial and valuable to them.

Effective recruitment strategies can include:

- Collaboration with Federally Qualified Health Centers (FQHC) and large clinics/hospitals
- Presenting the ECHO model at conferences, board meetings, faculty meetings and relevant seminars
- Medical/ Health policy/ MCO mailings lists and list serves
- Grand Rounds across your catchment area
- Community needs assessment
- Large clinics
- Provide CME
- Schedule well in advance
- Local media advertisements

Recruitment Examples:

- Recruitment Flyer

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### CYE ECHO EXPANSION CURRICULUM

*Additional content available in Appendix A*

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<td>Role of the Primary Care Provider</td>
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<td>Family Education and Support</td>
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<td>6</td>
<td>Medication Management</td>
<td>Abortive or Rescue agents; Anti-seizure medications; When to start; Choosing and using; When to stop</td>
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<td>Transition to Adult care</td>
<td>Reproductive health and patient self-management, as well as tips on when/how to introduce concepts of transition of care</td>
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SCHOOL OUTREACH

Teachers, bus drivers, school nurses and school administrators all play a vital role in supporting parents and caregivers so that CYE can thrive while at school and away from home. Providing training and tools is key to the successful ensuring seamless care coordination.

Training for Nurses and Teachers

- **An Advocate’s Manual: Legal Rights of CYE in School and Child Care, Epilepsy Foundation** – Provides tools to help families advocate on their own and reach a voluntary resolution of most disputes regarding their children’s rights
- **Delegation, Tracey Collins, DNP, RN** – Discusses the five rights of delegation
- **Rescue Medication Demonstration, Kate Brady, RN** – Demonstrates the administration of two seizure rescue medications, Diastat and Midazolam, using a training mannequin
- **Rescue Medication and Seizure Emergency Planning in Education Settings, Pediatric Care Online** – A webinar for
- **Epilepsy Rescue Medication, Richard Morse, MD** – Describes the emergency medications, Diastat (Diazepam Rectal Gel) and Medazelas, and their indicated use

Tools for Bus Drivers

- **Bus Driver Support for CYE, Epilepsy Foundation** – An informational poster for bus drivers with tips for transporting CYE

Tools for the Classroom

- **Managing Children with Epilepsy, Children’s Hospital of Orange County** – Basic treatment, assessments, and resources for school nurses
- **School Nurse Support and Poster, Epilepsy Foundation** – Demonstrates seizure first aid for tonic-clonic seizures
- **Seizure Action Plan for Schools**
- **Seizure First Aid and Instructions for School Nurse and Teacher Information Sheet** – A one-page template with steps for administering first aid with seizure medications and when to call for emergency services

TELEHEALTH

The 2017 AAP policy statement, *Nonemergency Acute Care: When It’s Not the Medical Home*, defines telehealth as a broad term that includes telemedicine as well as other health-related services using electronic information and communications technologies. The AAP has taken an active role in strategically improving
access to care for CYE in rural and underserved areas where there are a limited number (in some cases, none) pediatric neurologist.

Looking to get involved? Visit the AAP Section on Telehealth Care.

- What is Telehealth?
- Getting Started in Telehealth
- Provider to Patient Visits
- Coding and Payment
- Quality Improvement and Evaluation in Telemedicine
- Sample Documents
- TeleNeurology – Operational Workflow
- Template Letter to Patient
- Satisfaction Surveys
  - Outpatient Telemedicine Program-Neurology Consulting Physician Survey
  - Outpatient Telemedicine Program-Referring Provider Survey
  - Patient Survey

TRANSITIONS

Transitioning into the adult world can present several challenges for all children. This process may be more difficult for some youth with severe chronic conditions/complex diseases. Transition planning ensures that each individual receives the necessary services to achieve a smooth transition into adult life.

To start a transition improvement process, utilize the Six Core Elements of Health Care Transition from Got Transition in pediatric, family medicine and internal medicine practices.

