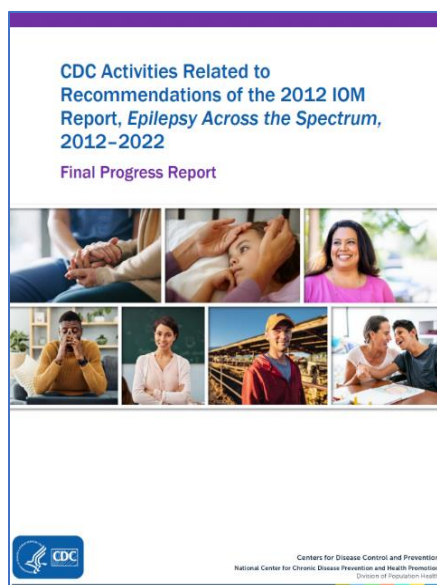


# CDC Activities Related to Recommendations of the 2012 IOM Report, *Epilepsy Across the Spectrum*, 2012–2022 Final Progress Report Highlights



The 2012 Institute of Medicine (IOM) report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*, identified 13 recommendations for public health actions to reduce the impact of epilepsy, advance epilepsy care, and improve quality of life among people with the disorder. These recommendations have been incorporated into the CDC Epilepsy Program’s intra- and extra-mural activities since the report’s release. *CDC Activities Related to Recommendations of the 2012 IOM Report Epilepsy Across the Spectrum, 2012–2022, Final Progress Report* is a 10-year inventory of these activities.

The report is organized by the core functions of public health: assessment, policy development, and assurance. For each of the IOM recommendations designated to CDC or within CDC’s scope of work, the report describes program activities, the output of these efforts, and select accomplishments. Impacts are described using the CDC Science Impact Framework (e.g., disseminating science, catalyzing action, effecting change).

To view the full report, visit the [CDC Epilepsy Program website](#).

## Select CDC Epilepsy Program Activities by IOM Recommendation

Assessment

### IOM Recommendation 1: Validate standards for case ascertainment

**CDC Activities:** Issued research cooperative agreements; used many data sources to examine health care, quality of life, access to care, mortality, and other epilepsy outcomes; published findings.

**Impact:** Disseminating Science

**Highlight:** Analyzed data from the Patient-Reported Outcomes Measurement Information System (PROMIS) Global Health Survey, which showed fewer adults with epilepsy have good or better physical and mental health compared to adults with other conditions.

### IOM Recommendation 2: Expand surveillance

**CDC Activities:** Funded/facilitated epidemiological studies; expanded surveillance efforts via public health surveys; published findings on prevalence, mortality, co-occurring conditions, sudden unexpected death in epilepsy (SUDEP), costs, and stigma.

**Impact:** Disseminating Science

**Highlight:** Provided updated national estimates of epilepsy and seizures costs per patient and nationally.

### IOM Recommendation 4: Early identification

**CDC Activities:** Funded and guided data collection on epilepsy incidence and risk factors; supported development and implementation of screening tools; analyzed the impact of co-occurring conditions.

**Impact:** Catalyzing Action

**Highlight:** Analyzing data from Medicaid claims revealed a high prevalence of comorbidities, as well as racial/ethnic disparities in the pattern of comorbidities, among people with epilepsy who use Medicaid.



**IOM Recommendation 7: Health professional education**

**CDC Activities:** Funded research and non-research cooperative agreements to support health care provider and other professional trainings; conducted outreach to community-based providers.

**Impact:** Effecting Change

**Highlight:** With CDC funds, the Epilepsy Foundation (EF) trained primary care providers, advance practice providers, and school nurses through the Project ECHO telementoring program.

**IOM Recommendation 8: Delivery and coordination of services**

**CDC Activities:** Funded EF to support community services and educational programs.

**Impact:** Catalyzing Action

**Highlight:** The CDC-funded 24/7 English and Spanish information and referral line at EF assisted about 100,000 people from 2011 to 2022 and provided at least 10,000 mental health referrals.

**IOM Recommendation 9: Educational opportunities for patients and families**

**CDC Activities:** Developed and promoted self-management programs via the Managing Epilepsy Well (MEW) Network; funded EF to increase educational resources.

**Impact:** Creating Awareness and Effecting Change

**Highlight:** From 2013 to 2021, EF implemented 74 MEW Network self-management programs in communities.

**IOM Recommendation 11: Public awareness efforts**

**CDC Activities:** Funded EF to develop, test, and share messages about epilepsy; shared resources via CDC communications channels.

**Impact:** Creating Awareness

**Highlight:** EF's #ShareMySeizure campaign reached more than 150 million people across the United States.

**IOM Recommendation 13: Engage people with epilepsy**

**CDC Activities:** Funded EF to create Community Action Boards and youth leadership councils; funded the MEW Network to develop and test self-management programs with input from people with epilepsy.

**Impact:** Shaping the Future and Effecting Change

**Highlight:** The MEW Network offers eight evidence-based programs that help adults with epilepsy learn self-management skills and address stress, memory problems, and depression.

**IOM Recommendation 3: Prevention efforts**

**CDC Activities:** Collaborated with academic, nonprofit, and small business partners and other CDC programs to develop and evaluate prevention efforts.

**Impact:** Effecting Change

**Highlight:** CDC used more than \$1 million in Small Business Innovation Research grants to support the development of point-of-care screening tools to detect neurocysticercosis infections that may cause seizures.

**IOM Recommendation 5: National quality measurement**

**CDC Activities:** Developed and tracked performance of the first Healthy People 2020 epilepsy objective.

**Impact:** Shaping the Future

**Highlight:** CDC's tracking showed that the proportion of adults with epilepsy and uncontrolled seizures who received appropriate medical care increased from 57.7% in 2010 to 65.7% in 2013, exceeding the 2020 target.

**IOM Recommendation 10: Information for media**

**CDC Activities:** Funded EF to design and conduct awareness campaigns; published epilepsy information in the *Morbidity and Mortality Weekly Reports* and via a government listserv.

**Impact:** Creating Awareness

**Highlight:** CDC and The Carter Center co-sponsored the American Journal of Public Health's special issue and commentary on health-related stigma, using epilepsy as a model.

**IOM Recommendation 12: Vision 20-20 and Epilepsy Leadership Council Partnerships**

**CDC Activities:** Participated in Vision 20-20 and Epilepsy Leadership Council meetings; coordinated workshops.

**Impact:** Catalyzing Action

**Highlight:** With the American Epilepsy Society, CDC coordinated a series of public health workshops to raise awareness of underused public health resources to engage partners in taking public health action.