

# ***Strengthen & Enhance Epilepsy Knowledge (SEEK) Training***

---

NATIONAL  
COORDINATING  
CENTER *for* EPILEPSY

*September 2022*

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN®



## FUNDER ACKNOWLEDGEMENT

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.



# CARING FOR PEDIATRIC PATIENTS WITH EPILEPSY UTILIZING CULTURAL HUMILITY, FAMILY-CENTERED CARE, AND SHARED DECISION-MAKING IN A MEDICAL HOME SETTING



**Ryan E. Gill, MD**

Assistant Professor

Neurology & Developmental Medicine

Kennedy Krieger Institute/Johns

Hopkins University SOM

*Baltimore, MD*



**Jessica Fealy, MD**

Assistant Professor

General Pediatrics

University of Michigan

*Ann Arbor, MI*



**Elizabeth Stout, BA**

Young Adult Representative

National Coordinating Center for

Epilepsy

*Ann Arbor, MI*

# DISCLOSURES

- We have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider of commercial services discussed in this activity.
- We do not intend to discuss an unapproved/investigative use of a commercial product/device in our presentation.



## OBJECTIVES

- Describe racial and ethnic disparities and social determinants of health in patients with epilepsy.
- Understand health equity and aspects of cultural competency in providing care.
- Understand barriers to effective communication with families with children and youth with epilepsy (CYE) and how to address them.
- Understand the benefits of a medical home when caring for CYE.



## EPILEPSY BACKGROUND

- There are approximately 13.5 million children and youth with special health care needs (CYSHCN) in the United States.<sup>1</sup>
  - Included among the CYSHCN are 470,000 children aged birth to 18 years living with epilepsy, the most common childhood neurologic condition in the US.<sup>2</sup>
- Epilepsy is a brain disorder where a person has recurring seizures.<sup>3</sup>
  - Seizures are sudden events that cause temporary changes in physical movement, sensation, behavior, or consciousness; they are caused by abnormal electrical and chemical changes in the brain.<sup>3</sup>



# EPILEPSY BACKGROUND

- Epilepsy is a condition that requires complex, coordinated systems of primary and specialty care.<sup>4</sup>
  - A lack of awareness of the treatment options by providers can significantly affect a patient's quality of life.<sup>5</sup>
  - However, only roughly one-third of children with epilepsy have access to comprehensive health care.<sup>6</sup>
  - Nationally, the number of pediatric neurologists is at least 20% below the need, resulting in limited access to care for CYE, especially in rural and medically underserved areas/populations (MUA/Ps).<sup>4,7</sup>
  - Approximately 20% of Americans live in rural areas, while only 9% of the nation's physicians practice in these areas.<sup>4</sup>



# Epilepsy Background References

1. Health Resources and Services Administration, Maternal and Child Health. Children and Youth with Special Health Care Needs. <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youthspecial-health-needs#2>. Published December 2020. Accessed August 12, 2021.
2. Epilepsy Data and Statistics. Centers for Disease Control and Prevention. <https://www.cdc.gov/epilepsy/data/index.html>. Published September 30, 2020. Accessed August 12, 2021.
3. S. Russ, K. Larson, N. Halfon. A National Profile of Childhood Epilepsy and Seizure Disorder. *Pediatrics*. February 2012. 129 (2) 256-264. <https://doi.org/10.1542/peds.2010-1371>.
4. Institute of Medicine (US) Committee on the Public Health Dimensions of the Epilepsies; England MJ, Liverman CT, Schultz AM, et al., editors. *Epilepsy Across the Spectrum: Promoting Health and Understanding*. Washington (DC): National Academies Press (US); 2012. 7, Educating People with Epilepsy and Their Families. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK100608/>.
5. Institute of Medicine. IOM Report Identifies Public Health Actions for Improving the Lives of Those with Epilepsy 2012. <http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=1337>.
6. Kenney MK, Mann M. Assessing systems of care for US children with epilepsy/seizure disorder. *Epilepsy Res Treat* 2013.
7. Child Neurology Foundation. I Am a Healthcare Provider. <https://www.childneurologyfoundation.org/providers-or-researchers/the-field-of-child-neurology/>. Published 2018. Accessed December 20, 2018.





