Data Needs

In *Older Americans 2004*, the Federal Inter-agency Forum on Aging-Related Statistics (Forum) identified 12 areas where more data were needed to support research and policy efforts. These areas included substantive topics as well as improved data collection methods and reporting. In this report, the Forum decided to focus the "Data Needs" section more narrowly on topics that could become new indicators, or improve existing indicators, if more or better data were available. The following six topics have been identified by the Forum as priority areas for indicator development: caregiving, elder abuse, functional limitations and disability, mental health, pension measures, and residential care. Either more national data are needed on the topic or there has been difficulty reaching consensus on relevant definitions and measurements.

Caregiving

There is growing recognition that family caregivers of older people with disabilities and/or moderate to severe cognitive impairment are under considerable strain. It is primarily informal (unpaid) family caregivers who provide the assistance that enables the great majority of chronically disabled older people to continue to live in the community rather than in specialized care facilities. It has been estimated that the annual economic value of informal eldercare exceeds national spending on formal (paid) care.[50] Disabled older people at risk of nursing home placement typically require at least 50 hours per week of personal assistance with functional activities.[51] Data are needed so that it will be possible to monitor the amount and sources of informal caregiving.

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.[52] There are no reliable national estimates of elder abuse, nor are the risk factors clearly understood. 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.

Functional Limitations 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 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 is often measured in different ways across surveys and censuses, 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. 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. Longitudinal data that can be used to monitor changes in patterns and in transitions in functional status are also needed.

Mental Health

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. There is also a need for more data and better measurement of the incidence and prevalence of Alzheimer's disease and other causes of dementia. Despite interest and increased efforts to track all of these disorders among older adults, obtaining national estimates has proven to be difficult. Research is underway to address the challenges in developing indicators of cognitive and mental health.

Pension Measures

As pension plans shift away from defined-benefit pensions and annuities to defined-contribution plans, irregular payments will become more important to older people's income. In the future, improved data measuring withdrawals

of money from these retirement investment accounts (deferred earned income in IRAs and 401ks) will lead to improved measurement of income and poverty for people age 65 and over.

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, we have little national data on the number and characteristics of facilities and the people living in these settings. Federal agencies associated with the Federal Interagency Forum on Aging-Related Statistics are therefore working together to design a new survey to obtain these estimates.