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## A Summary of the Institute of Medicine Report<sup>1</sup>:

### Epilepsy Across the Spectrum: Promoting Health and Understanding

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### Abstract

Approximately 1 in 26 people will develop epilepsy at some point in their lives. Although epilepsy is one of the nation's most common neurological disorders, public understanding is limited. A complex spectrum of disorders, epilepsy affects an estimated 2.2 million people in the United States. Living with epilepsy is about more than just seizures; it is often defined in practical terms, such as challenges, uncertainties, and limitations in school, social situations, employment, driving, and independent living. People with epilepsy are also faced with health and community services that are fragmented, uncoordinated, and difficult to obtain. The Institute of Medicine's report, *Epilepsy Across the Spectrum: Promoting Health and Understanding* [1], examines the public health dimensions of epilepsy with a focus on: (a) public health surveillance and data collection and integration; (b) population and public health research; (c) health policy, health care, and human services; and (d) education for providers, people with epilepsy and their families, and the public. The report's recommendations range from the expansion of collaborative epilepsy surveillance efforts, to the independent accreditation of epilepsy centers, to the coordination of

<sup>1</sup>This summary is an excerpted version of the report's Summary chapter and Chapter 9. Full-text versions of these chapters and the entire report are available as PDFs at [www.iom.edu/epilepsy](http://www.iom.edu/epilepsy). The members of the report's authoring committee, the Committee on the Public Health Dimensions of the Epilepsies, are listed at the end of this article.

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public awareness efforts, to the engagement of people with epilepsy and their families in education, dissemination, and advocacy activities. Given the current gaps in epilepsy knowledge, care, and education, there is an urgent need to take action—across multiple dimensions—to improve the lives of people with epilepsy and their families. The realistic, feasible, and action-oriented recommendations in this report can help enable short- and long-term improvements for people with epilepsy.

## Keywords

epilepsy; public health; health policy; surveillance; health care; education; quality of life; stigma

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Characterized by seizures that are unpredictable in frequency, epilepsy is a common neurological disorder that affects people of all ages, with onset most often occurring in childhood and older adulthood [2, 3]. Epilepsy is a spectrum of disorders<sup>2</sup>—the epilepsies—with a range of severities, widely differing seizure types and causes, an array of coexisting conditions, and varying impacts on individuals and their families. Epilepsy is the fourth most common neurological disorder in the United States after migraine, stroke, and Alzheimer’s disease [4]; it is estimated that 150,000 new cases are diagnosed in the United States annually [4] and that 1 in 26 individuals will develop epilepsy at some point in their lifetime [5].

While seizures are well controlled with medications and other treatment options for the majority of people with epilepsy [6], the impact of epilepsy goes well beyond the seizures. The challenges facing the estimated 2.2 million people with epilepsy in the United States [4] include having access to high-quality health care, becoming informed about and coordinating health care and community services, and dealing with stigma and common public misunderstandings. Living with epilepsy, particularly for people with refractory seizures, can involve challenges in school, uncertainties about social and employment situations, limitations on driving, and questions about independent living. Epilepsy can impose an immense burden on individuals, families, and society; the estimated annual direct medical cost of epilepsy in the United States is \$9.6 billion [7], which does not consider community service costs or indirect costs from losses in quality of life and productivity (these indirect costs are estimated to constitute the majority of the cost burden of epilepsy [8]). Further, epilepsy is associated with substantially higher rates of mortality than experienced in the population as a whole [9], with sudden unexpected death in epilepsy (SUDEP) being the most common cause of epilepsy-related deaths [10]. Estimates indicate that 10 years of life are lost for people whose epilepsy has a known cause and 2 years are lost for people with epilepsy from an unknown cause [11]. Additionally, estimates of the number of people with epilepsy who die of SUDEP range from 1 of every 10,000 newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery [12].

A significant challenge for people with epilepsy, as well as for the epilepsy field, has been the multitude of ways that epilepsy is perceived and, in many cases, misperceived. The centuries of misperceptions and misinformation about epilepsy have resulted in people with epilepsy being stigmatized [13]. As a consequence, people with epilepsy and their families may be faced with a lack of social support from extended family members; feelings of parental guilt; social isolation, embarrassment, and fear; and discrimination. Although

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<sup>2</sup>This summary does not include definitions of terminology used throughout the report; discussion of various epilepsy disorders, syndromes, or comorbidities; or explanations of the derivation of statistics that are presented. In-depth discussion of these areas and the supporting evidence for the committee’s recommendations and research, along with complete reference lists, appear in subsequent chapters of the report.

efforts are being made to correct these misconceptions and to better inform people about the epilepsies, doing so remains a challenge.

Throughout this report, the committee emphasizes the ways in which epilepsy is a spectrum disorder. Epilepsy comprises more than 25 syndromes and many types of seizures that vary in severity [14]. Additionally, people who have epilepsy span a spectrum that includes men and women of all ages and of all socioeconomic backgrounds and races/ethnicities, who live in all areas of the United States and across the globe. The impacts on physical health and quality of life encompass a spectrum as well, with individuals experiencing different health outcomes and having a range of activities of daily living that may be affected, including driving, academic achievement, social interactions, and employment. For some people, epilepsy is a childhood disorder that goes into remission (although the seizures may have lifelong consequences), while for others it is a lifelong burden or a condition that develops later in life or in response to an injury or other health condition. These many complexities of epilepsy make it a challenging health condition to convey to the general public to promote understanding and alleviate stigma.

## SCOPE OF WORK

In 2010, the Institute of Medicine (IOM) was asked to examine the public health dimensions of the epilepsies with a focus on four areas:

- public health surveillance and data collection and integration;
- population and public health research;
- health policy, health care, and human services; and
- education for providers, people with epilepsy and their families, and the public.

