Strengthen & Enhance Epilepsy Knowledge (SEEK) Training

September 2022

NATIONAL COORDINATING CENTER *for* EPILEPSY

American Academy of Pediatrics

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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.

Care Coordination & Health Care Transition for youth/young adults with Epilepsy and their Families

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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

- Emphasize the collaborative role of youth/ young adults and parents/guardians in care coordination and health care transition into adult care.

- Discuss care coordination, evidence for its use in epilepsy, and an implementation model.

- Discuss the current context of health care transition (HCT) especially for youth with epilepsy, HCT outcome evidence, and the Got Transition Six Core Elements.

Epilepsy Background

- There are approximately 13.5 million children and youth with special health care needs (CYSHCN) in the United States.[1]
  - 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.[2]
- Epilepsy is a brain disorder where a person has recurring seizures.[3]
  - 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.[3]

Epilepsy Background

- Epilepsy is a condition that requires complex, coordinated systems of primary and specialty care.[4]
  - A lack of awareness of the treatment options by physicians can significantly affect a patient's quality of life.[5]
  - However, only roughly one-third of children with epilepsy have access to comprehensive health care.[6]
  - 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).[4,7]
  - Approximately 20% of Americans live in rural areas, while only 9% of the nation's physicians practice in these areas.[4]

Epilepsy Background References

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Care Coordination

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Care Coordination Definition

- Pediatric care coordination is a patient- and family-centered, assessment driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families.

- Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes.

Source: Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5):e1451-e1460. doi:10.1542/peds.2014-0318

Why the Need for Care Coordination in Pediatric Epilepsy?

- ~25% of children with epilepsy experience symptoms of depression and or anxiety.
- ~ 20% of children with chronic epilepsy report suicidal ideation.
- ~30% of children with epilepsy have symptoms of ADHD and/or inattention.
- Other frequently associated conditions include:
  - Autism,
  - Cerebral palsy,
  - Cognitive impairment, and/or
  - Language impairment.

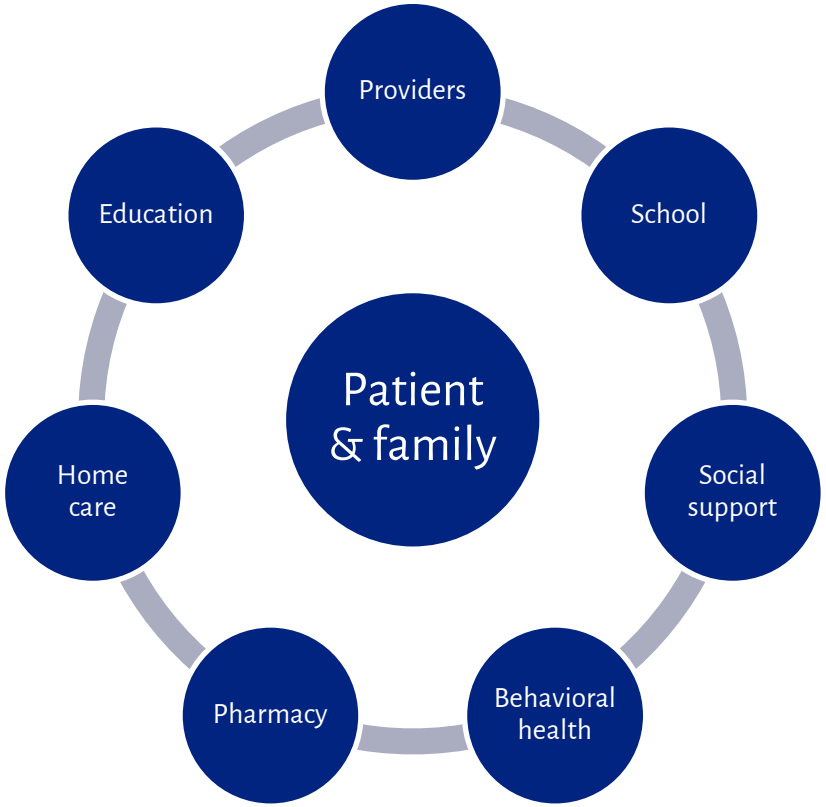
Care Coordination and the Medical Home

- Care coordination should be built around a **Medical Home.**
- A medical home:
  - Is an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families.
  - Extends beyond the four walls of a clinical practice.
  - It includes specialty care, educational services, family support and more.
- Components of the medical home:
  - Accessible,
  - Continuous,
  - Comprehensive,
  - Family-centered,
  - Coordinated,
  - Compassionate, and
  - Culturally effective.

