

NATIONAL
COORDINATING
CENTER *for* EPILEPSY

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®



This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U23MC26252, Awareness and Access to Care for Children and Youth with Epilepsy/ cooperative agreement. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

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 is 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 has been updated to include resources and best practices emerge from *2016 – 2019 cycle grantees*. **Please note, as of March 2019 the compendium is no longer being updated.**

A special thank you to –

Our Funders:

[Health Resources and Services Administration](#)
[Maternal and Child Health Bureau](#)

The 2013 – 2016 Grantees:

- [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](#)
- [Cleveland Clinic Foundation](#)
- [Parents Place of Maryland](#)

The 2016 – 2019 Grantees:

- [Boston Medical Center](#)
- [Children’s Hospital of Philadelphia](#)
- [Cleveland Clinic Foundation](#)
- [Epilepsy Foundation of Texas](#)
- [Epilepsy Foundation of Western/Central Pennsylvania](#)
- [Michigan Department of Health and Human Services](#)
- [University of Michigan](#)

For more information, contact the National Coordinating Center for Epilepsy staff at epilepsy@aap.org.

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SECTION ONE: BACKGROUND

Epilepsy is the most common childhood neurologic condition in the US with approximately 470,000 children and youth aged birth to 18 years affected. Children and youth with epilepsy (CYE) are at higher risk for developmental, intellectual, and mental health comorbidities requiring complex, coordinated systems of primary and specialty care.

It has been estimated that the number of pediatric neurologists is 20% below the national need, and many CYE, particularly those in rural and medically underserved areas, do not have access to high-quality coordinated care provided by a [medical home](#). 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 (CSNCHN); however, access is a multi-faceted problem with many causes.

- 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) 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 may be available. Many families must travel for several hours from rural areas or wait weeks/months for clinic appointments. Diagnostic studies such as an electroencephalogram (EEG) 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 may include adverse health outcomes as a result of lengthy wait times with delays in diagnoses and intervention, increased family and child stress and anxiety, and reliance on emergency room services.

These findings support the need for a coordinated system of care between CYE, families and caregivers, PCPs, neurologists, specialists, school personnel, and community partners. Building access to medical homes and increasing the knowledge, capacity and skill sets of PCPs in diagnosing, treating, and supporting CYE is necessary and critical in ensuring patient access to ongoing, high-quality care. The medical home can deliver [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](#).

Additional Resources

- [AAP Medical Home Policy Statement](#)
- [AAP National Center for Medical Home Implementation](#)
- [Incorporating Patient- and Family-Centered Care into Practice: The PA Medical Home Initiative](#)
- [Coping and Resilience Medical Home Resources, Cleveland Clinic](#): An informational brief regarding resiliency and behavioral health care coordination in the medical home.

- Patient-Centered Medical Home Resource Center

SECTION TWO: EPILEPSY OVERVIEW

Epilepsy is defined as recurrent, unprovoked seizures.

What is a seizure convulsion?

A sudden, stereotyped episode with change in motor activity, sensation, behavior, and/or consciousness due to an abnormal electrical discharge in the brain. If seizures continue repeatedly after the underlying problem is treated, the condition is called epilepsy.

Epilepsy is defined by any of the following conditions:

- At least two unprovoked (or reflex) seizures occurring >24 hours apart
- One unprovoked (or reflex) seizure and a recurrence risk (at least 60% over the next 10 years)
- Diagnosis of an epilepsy syndrome

There are approximately 14 million children and youth in the United States living with a special health care need according to the 2016/2017 National Survey of Children's Health Data. Epilepsy is the most common childhood neurologic condition in the US with approximately 470,000 children aged birth to 18 years affected.

STATE	NUMBER OF EPILEPSY CASES UNDER 18 YEARS
California	59,800
Texas	47,200
Florida	27,300
New York	26,600
Illinois	18,600

Seizures are classified into two groups:

1. **Generalized seizures** affect both sides of the brain.
 - **Absence seizures**, sometimes called petit mal seizures, can cause rapid blinking or a few seconds of staring into space.
 - **Tonic-clonic seizures**, also called grand mal seizures, can make a person
 - Cry out.
 - Lose consciousness.
 - Fall to the ground.
 - Have muscle jerks or spasms.