The committee was asked not to examine biomedical research priorities because the Epilepsy Research Benchmarks, developed in 2000, continue to be updated by the National Institute of Neurological Disorders and Stroke and collaborating agencies and organizations [15]. To accomplish its task the IOM convened the Committee on the Public Health Dimensions of the Epilepsies, which comprised 17 members with 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 communications. The IOM study had 24 sponsors: 12 federal agencies and 12 nonprofit organizations. Many of these sponsors are part of Vision 20-20, a coalition that focuses on epilepsy research, care, services, education, and advocacy efforts.

## A VISION FOR THE FUTURE

Throughout its report, research priorities, and recommendations, the committee describes its vision for achieving a better understanding of the public health dimensions of the epilepsies and for promoting health and understanding. The committee's vision for the future involves

- epilepsy surveillance efforts that include the development of active and passive data collection systems that are coordinated, comprehensive, accurate, and timely and that follow standardized methodologies to obtain valid measurement;
- enhanced prevention programs and well-designed epidemiologic studies that highlight areas ripe for further preventive efforts;
- access to patient-centered care for all individuals with epilepsy that incorporates a comprehensive and coordinated approach to both health and community services in

order to meet the range of physiological, psychological, cognitive, and social needs;

- care and community resources that reflect current research findings and best practices in clinical care, education, and coordination in order to provide each person with the best care, in the right place, at the right time, every time;
- a health care workforce sufficiently prepared to provide every person experiencing seizures with effective diagnostic, treatment, and management services that are delivered through team-based approaches to care and that take into consideration health literacy, cultural, and psychosocial factors;
- access to relevant and usable knowledge for all individuals with epilepsy and their families that meets their individual needs and allows them to participate effectively in patient-centered care, to achieve optimal self-management of their epilepsy, and to attain the highest possible physical and emotional well-being; and
- an improved public understanding of what epilepsy is—and is not—that supports the full inclusion of people with epilepsy at all levels of society and that eliminates stigma.

Much of this vision resonates with broad goals of chronic disease management, and to achieve it, collaborative efforts with professionals and organizations involved with other conditions, especially those that are comorbidities of epilepsy, will help to maximize resources and progress.

Given the current gaps in epilepsy knowledge, care, and education, the committee believes there is an urgent need to take action—across multiple dimensions—to improve care and services for people with epilepsy and their families. With this goal in mind, the committee examined the available evidence on surveillance, epidemiology, prevention, health care, community services, and education programs and campaigns and then developed recommendations and priorities for further research to improve these fields and the programs relevant to epilepsy. The following evidence-based recommendations aim to present realistic, feasible, and action-oriented steps that a variety of stakeholders can take to enable short- and long-term improvements for people with epilepsy. The research priorities provide directions for further developing the evidence base.

## **INCREASING THE POWER OF DATA AND PREVENTING EPILEPSY**

Comprehensive, timely, and accurate epilepsy surveillance data are needed to provide a better understanding of the burden of the disorder, its risk factors and outcomes, and health services needs. Current data sources provide a patchwork of surveillance activity that substantially limits the ability to understand, plan, and guide the provision of policies related to health care for people with epilepsy. Improvements are necessary to enable informed and effective action in prevention; health care quality, access, and value; quality of life and community services; and education and awareness. At present, public health researchers, policy makers, and advocates are “flying blind” due to the lack of adequate epilepsy surveillance data [16]. The nation’s data system for epilepsy can be strengthened by the collection of epilepsy-specific data and through collaborations with existing and emerging data-sharing efforts across health care providers and with other chronic diseases and disorders.

Ideally, a coordinated and comprehensive surveillance system for the epilepsies would collect data in several ways. To shed light on national trends and patient outcomes, surveillance would be longitudinal and nationally representative, enabling subgroup analysis by epilepsy type, population characteristics, and environmental factors. The nation’s data

collection efforts should be sufficiently robust to support active research projects on specific topics, but large amounts of data also can be collected passively, including through the increasing use of electronic health records, where well-designed databases can be mined for new insights. Given the ambition of this goal and the current economic environment, the committee has identified several priority areas that need attention, in order to improve the collection and utilization of epilepsy data over time:

- Surveillance data must be up to date, representative of the U.S. population, and collected using standardized methods to ensure validity and comparability across studies.
- Multiple data sources have to be linked to capture all of the necessary data on people with epilepsy and to avoid duplicate counting. New data sources, including those that may develop under health care reform, need to be reviewed for their potential to contribute to an understanding of epilepsy.
- Once more robust data are available, analyses should be performed to determine overall incidence, prevalence, health disparities, services use and costs, quality of and access to care, risk factors, comorbidities, health status, and quality-of-life outcomes, as well as data for specific subgroups.

A variety of efforts is needed to accomplish comprehensive surveillance of the epilepsies, close current knowledge gaps, and adequately inform policy makers, public health agencies, health care providers, and the general public. Coordinated action on multiple fronts will ensure the collection of epilepsy-related data from a range of data sources.

