Priorities for Pediatric Epilepsy Care: A Strategic Agenda

Current Landscape:

Resources related to pediatric epilepsy care are abundant but not well disseminated, making it difficult for patients, families, & health care professionals to find necessary information.

Primary care providers report limited knowledge & confidence when it comes to caring for children and youth with epilepsy (CYE).

Shared decision-making is the cornerstone of quality health care, but patients & families report feeling dismissed & not taken seriously by health care professionals.

The American Academy of Pediatrics National Coordinating Center for Epilepsy supports those working to improve access to coordinated, comprehensive, and quality care for children and youth with epilepsy (CYE).

With input from 300+ parents/caregivers, 100+ young adult patients, and 50+ health professionals, the Center has developed a strategic agenda to inform the work of pediatricians, pediatric subspecialists, allied health professionals, patient/family advocates, and researchers.

We encourage all those working in the field of pediatric epilepsy to refer to this document when undertaking new initiatives to improve the care of this population.
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### Resource Dissemination
- Conduct environmental scan to review existing resources.
- Post high-quality resources on National Coordinating Center for Epilepsy webpages.
- Develop, implement, & evaluate a resource dissemination strategy reaching patients, families, & health care providers.

Disseminate existing resources; do not recreate the wheel.

### Addressing System-level Issues
- Promote a sustainable, consistent payment & reimbursement structure for telehealth, care coordination, & advanced practice professionals.
- Work to remove barriers faced by & increase incentives for physicians who care for patients with medical complexity.
- Support equitable access to broadband so all patients/families can access reliable digital information & telehealth services.

### Education
- Determine types of education preferred by health care providers.
- Develop, implement, & evaluate epilepsy-specific trainings to health care providers.
- Provide patient/family-focused education through peer-to-peer linkages, support groups, & connections with family-based organizations.
- Encourage more in-depth epilepsy education in medical schools & residency training programs.
- Provide epilepsy-specific training opportunities to allied health professionals.
- Develop & promote an epilepsy awareness campaign for the general public to reduce the common misconceptions & stigma.

Educate health care providers, partners, & the general public about epilepsy.

### Promoting Health Equity & Culturally Competent Care
- Assess curricular gaps on health equity principles & culturally competent care in medical schools & residency programs; develop a plan to improve.
- Raise awareness about existing inequities in epilepsy care; develop a plan to eliminate.
- Ensure availability of interpretation services & cultural advocacy for patients/families, as needed.
- Provide resources for patients/families in the languages spoken by the populations served.
- Approach health care transition from pediatric to adult care through a culturally informed lens.

Deliver culturally competent care in an equitable manner to all CYE.

### Partnerships
- Connect primary care providers to local resources & supports to share with patients & families.
- Facilitate partnerships between clinical practices & non-traditional sites (eg, school-based health centers) to serve as telehealth hubs for patients & families without reliable broadband & hardware.
- Integrate mental/behavioral health, advanced practice, & allied health professionals into team-based epilepsy care.

Implement a holistic, collaborative approach to providing care to CYE.

### Research
- Seek to better understand the epilepsy care experiences of patients & families identifying as racial/ethnic minorities & those living in rural communities.
- Determine the epilepsy care needs of children & youth with medical complexities/multiple comorbidities.
- Better understand epilepsy diagnosis process to determine why patients/families experience challenges obtaining diagnosis.
- Determine the barriers to & opportunities for increasing team-based epilepsy care.
- Conduct additional research on the future of telehealth to determine how best to support patients, families, & health care professionals.

Learn more about what is needed to support CYE care.