The person may feel tired after a tonic-clonic seizure.

2. **Focal seizures** are located in just one area of the brain. These seizures are also called partial seizures.
 - **Simple focal seizures** affect a small part of the brain. These seizures can cause twitching or a change in sensation, such as a strange taste or smell.
 - **Complex focal seizures** can make a person with epilepsy confused or dazed. The person will be unable to respond to questions or direction for up to a few minutes.
 - **Secondary generalized seizures** begin in one part of the brain, but then spread to both sides of the brain. In other words, the person first has a focal seizure, followed by a generalized seizure.

Additional Resources

- [AAP Epilepsy and Comorbidities ECHO](#): The AAP Epilepsy and Comorbidities ECHO served as an interactive forum for healthcare professionals to improve access to quality healthcare for CYE in their respective practices.
- [Centers for Disease Control and Prevention](#): Find more information including managing epilepsy, data and statistics, preventing epilepsy, resources for parents, caregivers, and other professionals who may encounter people with epilepsy.
- [Child and Adolescent Health Measurement Initiative](#): Also known as the Data Resource Center for Child and Adolescent Health (DRC), this center uses public data from the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs to present information on the status of children's health throughout the United States.
- [Child Improvement Through Computer Automation \(CHICA\) Model](#).
- [CURE Epilepsy](#): Stay updated on the latest research for a cure for epilepsy.
- [Epilepsy Foundation](#): Dedicated to improving the quality of lives for people with epilepsy, find more information for your patients and connections to community resources.
- [Caring for Children and Youth with Epilepsy: What Primary Care Providers Need to Know Webinar Series](#): The series will aim to close the gap in knowledge and capacity in diagnosing, treating, and managing seizures and comorbidities by educating primary care providers through 10 webinar sessions.
- [National Association of Epilepsy Center Guidelines](#): Established guidelines for services, personnel, and facilities that characterized specialized epilepsy centers. The revised guidelines published in 2001 were a further step in the maturation of epilepsy centers.
- [Analysis of Health Care Coverage and Access Among Children, Adolescents, and Young Adults](#): An analysis of health care coverage and access among children, young adolescents, older adolescents, and young adults between 2010 and 2016.
- [AAP Telehealth Compendium](#): An online, evolving resource that offers general information and technical support for pediatricians who want to incorporate telehealth services into their practice.

SECTION THREE: DIAGNOSIS AND TREATMENT

Is it a seizure?

The Role of the Primary Care Provider in Seizure Diagnosis:

There are several opportunities for the primary care provider (PCP) to play a role in seizure diagnosis, particularly in cases of severe forms of epilepsy, such as [infantile spasms](#), that require emergent need for care.

- **Obtain History**
 - Obtain a clear history of the event, preferably in person and from a witness, so as to be able to distinguish the event from other non-epileptic events.
 - Identify key components of past and recent medical history including:
 - Known risk factors:
 - Pre/peri/post-natal complications
 - Head trauma
 - CNS infections
 - Febrile seizures
 - Other medical conditions
 - Recent symptoms (illness, head injury, lack of sleep, dehydration)
 - Developmental history
 - Medications/exposure to toxins (ETOH, illicit drugs, prescription medications)
 - Family history
 - Febrile seizures or epilepsy in 1st and 2nd degree relatives
- **Acute Seizure Evaluation**
 - Conduct routine lab tests:
 - Common tests:
 - Glucose
 - Electrolytes
 - Serum alcohol level
 - Toxicology drug screen
 - Anti-seizure medication levels (where applicable)
 - Yield is low in the absence of clinical signs/symptoms
 - Order on a case-by-case basis
- **Clinical Use of EEG**
 - The electroencephalogram (EEG) is an important test for evaluating patients with suspected seizures; however, limitations of the EEG must be recognized.
 - The EEG is limited with seizures arising from deeper brain areas, even during a seizure.
 - It is often valuable at the onset and offset of the seizure:
 - After a new onset seizure, optimal timing is not clear. However, the EEG is usually acceptable to conduct as outpatient
 - EEG within 24-48 hours after a seizure is more likely to be abnormal, but results must be correlated with clinical history.
 - EEG is very reliable for diagnosing:
 - Absence epilepsy