# Health Equity & Cultural Humility

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN®



# BASIC EPILEPSY EPIDEMIOLOGY

- ~1% (3.4 million) of the US population has active epilepsy.
- Impacts all racial and ethnic groups.
- Of conditions with adverse outcomes on health and academics in pediatrics, epilepsy is the costliest & 2nd most common.
- Children with epilepsy are more likely to live in poverty and their parents are more likely to report food insecurity.
- Direct yearly healthcare costs can range from \$10k-48k per year.



# Epilepsy Does Not Discriminate

- **African American & Hispanic** people are nearly **40%** of the 3.4 million persons diagnosed with epilepsy in the US.<sup>1</sup>
- Approximately **710,000 Hispanic** people are living with epilepsy.<sup>2</sup>
- Limited data suggest that more than **51,000 Indigenous and Alaska Native people** have active epilepsy.<sup>3</sup>
- 3 in 200 **Asians in America** have epilepsy.

1. Epilepsy Foundation. African Americans. Accessed on September 21, 2022. <https://www.epilepsy.com/specific-populations/african-americans>  
2. Epilepsy Foundation Multicultural Affairs. Epilepsy and Seizures in the Hispanic Community. Epilepsy.com. Updated October 10, 2017. Accessed on September 21, 2022. <https://www.epilepsy.com/article/2017/10/epilepsy-and-seizures-hispanic-community>  
3. Epilepsy Foundation Multicultural Affairs. National Native American Heritage Month. Epilepsy.com. Updated November 18, 2020. Accessed on September 21, 2022. <https://www.epilepsy.com/article/2017/10/epilepsy-and-seizures-hispanic-community>



# Epilepsy and African Americans in America

- More than **578,000 African American, non-Hispanic people** are living with active epilepsy in the US.<sup>2</sup>
- Over **25,000** are diagnosed with seizures or epilepsy each year.
- For many African Americans with epilepsy, access to appropriate care is a critical problem.
- More likely than white Americans to:
  - be **diagnosed with epilepsy in an emergency room** than white Americans.
  - **develop epilepsy over a lifetime** than white Americans.
  - experience a **medical emergency in which a seizure continues for 5 minutes or more without stopping.**



Image Source: Microsoft PowerPoint

1. Zack MM, Kobau R. National and State Estimates of the Numbers of Adults and Children with Active Epilepsy - United States, 2015. *MMWR Morb Mortal Wkly Rep.* 2017;66(31):821-825. Published 2017 Aug 11. doi:10.15585/mmwr.mm6631a1

2. *National Health Interview Survey (NHIS) 2017 and National Survey for Children's Health (NSCH) 2018-2019* [CDC. MMWR 2012, Nov 16;61\(45\):909-913.](#)

3. Institute of Medicine (US) Committee on the Public Health Dimensions of the Epilepsies, England MJ, Liverman CT, Schultz AM, Strawbridge LM, eds. *Epilepsy Across the Spectrum: Promoting Health and Understanding.* Washington (DC): National Academies Press (US); 2012.

# Epilepsy Among Hispanic and Latinx/a/o People

- **710,608** Hispanic and Latinx/a/o people in US have active epilepsy.
- Hispanic and Latinx/a/o people are **18.1%** of all people with active epilepsy.
- Community values and attitudes toward epilepsy:
  - Family orientation
  - Over protection, supervision
  - Emotional over-involvement
  - Stigma – person should be hidden



Image Source: Microsoft PowerPoint



# Epilepsy Among Asian and Indigenous People

- Research among Asians in America with epilepsy is limited.
- Limited data suggest that more than **51,000 Indigenous and Alaska Native people** have active epilepsy.
- However, the data we do have suggests that **255,000** Asians in America have epilepsy — or **3 in every 200**.



