

American Epilepsy Society/International League Against Epilepsy – North America Joint Task Force for Epilepsy Health Care Disparities

Draft Recommendations

In fall 2023, the American Epilepsy Society (AES) and the International League Against Epilepsy – North America (ILAE-NA) established a joint task force to explore the health care disparities experienced by people with epilepsy (PWE) and develop recommendations to address these disparities. The task force members (Appendix A) were chosen for their direct clinical experience, research background, or organizational roles in addressing epilepsy disparities and improving access to care in the United States. The task force’s charge was to:

1. List barriers to care for [NIH-designated populations experiencing health disparities](#) and other vulnerable groups, such as non-English speakers and Veterans.
2. List existing AES strategies to address the challenges listed in the first charge.
3. List actions needed to expand work to address disparities listed in the first charge, to include:
 - a. Internal actions
 - b. Actions related to advocacy
 - c. Actions related to research
 - d. Model programs that can be adopted more widely

Over 8 months, the task force met bi-weekly, with each session focused on disparities in one aspect of epilepsy care and research. Subject matter experts were identified by task force members and invited to present their work at each session. At the end of each session, the task force discussed possible action steps for improving access in the area of focus. The task force expresses gratitude to the following professionals who generously shared their time, expertise, and experiences throughout the information-gathering phase of the project:

- Sucheta Joshi, MD, FAES, Keck School of Medicine of USC
- Emily Johnson, MD, FAES, Johns Hopkins Medical Center
- Bernice “Bee” Martin Lee, Epilepsy Foundation
- Elaine T. Kiriakopoulos, MD, MPH, MSc, Geisel School of Medicine at Dartmouth
- Rosemarie Kobau, MPH, MAPP, Centers for Disease Control and Prevention
- Bruce Ovbiagele, MD, MSc, MAS, MBA, MLS, FAAN
- Karen Parko, MD, FAES, US Public Health Services, Indian Health Service, Retired
- Patty Osborne Shafer, RN, MN, FAES, Osborne Health Consulting
- Joseph I. Sirven, MD, FAES, Mayo Clinic
- Karen Skjei, MD, FAES, The El Paso Center for Seizures and Epilepsy
- Timothy E. Welty, PharmD, FAES, Drake University
- JoJo Yang, MD, University of North Carolina, Chapel Hill

Each session had a minimum of 10 participants from the task force, and a simple majority was used for decisions when needed.

The task force leaders aggregated and categorized the possible action steps. The task force completed two iterations of feedback, discussion, and revision.

What is epilepsy health care equity?

Health care equity for people with epilepsy (PWE) means that every person living with epilepsy has fair and just access to high-quality health care services and disparities in outcomes are mitigated. This is achieved by reducing - and eliminating where possible - barriers to care.

Background

Nature of inequities in epilepsy care

The following is a non-exhaustive list of factors that contribute to epilepsy health and healthcare disparities:

- Socio-economic status
- Race and ethnicity
- Sex and gender identity
- Sexual orientation
- Age
- Location and local resources (e.g., under-resourced urban areas, rural areas)
- Physicians and other health care providers deserts
- Non-English language preference
- Environmental
- Health system access and quality

For PWE, disease-specific stigma has a deleterious effect on care. People with epilepsy suffer from severe health and healthcare disparities compared to the general population. There is extensive literature on epilepsy health care disparities, including systematic and narrative reviews.^{1,2}

Barriers to accessing epilepsy healthcare

1. **Economic:** Barriers include lack of health insurance, being underinsured or relying on public insurance, and general economic insecurity. Additionally, physician shortages are more prevalent in areas with higher poverty rates and less favorable payor mixes.
2. **Social:** Many populations (e.g., Black, Hispanic, Native Americans, and LGBTQ+ communities) have historically not been or not felt included in health care systems. Healthcare providers may not be adequately trained to care for these traditionally underserved communities.
3. **Geographic:** Individuals with epilepsy living in rural areas often have limited access to specialized epilepsy centers and neurologists.
4. **Language:** Limited English proficiency poses a communication barrier and affects trust and cultural understanding between patients and health care providers.
5. **Workforce:** The U.S. lacks a sufficient number of health care professionals trained to provide care for people with epilepsy, including community health workers, nurses, pharmacists, and physicians.
6. **Knowledge:** There is insufficient research into effective methods for addressing disparities in epilepsy care.

