

# Data Needs

In a previous version of *Older Americans*, the Federal Interagency Forum on Aging-Related Statistics (Forum) identified six areas where better data were needed to support research and policy efforts related to older Americans: caregiving, elder abuse, functioning and disability, mental health and cognitive functioning, pension measures, and residential care. In this report, the Forum updates those areas and identifies new data sources when available. The report also includes a special feature on end-of-life issues. As statistics in these areas improve, the Forum will consider expanding the list of existing indicators for inclusion in future editions of *Older Americans*.

## Informal 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. Informal family caregivers of older people with high levels of personal care needs can face considerable strain providing such care.

Data on this aspect of caregiving is still needed; however, to begin addressing these concerns, the National Health and Aging Trends Study (NHATS) was initiated. NHATS, a representative study of older adults, along with a supplemental survey of informal caregivers, the National Study of Caregiving (NSOC), will provide researchers and policy makers with improved national estimates of caregiving and its impact on care recipients and caregivers. Annual NHATS data collection began in May, 2011; NSOC data collection ended in November, 2011. Public use files are planned for release in 2012.<sup>39</sup>

## 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.

Recently completed, the 2010 National Survey of Residential Care Facilities (NSRCF)—the first-ever national survey of residential care providers with as few as four beds—will fill essential data gaps related to residential care facilities such as assisted living communities. With the NSRCF, both facility- and resident-level data can be generated to produce estimates of residential care facilities and their residents. The NSRCF public use data files were released in December, 2011 and two initial National Center for Health Statistics (NCHS) Data Briefs, one on facilities and the other on residents, have been published.<sup>40</sup>

The NSRCF will fill many data gaps, but it is a one-time survey. Its replacement is the National Study of Long-Term Care Providers (NSLTCP), which is intended to provide national and state estimates, where possible, of the supply and use of major types of paid, regulated long-term care providers. NSLTCP includes residential care facilities and adult day services centers using survey data and home health care agencies, hospices and nursing homes using administrative data. The NSLTCP survey components will be fielded for the first time starting in late 2012. The NSLTCP survey will not routinely collect person-level data on a sample of residents as the NSRCF did;<sup>41</sup> however, NSLTCP can be used as a platform to which components may be added to obtain person-level data.

## Elder Abuse

Several expert panels and committees have reported a “paucity of research” on elder abuse and neglect. In response to this gap, the National Institute on Aging (NIA) funded a series of grants to develop survey methodologies for abuse and neglect surveillance.<sup>42</sup> The CDC (with the assistance of the member agencies of the Elder Justice Working Group) has developed preliminary definitions for elder abuse as a first step in designing recommended data elements for use in elder abuse surveillance.<sup>43</sup> 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 abuse.<sup>44</sup> In 2010, the National Academy of Sciences issued a report of a state-of-the-science meeting of leading experts on elder abuse held jointly by the National Institute on Aging and the National Academy of Sciences.<sup>45</sup> The report highlights recent advances and continuing challenges. As part of the effort to meet these challenges, for example, the CDC integrated questions on elder abuse in a survey on intimate partner violence that will provide routine data, a promising prelude to CDC undertaking a full-scale national prevalence and incidence survey.<sup>44</sup> The NAS panel also agreed that more innovative methods are needed to gather longitudinal data in this sensitive and complex area.

## 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.

Recent developments in the area of measurement of functioning and disability among the older population include:

- Adoption of a common set of disability questions originally developed for use on the American Community Survey (ACS), across Federal surveys. The National Health Interview Survey (NHIS) has added these new measures, which will enable continued comparison and testing of questions.<sup>46</sup>
- Ongoing data collection of the National Health and Aging Trends Study (NHATS), which will provide new estimates of multiple components of disability.
- Ongoing work of the UN-sponsored Washington Group on Disability Statistics to test and field a comparable set of disability questions across countries.<sup>47</sup>

## Mental Health and Cognitive Functioning

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<sup>48</sup> 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. In 2011, an expert group meeting reviewed results of tested survey measures and began to develop an implementation project.

Although there are several studies which report estimates of the prevalence of Alzheimer's Disease (AD) and other age-related cognitive impairment, 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 AD. A meeting convened by the National Institute on Aging (NIA) in 2009 to describe the prevalence of AD and other age-related cognitive impairment 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.<sup>49</sup> 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. The Toolbox will represent an attractive option for researchers wishing to obtain state-of-the-art data on cognition, emotion, sensation, and motor function. NIH Toolbox will be available for use in Fall 2012, and norms based on a nationally representative sample of over 5000 English and Spanish speakers between the ages of 3 and 85 will also be available (<http://www.nihtoolbox.org/default.aspx>).

## 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. For *Older Americans 2012*, the Forum has modified Indicator 10 (Net Worth) to better incorporate all types of wealth, including pension wealth, using the Federal Reserve Board's Survey of Consumer Finances (SCF). Previously, the Panel Study of Income Dynamics was used to measure Net Worth instead of the SCF.

Additionally, the Forum is working on a report that documents the ongoing shift towards defined-contribution plans and IRAs. The report provides different measurements of yearly pension withdrawals—the disparities in these measurements highlight the difficulties of measuring income for older Americans.

## End-of-Life Issues

The previous edition of *Older Americans* identified end-of-life issues as an urgent data need requiring new data collection efforts. This year's report addresses some of those data needs by including an end-of-life special feature highlighting two important aspects: the place of death and the type of care received (hospice and intensive care unit/coronary care unit (ICU/CCU)) in the month prior to death.

The end of life has been the subject of many studies and reports, including the *Health, United States, 2010* which presents a special feature on death and dying.<sup>50</sup> Data are presented on trends in the leading causes of death by age group and place of death, as well as characteristics of patients receiving hospice care and the services received by hospice care patients' families. Types of medications patients receive from hospice care are also highlighted. State data include preventable deaths (e.g., motor-vehicle traffic fatalities) and average number of intensive care days in the last 6 months of life for Medicare beneficiaries.<sup>40</sup>