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Epilepsy Across the Spectrum: Promoting Health and Understanding

IOM Committee on the
Public Health Dimensions of the Epilepsies



INSTITUTE OF MEDICINE
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IOM Committee

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Study Sponsors

Department of Health and Human Services (HHS) sponsors:

- Administration on Developmental Disabilities
- Center for Devices and Radiological Health (FDA)
- Center for Drug Evaluation and Research (FDA)
- National Center for Chronic Disease Prevention and Health Promotion (CDC)
- National Center on Birth Defects and Developmental Disabilities (CDC)
- Eunice Kennedy Shriver National Institute of Child Health and Human Development (NIH)
- National Institute of Mental Health (NIH)
- National Institute of Neurological Disorders and Stroke (NIH)
- National Institute on Aging (NIH)
- Office of the Assistant Secretary for Health
- Office of the Assistant Secretary for Planning and Evaluation
- Office on Women's Health

Vision 20-20 nonprofit organization sponsors:

- American Epilepsy Society (AES)
- Citizens United for Research in Epilepsy (CURE)
- Dravet.org
- Epilepsy Foundation
- Epilepsy Therapy Project (ETP)
- Finding a Cure for Epilepsy and Seizures (FACES)
- Hemispherectomy Foundation
- International League Against Epilepsy (ILAE)
- National Association of Epilepsy Centers (NAEC)
- Preventing Teen Tragedy
- Rasmussen's Encephalitis (RE) Children's Project
- Tuberous Sclerosis Alliance (TSA)

Statement of Task Highlights

The IOM committee was asked to conduct a study and prepare a report to recommend priorities in public health, health care and human services, and health literacy and public awareness for the epilepsies and to propose strategies to address these priorities. The study focuses on the following four topic areas:

- public health surveillance, collection, and data integration;
- population and public health research;
- health policy, health care, and human services; and
- patient, provider, and public education.

Timeline

- January 2011 – First committee meeting
- March 2011 – Committee meeting and public workshop on public health surveillance, population health research, and data collection
- June 2011 – Committee meeting and public workshop on health care quality and access and education of patients, families, and providers
- September and November 2011 – Committee meetings
- January to March 2012 – National Academies' Report Review
- March 30, 2012 - Report release

Epilepsy – Definition

- **Seizure** – disturbances in the electrical activity of the brain
- **Epilepsy** – two or more unprovoked seizures separated by at least 24 hours
- Epilepsy is a **spectrum of disorders**:
 - Many different types of seizures
 - Many causes
 - Many syndromes and types of epilepsy

Terminology

The committee believes the term “epileptic” should be discontinued because it has negative connotations.

The committee suggests using terms such as:

- “seizure medications” (to replace “anti-epileptic drugs”)
- “epilepsy seizures” (to replace “epileptic seizures”)

Magnitude

- 2.2 million people in the United States and more than 65 million people worldwide have epilepsy;
- 150,000 new cases of epilepsy are diagnosed in the United States annually;
- 1 in 26 people in the United States will develop epilepsy at some point in their lifetime;
- Children and older adults are the fastest-growing segments of the population with new cases of epilepsy;
- Epilepsy is the fourth most common neurological disorder in the United States after migraine, stroke, and Alzheimer's disease

Cross-Cutting Themes

- A common and complex neurological disorder
- Often affects quality of life
- Whole-patient perspective needed
- Effective treatments available but access falls short
- Data needed to improve epilepsy knowledge and care and to inform policy
- Strengthen health professionals' education
- Bolster education efforts for people with epilepsy and their families
- Eliminate stigma

Increase the Power of Epilepsy Data

At present, public health researchers, policy makers, and advocates are “flying blind” due to the lack of adequate epilepsy surveillance data.

Recommendation 1

Validate and Implement Standard Definitions and Criteria for Epilepsy Case Ascertainment, Health Care and Community Services Use and Costs, and Quality-of-Life Measurement

CDC, in collaboration with professional organizations and other federal entities should fund demonstration projects to validate and implement standard definitions for epilepsy case ascertainment, health care and community services use and costs, and measures of quality of life for use in different data collection systems and for different specific objectives.

Once validated, these definitions and criteria should be adopted by funding agencies and used in surveillance and research that is the basis for planning and policy making.

