

## Data Needs

In preparing this report, the Federal Interagency Forum on Aging-Related Statistics (Forum) identified several areas where more data are needed to support research and policy efforts. The Forum's observations complement suggestions that were reported at a National Academy of Sciences' workshop on how to improve data on aging.<sup>56</sup>

### Extending the age-reporting categories

Although a respondent's age is almost always collected in single-year increments, it is often reported in categories. Typically, the standard age categories used by statisticians and researchers to describe and analyze the older population are 65-74, 75-84, and 85 and over. However, because the average age of the 85 and over group has steadily increased over the past 15 years, it is now necessary to consider replacing the 85 and over age category with two new categories: 85-94 and 95 and over. This change may require sampling strategies to ensure an adequate sample size in these older age groups.

### Gathering information on older minorities

Although the number of studies that oversample older minorities has been increasing, the amount and quality of data available to researchers are still limited. There is a lack of basic data about aging minority populations, largely because of the small sample sizes of these populations and language barriers that prevent certain racial and ethnic groups from participating in surveys. The increasing number of older immigrants highlights the need to collect data on nativity and to analyze generational differences in health and well-being. Policy changes and cultural perceptions have brought increasing complexity to the definition and measurement of race and ethnicity. Currently, only the decennial census and the American Community Survey have a sufficient number of cases to make reliable estimates of the smallest racial and ethnic groups, but even these data lack critical health and disability information that is essential

to adequately study the well-being of older minorities.

### Improving measures of disability

Information on trends in 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 complex interactions with the environment. Furthermore, specific definitions of disability are used by some government agencies to determine eligibility for benefits. As a result, disability has been measured in different ways across surveys and censuses, and this has led to conflicting 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. At a minimum, questions designed to measure limitations in activities of daily living (ADLs), instrumental activities of daily living (IADLs), physical functioning, and other activities should use consistent wording and response categories whenever possible. Performance-based measures are another way to measure disability but often require additional survey resources. Studies using vignettes to measure disability are showing promising results.<sup>57</sup> Several interagency efforts currently are underway to compare disability measures across surveys and to assess the possible reasons for the different estimates. Federal agencies are working together to refine the way disability is measured for older people as well as to collect more systematic information on assistive technologies.

### Including the institutionalized population in national surveys

Because of the complex methodological issues involved with collecting data from people in institutions (along with the associated high data collection costs), the institutionalized population is often excluded from large national household-based surveys. According to the U.S. Census Bureau, the institutionalized population "includes persons under formally authorized, supervised care or custody in institutions at the time of enumeration. Such persons are classified as 'patients or inmates' of an institution regardless of the availability of

nursing or medical care, the length of stay, or the number of persons in the institution.”<sup>58</sup> Because this definition includes people in nursing homes, psychiatric hospitals, and long-term care hospitals for the chronically ill, mentally retarded, and physically handicapped,<sup>59</sup> this exclusion can become a critical issue for researchers who are interested in studying the entire older population. This is especially true for the older age groups. For example, in 2002, only 83 percent of the population age 85 and over was included in the civilian noninstitutionalized population (see “About This Report,” page VI).

## **Distinguishing between types of long-term care facilities and the transitions that occur between them**

The use of assisted-living facilities, group homes, continuing-care retirement communities, and other types of residential settings as alternatives to long-term care in a nursing home has grown over the last 15 years. For the purposes of demographic surveys, the U.S. Census Bureau typically defines people living in these settings as being part of the noninstitutionalized population.<sup>59</sup> Current surveys and censuses that include information on the noninstitutionalized population (as many federally-sponsored surveys do) rarely distinguish between these types of noninstitutional long-term care residences (or have sufficient sample size to do so). As a result, there is a lack of information on the characteristics of older people in different community-based residential care settings and their service use and health care needs. Perhaps more importantly, there is little information on the costs, duration, and transitions into and between different long-term care settings. This is made more difficult by the exclusion of the institutionalized population in many surveys, which precludes measuring transitions between community-based and institutional-based long-term care residential settings. Working in conjunction with several other interagency efforts, the Forum is collecting key data elements from federally-sponsored surveys to produce a compendium that provides detailed information on how the surveys include or exclude institutions from their sampling frames. Researchers and policymakers should consider developing consistent definitions of residential settings and include these data items on surveys.