Source: American Academy of Pediatrics. Medical Home. Accessed September 13, 2022.

Characteristics of Care Coordination

- Patient and family-centered.
- Proactive, planned, and comprehensive.
- Promotes self-care and independence.
- Emphasizes cross organizational relationships.



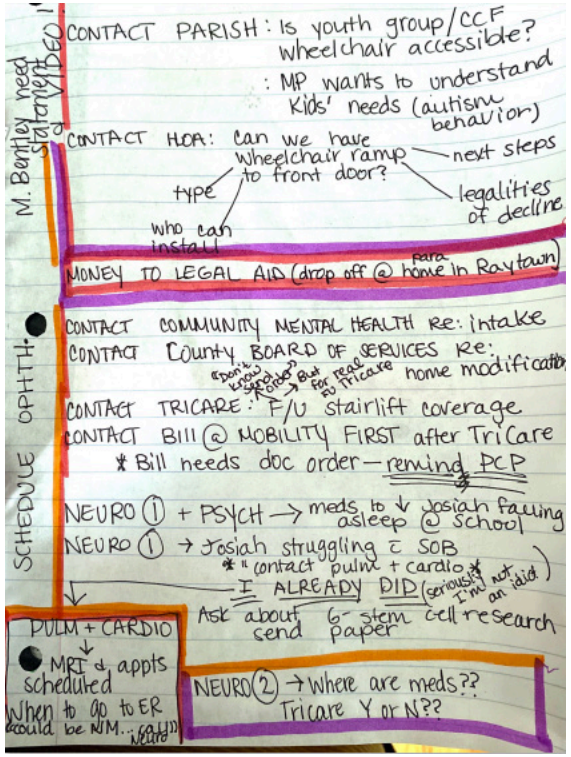
Source: Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5):e1451-e1460. doi:10.1542/peds.2014-0318

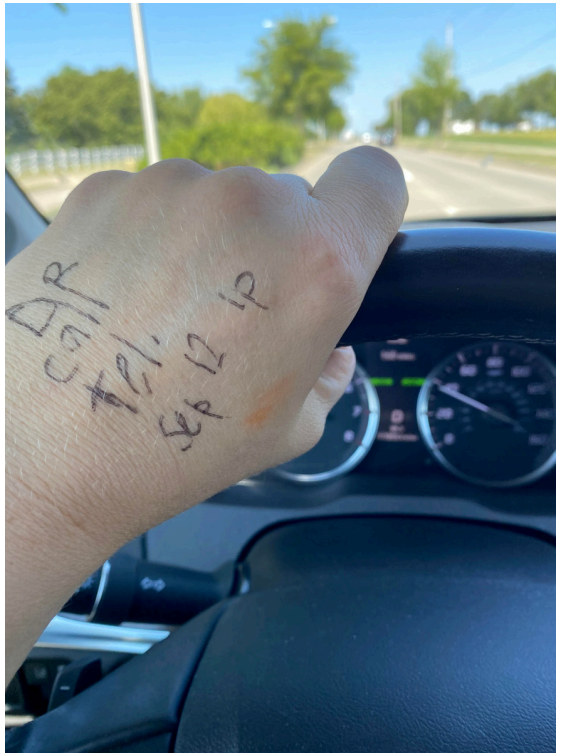
The Basic Elements of Care Coordination

- Establish responsibilities within team members, patient, and family.
- Collaborate with all team members.
- Communicate across all systems (primary care, subspecialists, and family).
- Facilitate transitions.
- Assess needs and establish clear goals.
- Clear plan of care that is sensitive to patient cultural values.
- Monitor and follow.
- Support self-management.
- Foster knowledge.
- Facilitate access to resources.

Care Coordination Works

- Studies show that care coordination:
  - Reduces symptoms of asthma in children with reactive airway disease.
  - Increase follow-up rate after an emergency room (ER) visit.
  - Reduces avoidable health care services for adults with diabetes.
- Decreases parental burden of care.





Images: A day in the life of the mother of two children with complex medical needs. (courtesy Dawn Graczyk)

Sources: Barnett, Tracey E., et al. "The effectiveness of a care coordination home telehealth program for veterans with diabetes mellitus: a 2-year follow-up." American Journal of Managed Care 12.8 (2006): 467.

