

## Data Needs

In *Older Americans 2008*, the Federal Interagency Forum on Aging-Related Statistics (Forum) identified six areas where better data were needed to support research and policy efforts. In this report, the Forum updates those six areas, identifying new data sources when available, and provides information on one additional topic area. These topics have been identified by the Forum as priority areas for data collection efforts related to older Americans: caregiving, elder abuse, functioning and disability, mental health and cognitive functioning, pension measures, residential care, and end-of-life issues.

### Caregiving

Informal (unpaid) family caregivers provide the majority of assistance that enables chronically disabled older people to continue to live in the community rather than in specialized care facilities. The annual economic value of informal eldercare exceeds national spending on formal (paid) care.<sup>42</sup> Many of these chronically disabled older adults have considerable needs, with some requiring at least 50 hours per week of personal assistance with functional activities.<sup>43</sup> Informal family caregivers of older people with high levels of personal care needs can face considerable strain providing such care. In recent years, it has become clear that data are needed to monitor the amount, sources, and outcomes of informal caregiving. In 2009, a new nationally representative data collection effort, the National Health and Aging Trends Study (NHATS), was funded. NHATS, a representative study of older adults, along with a supplemental survey of informal caregivers, will provide researchers and policy makers with improved national estimates of caregiving and its impact on care recipients and caregivers.

There remain data gaps across the spectrum of care providers. Recent data are not available for nursing homes or their residents or providers of home care or their clients. Data are also not available about newly emerging providers and it is not possible to combine information across all caregivers or all receivers of care.

## Residential Care

A general shift in state Medicaid long-term care policy and independent growth in private-pay residential care has led to an increasing set of alternatives to home care and traditional skilled nursing facilities. Residential care outside of the traditional nursing home is provided in diverse settings (e.g., assisted living facilities, board and care homes, personal care homes, and continuing-care retirement communities). A common characteristic is that these places provide both housing and supportive services. Supportive services typically include protective oversight and help with instrumental activities of daily living (IADLs) such as transportation, meal preparation, and taking medications, and more basic activities of daily living (ADLs) such as eating, dressing, and bathing. Despite the growing role of residential care, there has been little national data on the number and characteristics of facilities and the people living in these settings.

In *Older Americans 2008*, the Forum reported that federal agencies were working to design a new survey to obtain these estimates. As of 2010, the National Survey of Residential Care Facilities (NSRCF) is being fielded as the first-ever national survey of residential care providers. Residential care facilities include places such as: assisted living residences; board and care homes; and personal care homes that are licensed, registered, listed, certified, or otherwise regulated by a state. The NSRCF is designed to produce estimates of these places and their residents. It will allow for the identification of varied levels of supportive care and assistance by housing arrangement.

The NSRCF will fill a set of essential data gaps related to residential care facilities. Beyond residential care facilities, there remains a need for data to address questions about differences in health care costs by type of housing arrangement. For example, data are needed to assess how health care costs of older adults living in congregate housing settings compare to those that live in other settings.

## Elder Abuse

In 1998, the Institute of Medicine at the National Academies reported a “paucity of research” on elder abuse and neglect, with most prior studies lacking empirical evidence.<sup>44</sup> In response to this report, the Committee on National Statistics and the Committee on Law and Justice convened an expert panel to review the risk and prevalence of elder abuse and neglect. The panel published its report in 2003, finding that there are no reliable national estimates of elder abuse, nor are the risk factors clearly understood.<sup>45</sup> The need for a national study of elder abuse and neglect is supported by the growing number of older people, increasing public awareness of the problem, new legal requirements for reporting abuse, and advances in questionnaire design.

Following the 2003 report, the National Institute on Aging funded a series of grants to develop survey methodologies for abuse and neglect surveillance. The CDC (with the assistance of the member agencies of the Elder Justice Working Group) has developed preliminary definitions for elder maltreatment as a first step in designing recommended data elements for use in elder maltreatment surveillance. Additionally, a new indicator is being included in the *Healthy People 2020* initiative, increasing the number of states that collect and publicly report incidences of elder maltreatment.

## Functioning and Disability

Information on trends in functioning and disability is critical for monitoring the health and well-being of the older population. However, the concept of disability encompasses many different dimensions of health and functioning and their multifaceted interactions with the environment. Furthermore, specific definitions of disability are used by some government agencies to determine eligibility for benefits. As a result, disability is often measured in different ways across surveys, and this has led to disparate estimates of the prevalence of disability. To the extent possible, population-based surveys designed to broadly measure disability in the older population should use a common conceptual framework. Longitudinal data that can be used to monitor changes in patterns and in transitions in functional status also are needed.