The strengthened usefulness and diversity of data, as described above, would facilitate the identification of risk factors for epilepsy, comorbidities, and adverse events. Risk factor identification is an important first step in designing programs to prevent epilepsy and its most serious consequences. At present, many research questions and gaps remain where more complete information could provide a sound basis for prevention, including in public health, clinical care, education programs, and community efforts. Neurocysticercosis<sup>3</sup> is a growing concern in the United States [17-22] and represents a known risk factor for epilepsy [23]—one in which fundamental improvements in education and sanitary measures could decrease a specific infection [24] that causes epilepsy. Continued intervention efforts are needed to prevent the occurrence of traumatic brain injury (TBI), through mechanisms such as the use of seatbelts, to prevent TBI associated with motor vehicle accidents, as well as helmets, including improved helmet design, to reduce the occurrence and severity of TBI in sports and military combat. In addition, progress in the prevention of epilepsy's other risk factors—such as stroke, through targeted efforts to reduce risk factors, and brain infections such as meningitis, through sustained vaccination programs—will likely result in fewer new cases of epilepsy. Further options for primary prevention may come to light if epidemiologic studies identify other risk factors for epilepsies whose etiologies are currently unknown. Secondary prevention of seizures may be possible through the use of antidepressants. Prevention efforts are needed that target felt stigma and specific risk factors for death due to accidents and suicide among people with the epilepsies. Additionally, risk factors for SUDEP have been described [e.g., 25-29], but interventions to reduce the occurrence of this devastating outcome have not been evaluated in those at highest risk.

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<sup>3</sup>Neurocysticercosis is a parasitic brain infection that can cause epilepsy (see Chapter 3 of the report; [www.iom.edu/epilepsy](http://www.iom.edu/epilepsy)).

## 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**

The Centers for Disease Control and Prevention (CDC), in collaboration with professional organizations (e.g., the American Epilepsy Society [AES] and International League Against Epilepsy [ILAE]) and other federal entities, including the Centers for Medicare and Medicaid Services, Department of Defense, Veterans Administration, and National Institutes of Health (NIH), 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, which is the basis for planning and policy making.

## RECOMMENDATION 2

### **Continue and Expand Collaborative Surveillance and Data Collection Efforts**

The CDC should continue and expand its leadership in epilepsy surveillance and work with state and local public health researchers, academic researchers, and other relevant stakeholders (including other agencies within the Department of Health and Human Services). Surveillance efforts should be funded that use large, representative samples to determine the overall incidence and prevalence of epilepsy—and mortality—over time as well as in specific populations (e.g., different types of epilepsy, ages, genders, races/ethnicities, socioeconomic statuses). Data collection efforts should include the following:

- Population health surveys should expand their questions about epilepsy, its comorbidities, and health care services use and include these questions more frequently and consistently.
- Existing registries for comorbid conditions, such as the Surveillance, Epidemiology, and End Results program and state-based cancer registries, state-based Alzheimer's registries, and the Interactive Autism Network, should collect data on epilepsy.
- Efforts should be expanded to standardize the practices of coroners and medical examiners in evaluating and recording cause of death in people with epilepsy with the goal of working toward a national epilepsy-related death registry.
- Pilot projects should explore the linkage and use of emerging data collection and sharing partnerships using electronic health records and other electronic repositories (e.g., all-payer claims databases, regional health information organizations, the Health Maintenance Organization Research Network, NIH's Health Care Systems Research Collaboratory, the Health Care Cost Institute) for epilepsy surveillance and research.
- Epilepsy-specific data should be included in the NIH National Children's Study and future longitudinal studies.



## RECOMMENDATION 3

### Develop and Evaluate Prevention Efforts for Epilepsy and Its Consequences

The CDC should partner with the World Health Organization, ILAE, NIH, the Action Alliance for Suicide Prevention, and 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, sudden unexpected death in epilepsy (SUDEP), and suicide.

### IMPROVING HEALTH CARE

Improving the lives of people with epilepsy and their families, to a large extent, begins with access to high-quality, patient-centered health care that facilitates accurate diagnosis and effective treatments and management. The many challenges that people with epilepsy and their families face are so diverse, even from a medical point of view, that although treatment must continue to be held to high standards, it nevertheless should be tailored to individual patient needs and characteristics, and no single health professional discipline can provide all of the elements required for high-quality epilepsy care. Historically, persuading health professionals to work across professional boundaries has been difficult. One of the challenges for government and institutional policy makers will be to devise organizational structures and incentive systems that make it easy—even attractive—for people from multiple professions to work together.

Throughout this report, the committee has emphasized a number of important elements of epilepsy care including

- *patient centeredness*, recognizing that the “patient” may include the family, that people with epilepsy are more than their medical condition, and that quality-of-life factors are also important;
- *co-management* for patients with comorbid conditions whose care may cross specialty boundaries;
- *coordination*, involving a team of professionals across disciplines and sectors (e.g., housing, education, employment);
- *community orientation*, with the engagement of as many community resources as needed; and
- *education focused*, in order to improve the self-management skills of people with epilepsy and their family members, clinicians’ knowledge and skills, and the awareness and understanding of others who interact with people with epilepsy (e.g., teachers, social workers, emergency personnel).

Even in an ideal system of care, the epilepsies will remain complex to diagnose and treat. While significant progress has been made in developing seizure medications with fewer adverse effects, as well as in refining medical devices and surgical techniques for select types of epilepsy, much remains to be done to reduce the sometimes lengthy delays in diagnosis and referral to more advanced levels of care, to improve care for those with

refractory epilepsy, and to provide a better response to comorbidities, including mental health conditions. While this committee was asked not to explore biomedical research, over time there will be advances in this field that need to move into routine care in a timely and equitable fashion. No matter how specific epilepsy treatments have improved, currently care is not uniformly accessible due to geographic, economic, and other considerations; nor is it necessarily equitable, with troubling disparities suggested in the research that are based on racial/ethnic and socioeconomic factors [e.g., 30-32]. High-quality health care for epilepsy cannot be provided on a population basis until the problems of accessibility and equity are resolved.