Recommendation 2

Continue and Expand Collaborative Surveillance and Data Collection Efforts

CDC should continue and expand its leadership in epilepsy surveillance and work with relevant stakeholders. Surveillance should be funded that uses large, representative samples to determine the overall incidence and prevalence of epilepsy—and mortality—over time as well as in specific populations. Data collection efforts should:

- Expand epilepsy questions in population health surveys.
- Include epilepsy data in existing registries for comorbid conditions.
- Standardize the practices of coroners and medical examiners and work toward a national epilepsy-related death registry.
- Explore the linkage and use of emerging data collection and sharing partnerships using electronic repositories.
- Include epilepsy data in future longitudinal studies.

Prevent Epilepsy

Gaps in knowledge about epilepsy's risk factors, comorbidities, and outcomes limit the ability of programs to prevent epilepsy and its consequences.

Recommendation 3

Develop and Evaluate Prevention Efforts for Epilepsy and Its Consequences

CDC should partner with other stakeholders to develop and evaluate culturally appropriate and health literate prevention efforts that focus on:

- preventing neurocysticercosis in high-risk populations;
- continuing prevention efforts for established risk factors of epilepsy (e.g., traumatic brain injury, stroke, brain infections such as meningitis);
- preventing continued seizures in people with epilepsy and depression;
- reducing felt stigma; and
- preventing epilepsy-related causes of death, including accidents and injuries, SUDEP, and suicide.

Improve Health Care

While significant progress has been made in treating some types of epilepsy, much remains to be done to improve quality, access, and value of health care for people with epilepsy. Gaps include delays in diagnosis and referral, disparities in access to care for underserved and rural patients, and challenges in co-management of patients between primary care and specialty providers.

Recommendation 4

Improve the Early Identification of Epilepsy and Its Comorbid Health Conditions

AES and AAN should lead a collaborative effort with the wide range of relevant federal agencies and professional organizations to:

- Develop and validate screening tests for early identification of epilepsy in at-risk populations.
- Establish and disseminate a standard screening protocol for comorbidities with currently approved screening tests.
- Establish and disseminate a screening tool for early identification of patients with persistent seizures to lead to earlier referrals to an epileptologist.

Recommendation 5

National Quality Measurement and Improvement Strategy

AES, in conjunction with other professional organizations, should initiate the development of a national quality measurement and improvement strategy for epilepsy care.

The strategy should:

- develop and implement a plan to disseminate existing clinical guidelines;
- define performance metrics for epilepsy care;
- continue the implementation of a set of performance metrics that includes patient-generated measures; and
- conduct demonstration projects to validate performance metrics.

Recommendation 6

Establish Accreditation of Epilepsy Centers and an Epilepsy Care Network

NAEC and the AES should collaborate with relevant organizations to establish accreditation criteria and processes with independent external review mechanisms for accreditation of epilepsy centers.

Accredited epilepsy centers should work together to form an Epilepsy Care Network that includes data sharing, clinical trial and other research networking, professional education, and other collaborative activities.

Improve Health Professional Education

Gaps exist in health professionals' knowledge and skills in how to treat and care for people with epilepsy and its associated health conditions.

Recommendation 7

Improve Health Professional Education About the Epilepsies

AES and AAN should collaborate with relevant organizations to ensure that health professionals are sufficiently knowledgeable and skilled. These organizations should:

- Define essential epilepsy knowledge and skills.
- Conduct surveys to identify knowledge gaps.
- Evaluate existing materials and learning opportunities.
- Develop interactive materials and tools for integration into existing curricula and programs.
- Ensure that materials and programs reflect current research, clinical guidelines, and best practices.
- Explore and promote the use of innovative interdisciplinary approaches.
- Disseminate educational materials and tools widely.

Improve Quality of Life

Living with epilepsy is about much more than seizures. For people with epilepsy, the disorder is often defined in practical terms, such as challenges in school, uncertainties about social and employment situations, limitations on driving a car, and questions about independent living. At the same time, they are faced with health care and community services that are often fragmented, uncoordinated, and difficult to obtain.