## **Gathering national statistics on elder abuse**

The Institute of Medicine reports a “paucity of research” on elder abuse and neglect, with most prior studies lacking empirical evidence.<sup>60</sup> In fact, there are no reliable national estimates of elder abuse, nor are the risk factors clearly understood. Most studies have been cross-sectional and have not investigated the history of abuse. 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. In 2003, the National Research Council published a report that highlighted the need for funding agencies to make a long-term commitment to funding elder mistreatment research.<sup>61</sup>

## **Gathering information to understand the reasons for improvements in life expectancy and functioning**

One of the major successes of the 20th century is the increase in longevity and improved health of the older population. As life expectancy increases, the importance of effectively treating chronic diseases and reducing disability becomes ever greater. Understanding the underlying reasons for the improvements in longevity and functioning is a critical first step to further advances toward these goals. To this end, information is needed to understand the long-term improvements in the health of the older population stemming from better nutrition, increased access to medical care, improvements in the public health infrastructure, changes in lifestyles, better treatment of chronic diseases through new medical procedures and pharmaceuticals, and use of assistive devices and other technology.

## **Measuring Medicare enrollees’ health care use when they are in HMOs**

The percentage of Medicare enrollees in Health Maintenance Organizations (HMOs) peaked at 21 percent in 1999 and then declined; however, recent increases in payments to managed care plans under the Medicare Prescription Drug

Improvement and Modernization Act are expected to increase enrollments in HMOs. To date little information has been available on the use of health care services by Medicare enrollees who are in HMOs. The lack of such information leaves a major gap in our knowledge about the older population's use of care, and the gap is likely to become more serious.

### **Improving the way data are collected to measure both income and wealth**

Collecting data on economic well-being is often a difficult task. Many survey respondents either do not know their incomes or are unwilling to share this information with interviewers. This can result in missing data for a large proportion of respondents. A related problem with the collection of economic data is that most surveys use only income-based measures. This type of survey methodology does not capture the accumulated wealth (including the value of future pension payments) and assets on which many older people rely. New methods to gather income and wealth data are coming into use and are being refined, and their use should be encouraged in surveying older people. These methods are aimed at providing a better understanding of the total financial picture of older Americans facing retirement and those already retired, specifically at including information on individual retirement accounts and 401(k) and Keogh plans. While efforts are underway at a number of Federal agencies to change or improve the way income and wealth data are collected, it still remains a challenge to collect these data without adding to respondent burden.

### **Gathering information on the impact of transportation needs on the quality of life of older Americans**

While much is known about the safety issues of crash involvement and fatality rates of older people, more information is needed on the effects of transportation on the quality of life. The ability to move freely from place to place, while often taken for granted, is as crucial to the well-being of older people as it is to the rest of the population. For example, access to quality health care is effectively removed if an older person cannot get from his or her home to a medical facility. Although the

Bureau of Transportation Statistics collected this type of information in the 2001 National Household Travel Survey, an ongoing data collection effort is needed to continue to monitor the number of trips older people take and the types of transportation they use. This critical information will aid policymakers in planning for the transportation needs of older Americans.

### **Accounting for uncertainties in population projections that assess the size of the older population**

Population estimates and projections are used to assess the size of a population. Although estimates generally provide figures for the present and the past, projections estimate the size, composition, and distribution of the future population. Imbedded in population projections are assumptions about future trends in fertility, mortality, and migration. Different assumptions about these demographic processes can result in different projections of the future size of the population. Some researchers, for example, predict that death rates at older ages will decline more rapidly than the death rates assumed in the U.S. Census Bureau's current projections. This could result in the older population growing at a faster pace than is currently projected.<sup>2-4</sup> The U.S. Census Bureau is currently working on stochastic population projections that include confidence intervals to model the uncertainty of the agency's projections. It may be useful to be aware of alternative projections of the older population when creating policies and programs.

### **Collecting more State and local level data**

More data are needed at the State and local levels to help governments, communities, and organizations better monitor the health and economic status of their older populations. While there are a limited number of data collection efforts that yield reliable estimates at the State level (e.g., American Community Survey, Behavioral Risk Factor Surveillance System, and Local Employment Dynamics Program), more comprehensive data collection efforts are needed to accurately assess the well-being of older Americans within and between the States.

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