- Transitioning Youth to an Adult Health Care Provider (Spanish)
- Transitioning to and Adult Approach to Health Care without Changing Providers
- Integrating Young Adults into Adult Healthcare (Spanish)
Resources for Transitions

SUMMARY OF SIX CORE ELEMENTS

- Transitioning Youth to an Adult Health Care Provider

TRANSITION POLICY

- Transition Policy

TRANSITION TRACKING AND MONITORING

- Individual Transition Flow Sheet
- Transition Registry

TRANSITION READINESS

- Transition Readiness Assessment for Youth
- Transition Readiness Assessment for Parents/Caregivers

TRANSITION PLANNING

- Plan of Care
- Medical Summary and Emergency Care Plan
- Transition Health Care Checklist
- Health Insurance Card

TRANSFER OF CARE

- Transfer of Care Checklist
- Transfer Letter

TRANSFER COMPLETION

- Health Care Transition Feedback/Survey for Youth
- Health Care Transition Feedback/Survey for Parents/Caregivers

ADDITIONAL RESOURCES

- AAP/ACP/AAFP Transitions Clinical Report
- Facilitating Access to Care for Epilepsy and Transition Success
- Healthy Children Radio: Health Care Transitions
- Helping Adolescents Transition to Adult Health Care
• Journey to Adulthood
• Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home
• Finding Adult Providers
• Finding and Using Adult Health Care
• Independence Day: How to prepare a child with a neurologic condition for life on their own
• Cultural Competence: Essential Ingredient for Successful Transitions of Care
• Transition Care for Adolescents Tip Sheet
• Transition Tools: Adolescents
• Transitions from Pediatric Epilepsy to Adult Epilepsy Care (Plan for independence)
• Transitions from Pediatric Epilepsy to Adult Epilepsy Care (Independence unlikely)
• Transition Matters

MEDICAL HOME INTERVIEW VIDEOS
• How Does a Medical Home Support Transitioning from Pediatric to Adult Care?
• Why Is It Important for Primary Care Providers to Help Families Prepare to Transition from Pediatric to Adult Care?

SAMPLE DOCUMENTS
• Medical Summary Form – Medically Complex
• Medical Summary Form - Cognitive
• Preparing for Transition
• Stress Less Checklist
• Guide to Becoming Independent
• Transition Readiness Assessment Questionnaire
• Measuring the Transition Readiness of Youth with Special Healthcare Needs

VIDEO
• Hidden Illness
SECTION SIX: APPROACHES AND RESOURCES TO IMPROVING ACCESS TO SERVICES FOR CYE: FOR FAMILIES

Build A Strong Support Team

- Epilepsy Toolkit
- How to talk about epilepsy with others
- Understand who might be on your healthcare team
- Working with your healthcare team

Diagnosis and Treatment

- Diagnosis 101
- Diagnosis 101 – The basics (video)
- Learn treatment basics
- Learn more details about your treatment options, including medication, surgery, diets and devices
- Managing my seizures 101
- Understand how epilepsy can impact your mood and behavior
- The L.E.A.P. to Understanding – Pennsylvania Local Epilepsy Awareness Project
  - Outcomes and Summary of Findings
- Therapies

HealthyChildren.org

- Seizure Medications for Children & Teens (Audio)
- Practical Tips for Parents of Children who Take Seizure Medication (Audio)
- Talking About Epilepsy with Children, Family and Friends (Audio)
- Seizures and Epilepsy in Children (Spanish) (Audio)
- Seizures (Spanish) (Audio)
- Epilepsy and Children: Diagnosis and Treatment (Spanish) (Audio)
- How to Support a Child with Epilepsy (Spanish) (Audio)
- Children and Epilepsy at School (Audio)
- Seizure Safety: Tips for Parents (Spanish) (Audio)
- Febrile Seizures (Spanish) (Audio)
- What is a Child Neurologist? (Audio)

Maintaining a Healthy Lifestyle

- Understand and identify your seizure triggers
- Reduce seizures by using these practical lifestyle tips
Making the Most of Every Office Visit

- Review these simple tips for working with your healthcare team
- Making the Most of Doctor Visits
- Medical Visit Checklist (Epilepsy & My Child Toolkit)
- Questions to Ask During Medical Visit (Epilepsy & My Child Toolkit)

Mental Health and Bullying

- Bullying Prevention
- Center for Parent Information and Resources
- Mental Health Toolkit Epilepsy
- Integration of Mental Health Screening May Prevent Suicide in Epilepsy