7. **Digital Divide:** While telehealth offers a potential solution for epilepsy care access, digital literacy, and internet connectivity disparities limit its effectiveness for many patients. Digital literacy and connectivity are not universal and can exacerbate inequities.

Approaches to Address Epilepsy Health Care Disparities

The task force recommends that the AES Board of Directors create a subcommittee within the Diversity, Equity, and Inclusion (DEI) Committee to monitor and promote the implementation of these recommendations.

Research-related Recommendations

- 1. Develop an AES grant mechanism that supports research into the social determinants of health (SDOH) in epilepsy.** No dedicated AES grant mechanism is designed to encourage research on addressing health disparities (for junior or established investigators of any sociodemographic background). The AES Sergievsky Award for Epilepsy Health Equity and Diversity is available for junior investigators who self-identify as members of underrepresented populations and encourages research on SDOH but is open to other topics.
 - This mechanism will attract more individuals who focus on SDOH and public health in epilepsy, engage current members with the new grant mechanism to focus on SDOH and foster collaboration between epilepsy researchers and researchers outside of epilepsy. It will also prepare AES members for new NINDS funding, such as the Community-Engaged Health Equity Research in Neuroscience Initiative (R01 CT Not Allowed).
- 2. The task force recommends that NINDS consider broadening the collection of SDOH data beyond age, gender, race, and ethnicity within epilepsy common data elements (CDE).** As a task force, we recommend including more SDOH data in CDEs. The task force acknowledges that SDOH can vary across study populations, such as children and local vulnerable populations. ICD-10-CM SDOH Z-codes can be used by researchers to harness EMR data for research purposes:
 - Z55 – Problems related to education and literacy Illiteracy
 - Z56 – Problems related to employment and unemployment
 - Z57 – Occupational exposure to risk factors
 - Z58 – Problems related to physical environment
 - Z59 – Problems related to housing and economic circumstances
 - Z60 – Problems related to social environment
 - Z61 – Problems related to upbringing
 - Z62 – Problems related to upbringing
 - Z63 – Other problems related to the primary support group, including family circumstances
 - Z64 – Problems related to certain psychosocial circumstances
 - Z65 – Problems related to other psychosocial circumstances
- 3. All epilepsy clinical research grant applications funded by public or private institutions should include a plan to engage, recruit, and retain populations to ensure the study's representativeness.** *Representativeness of studies* refers to the extent to which the participants in a clinical study are similar to the broader population the trial aims to represent. It is essential to ensure that the results can be applied to the broader population and that those potential treatments or interventions are safe and effective for all

individuals. The National Academy of Sciences has provided recommendations to improve the representativeness of clinical studies.³

4. **The task force supports the National Academy of Sciences recommendation that journal editors require information on the representativeness of trials and studies for journal submissions, particularly relative to the affected population.** The Council of Science editors provide an [approach to improving representativeness in publications](#). Promoting research reporting guidelines for publications involving health equity among marginalized populations may help prevent the continued legacy of health research from exploiting these groups.

The task force considered many areas of epilepsy research that can impact disparities. Potential high-impact research topics include:

- Impact of including time in the patient visit to address social issues (e.g., if the patient is having trouble filling prescriptions, follow up at the next visit to ensure the issue was resolved). By discussing these issues, the patient visit may be more valuable. Perhaps have staff call the patient/family a couple of weeks after the patient visit to ensure they have what they need to succeed.
- Impact of the studio model for engaging the community in epilepsy care and research: Engage various communities via a studio process, facilitating project-specific input from community and patient stakeholders to enhance research design, implementation, and dissemination.
- Impact of epilepsy self-management (ESM) on real-world health outcomes and health care resource utilization and encourage collaborative approaches for this data collection.
- Innovative ways of supporting parent well-being, which is critical for children with epilepsy to thrive, have been called out by the Surgeon General.
- Optimizing school settings, etc., could have a substantial impact on children with epilepsy.
- Utilization of community health workers (CHW) in epilepsy care, e.g., 1) the health and functional outcomes of people with epilepsy who are provided with and engage in support from a CHW; 2) the effect of integrated epilepsy-trained CHW on health care utilization and 3) patient experience when their epilepsy care is supplemented with support from epilepsy-trained CHWs.
- Interprofessional analyses of the roles that Advance Practice Providers (e.g., nurse practitioners, physician associates), nurse educators/specialists, CWHs, pharmacists, and neuropsychologists can play in epilepsy patient care.
- Projects that include Advanced Practice Providers (APP) as active members of research teams for AES, NIH, AHRQ, HRSA, and CDC grants related to epilepsy.