An important element in quality care is access to specialized epilepsy centers, especially for people with refractory epilepsy. Epilepsy centers are vital in providing specialized epilepsy care and have the potential to build on their current efforts by forming a network for health professional education, clinical research, and data collection and analysis. To ensure the ongoing quality of their work, as well as appropriate recognition for it, the centers should develop a robust external accreditation process. A national quality measurement and improvement strategy for epilepsy should be developed and implemented. Standardization and implementation of quality metrics will hold health care providers accountable for adherence to practice guidelines and will allow people with epilepsy and their families to have more information in selecting care providers.

Expanding access either to specialized epilepsy care or to high-quality care in community settings is hampered by the shortage of clinicians with adequate knowledge and skill related to epilepsy and its comorbidities. Research suggests that primary care and specialist physicians alike have significant gaps in knowledge about epilepsy [e.g., 33-36]. Further, many types of health professionals, in addition to physicians, are involved in epilepsy care. These include nurses, nutritionists, pharmacists, psychologists, and clinical social workers. Health professionals need current knowledge about many aspects of the epilepsies: seizure recognition and diagnosis; prevention strategies and treatment options; associated risks, comorbidities, and safety concerns; necessary social services; psychosocial and quality-of-life factors; and the need to counter stigma, as well as the array of educational and community resources that may be available to and needed by individual patients. The specific types and depth of knowledge required vary across professions, depending on the roles, responsibilities, and scope of practice of the professionals and the specific settings in which they work.

## RECOMMENDATION 4

### Improve the Early Identification of Epilepsy and Its Comorbid Health Conditions

The AES and the American Academy of Neurology (AAN) should lead a collaborative effort with the wide range of relevant professional organizations (including primary care professional organizations) and federal agencies (including the CDC and Health Resources and Services Administration), and others that promote and disseminate screening programs to

- develop and validate screening tests for the early identification of epilepsy in at-risk populations (e.g., people with developmental disabilities; people with mental health conditions; people who have had a traumatic brain injury, brain tumor, or stroke);
- establish and disseminate a standard screening protocol for people with epilepsy that implements screening on a regular basis for comorbidities with currently approved screening tests (e.g., for bone disease, depression, generalized anxiety disorder); and



- establish and disseminate a screening tool for the early identification of patients with persistent seizures that would lead to earlier referral to an epileptologist for further diagnosis and treatment.

## RECOMMENDATION 5

### Develop and Implement a National Quality Measurement and Improvement Strategy for Epilepsy Care

The AES, in conjunction with other professional organizations involved in epilepsy care, education, and advocacy (including primary care professional organizations) should initiate the development of a national quality measurement and improvement strategy for epilepsy care. An independent organization with expertise in quality measurement and care should assist in the development of the national strategy, particularly the development of performance metrics. The national quality improvement strategy should

- develop and implement a plan to disseminate existing clinical guidelines and educate health professionals and people with epilepsy and their families about them;
- define performance metrics for epilepsy with specific attention to access to care for underserved populations, access to specialized care, co-management of care among all health care epilepsy providers, and coordination of care with other health care providers and community services organizations;
- continue the development and implementation of a set of performance metrics that includes patient-generated measures; and
- develop demonstration projects to validate performance metrics and test the feasibility of tracking outcomes of care.

## RECOMMENDATION 6

### Establish Accreditation of Epilepsy Centers and an Epilepsy Care Network

The National Association of Epilepsy Centers and the AES should collaborate with relevant organizations to establish accreditation criteria and processes with independent external review mechanisms for the 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.

- Independently accredited epilepsy centers should
  - emphasize patient-centered care that focuses on co-management approaches with primary care providers, mental health care providers, and other specialists;
  - ensure that community service providers are an integral part of the centers and actively collaborate with them to link people with epilepsy to services for all facets of the individual's health and well-being;
  - use standardized performance metrics for quality epilepsy care;
  - publicly report on a standard set of quality, outcome, and health services data;
  - provide onsite education and training for epilepsy specialists (e.g., technicians, nurses, researchers, physicians) as well as educational

opportunities, particularly continuing education, for other health and human services professionals in the community; and

○ serve as sites for pilot projects on innovative approaches to improving co-management and coordination of care, as well as health care quality, access, and value for people with epilepsy.

- The Epilepsy Care Network of Accredited Epilepsy Centers should
  - conduct collaborative clinical and health services research;
  - collect, analyze, and disseminate quality, outcome, and health services data from all of the accredited centers; and
  - collaborate and partner with state health departments and other health care providers to ensure coverage across rural and underserved areas through telemedicine, outreach clinics, and other mechanisms.

## RECOMMENDATION 7

### Improve Health Professional Education About the Epilepsies

The AES and AAN should collaborate with relevant professional organizations that are involved in the education of the wide range of health professionals who care for people with epilepsy to ensure that they are sufficiently knowledgeable and skilled to provide high-quality, patient-centered, interdisciplinary care. In their efforts to improve health professional education, these organizations should do the following:

- Define essential epilepsy knowledge and skills for the range of health professionals who care for people with epilepsy and their families.
- Conduct surveys of the relevant health professionals to identify knowledge gaps and information needs.
- Evaluate the efficacy and reach of existing educational materials and learning opportunities (e.g., websites, continuing education courses).
- Develop engaging and interactive educational tools, such as online modules, that meet specific learning needs and could be easily integrated into existing curricula and education programs.
- Ensure that educational materials and programs for health professionals reflect current research, clinical guidelines, and best practices. These educational materials and programs also should convey positive messages that reduce stigma and reinforce the need for (and skills associated with) clear health communication, which takes into account the culture and health literacy of the target audience.
- Explore and promote opportunities to expand the use of innovative interdisciplinary educational approaches, such as high-fidelity simulation.
- Disseminate educational materials and tools widely to health professional educators and other relevant professional associations and organizations.