- Juvenile Myoclonic epilepsy
- Benign Rolandic epilepsy
- Infantile spasms and other epileptic encephalopathies
- **Neuroimaging**
 - **Emergent Imaging:**
 - Incidence of lesions requiring acute intervention in children presenting with a first seizure is ~2%.
 - Indicated to detect serious abnormality with immediate treatment implications (e.g. hemorrhage) → Order head Computed Tomography (CT)
 - **Non-urgent Imaging:**
 - To detect abnormalities that might affect prognosis and treatment decisions → Order brain MRI
 - **Magnetic Resonance Imaging (MRI) is particularly indicated for:**
 - Onset of seizures at any age with evidence of focal onset in the medical history or on EEG
 - Onset of unclassified or apparently generalized seizures in the first year of life or in adulthood
 - Evidence of a focal fixed deficit on neurologic exam
 - Difficulty in obtaining control of seizures with the first-line anti-seizure medications
 - Loss of control of seizures with medication or a change in the seizure pattern that may imply a progressive underlying lesion
 - **The Ideal Practice**
 - In a non-acute situation, obtain brain MRI in all patients with epilepsy, except in patients with a definite electroclinical diagnosis of idiopathic generalized epilepsy syndrome (absence, juvenile myoclonic epilepsy) or benign childhood focal epilepsy syndromes (BECTS – Rolandic epilepsy)
 - **Other Tests**
 - Genetic tests are usually considered in epileptic encephalopathies and infantile spasms
 - Karyotype
 - Chromosome Microsomal Analysis
 - Targeted gene testing/gene panels
 - Whole exome sequencing
 - Metabolic testing
 - Specific blood tests
 - Lumbar Puncture for metabolic tests
 - Ancillary testing
 - Ophthalmology
 - Rarely skin or muscle biopsies

Resources for Management and Treatment

- [Seizure Disorders](#)
- [Status Epilepticus](#)
- [Sleep Disturbances](#)
- [Prenatal Drug Abuse and Neonatal Drug Withdrawal Syndrome](#)

- [Head Injuries](#)

Resources for Dietary Therapies

- [Ketogenic Diet](#)
- [Modified Atkins Diet](#)
- [Low Glycemic Index Treatment](#)

Resources for Medication Management

- [Adverse Effects of Antipsychotic Medications](#)
- [Anti-Epileptic Medication Guide](#)

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

Additional Resources

- [Epilepsy 101](#), American Epilepsy Society
- [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.
- [Epilepsy in Children: Diagnosis and Treatment: For Parents](#)
- [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):
 - [Coding Fact Sheets](#)
 - [Private Payer Advocacy](#)

SECTION FOUR: COMORBIDITIES

80% of children with active epilepsy had a behavioral disorder and/or cognitive impairment in 2014.

CYE are at higher risk for developmental, intellectual, and mental health comorbidities with 80% of CYE experiencing cognitive impairment and/or at least one DSM-IV-TR disorder according to the [Neurobehavioral Comorbidities in Children With Active Epilepsy: A Population-Based Study](#) which found four comorbidities most commonly associated with epilepsy.

- Attention-deficit/hyperactivity Disorder (ADHD)
- Learning Disabilities
- Mental Health Comorbidities: Depression, Anxiety, Autism spectrum disorders
- Other Concerns for CYE

ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (ADHD)

The [National Institute of Mental Health](#) defines ADHD as a “brain disorder marked by an ongoing pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning of development.”¹⁵ The signs and symptoms may differ in individuals with ADHD, but the hallmarks of inattention, hyperactivity and impulsivity are key behaviors found in children. Most children diagnosed with ADHD have a combination of these behaviors and may be successfully treated with medical and/or behavioral therapies. In CYE, it has been found that there is a 20-50% prevalence rate versus a prevalence of 7-9% in the general population. CYE with ADHD often have additional mental health comorbidities such as oppositional defiant disorder, conduct disorder, learning disorders, depression, anxiety, and autism spectrum disorders.³⁷

Diagnosing ADHD

The American Academy of Pediatrics (AAP) published [clinical recommendations](#) for the diagnosis and evaluation of ADHD in children with companion [recommendations for families](#). (ADHD: Clinical Practice Guideline for the Diagnosis; Diagnosing ADHD).