Clinical Care-related Recommendations

1. **Adopt the WHO framework** for integrating mental health services into epilepsy care, ensuring a holistic approach to patient management.
2. **Expand care models** to include **telehealth** and digital tools for epilepsy management. Incorporate video appointments, email communication, automated prescription refills, and seizure-tracking tools to enhance patient engagement and care accessibility.
3. **Form a workgroup** to develop AES guidelines for **Evidence-based Self-Management (ESM)**. These guidelines can follow models like population health frameworks for diabetes and asthma while leveraging the existing ESM programs from the CDC's Managing Epilepsy Well (MEW) Network.
4. **Adopt ICD-10-CM Z-codes for SDOH screening**. This will allow researchers to use electronic medical records (EMR) data for clinical research and tracking epilepsy care outcomes.
5. **Develop accessible programs** for populations with non-English language preferences, focusing on Hispanic, immigrant, and migrant communities, to promote the linguistic aspect of culturally competent epilepsy care.
6. **Promote diversity in epilepsy care teams by** ensuring epilepsy centers recruit and train a diverse workforce, including physicians, nurses, social workers, and pharmacists, to better reflect patient demographics.
7. **Create educational programs** designed for providers working with culturally diverse populations. These programs should promote cultural competence and humility and improve care for patients outside their cultural backgrounds.
8. **Establish a national ECHO program** for neurologists focused on refractory and rare epilepsies. This program should train primary care providers and other health care professionals in epilepsy care without requiring direct patient-specialist interaction.
9. **Consider integrating more interprofessional care** (e.g., with Advanced Practice Providers (APPs), nurse specialists/educators, CHWs, pharmacists, and neuropsychologists) into clinical epilepsy care to improve patient outcomes and enhance care delivery. Explore models like those outlined in recent studies on how neurologists are using apps to aid in epilepsy management.
10. **Advocate for including** nurse specialists, educators, CHWs, pharmacists, and neuropsychologists as core members of epilepsy care teams. Ensure they are recognized and reimbursed by health insurers. This builds on past initiatives like the Living Well with Epilepsy conferences and the 2012 Institute of Medicine report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*.⁴
11. **Collaborate with the NAEC** to engage epilepsy center leaders in understanding the evidence-based role of CHWs. Explore opportunities to integrate CHWs into epilepsy center care teams to improve care for those with epilepsy.
12. **Work to establish guidelines** for pharmacist involvement in epilepsy care and create practice models that fully integrate pharmacists into patient care teams.

Advocacy-related Recommendations

1. **Advocate for a National Plan for Epilepsy** focused on reducing disparities in epilepsy health care access and outcomes.
2. **Advocate for universal health coverage**, ensuring adequate care for advanced epilepsy treatments. Many state Medicaid systems do not cover these treatments, and some do not allow out-of-state care. The Congressional Budget Office estimates that the uninsured rate will rise from 7.7% to 8.9% by 2034, with the most significant increase in the 19-44 age group, a key demographic for epilepsy surgery.⁵
3. **Promote CMS reimbursement** for using ICD-10-CM Social Determinants of Health (SDOH) Z codes to address broader health care needs in epilepsy care.
4. **Push for policy changes** supporting CMS reimbursement for delivering ESM as a standard of care. Partner with NAEC, AANN, and NASW to educate providers, trainees, and patients about accessible, telehealth-based ESM programs.
5. **Promote reimbursement for self-management education** delivered by nurses, supported by federal, state, and private payors. Develop and evaluate curricula for epilepsy nurse educators based on competencies being finalized by the ILAE Nursing Section.
6. **Engage individuals with epilepsy** in advocacy efforts to improve access to ESM and highlight the importance of policy changes that sustain these supports.
7. **Support research funding** to expand access to culturally adapted, evidence-based ESM programs for all people with epilepsy (see above).
8. **Advocate for insurance coverage** for community health workers (CHWs) who screen for and address social determinants of health in epilepsy care.
9. **Support payment authorization** for services provided by epilepsy-certified CHWs, including care coordination, seizure education, and medication adherence counseling.
10. **Collaborate with CHW organizations** to expand accredited epilepsy-specific training for CHWs in diverse communities and clinical settings.
11. **Champion epilepsy-specific CHW training** and certification to clearly define CHW roles in clinical epilepsy care teams. Expand access to virtual, accredited training through AES initiatives.
12. **Advocate for home nursing visits** for individuals with epilepsy who are homebound, enabling nurses to assess and address health disparities that may jeopardize patient safety and prevent unnecessary ER visits.
13. **Partner with city, county, and state public health departments** to ensure epilepsy is included in community and public health programs.
14. **Collaborate with pharmacy organizations** to advocate for pharmacists' recognition as integral health care providers in epilepsy care.
15. **Advocate for access to driving and travel assistance devices** to support individuals with epilepsy in maintaining independence and mobility.