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Leveraging Telehealth In Care Coordination

- While ~20% of the US population lives in rural areas, less than 9% of physicians practice in rural areas.
- Most pediatric neurologists practice in urban areas.
- Telehealth is a tool that can be leveraged to successfully accomplish integrated care for patients without easy access to specialized care.
- During the COVID-19 epidemic, the number of telemedicine encounters went from 7 in 2019 to 1034 in 2020 at Children's Mercy Kansas City a level three epilepsy center.
- The COVID-19 epidemic has revealed a unique opportunity for physicians to leverage telehealth to improve care coordination.
- Through efforts such as the Reaching Out for Epilepsy in Adolescents and Children through Telemedicine (REACT) program the Health Resources and Services Administration in collaboration with AAP is funding a major effort helping to increase access to care for CYE through telehealth strategies that provide direct care, including teleconsultation, tele-education, telemedicine and mobile health.

Source: The Children's Mercy Hospital. Reaching Out for Epilepsy in Adolescents and Children through Telemedicine (REACT). ChildrensMercy.org. Accessed September 27, 2022. https://www.childrensmercy.org/childrens-mercy-research-institute/studies-and-trials/epilepsy-in-adolescents-and-children-telemedicine/

Health care Transition (HCT)

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What is Pediatric to Adult Transition?

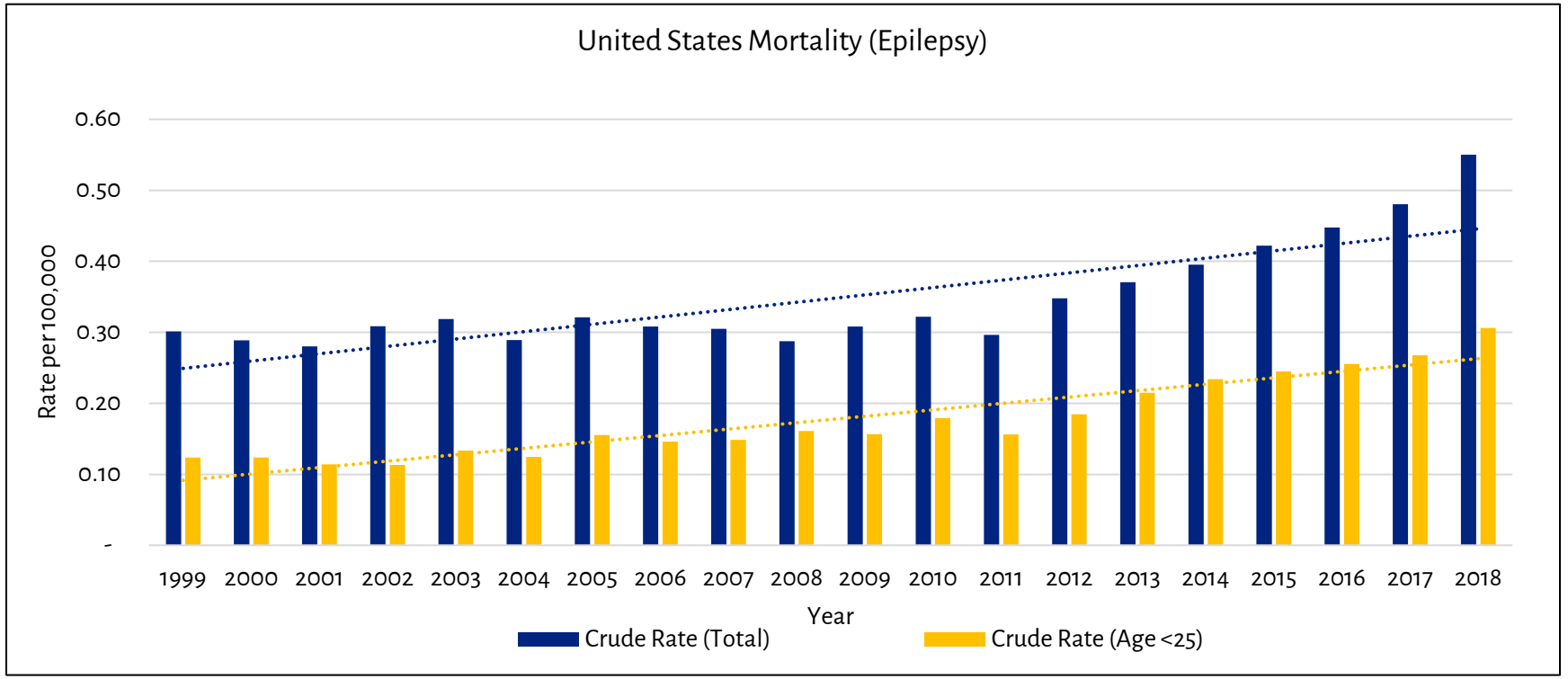
- **Definition:** Health care transition is the process of moving from a child to an adult model of health care with or without a transfer to a new clinician.
- **Transition ages** span ages 12-14 to 18-25 years old.
- **Transition Goals for Youth/Young Adults and Clinicians:**
  - Improve the ability of youth and young adults to manage their own health and effectively use health services.
  - Have an organized clinical process in pediatric and adult practices to facilitate transition preparation, transfer of care, and integration into adult-centered care.

