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Divider Title: 7

TAB 7: DEMOGRAPHICS

This section includes a collection of articles that reviews demographic problems of long-term care.

DEMOGRAPHICS

ADVISORY PANEL ON ALZHEIMER'S DISEASE. REPORT ON ETHNIC AND CULTURAL ISSUES IN ADRD. WASHINGTON, DC: PUBLIC HEALTH SERVICE, 1992.

CUNNINGHAM, P., AND C. MUELLER. CHARACTERISTICS OF RESIDENTS IN FACILITIES FOR THE MENTALLY RETARDED. WASHINGTON, DC: PUBLIC HEALTH SERVICES/AHCPR, NATIONAL MEDICAL EXPENDITURE SURVEY RESEARCH FINDINGS 6, DHHS PUBLICATION NUMBER (PHS) 90-3468, SEPTEMBER 1990.

LAIR, T. A PROFILE OF NURSING HOME USERS UNDER AGE 65. WASHINGTON, DC: PUBLIC HEALTH SERVICES/AHCPR, NATIONAL MEDICAL EXPENDITURE SURVEY RESEARCH FINDINGS 13, AHCPR PUBLICATION NUMBER 92-0060, AUGUST 1992.

MANTON, KENNETH G., LARRY CORDER, AND ERIC STALLARD. "CHANGES IN THE USE OF PERSONAL ASSISTANCE AND SPECIAL EQUIPMENT FROM 1982 TO 1989: RESULTS FROM THE 1982 AND 1989 NLTCs." THE GERONTOLOGIST, VOLUME 33, NUMBER 2, PP. 168-176, 1993.

RAFFERTY ZEDLEWSKI, SHEILA, AND TIMOTHY D. MCBRIDE. "THE CHANGING PROFILE OF THE ELDERLY: EFFECTS ON FUTURE LONG-TERM CARE NEEDS AND FINANCING." THE MILBANK QUARTERLY, VOLUME 70, NUMBER 2, 1992.

SUMMARY
REPORT ON ETHNIC AND CULTURAL ISSUES IN ADRD
Advisory Panel on Alzheimer's Disease

This chapter review the literature on ethnic and cultural issues in Alzheimer's Disease and related disorders. As with the rest of the population, the overall population of ethnic elders--African Americans, Asian Americans and Pacific Islanders, American Indians and Alaska Natives, and Hispanics--is growing and with it their needs for long-term care. Although there is some suggestive evidence, it is not known whether specific ethnic groups have a different risk of Alzheimer's Disease than the nonethnic population. Ethnic groups tend to use less in the way of formal long-term care services. This is partly because services tend not to be culturally appropriate. This lower level of use also reflect different cultural and family traditions. The report ends with a call for more research on Alzheimer's Disease and ethnic groups.

FOURTH REPORT OF THE ADVISORY PANEL ON
**ALZHEIMER'S
DISEASE**

1992

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health
National Institute of Mental Health

REPORT ON ETHNIC AND CULTURAL ISSUES IN ADRD

Alzheimer's disease and related dementias affect millions of Americans, without regard to their social class, racial or ethnic group, or country of origin. Ethnicity, race, and economic status exert a complex set of influences upon the manner in which ADRD, and many other diseases, present themselves and how families respond to these disorders. Thus, dementia must be understood by researchers and treated by clinicians within its cultural as well as biophysiological and psychological contexts (Gaines 1988-1989). Such clarification will benefit the mainstream population as well as ethnic subpopulations, since significant cultural variations exist within the general population as well (Cohler 1982; Gelfand 1982; Holzberg 1982; Markides 1980).

Today, discussion of cultural diversity—ethnicity—most often identifies four major U.S. ethnic subgroups: African Americans (Blacks), Asian Americans and Pacific Islanders (or Pan-Asian populations), American Indians and Alaska Natives, and Hispanics (or Latinos) (Baker 1988a; Carter 1982; Jackson 1988; Kim 1983; Manuel 1982; Torres-Gil and Fiedler 1986-87; Valle 1989b). These four classifications, albeit a shorthand for a widely diverse set of populations within each subgroup,* have been found useful for sociopolitical purposes. Thus, they will be used in this report as reflecting current usage and operational convention. The combined phrase "ethnic minority" is used occasionally in this report as a

* Indeed, the term "Asian Americans" represents more than 50 distinct linguistic groups. African Americans include persons who can trace their roots to Africa, who were born in Africa, or who were born in the Caribbean Islands. Hispanics count more than 25 different countries of national origin. American Indians and Alaska Natives encompass over 500 federally recognized tribes and groups, with at least 30 different languages.

reminder that the subject populations are characterized and differentiated from others by both ethnocultural factors and status as a minority population.*

Race is a cultural or folk concept of relatively recent historical origin, used primarily in the United States and a few other cultures (Gaines 1988-89). Practically speaking, race, as a scientific variable, refers to the phenotype or physical appearance of a group, with the main racial designations identified broadly as caucasoid, negroid, and mongoloid. As a dominant factor in American life, race may be an appropriate variable in research evaluating access to service systems and the distribution of resources, particularly in situations in which political power and influence are, or historically have been, involved. Thus, as in the case of other health and human service realms, racial discrimination may be a factor in access to and resource allocation regarding ADRD services. However, this issue, like those of culture and ethnicity, must be approached, not as a tacit assumption, but as an empirical question. Furthermore, *research should be undertaken to examine whether social class factors—rather than either ethnic/cultural or racial considerations—may be the principal influences impeding access to, and utilization of, services.*