Image Source: Microsoft PowerPoint



1. Epilepsy Foundation. Asian American and Pacific Islander Heritage Month 2018. Epilepsy.com. Updated May 01, 2018. Accessed September 21, 2022. <https://www.epilepsy.com/stories/asian-american-and-pacific-islander-heritage-month-2018>
2. Chung K, Ivey SL, Guo W, et al. Knowledge, attitudes, and practice toward epilepsy (KAPE): a survey of Chinese and Vietnamese adults in the United States. *Epilepsy Behav.* 2010;17(2):221-227. doi:10.1016/j.yebeh.2009.11.023



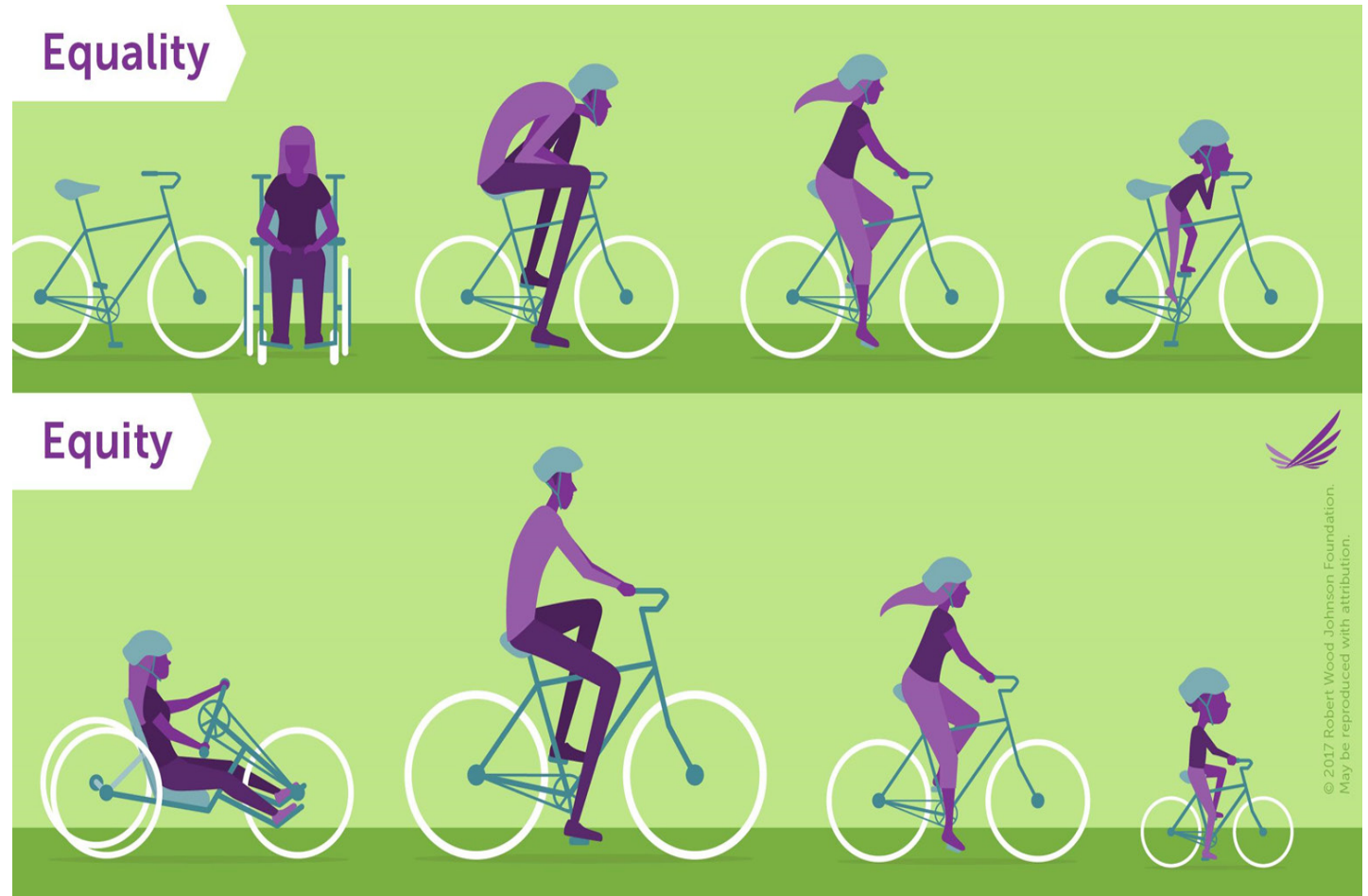
# WHAT IS A “SOCIAL DETERMINANT OF HEALTH”?