The AAP clinical recommendations follow the Diagnostic and Statistical Manual of Mental Disorders (DSM-5,2013) Criteria for diagnosis which include:

- At least 6 symptoms of inattentions and/or at least 6 symptoms of hyperactivity and impulsivity
- Occurrence before age 12
- Must occur in at least two settings (home and school)

The [National Institute for Children’s Health Quality \(NICHQ\) Vanderbilt Assessment Scales](#) are intended for use by health care professionals to help diagnose ADHD in children ages 6-12 and may be used for free when credited as an original source. A 2nd Edition version with a complete toolkit is available from the [AAP Bookstore](#). The assessments may be utilized by both the teacher and the parent to help support a possible diagnosis and monitor care.

Treatment of ADHD

The [AAP clinical practice guidelines](#) support that CYE may safely be treated with FDA-approved medications in addition to evidence-based parent and/or teacher administered behavioral therapy; however, this may vary due to the age of the patient.

LEARNING DISABILITIES

Learning disabilities among CYE is approximately 32% with severity correlating with the degree of learning impairment (learning disability). CYE with mild to moderate epilepsy are less likely to be affected with learning disabilities than those with a more severe condition. Learning disabilities, cognitive impairment and intellectual disabilities are words often used interchangeably yet, incorrectly.

- **Cognitive Impairment:** Difficulty with memory and thinking skills
- **Learning Disability & Intellectual Disability (ID):** Difficulty learning and retaining the same knowledge base as peers who do not have a learning disability. Although these disability types are often used interchangeably, [Healthychildren.org](https://www.healthychildren.org) expresses that children with an ID may have mild to severe difficulties “in both intellectual functioning (e.g. communicating, learning, problem solving) and adaptive behavior (e.g. everyday social skills, routines, hygiene.)”

Like epilepsy, [learning difficulties](#) are neurologically-based processing problems that can interfere with CYE abilities to read, write and/or do math. CYE may have normal intelligence, but have a difficult time processing information, remaining organized or be affected by long or short- term memory problems. They may also be adversely impacted by the type of seizure they are diagnosed with.

CYE with day-time seizures may be adversely impacted by:

- Reduced alertness
- Decreased short term memory storage and “abstraction”

CYE with night-time seizures may have difficulty:

- Consolidating memories
- Difficulty with language

Educating families and patients is core to helping individuals with learning disabilities achieve their highest potential. The skills CYE learn may help them become high-functioning adults that can engage in self-care management. (NIH, Ch.7)

Visit [Healthychildren.org](https://www.healthychildren.org) for more information for families about learning disabilities.

DEPRESSION

In 2007, *Pediatrics* published “[Guidelines for Adolescent Depression in Primary Care \(GLAD-PC\): I. Identification, Assessment, and Initial Management](#)” to help primary care physicians manage adolescent depression. Depression has been reported in 8-35% of CYE with higher rates of depression reported in adolescents who have a history of seizures in public places.

The screening tools included in the guidelines are meant to be a diagnostic aid in the screening of depression, but “person-to-person interviews” by a mental health professional using the DSM-5 criteria is crucial to accurate diagnosis. A full chart of Mental Health Screening and Assessment Tools for Primary Care can be found [here](#).

ANXIETY

ADHD has been found to be present in 20-50% patients with epilepsy. The [Generalized Anxiety Disorder 7-item](#) (GAD-7) is a quick tool that should be used for screening and monitoring symptom severity aiding

clinical assessment and diagnosis by a mental health professional.

AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is growing in prevalence in the US with individuals with ASD having a higher than average risk of epilepsy, reportedly co-occurring at rates of 8.6%. [National Institute of Neurological Disorders and Stroke](#) found that about 20-30 percent of children with ASD develop epilepsy by the time they reach adulthood.²⁴ Research also supports increased risk of epilepsy in ASD among females and individuals with intellectual disability.

OTHER CONCERNS FOR CYE

Stigma

According to the [National Profile of Childhood Epilepsy and Seizure Disorder](#), CYE may have difficulties beyond seizures, seizure medications, and co-morbid conditions. The report suggests that CYE may be perceived as “different” by their peers as well as significantly less likely to receive care in a medical home, which leads to a higher risk of having unmet needs for care coordination, medical care, and mental health services. Further, this disparity likely coincides with findings that children and youth from racial and ethnic minorities, as well as lower income families, are disproportionately affected by epilepsy. It has been found that even when CYE screen positive for a behavioral health concern that a referral is made on 20% of the time, with stigma cited as the primary barrier for lack of follow-through.³⁴

Sudden Unexpected Death from Epilepsy

SUDEP is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy. In SUDEP cases, no other cause of death is found when an autopsy is done. Each year, about 1 in 1,000 adults and 1 in 4,500 children with epilepsy die from SUDEP.³⁸ This is the leading cause of death in people with uncontrolled seizures.

The person with epilepsy is often found dead in bed and doesn't appear to have had a convulsive seizure. About a third of victims do show evidence of a seizure close to the time of death while most, but not all, cases of SUDEP occur during or immediately after a seizure. The exact cause is not known, but possible factors include pauses in breathing as a result of a seizure, dangerous heart rhythm as a result of a seizure, or mixed causes of breathing problems and irregular heart rhythms. They are often found lying face down. No one is sure about the cause of death in SUDEP. Some researchers think that a seizure causes an irregular heart rhythm.³⁸ More recent studies have suggested that the person may suffocate from impaired breathing, fluid in the lungs, and being face down on the bedding.

As of today, there is no way to prevent SUDEP other than by better controlling seizures. Therapies and seizure-management practices are common ways to control seizures.

Steps can be taken to avoid SUDEP:

- Avoid seizure triggers, if these are known. Read more information about seizure triggers on the [Epilepsy Foundation website](#).
- Avoid drinking too much alcohol.
- Learn how to better control seizures with epilepsy [self-management programs](#).
- Get enough sleep.
- Train adults in the house in [seizure first aid](#).

The [Danny Did Foundation](#) offers many resources and materials on SUDEP for parents, caregivers, students, schools, and medical professionals

Additional Resources

- [Danny Did Foundation Addressing A Seizure: Steps to Take](#): A simple, helpful blueprint on how to respond to a seizure. Consider using the PDF to post and share with families.
- [Danny Did Foundation Seizure Safety / SUDEP Info Publication](#): This brochure outlines some of the most important areas of concern that those with epilepsy are likely to have.
- [Danny Did Seizure Safety Quiz](#): Best for sharing in a classroom setting or a youth group to spread basic but critical understanding about seizures and epilepsy.
- [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
- [Epilepsy Foundation SUDEP Institute](#): The Epilepsy Foundation's SUDEP Institute works to prevent Sudden Unexpected Death in Epilepsy (SUDEP) and support people bereaved by SUDEP and other epilepsy-related deaths.
- [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.
- [Pediatric Epilepsy and Depression](#): An informational brief from Cleveland Clinic that includes symptoms, impact, and treatment options for depression among CYE.

SECTION FIVE: FAMILIES AS PARTNERS

Pediatric epilepsy extends beyond the CYE 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. However, a [2016 survey](#) showed that siblings are more likely to feel protective rather than resentful towards their sibling. Mothers of CYE have also reported [higher rates of depression](#), particularly among children with new-onset epilepsy.

Education for family members, teachers, and caregivers to recognize seizures and to intervene appropriately when needed is also critical. CYE need to have a seizure safety plan or a seizure action plan at school that should be updated annually. Family-centered care assures the health and well-being of children and families through a respectful family-professional partnership, honoring the strengths, cultures, traditions, and expertise that everyone - but particularly the family - bring to the relationship. To be most effective, the provision of healthcare for CYE must engage all stakeholders.