Safety and Injury Prevention

- Driving and Epilepsy (State by State Eligibility)
- Recognizing Risks
- Staying safe in different situations
- Understanding SUDEP

Seizure First Aid

- Learn all about seizure first aid
- Seizure Response Plan
- Wheel Chair First Aid – English
- Wheel Chair First Aid – Spanish

Tracking Seizures and Medical Information

- Learn why it is important to track your seizures
- Seizure Observation Record
- My Epilepsy Diary

Videos and Webinars

- 1 in 26: Introduction
- 1 in 26: Epilepsy in Our Own Words
- 1 in 26: Everyone Should Know
- ADHD and Epilepsy
- ADHD and Epilepsy HD
- Anti-seizure medications and rescue seizure medications
- Anti-Seizure and Rescue Medications HD
- Anxiety and Epilepsy
- Anxiety and Epilepsy HD
• Cognition in Children with Epilepsy
• Cognition in Children with Epilepsy HD
• Concentration/Studying and Seizures
• Depression and Epilepsy in Children and Adolescents
• Depression & Epilepsy in Children and Adolescents HD
• Diagnosing Epilepsy
• Diagnosing Epilepsy HD
• Diastat and 911
• Discussing SUDEP
• EEG and Epilepsy
• Epilepsy and Genetics
• Epilepsy Patient and Parent Perspective
• Epilepsy A Patient and Parent Perspective HD
• Exercise/Overexertion and Seizures
• Febrile Seizures
• How Epilepsy Affects Children
• Medications and Learning
• Medications and Mood
• Missing Medication
• Outgrowing Epilepsy
• Pediatric Epilepsy Surgery
• Pediatric Psychogenic Non-Epileptic Seizures (PNES)
• Pediatric Psychogenic Non-Epileptic Seizures HD
• Puberty and Seizures
• Remembering Medication
• Restricting Activity
• Seizure or ADHD?
• Seizures and Sleep
• Tackling Stress Like a President HD
• Taking Epilepsy to School
• Taking Epilepsy to School HD
• Technology Pinpoints Toddlers Seizures
• Transitioning Teens with Epilepsy
• Transitioning Teens with Epilepsy HD
• Video Games and Epilepsy
• What is an EEG
• What is Epilepsy
• What Parents Need to Know about Epilepsy Surgery
• What Parents Need to Know About Epilepsy Surgery HD
• When Your Child is Newly Diagnosed with Epilepsy
• When Your Child is Newly Diagnosed with Epilepsy HD – Dr. Tatiana Falcone
• When Your Child is Newly Diagnosed with Epilepsy HD – Dr. Jane Timmons-Mitchell
• When Your Child is Newly Diagnosed with Epilepsy HD – Dr. Wyllie
• When Your Child is Newly Diagnosed with Epilepsy Panel HD
• Who Are Some Well Known with Epilepsy
• Why Should You Treat Seizures with Medication

Videos and Webinars (For Youth)
• Driving and Epilepsy
• Drinking and Smoking
• Epilepsy and Other Conditions
• Forgetting Medication
• Having Children
• Learning and Epilepsy
• Medications and Birth Control
• Outgrowing Epilepsy
• Surgical Treatment
• Transition to Adult Provider
• Youth Ask the Doctor (all questions in one video)

Additional Videos for When a Child is Newly Diagnosed with Epilepsy

Video 1 - Elaine Wyllie, MD, Pediatric Epileptologist, Professor
Video 2 - Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor
Video 3 - Laura Neece-Baltaro, Epilepsy Educator
Video 4 - Jane Timmons-Mitchell, PhD, Clinical Child Psychologist
# Appendix A: Pre-recorded ECHO Didactics