Issues of cultural diversity have not been a major focus of those engaged either in the conduct of research or the development of service systems related to ADRD. From the scientific perspective, the diversity among ADRD patients of differing ethnic backgrounds and cultural settings may help us elucidate the common biophysiological core of the Alzheimer's disease process itself. Moreover, if greater equity in the treatment of ADRD patients and their families within our Nation's health care and social services systems is to be achieved, programs must be designed that take account of cultural diversity among ADRD victims.

In past reports, the Panel has noted the special needs of what traditionally have been medically underserved populations; it has

* As a side note, there is no completely satisfactory way to designate persons from the general/majority group population within the United States or elsewhere. Use of the term "white" or "non-Hispanic white" is a racial or phenotype designation and not a cultural one. "Anglo" or "Euro-Anglo" is, itself, a generic term and does not provide a completely accurate designation, since many Anglos are not European, e.g., South African emigrants or persons of Jewish background (an ethnocultural group, albeit with variation in country of origin). Various authors have articulated the issue of intra-ethnic diversity relative to the non-Hispanic white elderly (Cohler 1982; Gelfand 1982; Holtzberg 1982; Markides 1980, 1982).

identified how issues of diagnosis, access to care, and the course of treatment may differ across our heterogeneous aging population. This supplemental report of the Panel focuses more closely upon the effects that ethnic and cultural differences in ADRD can have in the conduct of scientific inquiry into the dementias and the effects these differences already are having in the treatment of patients with ADRD. It discusses not only the research needs in the field, but also the current problems faced by ethnic elders in seeking and accepting ADRD related services. The Panel's recommendations, by necessity, are not specific to any single ethnic or cultural population. What is presented is a framework within which research and health care service delivery may function in a culturally sensitive manner.

Demographic Trends

The overall population of ethnic elders—African Americans, Asian Americans and Pacific Islanders, American Indians and Alaska Natives, and Hispanics—is growing rapidly; their needs for health care are growing concomitantly. While the proportion of elderly within most ethnic groups in the United States is lower than is found in our general population (AARP 1986), the ethnically and racially diverse elderly population is growing at more than twice the rate of the overall elderly population (Gibson 1986; Manuel 1982, 1988). The number of U.S. ethnic elderly has doubled with each census since 1960, a pattern expected to continue well into the next century (Harper 1990; Valle 1988-89). Among Asian Americans, for example, the Chinese and Japanese populations are aging particularly rapidly as children bring older parents to the United States in increasing numbers. By the year 2030, ethnic elderly minority groups combined may well constitute a majority of the elderly population, particularly in some regions and urban areas (Cuellar 1990a, 1990b; Manuel 1988; Morioka-Douglas and Yeo 1990; Richardson 1990).

Notwithstanding the growing numbers of ethnic elderly, many local communities lack the vital information, education, and resources necessary to aid ethnic elders and families who are confronting ADRD. Ethnic populations may have differing expectations and understanding of the normal aging process; indeed, variations may be found not just across ethnic populations, but within them as well. Thus, ADRD may not be recognized until late in the disease process, at which point some caregiving options may

be foreclosed. Moreover, long-term care programs, oriented predominantly toward the majority U.S. population, may lack the organized capacity to work with and appropriately serve some ethnic group ADRD victims and their caregivers. With the tremendous increase in the population of ethnic elders, greater attention to these concerns is both timely and imperative. *Alzheimer's disease research and health services delivery agendas should be broadened to reflect the wide cultural diversity encountered in our society.*

Dimensions Often Confused With Ethnic Status

To gain a clear understanding of the "ethnic experience," it is necessary to identify systemic, social class, and ethnocultural variables that may impinge on patterns of behavior (Baker et al. 1990; Valle 1989a, 1989b). The four sociopolitical groupings described above, by necessity, intermix such critical dimensions as culture or ethnicity, language, degree of acculturation to the mainstream culture, education and literacy, religion, socioeconomic status, race, and genetic or other biophysical differences. Systemic variation also exists in social environments and resources available to the individual, sometimes reflecting institutional racism or other types of discrimination, sometimes reflecting individual choice.

For example, older Asians who have recently immigrated to the United States to be with their children face multiple jeopardies of culture shock, linguistic difficulty, decreased value in the new environment for their cultural knowledge or experience, and greater social alienation (Sakayue et al. in press). Their situation may be substantially different from that confronting older Asian Americans who have resided in the United States for an extended period of time. So-called "culture-bound syndromes"—disorders occurring solely within a particular culture or ethnic group—have been described for Asian Americans, some American Indians and Alaska Natives, and some recently immigrated Hispanics. The disorders are not recognized in the majority culture and are often difficult to translate in terms comprehensible to Western medicine (Westermeyer 1985). Moreover, the language used by many ethnic elders to describe affective concerns and philosophies is often difficult to translate.

