



Summary

A Reprint from *Epilepsy Across the Spectrum: Promoting Health and Understanding*¹

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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. Epilepsy is a spectrum of disorders²—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; it is estimated that 150,000 new cases are diagnosed in the United States annually and that 1 in 26 individuals will develop epilepsy at some point in their lifetime.

While seizures are well controlled with medications and other treatment options for the majority of people with epilepsy, the impact of epilepsy goes well beyond the seizures. The challenges facing the estimated 2.2 million people with epilepsy in the United States 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, 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). Further, epilepsy is associated with substantially higher rates of mortality than experienced in the population as a whole, with sudden unexpected death in epilepsy (SUDEP) being the most common cause of epilepsy-related deaths. 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. 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.

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. 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 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. 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

¹ The entire report is available as a PDF at 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.

² 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 and their references. Discussion of these areas and citations for the information presented in the summary appear in subsequent chapters of the report.



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. This report aims to provide evidence and impetus for actions that will improve the lives of people with epilepsy and their families.

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. 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. Critical to realizing this vision will be additional research to further develop the evidence base as outlined in the research priorities in Chapter 9.

INCREASING THE POWER OF EPILEPSY DATA

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. 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.

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 Epi-



lepsy [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.

PREVENTING EPILEPSY

An important first step in designing programs to prevent epilepsy and its consequences is the identification of risk factors,

comorbidities, and outcomes for epilepsy. 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. Neurocysticercosis³ is a growing concern in the United States and represents a known risk factor for epilepsy—one in which fundamental improvements in education and sanitary measures could decrease a specific infection 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, but interventions to reduce the occurrence of this devastating outcome have not been evaluated in those at highest risk.

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., TBI, 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.

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. While significant prog-

³ Neurocysticercosis is a parasitic brain infection that can cause epilepsy (Chapter 3).



ress has been made in developing seizure medications with fewer adverse effects, as well as in refining devices and surgical techniques for specific types of epilepsy, much remains to be done to reduce the sometimes lengthy delays in diagnosis and referral to more advanced levels of care and to improve care for those with refractory epilepsy. Currently, troubling disparities are suggested in the research, based on racial, ethnic, and socioeconomic factors. High-quality health care for the epilepsies cannot be provided on a population basis until the problems of accessibility, efficiency, and equity are resolved. An important element in high-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. Developing and maintaining a national quality measurement and improvement strategy is another critical component of ensuring high-quality epilepsy care. This strategy would help hold providers accountable for adherence to practice guidelines through the standardization and implementation of quality metrics.

Building the health care workforce's knowledge base and skill sets in diagnosing, treating, supporting, and generally working with people with epilepsy is also necessary to ensure that people with epilepsy and their families have access to high-quality care. 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. 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 TBI, 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 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 materi-

als 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

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 examines 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, transporta-



tion, 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. 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. Obtaining 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 condition, and reduce concerns about stigma.

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 some surveys have suggested that attitudes regarding epilepsy have become less negative over time, 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, and overcoming it is an important goal for the field.

For the public in general, the news and entertainment media are significant sources of health information. Unfortunately, inaccurate depictions of people with epilepsy and of severe seizures, used for dramatic effect, reinforce negative perceptions. Clear messages conveyed through multiple forms of media, including social media and the Internet, along with diverse educational activities targeted to specific audiences, are necessary for successful stigma reduction and public awareness efforts. Any such efforts, local or national, should take into account the health literacy and cultural characteristics of target audiences, with different strategies developed for reaching each audience.

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 and research organizations and government agencies are working together to create a strong, 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 and the development of public-private partnerships. Vision 20-20 could be the driving force for developing strategies and plans for 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.

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, TBI, 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 advocates and educators are people with epilepsy and their family members who are willing to speak out in order to provide a more complete 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.

PROMOTING HEALTH AND UNDERSTANDING

Much can be done to improve the lives of people with epilepsy. This report 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 system offers an opportunity to improve the lives of 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 the epilepsies among the general public will reduce stigma and enable the participation of people with epilepsy in society to the fullest extent of their capabilities. Through collaboration and commitment over time, the bold goals outlined in the committee's recommendations can be accomplished.

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