Patient Handouts/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)
- [Ketogenic Diet: Treating Children’s Seizures with Food \(Spanish\)](#) (Audio)
- [Headaches: When to Call the Pediatrician \(Spanish\)](#) (Audio)

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](#)
- [Topics for Learning Collaborative](#)

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](#)

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 \(State by State Eligibility\)](#)
- [Epilepsy and SUDEP](#)
- [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

- [A Mind Unraveled](#)
- [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
- Compassion and Empathy
- 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 and Genetics
- Epilepsy and IEPs
- Epilepsy Patient and Parent Perspective
- Epilepsy A Patient and Parent Perspective HD
- Exercise/Overexertion and Seizures
- Febrile Seizures
- Medications and Learning
- Medications and Mood
- Missing Medication
- Outgrowing Epilepsy
- Pediatric Epilepsy Surgery
- Pediatric Psychogenic Non-Epileptic Seizures (PNES)
- Puberty and Seizures
- Remembering Medication
- Restricting Activity
- Seizure or ADHD?
- Seizures and Sleep
- Tackling Stress Like a President HD
- Taking Epilepsy to School
- Transitioning Teens with Epilepsy
- Video Games and Epilepsy
- What Parents Need to Know about Epilepsy Surgery
- When Your Child is Newly Diagnosed with Epilepsy – Dr. Tatiana Falcone

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

[Video 3](#) - Laura Neece-Baltaro, Epilepsy Educator

[Video 2](#) - Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor

[Video 4](#) - Jane Timmons-Mitchell, PhD, Clinical Child Psychologist

Additional Resources

- [Care Coordination Measures Atlas, Agency for Healthcare Research and Quality](#): A guide for measuring care coordination in the primary care practice.
- [Family Voices YouTube Channel](#)
- [Healthychildren.org](#): A compilation of resources from the AAP for seizure and associated concerns for families.
- [The Parents Place of Maryland](#): Offers a variety of programs and services that continue to support families of children with disabilities and special health care needs.

SECTION SIX: 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).

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

Additional Resources

- [Quality Improvement in Epilepsy Provider Checklist](#)
- [Developing Aim Statements](#)
- [Establishing Measures](#)
- [Selecting Changes](#)
- [Testing Changes](#)
- [Spreading Changes](#)
- [How to Improve with the Model of Improvement- Free QI Webinar](#)

SECTION SEVEN: TELEHEALTH

What is Telehealth?

As defined by the [American Telemedicine Association \(ATA\)](#) “telemedicine is the use of medical information exchanged from one site to another via electronic communications to improve a patient’s clinical health status”. The [Agency for Healthcare Research and Quality \(AHRQ\)](#) states, “telehealth is the use of telecommunications technologies to deliver health-related services and information that support patient care, administrative activities, and health education”. The [Centers for Medicare & Medicaid Services \(CMS\)](#) define it as “a two-way, real-time interactive communication between a patient and a physician or practitioner at a distant site through telecommunications equipment that includes, at a minimum, audio and visual equipment.” The terms telemedicine and telehealth are considered synonymous and are used interchangeably to describe use of electronic information and telecommunications technologies to support clinical health care, patient and professional health-related education, public health and health administration.

How to get started with Telehealth

The initial phase of any telehealth project includes assessing needs, setting goals, and identifying the resources. Establishing a broad-based support team is essential to the successful identification, development and implementation of the program. Following are key team members:

Administrative Champion:

- Responsible for managing contracts, communicating with and recruiting the telehealth partners (typically vendors, insurers, or service providers) and identifies office personnel support roles. This team member may also be responsible for identifying any regulatory issues regarding the use of telehealth in their region. [View](#) sample job description.

Financial Champion:

- Responsible for understanding the costs and revenues, formulates the business plan and monitors the financial dynamics over time. It is crucial to have a clear understanding of payment for telehealth in the region.

