

Surveillance and BRFSS

Background

The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, ongoing telephone health survey system, annually tracking health conditions and risk behaviors in the United States since 1984. It is conducted by all states' public health authorities under the direction of the Centers for Disease Control and Prevention (CDC).

As an optional supplement to the survey, states can include modules measuring self-reported data on individuals' cognitive decline and caregiving needs. Questions from the modules are asked to help understand whether subjective cognitive decline (SCD) affects the respondent's ability to work and function, and what kind of assistance the individual needs or provides to others. In 2013, Illinois was one of 20 states to conduct BRFSS surveys using the Cognitive Module, up from 19 states in 2011.

Why is this important?

- BRFSS modules are used to identify patterns of disease, investigate emerging health issues and estimate the prevalence, impact and burden of these trends in every state; and
- BRFSS data is used by policy stakeholders during the design, implementation and evaluation of health awareness, education and disease prevention programs.

To make Illinois a dementia-capable state, policymakers at every level of government need access to as much information as possible about the prevalence and impact of Alzheimer's disease and related dementias. The extremely broad reach of BRFSS and its well-established methodology provides a detailed window into Illinois residents' levels of SCD and involvement in caregiving activities.

The results of the 2013 BRFSS Cognitive Module were striking and point to the need for immediate action in Springfield. Of the Illinois residents aged 45 and over who

were surveyed, 9.7 percent reported they were experiencing confusion or memory loss that is happening more often or is getting worse. Veterans (11.9 percent) were 20 percent more likely than the general population to suffer from SCD, while 19.6 percent of people who qualify as disabled reported SCD. For those who indicated SCD, only 22.9 percent had spoken to a healthcare provider, a figure that dipped to 15.7 percent among people 60 years of age and over.

The menu of services offered by various levels of government was also reported to be extremely limited: 40.3 percent of Illinois residents surveyed under the Cognitive Module indicated that they were experiencing functional difficulties, 22.8 percent live alone and nearly 59.1 percent stated that they require assistance, but less than 7 percent had received any help in the last 30 days. The gaps between symptoms, awareness, need and service availability seem readily apparent.

It should also be noted that these respondents were interviewed in 2013, at least 18 months before Illinois' government shutdown on July 1, 2015.

What do we want to happen?

A deeper understanding of the epidemiology of Alzheimer's disease and the physical, economic, emotional and social burden borne by caregivers will not only serve an academic or medical purpose; the information gained will help policymakers in Illinois reform current service delivery programs to maximize their effectiveness and efficiency, reducing the overall cost to taxpayers as the Alzheimer's patient population grows in the coming decades. Providing funding for regular deployment of the Cognitive and Caregiving modules in Illinois' annual BRFSS surveys is an investment that the state should make to improve the design, allocation and delivery of services for people and families facing Alzheimer's disease or a related dementia.