## IMPROVING COMMUNITY RESOURCES AND QUALITY OF LIFE

Because of the range of seizure types and severities and the high rate of comorbid health conditions, the ways in which quality of life is affected by epilepsy vary widely. The burden of seizures and epilepsy, particularly severe forms of epilepsy, can be overwhelming for many people with epilepsy and their families. The social and emotional toll of care can place financial and emotional strains on marriages and families and can alter roles, relationships, and lifestyles. Many speakers at the committee's workshops emphasized that epilepsy—

regardless of its level of severity—creates life challenges because of the unpredictability of seizures. This report has examined the range of community services—daycare and school, employment, transportation, housing, sports and recreation, and others directed at family support—relevant to improving quality of life for people with epilepsy. The committee urges improvements to community services and programs to ensure that they are

- patient centered to meet the needs of the person with epilepsy;
- locally focused, taking into account the full range of resources in the area;
- easily accessible;
- thoroughly evaluated;
- closely linked to health care providers, particularly epileptologists and epilepsy centers; and
- innovative and collaborative in working with organizations and agencies focused on other neurological and chronic conditions or on similar service needs.

## RECOMMENDATION 8

### Improve the Delivery and Coordination of Community Services

The CDC, state health departments, and the Epilepsy Foundation, in collaboration with state and local Epilepsy Foundation affiliates and other relevant epilepsy organizations, should partner with community service providers and epilepsy centers to enhance and widely disseminate educational and community services for people with epilepsy that encompass the range of health and human services needed for epilepsy, its comorbid conditions, and optimal quality of life. These services include support groups; vocational, educational, transportation, transitional care, and independent living assistance; and support resources, including respite care for family members and caregivers. Specific attention should be given to identifying needs and improving community services for underserved populations. These efforts should

- support and expand efforts by the Epilepsy Foundation’s state and local affiliates and other organizations to link people with epilepsy and their families to local and regional resources, emphasizing active collaboration among affiliates in the same region or with similar interests;
- develop innovative partnerships and incentives to collaborate with organizations and public-private partnerships focused on other neurological and chronic diseases or disorders;
- conduct and evaluate pilot studies of interventions to improve the academic achievement of students with epilepsy;
- maintain effective private, state, and national programs that assist people with epilepsy regarding transportation, employment, and housing;
- develop and disseminate evidence-based best practices in employment programs for people with epilepsy;
- identify and disseminate best practices for the coordination of health care and community services, including programs using patient and parent navigators;
- provide a 24/7 nonmedical help line offering information on epilepsy and links to community resources (this effort should involve collaboration with similar efforts for related health conditions); and

- develop, disseminate, and evaluate educational and training opportunities (including interactive web-based tools) for community service providers focused on epilepsy awareness and seizure first aid training.

## **RAISING AWARENESS AND IMPROVING EDUCATION**

### **Patient and Family Education**

Research consistently demonstrates that many people with epilepsy do not have a solid understanding of basic information about their condition—how it is diagnosed, seizure precipitants or triggers, types of seizures, the purpose and potential side effects of seizure medications, safety concerns, and the risks and potential consequences of seizures [37]. Additionally, the diagnosis of epilepsy, although given to an individual, affects the entire family and its constellation of friendships and other relationships. At onset all are confronted with the immediate need to learn about the disorder, and their information needs continue throughout the course of treatment and management.

Education for people with epilepsy and their families plays an important role in adapting to life with epilepsy, developing self-confidence, and becoming competent in self-management, which entails being aware of one's own needs and being able to access resources to meet those needs [38]. Obtaining the requisite knowledge and skills related to epilepsy and its management can also promote optimal well-being and quality of life for people with epilepsy and their families, help prevent misconceptions about the disorder, and reduce concerns about stigma.

People with epilepsy and their families should

- receive and have access to up-to-date, accurate information about epilepsy, treatment options, and associated comorbidities and risks, including SUDEP, as well as information about available vocational and community resources and health care services upon diagnosis and throughout their care;
- have access to information that meets their specific needs and that is clearly written and communicated, appropriate for various health literacy levels, and linguistically and culturally appropriate;
- build knowledge and self-management skills, including how to solve problems, make decisions, use resources, develop partnerships with health care providers, and participate actively in patient-centered care; and
- have access to appropriate educational resources and opportunities regardless of their socioeconomic status, demographic group, culture, or geographic location.

## **RECOMMENDATION 9**

### **Improve and Expand Educational Opportunities for People with Epilepsy and Their Families**

To ensure that all people with epilepsy and their families have access to accurate, clearly communicated educational materials and information, the Epilepsy Foundation, the Epilepsy Therapy Project, the CDC, and other organizations involved in Vision 20-20 should collaborate to do the following:

- Conduct a formal evaluation of currently available epilepsy websites and their educational resources to ensure that they meet requirements of clear health communication and are linguistically and culturally appropriate for targeted audiences. This requires thorough testing of content with target audiences, including underserved groups, and revision as necessary.