Clinical Champion(s):

- Responsible for identifying clinical support needs, training needs for staff in telehealth work flow and procedures, defining the workflow of telehealth encounters, developing and approving care protocols, and monitoring clinical quality over time. This member should also be well versed in local and national the telehealth policies and regulations.

Technical Champion:

- Responsible for assessing bandwidth and equipment needs, explores integrations with existing telehealth systems in the region, medical records, scheduling and payment systems, participates in installation and ongoing training in the use of the technology.

Once the team is formed, the team should establish/utilize a [checklist](#) of activities required before launching. It is also helpful to identify a start date to assist the practice with preparing for these transitions in the workflow. A "soft go-live" is helpful as this can help the team to work out unexpected kinks and receive feedback from the office on the processes in advance of the true start date. The AMA Steps Forward

Initiative also includes a downloadable checklist for [primary care providers](#) or [specialists](#).

Consider joining the American Academy of Pediatrics [Section on Telehealth Care](#).

Additional Resources

- [What is Telehealth?](#)
- [Directory of Telehealth Programs](#)
- [Getting Started in Telehealth](#)
- [Provider to Patient Visits](#)
- [Coding and Payment](#)
- [Getting Paid for Telehealth](#)
- [Quality Improvement and Evaluation in Telemedicine](#)
- [Sample Documents](#)
- [TeleNeurology – Operational Workflow](#)
- [Telehealth Compendium](#)
- [Template Letter to Patient](#)
- [Sample Protocol](#)
- [Satisfaction Surveys](#)
- [Start-up Checklist](#)
- [National Consortium of Telehealth Resource Centers](#)

SECTION EIGHT: PROJECT ECHO®

Project ECHO is a model of health care delivery and education, linking team of experts at the academic health centers with healthcare professionals in local communities. 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 to address 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: Community of learners 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
- Community needs assessment
- Grand Rounds across your catchment area
- Large clinics
- Local media advertisements
- Medical/ Health policy/ MCO mailings lists and list serves
- Presenting the ECHO model at conferences, board meetings, faculty meetings and relevant seminars
- Provide incentives, such as CME, MOC Part 2 and 4
- Schedule well in advance

Recruitment Examples:

- [Recruitment Flyer](#)
- [Recruitment Brochure](#)

Managing Students with Seizures ECHO: The Importance of School Nurses (2019)

The AAP and Epilepsy Foundation of America are hosting a tri-weekly (every three weeks), eight-session learning collaborative, Managing Students with Seizures ECHO: The Importance of School Nurses. Project ECHO® (Extension for Community Healthcare Outcomes) is a telementoring platform designed to create

communities of learners by bringing together health care providers and subject matter experts using didactic and case-based presentations, fostering an “All TEACH, ALL LEARN” approach. Participating school nurses can expect to:

- Increase knowledge and self-efficacy around managing students with seizures.
- Increase communication between school nurses, other school personnel and parents to improve care coordination of students with seizures.
- Learn best practices to create a safe and supportive school environment for students with seizures.
- Gain access to resources to support the care of students with seizures.

School nurses are eligible to participate and encouraged to invite other school personnel to join as applicable. Continuing education credits are available at no cost. As part of the registration process, participants will be asked to provide additional information about their school.

Session #	Title
1	Seizures and Epilepsy – The Importance of Seizure Recognition
2	The Latest in Seizure First Aid and Use of Rescue Therapies
3	Managing Seizures in a School Setting: Delegation and Training
4	Comorbidities and Impact on Mood, Learning and School Performance
5	Social and Emotional Impact of Epilepsy on Students with Seizures
6	Managing Seizure Medications and Referral to Comprehensive Epilepsy Care
7	When Events are Not Epilepsy
8	504, IEP Plans, and Other Resources for Students with Seizures

AAP Epilepsy and Comorbidities ECHO (2018)

The AAP Epilepsy and Co-morbidities ECHO program served as an interactive forum for healthcare professionals to learn and improve access to quality healthcare for children and youth with epilepsy (CYE) incorporating quality improvement (QI) measures. Recommendations for care provided in the American Academy of Neurology (AAN) measure set for epilepsy were utilized to assist primary care practices in improving quality of care through evidence-based processes to reach desired outcomes. Using this as the framework, the ECHO program used QI methodology to improve:

- Early and accurate diagnosis
- Reduction and monitoring of anti-seizure therapy
- Improved care coordination
- Patient-centered care
- Patient education
- Timely and appropriate referrals
- Health care transitions

The ECHO sessions was conducted monthly for 1 hour combining both a brief lecture presentation and deidentified, in-depth practice-based cases in the format of PDSA cycles for discussion, problem-solving

and guidance.