Why Discuss Health Care Transition for Youth with Epilepsy?

- **Mortality** rates for youth with epilepsy increase in the transition years.
- **Outcome studies** of health safety and adverse effects for youth with special health care needs **without a structured health care transition (HCT) process show:**
  - Medical complications, increased morbidity.
  - Lower self-reported health and wellbeing.
  - Problems with treatment and medication adherence.
  - Discontinuity of care/lost to follow up.
  - Youth/young adult/family dissatisfaction.
  - Poor communication between systems of care and clinicians.
  - Increased hospitalizations and ER use.

Source: White PH, Cooley WC, Transitions Clinical Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018; 142:85-104.

Twenty Year Mortality Trend Rate for Epilepsy



The crude death rate for epilepsy in the US was 0.55 per 100,000 in 2018. For those < 25 years of age, the rate was 0.31 per 100,000. These are the highest documented rates for epilepsy and represents a 190.7% and 247.5 % rate increase since 2000, respectively.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2018 on CDC WONDER Online Database, released in 2020. Data are from the Multiple Cause of Death Files, 1999-2018, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at http://wonder.cdc.gov/ucd-icd10.html on July 23, 2020, 12:14:32 PM

Who Receives Transition Planning Guidance from Physician?

National US Survey of Children's Health, 2019-2020

- **76% of youth with special health care needs (YSHCN) did not receive transition planning guidance from their physician.**
- 82% of youth without special health care needs did not receive transition planning guidance from their physician.
- National Performance Measure on Transition is based on whether:
  - Physician spoke with child/adolescent privately without an adult in the room during the last preventive check-up;
  - If a discussion about transitioning to adult care was needed it must have happened; and
  - Physician actively worked with child/adolescent to gain skills and understand changes in their health care.

Source: Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. ChildHealthData.org. Accessed December 7, 2020.

What is the Outcome Evidence for a Structured Transition Process?

Statistically significant improvement shown in:

Population Health

- Adherence to care, self-care skills, quality of life, and self-reported health.

Experience of Care

- Increased satisfaction and reduction in barriers to care.

Utilization

- Decrease in time between last pediatric and first adult visit and increase in adult visits.
- Decreased hospital admissions and length of stay.

Sources: Gabriel P, McManus M, Rogers K, White P. Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review. *J Pediatr*. 2017;188:263-269.e15. doi:10.1016/j.jpeds.2017.05.066.
Schmidt A, Ilango SM, McManus MA, Rogers KK, White PH. Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review. *J Pediatr Nurs*. 2020;51:92-107. doi:10.1016/j.pedn.2020.01.002

Pediatric to Adult Health Care Transition

- The Academy of Pediatrics (AAP), American Academy of Family Physician (AAFP), and the American College of Physicians (ACP) Clinical Report Recommendations clarify:
  - TRANSITION ≠ TRANSFER or PLANNING alone.
  - TRANSITION = planning, transfer, and integration into adult care.

Image Source: Microsoft PowerPoint

Sources: White PH, Cooley WC, Transitions Clinical Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics.* 2018; 142:85-104.

Medical Professional Societies' Guidance

- AAP/AAFP/ACP updated **Clinical Guidelines in 2018** with guidance on evidence informed processes.
- The clinical report targets all youth, beginning at age 12.
- Algorithmic structure with emphasis on planning:
  - Branching for YSHCN.
  - Application to primary and specialty practices.
- Extends through transfer of care to adult medical home and adult specialists.
- **Recommendations: Focus on all three aspects of transition (ie, planning, transfer, and integration) into adult care using a structured QI approach utilizing the Six Core Elements.**

Age 12	Youth and family aware of transition policy
Age 14	Health care transition planning initiated
Age 16	Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care
Age 18	Transition to adult approach to care
Age 18-22	Transfer of care to adult medical home and specialists with transfer package

Sources: White PH, Cooley WC, Transitions Clinical Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018; 142:85-104.

SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE

Source: Got Transition. Six Core Elements of Health care Transition™. Gottransition.org. Accessed September 13, 2022. https://www.gottransition.org/six-core-elements/

There are three sets of customizable tools available for different practice settings.

Click below for information and samples of each core element and full Six Core Elements packages.

TRANSITIONING YOUTH TO AN ADULT HEALTH CARE CLINICIAN

For use by Pediatric, Family Medicine, and Med-Peds Clinicians

Click for details on each element.

Six Core Elements Package

Six Core Elements Package En Español

Full Implementation Guide

TRANSITIONING TO AN ADULT APPROACH TO HEALTH CARE WITHOUT CHANGING CLINICIANS

For use by Family Medicine and Med-Peds Clinicians

Click for details on each element.

Six Core Elements Package

Six Core Elements Package En Español

Full Implementation Guide

INTEGRATING YOUNG ADULTS INTO ADULT HEALTH CARE

For use by Internal Medicine, Family Medicine, and Med-Peds Clinicians

Click for details on each element.

Six Core Elements Package

Six Core Elements Package En Español

Full Implementation Guide

Click here to request a customizable version of any tools.

Source: Got Transition. Six Core Elements of Health care Transition™. Gottransition.org. Accessed September 13, 2022. https://www.gottransition.org/six-core-elements/

Key Take Aways for Bringing HCT into the Continuity Clinic

- **Be explicit and start early** (age 12-14) with a structured HCT process that lets youth and young adults know how your practice will support them as they move into adulthood and the adult health care system.
- **Arm youth and young adults with the information** they need to manage their health and health care; assess their skills and teach them where to find information.
- **Inform youth about confidentiality** and privacy laws and the adult model of care that occurs at age 18 and how it effects their health, health care, and their shared decision-making role with their physician.
- **Share a medical summary and a plan of care** with the youth/young adult and with all the adult clinicians involved with the youth's care coordination.
- **Warm hand-off** is key, and telehealth can be utilized easily through a joint telehealth visit between the young adult, pediatric and adult physicians.
- **Follow-up**: Be sure the young adult made and kept their first adult appointment to keep them engaged in their care.

Considerations from Lived Experience

- A multitude of changes initially occur at 18 years old, therefore gradually implementing a carefully planned health care transition by the patient and provider is very helpful and makes for a smoother process.
- Patients may assume a health care transition simply means changing to a new provider, so it is important they understand the full scope of the transition, including their new roles and responsibilities.
- Epilepsy is a condition with a wide range of impacts, and care coordination with a medical home makes it easier to effectively manage all realms of health, including other conditions.

Summary

- **Care coordination** should occur within the context of a medical home, be patient centered, promote self-care and independence, and emphasize cross organizational relationships.
- Care coordination must be intentional and planned, with clear responsibilities designed to facilitate communication and collaborations, with the ultimate goal of providing integrated care addressing all aspects of patients' lives.
- **Transition** is a time of high mortality and morbidity for youth with epilepsy.
- To improve outcomes and health care transition success, physicians should provide a structured approach that starts early and assists youth and young adults in gaining the self-management skills and information to be equal partners in their adult health care.
  - Physicians that can provide continued assistance that is thorough and comprehensive for CYE and their caregivers is key for a successful health care transition and care coordination.

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AAP Resources

- National Coordinating Center for Epilepsy
  - National Coordinating Center for Epilepsy – Care Coordination
    - National Resource Center for Patient/Family-Centered Medical Home: https://www.aap.org/en/practice-management/medical-home
    - Care Coordination Resources: https://www.aap.org/en/practice-management/care-delivery-approaches/care-coordination-resources/
  - National Coordinating Center for Epilepsy – Health Care Transition
    - Children and youth with epilepsy (CYE) transitioning to adult care may face additional access to care challenges. Pediatric and adult physicians must be able to bridge the gap and work in conjunction with other health care professionals to insure effective and efficient care delivery. Proper transition planning ensures that everyone receives the necessary services to achieve a smooth transition into adult life.

Additional Resources

- Care Coordination. Content last reviewed August 2018. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/ncepcr/care/coordination.html
- Got Transition resources:
  - Clinician Resources
  - Youth And Young Adult Resources
  - Family HCT Tool Kit and Resources
  - 2022 Coding and Reimbursement Tip Sheet with Clinical Vignettes
  - Intellectual Disabilities/Developmental Disabilities (ID/DD) Tools and Resources

Questions?

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