

IOM report identifies public health actions for improving the lives of those with epilepsy

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An estimated 2.2 million people in the United States live with epilepsy, a complex brain disorder characterized by sudden and often unpredictable seizures. The highest rate of onset occurs in children and older adults, and it affects people of all ethnicities and socio-economic backgrounds, yet this common disorder is widely misunderstood. Epilepsy refers to a spectrum of disorders with seizures that vary in type, cause, severity, and frequency. Many people do not know the causes of epilepsy or what measures to take if they witness a seizure. A new report from the Institute of Medicine highlights numerous gaps in the knowledge and management of epilepsy and recommends actions for improving the lives of those with epilepsy and their families and promoting better understanding of the disorder.

Effective treatments for epilepsy are available but access to treatment and timely referrals to [specialized care](#) are often lacking, the report's expert committee found. Reaching rural and underserved populations, as well as providing state-of-the art care for people with [persistent seizures](#), is particularly crucial. The report's recommendations for expanding access to patient-centered health care include early identification and treatment of epilepsy and associated health conditions, implementing measures that assess quality of care, and establishing accreditation criteria and processes for specialized epilepsy centers. In addition, the wide variety of health professionals who care for those with epilepsy need improved knowledge and skills to provide the highest quality health care.

Some causes of epilepsy, such as [traumatic brain injury](#), infection, and stroke, are preventable. Prevention efforts should continue for these established risk factors, as well as for recurring seizures in people with epilepsy and depression, and for epilepsy-related causes of death, the report says.

People with epilepsy need additional education and skills to optimally manage their disorder. Consistent delivery of accurate, clearly communicated health information from sources that include health care professionals and epilepsy organizations can better prepare those with epilepsy and their families to cope with the disorder and its consequences, the report says. Accurate, current data on the extent and consequences of epilepsy and its associated health conditions are especially needed to inform policymakers and identify opportunities for reducing the burden of epilepsy.

Living with epilepsy can affect employment, driving ability, and many other aspects of quality of life. The report stresses the importance of improved access to a range of community services, including vocational, educational, transportation, transitional care, and independent living assistance as well as support groups. The committee urged collaboration among federal agencies, state health departments, and relevant epilepsy organizations to improve and integrate these services and programs, particularly at state and local levels.

Misperceptions about epilepsy persist and a focus on raising public awareness and knowledge is needed, the report adds. Educating community members such as teachers, employers, and others on how to manage seizures could help improve public understanding of epilepsy. The report suggests several strategies for stakeholders to improve public knowledge of the disorder, including forming partnerships with the media, establishing advisory councils, and engaging people with [epilepsy](#) and their families to serve as advocates and educators within their

communities.

Provided by National Academy of Sciences

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