- Develop a central, easily navigated website (“clearing house”) that provides direct links to websites containing current, accurate epilepsy-related information for individuals and their families. This centralized resource should be comprehensive; it should include concise, easy-to-understand descriptions of the information available on the linked websites and up-to-date contact information for epilepsy organizations; and it should be widely disseminated to health care providers and people with epilepsy and their families.
- Ensure that educational resources are up to date, are effective, and reflect the latest scientific understanding of the epilepsies and their associated comorbidities and consequences.
- Engage a wide and diverse spectrum of people with epilepsy and their families in the development of online educational resources to ensure that the content meets the specific needs of target audiences at the outset.
- Support the development, evaluation, replication, and expanded use of self-management and educational programs, including those developed through the Managing Epilepsy Well Network.
- Engage state and local Epilepsy Foundation affiliates, epilepsy centers, and health care systems and providers to expand the dissemination of available educational resources and self-management tools to people with epilepsy and their families.
- Explore the development of a formal, standardized certificate program for epilepsy health educators.

### Public Awareness and Knowledge

While surveys have suggested that attitudes regarding epilepsy have become less negative over time [39], it is not certain how contemporary attitudes compare and whether overall improvements in attitudes have affected behavior. Compelling testimony from families dealing with epilepsy and research on employment suggest that problems of stigma remain widespread. Efforts to increase public awareness and knowledge are motivated by the expectation that information that reduces misconceptions and misinformation will improve attitudes and, ultimately, behavior toward people with epilepsy and thereby reduce stigma. Stigma, whether felt or overtly experienced, has many negative consequences for both health and quality of life [40], and overcoming it is an important goal for the field.

For the public in general, the news and entertainment media are primary sources of health information. Unfortunately, inaccurate depictions of people with epilepsy and of severe seizures, used for dramatic effect, reinforce negative perceptions [41]. An ongoing effort is needed to create key partnerships within the entertainment media to encourage less sensationalistic portrayals and more opportunities for the passive acquisition of accurate knowledge about epilepsy, recognizing that the entertainment media have limits as educational vehicles. Meanwhile, the news and information (versus entertainment) media can be approached with story ideas about various aspects of epilepsy and its care— new treatments, compelling personal stories, epilepsy in specific population groups (e.g., military veterans), and so on.

Using multiple forms of media, including social media and the Internet, clear messages, and diverse activities targeted to specific audiences would increase the chances of success for stigma reduction and public awareness efforts. Any such efforts should take into account the health literacy and cultural characteristics of target audiences, with different strategies developed for reaching each audience, one of which should be policy makers. Some campaigns for chronic conditions have effectively used high-profile spokespeople [42-45].

Campaigns can be local or national; the infrastructure of state and local epilepsy organizations could be a valuable resource for extending a national campaign's reach to communities. Successful, multifaceted campaigns are expensive, need to be sustained over a period of years, must include an effective formative evaluation strategy to enable revision of messages and tactics as needed, and yet must be flexible enough to respond to unanticipated opportunities.

## RECOMMENDATION 10

### Inform Media to Improve Awareness and Eliminate Stigma

The CDC and other Vision 20-20 and relevant organizations should support and bolster programs that provide information to journalists and to writers and producers in the entertainment industry to improve public knowledge about epilepsy and combat stigma. Efforts to collaborate and engage with the media should include the following:

- Promote more frequent, accurate, and positive story lines about and depictions of characters with epilepsy.
- Continue to encourage high-profile individuals with epilepsy (or high-profile individuals who have family members with epilepsy) to openly discuss their experiences and act as spokespeople.
- Establish partnerships with stakeholders that represent related conditions associated with stigma (e.g., mental health). Efforts could include the development of fellowships or integration of epilepsy information into existing education programs for journalists.
- Continue to work with national and local news media on breaking news about epilepsy research and human interest stories.
- Disseminate regular updates on research and medical advances to journalists and policy makers through a variety of mechanisms, including e-mail updates, listserv messages, social media, and face-to-face meetings.

## RECOMMENDATION 11

### Coordinate Public Awareness Efforts

The Epilepsy Foundation and the CDC should lead a collaborative effort with relevant stakeholder groups, including other members of Vision 20-20, to continue to educate the public through awareness efforts, promotional events, and educational materials and should collaborate to do the following:

- Establish an advisory council of people with epilepsy and their families, media and marketing experts, private industry partners, and health care experts to meet regularly and to inform future efforts.
- Develop shared messaging that emphasizes the common and complex nature of the epilepsies and the availability of successful seizure therapies and treatments.
- Explore the feasibility and development of an ongoing, coordinated, large-scale, multimedia, multiplatform, sustainable public awareness campaign that would start by targeting key audience segments to improve information and beliefs about the epilepsies and reduce stigma.
- Ensure that all awareness campaigns include
  - consideration of health literacy, cultural appropriateness, and demographics of target audiences (e.g., age, gender);



- rigorous formative research and testing of materials throughout the campaign; and
- appropriate evaluation and follow-up tools and efforts.

## **STRENGTHENING STAKEHOLDER COLLABORATION**

Epilepsy advocacy organizations are working to pull together diverse stakeholders in order to create a stronger, united voice for change. Efforts are being made by a number of organizations to advance research and to improve health care and human services for people with epilepsy and their families. One of the impressive collaborative efforts is the uniting of more than 20 nonprofit organizations and 3 federal agencies in the Vision 20-20 coalition, which focuses on moving the epilepsy field forward through coordinated efforts among task force members and the development of public-private partnerships. Vision 20-20 could be the driving force for developing strategies and plans for the implementation of this report's research priorities and recommendations, including monitoring and evaluating progress over the short and long term. This coalition has the breadth and depth of expertise to take the public health agenda provided in this report and move it forward into action steps to improve the lives of people with epilepsy.