- Social determinants of health (SDOH): “particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage.” This includes:
  - Race/Ethnicity
  - Religion
  - Sex/Gender/Sexual orientation
  - Regional/Geographic residence
  - Caregiver’s education
  - Socioeconomic status (SES)/Insurance type
  - English fluency
  - Nativity/Immigration status



# EQUALITY VS EQUITY

- **Equality** equals sharing and division, keeping everyone at the same level. It gives the same thing to all people, regardless of their needs.
- **Equity** demands that individual needs are taken into consideration. It accounts for identities (race, ethnicity, ability, nationality, gender, etc) and circumstances that may otherwise hinder the success of one participant over another.





# SOCIAL DETERMINANTS OF HEALTH IN PEDIATRIC EPILEPSY

- Children and Youth with Epilepsy (CYE):
  - 3-6x more likely to have neurodevelopmental or psychological disorders<sup>1,2</sup>
    - Only 30% receive mental health care<sup>1,2</sup>
  - 4x increased risk of premature death<sup>3,4,5</sup>
  - 55% live in poverty<sup>3,4,5</sup>
  - 32% live in a rural area<sup>3,4,5</sup>
  - 53% have public insurance<sup>3,4,5</sup>
  - 64% have low health literacy<sup>3,4,5</sup>

Sources:

<sup>1</sup>Caplan R, Siddarth P, Gurbani S, Ott D, Sankar R, Shields WD. Psychopathology and pediatric complex partial seizures: Seizure-related, cognitive, and linguistic variables. *Epilepsia*. 2004;45(10):1273–1281. doi:10.1111/j.0013-9580.2004.58703.x.

<sup>2</sup>Ott D, Siddarth P, Gurbani S, Koh S, Tournay A, Shields WD, Caplan R. Behavioral disorders in pediatric epilepsy: Unmet psychiatric need. *Epilepsia*. 2003;44(4):591–597. doi:10.1046/j.1528-1157.2003.25002.x.

<sup>3</sup>Paschal AM, Mitchell QP, Wilroy JD, Hawley SR, Mitchell JB. Parent health literacy and adherence-related outcomes in children with epilepsy. *Epilepsy & Behavior*. 2016;56:73–82. doi:10.1016/j.yebeh.2015.12.036.

<sup>4</sup>Widjaja E, Smith ML, Jette N, Payne E. Patient and hospital characteristics are associated with cost of hospitalizations in children with epilepsy. *Epilepsy & Behavior*. 2013;28(3):335–342. doi:10.1016/j.yebeh.2013.05.031.

<sup>5</sup>Wilson DA, Malek AM, Wagner JL, Wannamaker BB, Selassie AW. Mortality in people with epilepsy: A statewide retrospective cohort study. *Epilepsy Research*. 2016;122:7–14. doi:10.1016/j.eplepsyres.2016.01.008.



# HEALTH LITERACY AND OUTCOMES FOR CYE

- The prevalence of epilepsy is higher in households with lower parental education.<sup>1</sup>
- Lower health literacy and education can also lead to decreased access to care and lower adherence to treatment plans.<sup>2</sup>
- There are no pediatric studies assessing English proficiency, nativity, or immigration status.<sup>4</sup>

Sources:

<sup>1</sup>Kroner BL, Fahimi M, Kenyon A, Thurman DJ, Gaillard WD. Racial and socioeconomic disparities in epilepsy in the District of Columbia. *Epilepsy Research*. 2013;103(2–3):279–287. doi:10.1016/j.eplepsyres.2012.07.005.

<sup>2</sup>Rahma S, Khasro I. Drug compliance in epileptic children in Sulaymani Governate. *Iraqi Postgraduate Medical Journal*. 2010;9(2):158–162.

<sup>4</sup>Wagner J, Bhatia S, Marquis BO, et al. Health Disparities in Pediatric Epilepsy: Methods and Lessons Learned [published online ahead of print, 2022 Aug 5]. *J Clin Psychol Med Settings*. 2022;1-10. doi:10.1007/s10880-022-09898-1

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



# PEDIATRIC EPILEPSY RESEARCH CONSORTIUM (PERC)

## HEALTH EQUITY SPECIAL INTEREST GROUP

- Race/ethnicity are the strongest and most consistently documented social determinants related to epilepsy outcomes.
  - No studies examining racial disparities in long term outcomes
- Lower SES: ↓ adherence to medication, ↑ Emergency Department (ED) visits, and ↑ risk of mortality.
- Uninsured & public insurance: significant gaps in specialized epilepsy care access and ↑ ED visits.

