



Introduction to Institute of Medicine Report

Epilepsy Across the Spectrum: Promoting Health and Understanding

On March 30, 2012, the Institute of Medicine (IOM) released a landmark report on the epilepsies. Entitled, "*Epilepsy Across the Spectrum: Promoting Health and Understanding*" the report highlighted numerous gaps in the knowledge and management of epilepsy and recommended actions for improving the lives of those with epilepsy and their families and for promoting better understanding of the disorder.

The Institute of Medicine is one of four organizations (National Academy of Sciences, National Academy of Engineering, National Research Council, and IOM) that comprise the National Academies. Established by Congress in 1863, and signed by President Lincoln, the National Academies is a non-governmental institution that brings together individuals with a variety of scientific and technological expertise to address issues considered of national importance. Each panel consists of approximately 10-20 members from within the field under investigation as well as in related areas. The panels compile available scientific information and testimonies from members of the scientific community and the public to determine what exists on a chosen topic and make recommendations as to what can and should be done. The report receives review by a second group of independent experts anonymous to the committee before being revised and transmitted to the agency or organizations that sponsored the study and then released to the public. The resulting reports are considered highly significant and can serve to guide future policies.

The IOM was asked by 24 sponsoring epilepsy organizations (half federal agencies and half from Vision 20-20, a coalition of nonprofit organizations focusing on epilepsy research, care, services, education and advocacy*) to examine the public health dimensions of the epilepsies, focusing on four areas:

- Public health surveillance and data collection
- Population and public health research
- Health policy, health care and human services
- Education for providers, people with epilepsy and their families, and the public.

Specific questions being addressed were:

- How can the public health burden of epilepsy for patients and families be more accurately assessed?

- What priorities for future population health studies could inform treatment and preventions?
- How can the access to health and human services and the quality of care for people with epilepsy be improved?
- How can the education and training of professionals who work with people with epilepsy be improved?
- How can the understanding of epilepsy in patients and the general public be improved to create supportive communities?

The Statement of Task concentrated on the public health aspects rather than on biomedical research questions because the latter were considered covered by the National Institute of Neurological Diseases and Stroke (NINDS) through the Epilepsy Research Benchmarks, developed in 2000 and updated in 2007. The report was expected to have a largely domestic focus, yet identify major international issues.

Both the voluntary and governmental sponsors submitted over 150 names as recommendations for panel members. The seventeen final members had expertise in epilepsy care, health services research, epidemiology, public health surveillance, mental health services, health care services and delivery, health literacy, public health, education and communication. The panel was chaired by Mary Jane England, M.D. (Names of the Committee members can be found at the end of the attached summary.)

Three public meetings were held during the first six months of 2011. The first, in January in Washington, D.C., concentrated on the background and context for the study, including: the adequacy of existing epidemiological and public health surveillance data; quality of and access to care from the patient/family and provider perspectives; and what is needed to educate patients, providers and the public. This was followed by two workshops, in March in Los Angeles, and in June, in Washington, DC, which addressed the specific questions in the Statement of Task. At all three meetings, members of the public testified, as did representatives of the scientific and medical communities. More than 80 people provided formal presentations and personal stories and the committee also heard from individuals via email. Following the three meetings, the panel continued to meet in sessions closed to the public to examine the data and testimonies and write their report. As Dr. England said in her introduction, "The committee's work was greatly enhanced by the testimony and presentations provided by people with epilepsy, their family members and friends, epilepsy researchers, and health professionals. Their compelling insights into the challenges that epilepsy imposes spurred the committee toward developing practi-



cal, action-oriented recommendations to improve the lives of people with epilepsy.” (p. x) The report was reviewed independently in draft form by individuals with diverse perspectives and technical expertise. Their comments and suggestions were taken into consideration by the committee.

The final report is nearly 540 pages in length, including appendices. It has been published in book form but is also available for free PDF download through the National Academies Press: www.nap.edu. The emphasis is on epilepsy as a spectrum disorder, composed of many syndromes and seizure types that vary in severity, involve multiple co-morbidities, and cross the age span in the United States and around the world. The report emphasizes five key messages (also from Dr. England’s introduction, p. x):

- Epilepsy is a common and a complex neurological disorder that affects health and quality of life.
- Effective treatments are available for many types of epilepsy, but timely referrals and access to these treatments fall short. Better data from surveillance and research could improve epilepsy care and prevention.
- Many health professionals need to be better informed about epilepsy.
- Education efforts for people with epilepsy and their families need to be thorough and sensitive to health literacy and cultural considerations.

- The stigma of epilepsy has to be eliminated.

These messages are incorporated into thirteen specific recommendations, which are detailed in the attached summary. The recommendations can be divided into three major topic areas, each of which contain detailed sub-recommendations:

- Recommendations #1-3 Surveillance and Prevention
- Recommendations #4-7 Healthcare Providers
- Recommendations #8-11, 13 Patients, Families and Education
- Recommendation #12 Vision 20-20 Working Groups and Collaborative Partnerships.

Each recommendation also identifies the organization(s), which should take primary responsibility for its implementation. These can be found in the attached summary.

This report is the most comprehensive attempt to address issues facing people with epilepsy, their families and those who provide care. It identifies current gaps in knowledge, care and education. It provides research priorities to address these gaps and recommends specific actions to follow to achieve short- and long-term improvements for people with epilepsy.

by Margaret Jacobs and Frances E. Jensen, MD

The epilepsy patient and professional communities thank the Committee and the IOM staff for the enormous efforts that went into this report.

***Vision 20-20 Sponsors:**

- American Epilepsy Society
- Citizens United for Research in Epilepsy
- Dravet.org
- Epilepsy Foundation
- Epilepsy Therapy Project
- Finding A Cure for Epilepsy and Seizures
- Hemispherectomy Foundation
- International League Against Epilepsy
- National Association of Epilepsy Centers
- Preventing Teen Tragedy
- Rasmussen’s Encephalitis Children’s Project
- Tuberous Sclerosis Alliance

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- National Institute of Mental Health
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- Office of the Assistant Secretary for Health
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