Vision 20-20 could create a framework and mechanism for continued cross-organizational collaboration by establishing a set of working groups in key areas. Such groups could monitor advances in the epilepsy field, share and disseminate information, engage a diverse spectrum of people with epilepsy and their families, and create a united voice for advancing research, care, and education. For example, a working group on health policy, health reform, and advocacy could monitor legislative and policy activities at the local, state, and national levels; activate people with epilepsy and their families to play a role in informing policy makers; and advocate for legislation and policy changes that could improve health and quality of life for people with epilepsy. A working group on surveillance and population health and health services research could develop a comprehensive strategy to encourage people with epilepsy to participate in a broad range of research efforts from population-based surveillance to research focused on self-management and education. Among other efforts, it also could request and advocate for the regular inclusion of questions targeted to epilepsy, its comorbidities, and epilepsy-related health care services in national and state health surveys.

## **RECOMMENDATION 12**

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

The member organizations of Vision 20-20 should continue their collaborative endeavors and further these efforts by expanding ongoing working groups that aim to advance the field, support people with epilepsy and their families, and educate the public. They should explore partnerships with other organizations as well as with stakeholders who represent related conditions (e.g., mental health, traumatic brain injury, stroke, autism spectrum disorders). The working groups should communicate regularly, identify common goals, develop strategic plans, and, when possible, carry out joint activities. The working groups should focus on, but not limit their efforts to, the following areas:

- 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.

## ENGAGING PEOPLE WITH EPILEPSY AND THEIR FAMILIES

Among the most persuasive epilepsy advocates and educators are people with epilepsy and their family members who are willing to speak out in order to provide a truer picture of the disorder and its impact. While many people may be willing to play such a role, training and support will help them do so more effectively. This may be the case regardless of whether they are advocating for improvements in care in general terms, working with support groups serving other families, or advocating for a higher level of service for themselves, a special school accommodation for their child, or a new medication regimen for their parent. People with epilepsy and their families also advance knowledge about epilepsy and its treatment when they participate in clinical research studies, surveys, and other investigations into ways to improve care and increase understanding of the meaning of epilepsy in individuals' lives.

## 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, work to educate themselves and others about the epilepsies, participate in research, and be active advocates for improvements in care and services for themselves, their family members, and other people with epilepsy. Given their interests and to the extent possible, people with epilepsy and their families should

- become informed about epilepsy and actively participate in and advocate for quality health care and community services with policy makers at the local, state, and national levels;
- discuss best options for care with health care providers, including exploring referrals to epileptologists or epilepsy centers and learning about available community resources and services as needed;
- consider participation in available research and surveillance opportunities;
- engage with teachers, school officials, daycare workers, coaches, and other professionals to educate them about epilepsy and ensure that necessary services and accommodations are provided;
- talk openly, when possible, with family, friends, and colleagues about epilepsy and the impact it has on daily living and quality of life;
- actively participate in support networks to share experiences with other people with epilepsy and their families; and
- work with nonprofit organizations to raise awareness and educate others about epilepsy and participate in advocacy efforts.

## CONCLUSION

Much can be done to improve the lives of people with epilepsy. This review of the public health dimensions of the epilepsies highlights numerous gaps in knowledge about and management of epilepsy and also presents opportunities to move the field forward. Improvements in surveillance methods and electronic health records hold promise for more precise information about the epilepsies, which could enable better identification of high-

risk groups and better matching of treatments to individuals. There are a number of opportunities for the public health community to improve efforts to prevent epilepsy and its consequences. The growing emphasis on quality of care, as well as access and cost containment, in the U.S. health care system offers an opportunity to improve care for this large patient group. Preparing health professionals to provide better epilepsy care, although a challenge, will help improve quality and reduce costs. Consistent delivery of accurate, clearly communicated health information can better prepare people with epilepsy and their families to cope with the disorder and its consequences. Efforts aimed at raising awareness about epilepsy among the general public will reduce stigma and enable the full participation of people with epilepsy in society. Through collaboration and commitment over time, the bold goals outlined throughout this report can be accomplished.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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### Highlights

- The Institute of Medicine report examines the public health dimensions of epilepsy.
- It focuses on surveillance, prevention, health care, human services, and education.
- It highlights gaps in epilepsy knowledge, care, and education.
- The report calls for immediate action—across multiple dimensions—to improve lives.



**BOX 1****Research Priorities for Improving Surveillance and Prevention**

To improve surveillance and prevention of epilepsy and its consequences, the following areas should be considered priorities for future research:

- Studies to identify effective interventions for epilepsy accompanied by mental health comorbidities
- Studies that test whether treatment of comorbid mental health conditions ameliorates adverse outcomes
- Case-control studies of risk factors for injuries, suicide, status epilepticus, and sudden unexpected death in epilepsy (SUDEP)
- Population-based studies using existing data resources that have included epilepsy, such as the National Survey of Children's Health
- Studies to examine the capacity of data systems to link seizure medication use and birth outcomes
- Continued research on the risk factors for epilepsy of unknown, genetic, or presumed genetic cause<sup>a</sup>
- Studies on the directionality of the relationship between epilepsy and its comorbidities, risk factors for developing an epilepsy comorbidity, and prognosis of epilepsy in people with comorbidities present before the onset of epilepsy
- A longitudinal study that examines epilepsy's outcomes (for example, a study of cognition in people with different syndromes, seizure types, and seizure frequencies that includes a sufficient number of older adults to enable studies of risk factors for cognitive deterioration)
- Long-term prospective studies that examine the effects of epilepsy surgery on cognitive function and that include appropriate control groups
- Studies or analyses that inform new approaches to randomized controlled trials in epilepsy, in order to minimize the time spent on placebo or on a study drug that is ineffective and thus minimize the risk for SUDEP
- Studies that develop and evaluate educational programs to improve the knowledge of coroners and medical examiners about SUDEP and other epilepsy-related deaths
- Evaluation of behavioral interventions on health outcomes and quality of life for people with epilepsy
- Development of screening methods and criteria to identify children with epilepsy and cognitive comorbidities through the use of educational records

<sup>a</sup>Previously known as idiopathic or cryptogenic.