Education-related Recommendations

1. **Expand the APP workforce** trained in epilepsy care and education. APPs work across the care continuum, including prescribing medication, managing epilepsy monitoring units, post-surgery care, outpatient services, and high-risk situations like pregnancy. They are crucial in educating patients, families, teachers, and first responders about epilepsy.
2. **Develop a curriculum for Neurology APPs** specializing in epilepsy care, fostering more comprehensive provider training and enhancing care delivery.
3. **Formalize the role of epilepsy education nurses and other APPs** in clinical and community settings. Nurses, the largest health care workforce, are crucial to educating patients and caregivers, but this role is often undervalued and unsupported. Establishing an official role for nurses in epilepsy education would help ensure that patients and families receive equitable and comprehensive care, particularly in managing epilepsy self-care.
4. **Train nurses and APPs** to screen for social determinants of health (SDOH) and tailor care to effectively meet individual needs.
5. **Collaborate with nursing and APP schools and professional organizations** to integrate epilepsy education into curricula and continuing education programs. Currently, epilepsy and seizures are minimally covered in nursing and other APP education, except for those affiliated with epilepsy centers. Partnerships with professional nursing organizations, especially those outside of neurology, can help close the knowledge gap and reduce disparities in care.
6. **Hold a symposium on epilepsy health care disparities** at each AES annual meeting

References

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Appendix A: AES/ILAE-NA Joint Task Force for Epilepsy Disparities Members

Task force co-chairs:

Jaideep Kapur, MD, PhD, FAES, University of Virginia
William H. Theodore, MD, FAES, National Institute of Neurological Disorders and Stroke (NINDS)

Task force members:

Dave Clarke, MBBS, FAES, University of Texas at Austin
Mill Etienne, MD, FAES, Bon Secours Medical Group
Camilo Gutierrez, MD, FAES, University of Maryland Medical Center
Barbara C. Jobst, MD, Dr. med, FAES, Geisel School of Medicine at Dartmouth
Emily Johnson, MD, FAES, Johns Hopkins Medical Center
Sucheta Joshi, MD, FAES, Keck School of Medicine of USC
Omar Khan, MD, FAES, United States Department of Veterans Affairs
Elaine T. Kiriakopoulos, MD, MPH, MSc, Geisel School of Medicine at Dartmouth
David M. Labiner, MD, FAES, University of Arizona
Fred A. Lado, MD, PhD, FAES, Northwell Health
Alain Lekoubou Looti, MD, MS, Penn State University
Daniel H. Lowenstein, MD, University of California San Francisco
Karen Parko, MD, FAES
Annapurna Poduri, MD, MPH, FAES, Boston Children's Hospital
Ellen Riker, MHA, National Association of Epilepsy Centers (NAEC)
Renée Shellhaas, MD, MS, FAES, Washington University in St. Louis
Joseph I. Sirven, MD, FAES, Mayo Clinic
Karen Skjei, MD, FAES, The El Paso Center for Seizures and Epilepsy
John M. Stern, MD, MA, FAES, Geffen School of Medicine at UCLA
Timothy E. Welty, PharmD, FAES, Drake University
Shawna L. Strickland, PhD, CAE, RRT, American Epilepsy Society (AES)
Adam Eickmeyer, MPH, American Epilepsy Society (AES)