There are several current national and international activities that will result in greater depth and comparability in information on functioning and disability. Federal agencies continue to work together to find ways to compare existing measures of functioning and disability across different surveys and to develop new ways to measure this complicated, multidimensional concept. For example, the disability questions developed by an Interagency Workgroup for the American Community Survey are being adopted by other federal surveys. Methodological research on these newly developed disability measures is being conducted as part of the National Health Interview Survey. The new National Health and Aging Trends Study (NHATS) includes measures of disability and functional status that will capture multiple components of disability, including the intersection of environment and physical and cognitive functioning, as well as the relationship between limitations and overall health and quality of life. In response to a request from National Institute on Aging, the National Academies recently convened a panel to investigate additional ways to address these complex issues. Their workshop report describes a number of innovative ways to enhance comparability and improve validity across surveys and in different settings.<sup>46</sup>

International developments include work from the Washington Group on Disability Statistics, a UN-sponsored city group, and the Budapest Initiative on Health State, a UNECE-WHO-Eurostat task force, to develop comparable questions sets to measure functioning across a range of domains. The Washington Group also is developing questions to assess the impact of environmental factors including assistive devices on participation in society. The questions developed by these groups are undergoing cognitive and operational testing at the U.S. National Center for Health Statistics. In addition, a set of nationally representative longitudinal studies of the older population provides tools to monitor the dynamics of disability using comparable or harmonized measures.<sup>47</sup>

## Mental Health and Cognitive Functioning

Research that has helped differentiate mental disorders from “normal” aging has been one of the

more important achievements of recent decades in the field of geriatric health. Depression, anxiety, schizophrenia, and alcohol and drug misuse and abuse, if untreated, can be severely impairing, even fatal. Despite interest and increased efforts to track all of these disorders among older adults, obtaining national estimates has proven to be difficult. International efforts by the Washington Group on Disability Statistics and the Budapest Initiative on Measuring Health State are underway to develop comparable short sets of survey questions to measure cognitive and psychological functioning along with measures of sensory functioning, mobility, upper body functioning, pain, fatigue, communication, and learning.

While there are several studies which report estimates of the prevalence of Alzheimer's, one of the major barriers to reliable national estimates of prevalence is the lack of uniform diagnostic criteria among the national surveys that attempt to measure dementia or Alzheimer's. A meeting convened by the NIA in 2009 to describe the prevalence of Alzheimer's concluded that most of the variation in prevalence estimates is not driven primarily by the reliability of the measures or instruments per se but by systematic differences in the definition of dementia. Research is underway to address the challenges in developing consistent indicators of cognitive and mental health. Although not intended to be a platform for the diagnosis of neurological disorders, the NIH Toolbox on the Assessment of Neurological and Behavioral Functions will allow different epidemiological studies to collect harmonized or comparable measures on many domains of cognitive, emotional, motor, and sensory function.

## Pension Measures

As pension plans shift away from defined-benefit pensions and annuities to defined contribution plans, official statistical sources on income and poverty fail to measure substantial amounts of retirement income formerly provided by defined-benefit pensions. The common practice is to transfer retirement plan accumulations to IRAs and to take the money out of IRAs as irregular payments. These payments are not included as money income in the most widely used government surveys. Improved measurement of withdrawals from retirement investment accounts

(deferred income in IRAs and 401ks) would result in improved measurement of retirement income.

## End-of-Life Issues

The end of life is recognized as a uniquely difficult time for patients and their families. Many issues tend to arise, including decisions about medical care; caregiving, both formal and informal; transitions in living arrangements among community, assisted living, and nursing homes; financial impacts; whether to use advance directives and living wills, etc. Documented problem areas include poor management of pain and symptoms; lack of communication by providers; decision-making processes regarding treatment; and insufficient attention to patient preferences.<sup>48</sup>

The end of life has been the subject of many studies and reports, including an Institute of Medicine (IOM) report in 2003 titled "Describing Death in America: What We Need to Know."<sup>49</sup> The IOM report documented many gaps in our knowledge on how well the needs of individuals near the end of life are being met. Some questions identified in the IOM report are:

- ◆ Where are people dying and how much of the end of their lives is spent in those settings?
- ◆ Who is providing care for them as they die? Do institutional settings support family presence at the end of life?
- ◆ Are physical and psychological symptoms being identified and treated (including but not limited to pain)?
- ◆ How many persons experience impaired cognitive function before death?
- ◆ How do patients and loved ones perceive their quality of life at various time points prior to death?
- ◆ Are loved ones supported through the grieving process?

To this end, there is a need for national data to monitor the experiences of older adults nearing death as well as those closely linked to these individuals. Information on some of these topics will be available with the release of *Health, United States, 2010*, which will include a special feature on death and dying.<sup>50</sup>