Session	Title
1	Epilepsy Overview
2	Workflow Processes and the PDSA Cycle
3	Comorbidities of Epilepsy
4	Testing and Diagnosis of Epilepsy
5	Medication Management
6	Safety and Education for Epilepsy
7	Role of PCP in a Medical Home Setting
8	Transition to Adult Care

Transition ECHO (2017)

The AAP Transition ECHO served as a forum for health care professionals to learn how to successfully transition youth from pediatrics to the adult care system. Participants used quality improvement techniques to support planning and transfer of care to ensure that all youth and young adults, including those with epilepsy, successfully transition into adult care. All healthcare professionals, including office staff, who had an interest in improving transitional care for youth and young adults (including patients with epilepsy) participated in the program.

- Received up-to-date information on clinical recommendations from the [Clinical Report on Transition](#) and nationally recognized transition model, “[Six Core Elements of Health Care Transition](#)”.
- Acquired evidence-based health care transition tools and resources.
- Identified quality improvement lessons learned around transition from colleagues caring for youth and young adults with epilepsy.
- Accessed guidance and recommendations related to transition from peers and national experts.
- In partnership with Got Transition, a standardized curriculum was been developed with the flexibility to evolve as new information becomes available as well as additional feedback is received from clinic participants.

Session #	Title
1	Overview of Health Care Transition
2	How to Begin a Health Care Transition Process for Your Practice

3	Adult Approach to Health Care; Find and Partner with Adult Clinicians
4	Taking it to the Streets: Family Engagement
5	Coming Together: Create and Share a Consistent Health Care Transition Approach (Policy)
6	Partner to Assess Health Care Transition Readiness and Add Transition to the Plan of Care
7	Transfer and Integration into Adult Health Care: Clinician Roles
8	Guardianship

SECTION NINE: POLICIES AND PUBLICATIONS

American Academy of Pediatrics

- [Evaluation of Learning Difficulties in Epileptic Children with Idiopathic Generalized Epilepsy and 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](#)
- [The Medical Home](#)

American Academy of Neurology

- [Epilepsy Update 2017 Quality Measurement Set](#)
- [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](#)

SECTION TEN: 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](#)
- [Epilepsy Rescue Medication, Richard Morse, MD](#): Describes the emergency medications, Diastat (Diazepam Rectal Gel) and Medazepam, and their indicated use

Tools for Bus Drivers

- [Bus Driver Support for CYE, Epilepsy Foundation](#): A one-page tool 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

SECTION ELEVEN: HEALTH CARE TRANSITION

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 \(Spanish\)](#)

Coding and Reimbursement

- [2019 Coding and Reimbursement Tip Sheet for Transition](#)
- [SUMMARY OF SIX CORE ELEMENTS](#)
- [Transitioning Youth to an Adult Health Care Provider](#)

Transition Policy

- [Transition Policy](#)
- [Health Care Transition Policy Checklist](#)

Transition Tracking and Monitoring

- [Individual Transition Flow Sheet](#)
- [Transition Registry](#)
- [Monthly Tool for Transition](#)

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
- Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home
- Finding Adult Providers
- Finding and Using Adult Health Care
- Cultural Competence: Essential Ingredient for Successful Transitions of Care
- The Differences Between Pediatric and Adult 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
- 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

- Transfer of Care Checklist
- Health Care Transition Process Measurement Tool
- Guide to Becoming Independent
- Transition Readiness Assessment Questionnaire
- Measuring the Transition Readiness of Youth with Special Healthcare Needs

Video

- Hidden Illness

APPENDIX A: REFERENCES AND RESOURCES

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