Source: Wagner, J., Fedak, R. E., Garcia, S. R., Joshi, C., Kumar, G., Marquis, B. O., Park, M., Rao, K., Patel, E., Bhatia, S., & Skjei, K. (2021, April). *Health disparities in pediatric epilepsy*. Poster presented at the Society of Pediatric Psychology Annual Conference [Virtual]. Retrieved from [https://pedpsych.org/wp-content/uploads/2021/06/SPPAC-Program-2021\\_v3.pdf](https://pedpsych.org/wp-content/uploads/2021/06/SPPAC-Program-2021_v3.pdf)



# PEDIATRIC EPILEPSY RESEARCH CONSORTIUM (PERC) SCOPING REVIEW: PRELIMINARY FINDINGS

- **Disparities exist but there are limited studies that directly assess disparities in CYE.**
- Any disparity results are often underemphasized (ie, hidden in the text or table).
- Race categorized as White/Non-White.
- Health disparities exist within the broader context of structural racism.



# CULTURAL HUMILITY

- **Cultural Humility:** Listening with the intention of honoring the patient's beliefs, customs, race/ethnicity, gender identity, sexual orientation, socioeconomic needs, educational background, lived experience, and values.
- Get to know your community: resources, disparities, different populations, languages, and belief systems.
- Don't assume! ASK about background, religion, and culture to avoid stereotyping.
- Use words and actions to demonstrate your interest in understanding the patient and collaborating on a plan to fit their needs and confirm understanding.



# Shared Decision-making in a Medical Home Setting

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN®



## HOW CAN PEDIATRICIANS HELP?

- Recognize impact of SDOH in CYE and epilepsy outcomes.
- Understand that disparities in health outcomes can be related to the broader context of structural racism.
- Fostering effective communication necessitates an understanding of the SDOH that impact each patient.
- Providing a medical home to help facilitate shared decision making.
- Practicing **Cultural Humility**.



# IMPORTANCE OF A MEDICAL HOME

- [AAP Medical Home](#) model was developed to improve the delivery of care to children and adolescents with special health care needs.
- The medical home team utilizes Family Centered Care principles and includes patients, families, specialists, primary care physicians (PCPs), and the community.
- Benefits:
  - Foster high quality care and reduce disparities in treatment
  - Coordinate specialists, therapy referrals, hearing/vision screening, education supports, ensure routine health maintenance
  - Transition planning to adult medical care
  - Improve caregiver confidence and decrease ED utilization/readmission





# RESIDENT CONTINUITY CLINIC AS A MEDICAL HOME

- Highly rated by patients and families due to more timely service and fewer unmet needs.
- Patients and families appreciate help identifying and accessing resources and helping with paperwork.
- Decreased use of emergency services.
- Increased use of dental services.



# SHARED DECISION-MAKING IN EPILEPSY CARE

- Patients that are inadequately informed about treatment and management options reported **higher rates** of dissatisfaction.
- Patients perceive anti-seizure medication (ASM) drug choices and treatment options to be clinician-dominant.
- **Shared decision-making in epilepsy care** = Clinicians and patients discuss treatment options and make decisions **TOGETHER** using the best available evidence.
  - Promotes patient-centered care
  - ↑ patient understanding
  - ↑ adherence to treatment plans



# SHARED DECISION-MAKING TOOLS IN EPILEPSY CARE

- Collaborative Deliberation
  - *Team Talk* → *Option Talk* → *Decision Talk*
- Decision Aids
  - Variety of formats, help patients and families understand pros and cons of treatments, can facilitate shared decision-making with less face-to-face time
  - Can be reviewed before discussion so patients feel more prepared
- Option Grids
  - Single page grid with FAQ's and 2-3 options in a grid



## CONSIDERATIONS FROM LIVED EXPERIENCE

- Consider that patients may be more likely to adhere to treatment plans if they were involved in the development.
- Managing epilepsy can be especially challenging for patients with other medical conditions and having a medical home to coordinate the various components of health is significantly helpful.
- Shared decision-making is an essential part of providing family-centered care and team-based care within a medical home.
- With shared decision-making, CYE and their family perspectives are valued, and they are included as part of the team in decisions related to treatment plans and management of their health.