**BOX 2****Research Priorities for Improving Health Care**

To improve health care for people with epilepsy, the following areas should be considered priorities for future research:

- Development of methods for early identification of and new treatment approaches for refractory epilepsy
- Development of screening tools (useful in clinic settings) for the early identification of people with epilepsy who have potential cognitive impairments
- Development of decision-support tools for electronic health records for use by primary care and emergency room providers regarding care of persons with epilepsy, the use of screening tests, and referral steps for further evaluation and care
- Comparisons of the efficacy of brand and generic formulations of seizure medications
- Comparative effectiveness studies of epilepsy therapies and of treatments used to manage epilepsy (including reducing medication side effects) and comorbidities, with initial attention to setting priorities for this research
- Health services research on the provision and effectiveness of epilepsy care by primary care providers, neurologists, and epileptologists, including referrals to epilepsy centers and to specialists for care of comorbidities
- Assessment of differences in the utilization of epilepsy health care services, particularly for underserved populations
- Studies of the capacity of the workforce that cares for people with epilepsy
- Studies that examine value measures for epilepsy care as well as potential reductions in health care costs through changes in access to specialized care and improved coordination with providers caring for comorbid health conditions
- Analysis of cost savings by reducing emergency department use and hospitalizations
- Assessment of incentive strategies for the participation of clinical staff in collaborative service models and co-management of complex cases, including strategies to promote timely referral to surgery, mental health services, and higher levels of care

**BOX 3****Research Priorities for Improving Health Professional Education**

To improve health professional education about epilepsy, the following areas should be considered priorities for future research:

- Identification of knowledge gaps across health professions that relate to areas such as seizure recognition and classification; new treatment options; sudden unexpected death in epilepsy (SUDEP); and appropriate treatment modalities for specific subpopulations, including infants and children, women, individuals with severe epilepsy syndromes, people with complex comorbidities, and older adults
- Development and testing of educational interventions and incentives that will expand the reach of education and training opportunities about epilepsy and its associated comorbidities for health professionals outside of the epilepsy field (e.g., primary care, psychiatry, psychology, nursing)
- Assessment of current attitudes and beliefs of U.S. health professionals about epilepsy and the impact of these beliefs and attitudes on stigma and on access to and quality of care
- Evaluation of curricula and content of advanced training programs for physicians, nurses, and physician assistants for epilepsy-specific content and identification of specific opportunities and strategies for improving these types of programs
- Evaluation of innovative teaching strategies, such as online epilepsy education and simulation programs, to determine their suitability as models for a range of health professionals and others who interact with people with epilepsy, including teachers, daycare workers, coaches, and social workers
- Assessment of the format and frequency of educational and training opportunities existing within epilepsy centers in order to establish best practices for engaging clinicians in continuous, interdisciplinary learning
- Development and assessment of educational interventions and resources focused on communication skills and strategies for discussing sensitive topics (e.g., SUDEP, suicide, risks associated with medication nonadherence, treatment preferences)

**BOX 4****Research Priorities for Improving Quality of Life and Community Resources**

To improve quality of life and community resources for people with epilepsy, the following areas should be considered priorities for future research:

- Development of interventions to identify academic problems and improve academic achievement in students with epilepsy
- Identification of factors that increase the resiliency of the individual and family and of behaviors that improve quality of life
- Evaluations of community programs that go beyond process measures and assess outcomes for people with epilepsy and their families
- Evaluations of the effectiveness of vocational rehabilitation programs
- Identification of creative and innovative models of funding community service providers and collaborations
- Development of performance indicators for vocational and other community services and independent living programs

**BOX 5****Research Priorities for Improving Patient and Family Education**

To improve the education of people with epilepsy and their families, the following areas should be considered priorities for future research:

- Assessment of the information needs of specific subpopulations, including women, men, older adults, children and adolescents, youths transitioning to adulthood, racial/ethnic minorities, people with low socioeconomic status, individuals with more severe forms of epilepsy or comorbidities and their families, individuals with cognitive limitations, and individuals with seizure-like events with a psychological basis
- Assessment of information needs associated with epilepsy-related risks such as injuries, suicide, status epilepticus, and sudden unexpected death in epilepsy
- Identification of best practices, effective strategies and preferred formats, and innovative mechanisms for educating patients and families, especially individuals in underserved populations
- Development of a knowledge base to support comprehensive educational programs that feature content for epilepsy-specific self-management as well as relevant aspects of the chronic care management models
- Testing of methods for developing educational programs and resources that appropriately reflect health literacy, cultural diversity, developmental stage, cognitive ability, and gender
- Examination of the role that educational materials and programs, support groups, and counseling resources may play in helping individuals and their families successfully cope with stigma and related concerns, such as the fear of having a seizure in public

**BOX 6****Research Priorities for Improving Public Awareness and Knowledge**

To improve public awareness and knowledge, the following areas should be considered priorities for future research:

- Surveys (e.g., General Social Survey, HealthStyles Survey) that capture trends in knowledge and awareness and attitudes and beliefs about epilepsy over time and in specific subpopulations
- Evaluations of websites seeking to promote accurate knowledge about epilepsy (e.g., Talk About It) to determine effective strategies for educating the public through online resources
- Evaluation of public awareness campaigns that include documentation and analysis of pre- and post-campaign data to assess changes in public understanding of and beliefs about epilepsy and to establish best practices in developing public awareness efforts