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<td>Project ECHO-NM</td>
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<td>Chalongchai Phitsanuwong, MD</td>
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| Medication Management | Ahmed Abdelmoity, MD | Project ECHO-KS/MO |
| Other treatments: Beyond anti-seizure medications | Ahmed Abdelmoity, MD; Lindsey Thompson, MS, RD, CSP, LD | Project ECHO-KS/MO |
| <strong>Nonepileptic Paroxysmal Events</strong> |  |
| Seizure Mimics: Nonepileptic Paroxysmal Events | Glen Genton, MD | Project ECHO-NM |
| Seizure Mimics: Nonepileptic Paroxysmal Events | Glen Genton, MD | Project ECHO-NM |
| Clinical Semiology of Nonepileptic Seizures | Kenneth Imerman, MD | Project ECHO-NM |
| <strong>Office Management</strong> |  |
| Day-to-Day Management | Carolyn Green, MD | Project ECHO-CO |
| At the Office | Carolyn Green, MD; Jeremy Toler, MD | Project ECHO-CO |
| <strong>Psychosocial Needs in Treating Pediatric Epilepsy</strong> |  |
| Parental Psychosocial Needs in Treating Pediatric Epilepsy | Mark Pedrotty, PhD | Project ECHO-NM |
| <strong>Quality Improvement</strong> |  |
| Quality Improvement in Pediatric Epilepsy | Ramesh Sachdeva, MD, PhD, JD, FAAP | AAP Coordinating Center |
| Quality Improvement | Steven Kairys, MD, MPh, FAAP; C Eve J Kimball, MD, FAAP | AAP Coordinating Center |
| PDSA Cycle | Trisha Calabrese, MPH | AAP Coordinating Center |
| Quality Improvement and Pediatric Epilepsy | Eve-Lynn Nelson, PhD | Project KS/MO |
| Quality Improvement | Kenneth Silver, MD | Project ECHO-ECHO Chicago |
| <strong>Reproductive Health</strong> |  |
| Reproductive Health and CYE | Mikiko Yamada, M.S., PharmD., Ph.C. | Project ECHO-NM |
| <strong>Role of Primary Care Provider</strong> |  |
| PCP's and Neurologists as Partners | Susan Arnold, MD | Project ECHO-NM |
| Role of the Primary Care Provider | Chalongchai Phitsanuwong, MD | Project ECHO-ECHO Chicago |
| Childhood Epilepsy and the Primary Care Physician | Sucheta Joshi, MD, FAAP | University of Michigan |
| Pharmacist Role in Pediatric Epilepsy | Mikiko Yamada, M.S., PharmD., Ph.C. | Project ECHO-NM |
| First Contact | Carolyn Green, MD | Project ECHO-CO |
| Role of the Primary Care Provider | Megan Gustafson, BSN, RN | Project ECHO-KS/MO |
| <strong>Sleep Disorder</strong> |  |
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| <strong>Staring Spells</strong> |  |
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| <strong>Status Epilepticus</strong> |  |
| Seizure Emergencies: Status Epilpepticus | Kenneth Silver, MD | Project ECHO-ECHO Chicago |
| Status epilepticus | Glen Fenton, MD | Project ECHO-NM |</p>
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<td>Status Epilepticus- Part 3: Management</td>
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<td><strong>Testing &amp; Diagnosis</strong></td>
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<td>The Electroencephalogram</td>
<td>Glen Fenton, MD</td>
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<td>Carolyn Green, MD</td>
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<td>The Use and Abuse of EEG</td>
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<td>Pediatric Epileptic Encephalopathies</td>
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<td>The Neuropsychology of Epilepsy Part I</td>
<td>Brock Frost, PhD</td>
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<td>The Neuropsychology of Epilepsy Part II</td>
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<td>Finding the Source of a Focal Seizure in the Brain with an EEG or MRI</td>
<td>Bruce Fisch, MD</td>
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<td>EEG Basics: Classifying Seizure Disorders</td>
<td>Bruce Fisch, MD</td>
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Appendix B: References and Resources

Access to Care


Anxiety


Attention Deficit Hyperactivity Disorder


Autism


Depression


**Ketogenic Diet**


**Physical Exercise**


**School and Children with Special Needs**


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The American Academy of Pediatrics (AAP) does not endorse external web site content and/or sources found within this compendium.
Seizure Plans and Trackers


Traumatic Brain Injury | Concussion


Transitions

- Transition from Pediatric to Adult Specialty Care for Adolescents and Young Adults with Refractory Epilepsy: A Quality Improvement Approach. https://www.aesnet.org/clinical_resources/practice_tools/transition_tools_adolescents.

Other Resources