## SUMMARY

- Epilepsy is a common and costly neurological condition (ie, fiscally, medically, and socially).
- Disparities in epilepsy care exist but are underemphasized and need to be directly investigated.
- Shared decision-making can improve communication, patient satisfaction, and treatment adherence.
- Utilizing the medical home model (such as a resident continuity clinic) can improve coordination, care, and reduce disparities.



# REFERENCES

- Butcher JS, Wolraich ML, Gillaspay SR, Martin VG, Wild RC. The impact of a Medical Home for children with developmental disability within a pediatric resident continuity clinic. *J Okla State Med Assoc.* 2014;107(12):632-638.
- Chung K, Ivey SL, Guo W, et al. Knowledge, attitudes, and practice toward epilepsy (KAPE): a survey of Chinese and Vietnamese adults in the United States. *Epilepsy Behav.* 2010;17(2):221-227. doi:10.1016/j.yebeh.2009.11.023
- Institute of Medicine (US) Committee on the Public Health Dimensions of the Epilepsies, England MJ, Liverman CT, Schultz AM, Strawbridge LM, eds. *Epilepsy Across the Spectrum: Promoting Health and Understanding.* Washington (DC): National Academies Press (US); 2012.
- Kash B, Tan D, Tittle K, Tomaszewski L. The Pediatric Medical Home: What Do Evidence-Based Models Look Like? *The American Journal of Accountable Care*, June 2016, Volume 4 Issue 2.
- *National Health Interview Survey (NHIS) 2017 and National Survey for Children's Health (NSCH) 2018-2019 CDC. MMWR 2012, Nov 16;61(45):909-913.*
- Pickrell WO, Elwyn G, Smith PE. Shared decision-making in epilepsy management. *Epilepsy Behav.* 2015;47:78-82. doi:10.1016/j.yebeh.2015.01.033
- Stubbe DE. Practicing Cultural Competence and Cultural Humility in the Care of Diverse Patients. *Focus (Am Psychiatr Publ).* 2020;18(1):49-51. doi:10.1176/appi.focus.20190041
- Wagner J, Bhatia S, Marquis BO, et al. Health Disparities in Pediatric Epilepsy: Methods and Lessons Learned [published online ahead of print, 2022 Aug 5]. *J Clin Psychol Med Settings.* 2022;1-10. doi:10.1007/s10880-022-09898-1
- Zack MM, Kobau R. National and State Estimates of the Numbers of Adults and Children with Active Epilepsy - United States, 2015. *MMWR Morb Mortal Wkly Rep.* 2017;66(31):821-825. Published 2017 Aug 11. doi:10.15585/mmwr.mm6631a1



# AAP RESOURCES

- [National Coordinating Center for Epilepsy](#)
  - [Caring for Children and Youth with Epilepsy: What Primary Care Providers Need to Know \(webinar series\)](#)
  - [Managing Pediatric Epilepsy](#)
  - [Epilepsy Resources for Health Care Professionals: Shared Decision-Making](#)
- [National Resource Center for Patient/Family-Centered Medical Home](#)
- Adams RC, Levy SE; COUNCIL ON CHILDREN WITH DISABILITIES. Shared Decision-Making and Children With Disabilities: Pathways to Consensus. *Pediatrics*. 2017;139(6):e20170956. doi:10.1542/peds.2017-0956
- Katkin JP, Kressly SJ, Edwards AR, et al. Guiding Principles for Team-Based Pediatric Care. *Pediatrics*. 2017;140(2):e20171489. doi:10.1542/peds.2017-1489



## ADDITIONAL RESOURCES

- [Patient Assistance | Epilepsy Foundation](#)
- [Summer Camp | Epilepsy Foundation](#)
- [Resources and Seizure Action Plans for Summer Camp | Epilepsy Foundation](#)
- [Resource Guide | Support Program for Parents of Teens with Epilepsy | CDC](#)
- [You Are Not Alone: Support Program for Parents of Teens with Epilepsy | CDC](#)
- [Managing Epilepsy Well Network](#)





# QUESTIONS?

If you have any questions regarding the presentation, please feel free to contact The National Coordinating Center for Epilepsy ([epilepsy@aap.org](mailto:epilepsy@aap.org)).