Recommendation 8

Improve the Delivery and Coordination of Community Services

CDC and other epilepsy organizations, should partner with community service providers and epilepsy centers to enhance and widely disseminate educational and community services for people with epilepsy. Specific attention should be given to identifying needs and improving community services for underserved populations. These efforts should:

- Link people to local and regional resources.
- Develop innovative partnerships with organizations working with related diseases or disorders.
- Conduct pilot studies of academic achievement interventions.
- Maintain effective transportation, employment, and housing programs.
- Identify evidence-based best practices in employment programs.
- Develop best practices for coordination of health care and community services.
- Provide a 24/7 nonmedical help line.
- Develop educational opportunities for community service providers.

Improve Education for People with Epilepsy and Their Families

Education helps people with epilepsy and their families adapt to life with epilepsy, develop self-confidence, and competently manage the disorder and its comorbidities. However, access to resources and programs that are accurate, up-to-date, easy to understand, and linguistically and culturally appropriate is inconsistent.

Recommendation 9

Improve and Expand Educational Opportunities for Patients and Families

To ensure that people with epilepsy and their families have access to accurate, clearly communicated educational materials and information, epilepsy organizations should:

- Evaluate epilepsy websites and their educational resources.
- Develop a central website with links to other online resources.
- Ensure resources are up-to-date, effective, and reflect current science.
- Engage people with epilepsy in the development of online resources.
- Support the development and use of self-management and educational programs.
- Engage EF affiliates, epilepsy centers, and health care systems and providers to disseminate resources and self-management tools.
- Explore the development of a certificate program for epilepsy educators.

Raise Public Awareness

Public misperceptions and misinformation about epilepsy have persisted over centuries and continue to exist. Stigma and internalized fears of discrimination and prejudice affect the quality of life of people with epilepsy.

Recommendation 10

Inform Media to Improve Awareness and Eliminate Stigma

CDC and other Vision 20-20 organizations should support and bolster programs that provide information to the media to improve public knowledge and combat stigma. Efforts should:

- Promote frequent, accurate, and positive story lines about characters with epilepsy.
- Encourage high-profile individuals with epilepsy to speak openly.
- Establish partnerships with stakeholders that represent related conditions associated with stigma.
- Continue to work with media on news and human interest stories about epilepsy.
- Disseminate regular updates on research and medical advances to journalists and policy makers.

Recommendation 11

Coordinate Public Awareness Efforts

EF and CDC should lead a collaborative effort with relevant organizations to educate the public through awareness efforts, promotional events, and educational materials and should:

- Establish an advisory council.
- Develop shared messaging that emphasizes the common and complex nature of the epilepsies.
- Explore the feasibility of an ongoing, coordinated, large-scale, multimedia, multiplatform, sustainable public awareness campaign.
- Ensure that all awareness campaigns include:
 - consideration of health literacy, cultural appropriateness, and demographics of target audiences;
 - rigorous formative research and testing throughout the campaign; and
 - appropriate evaluation and follow-up.

Strengthen Stakeholder Collaboration

Epilepsy advocacy and research organizations and government agencies are working together to create a strong, united voice for change; to advance research; and to improve health care and human services for people with epilepsy and their families.

Recommendation 12

Continue and Expand Vision 20-20 Working Groups and Collaborative Partnerships

The members of Vision 20-20 should continue their efforts and expand ongoing working groups that communicate regularly, identify common goals, develop strategic plans, and, when possible, carry out joint activities. The working groups should focus on:

- health policy, health reform, and advocacy;
- surveillance and epidemiologic and health services research;
- health care and community resources and services;
- education of health professionals;
- education of people with epilepsy and their families; and
- public education and awareness.

Engage People with Epilepsy and Their Families

Among the most persuasive advocates and educators are people with epilepsy and their families who are willing to speak out to provide a more complete picture of the disorder and its impact.

Recommendation 13

Engage in Education, Dissemination, and Advocacy for Improved Epilepsy Care and Services

People with epilepsy and their families should, to the extent possible:

- become informed about epilepsy and actively participate in and advocate for quality health care and community services;
- discuss best options for care with health care providers;
- consider participation in research;
- engage with community professionals to educate them about epilepsy and ensure that needed services and accommodations are provided;
- talk openly, when possible, about epilepsy and its impact on life;
- actively participate in support networks; and
- work with nonprofit organizations to raise awareness and participate in advocacy efforts.

Thank You!

- **Questions? Email:**
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