Among Hispanic elders (Greene and Monahan 1984) and in a number of other ethnic subcultures, the pattern of not seeking

services and treatment beyond the informal caregiving network is believed to be based, in part, on having available a wide scope of kinship relationships. Whether such kinship bonds in fact obtain for most of the ethnic elders (or have been overly idealized by policy-makers), and whether these account for the elders' service utilization decisions, are questions that have not been well researched (Sokolovsky 1985). In contrast, there is a widespread perception that African American elders may avoid using formal services because they have experienced relative inequalities in the health care and educational systems, leaving them with inadequate knowledge of and minimal trust in such systems. More research is needed to determine the accuracy of these perceptions and beliefs.

Thus, while the fact of minority subgroup membership is held in common by the ethnic elderly, and many basic issues are similar, each ethnic group has had a unique experience. Moreover, within each ethnic group, different constellations of problems arise based on such factors as socioeconomic status, sociopolitical history, and duration of U.S. residency, among others. If we fail to distinguish among, and control or account for these factors, they will confuse our interpretation of any observed differences among groups, whether we are concerned with sociopolitical issues in service delivery or with basic questions about ADRD as diseases.

Incidence and Prevalence of AD in Ethnic Populations

Insufficient data have been amassed regarding the relative prevalence of AD among our Nation's various ethnic groups. For example, a recent study in China that found the prevalence of AD in Shanghai to be similar to that encountered in the mainland U.S. population (Yu et al. 1989; Zhang et al. 1990) is interesting, but its findings cannot be extrapolated into conclusions about the prevalence of AD in Asian Americans. Research to clarify the relative prevalence of AD among U.S. ethnic groups has become all the more important in light of increased prevalence estimates for the Nation's general population, based on a recent study (Evans et al. 1989, 1991).

Several tentative leads have emerged. The Epidemiological Catchment Area studies conducted by NIMH and another small clinical study (Serby et al. 1987) suggest that African Americans (and, perhaps, also Asian Americans) appear to show relatively

higher prevalence rates for multi-infarct dementia than the general population. This finding may corroborate a hypothesis of long standing that such a pattern would hold true due to elevated levels of hypertension and other cardiovascular risk factors in these groups (Baker 1988b; Folstein et al. 1985; Valle 1981).

Only a few studies have examined ADRD in ethnic populations. While some larger studies have included certain ethnic subgroups in their samples, the absolute numbers of these subjects are often too limited to provide data adequate to generate reliable estimates. Moreover, data are not gathered with sufficient precision to control for the heterogeneity of the ethnic subgroups themselves. For example, in addition to the problem that few of the available databases have separated Hispanics from non-Hispanic whites, in most studies in which they have been separated, the population remains pooled, not taking into account the heterogeneous subgroups that comprise the Hispanic population (Garcia 1985).

Alternately, those few studies that have documented heterogeneity tend to have subgroups that are too small or unrepresentative to address ADRD concerns. The three Hispanic subgroups in the Hispanic Health and Nutrition Examination Survey, for example, included only a few hundred older persons, and no subjects age 75 or older (Treveno 1990). Further inquiry is needed to determine whether overall differences found between the major ethnic classifications can be substantiated across the various subgroups within these classifications and, if so, whether they are due to a genetic factor, differences in lifestyle (e.g., diet), or social class factors (Holzer et al. 1984). At this point, no controlled studies permit such determinations.

Quite simply, insufficient epidemiologic data have been collected to provide precise delineation of the incidence and prevalence of AD among each of the four major ethnic groupings—African Americans, Hispanics, Asian Americans and Pacific Islanders, and American Indians and Alaska Natives. The closest proxy information has come from studies that have classified their subjects not by diagnostic categories (such as AD or multi-infarct dementia) but by degree of cognitive impairment.

Data from a number of these studies have suggested that cognitive impairment, a possible early manifestation of dementing disease, is more frequent in ethnic populations. The Epidemiological Catchment Area studies (Holzer et al. 1984) that administered

a version of the Mini-Mental State Examination (Folstein et al. 1975) reported relatively high levels of cognitive impairment among adult African American and Hispanic populations, almost double the levels of cognitive impairment found in the general population. The work of Lopes-Agueros et al. (1984) with a community sample of Hispanics also found higher than average levels of cognitive impairment.

The explanatory factors for these differences remain open to question. Some research has suggested that the purported differences in cognitive impairment among ethnic U.S. populations may be an artifact linked to the instruments chosen to measure that impairment. Measures such as the Mini-Mental State Examination may be insufficiently attuned to cultural differences exhibited by ethnic populations in the United States to reflect accurately the level of cognitive impairment both within and across the populations. If this is the case, the data on cognitive impairment may severely misrepresent the actual incidence and prevalence of ADRD in U.S. ethnic populations. Alternatively, other research suggests that the cognitive impairment data are not artifactual, but indeed reflect, or are paralleled by, higher rates of functional impairment and/or associated brain pathology in some ethnic minority groups. For example, according to data from the Household Survey component of the 1987 National Medical Expenditure Survey, compared with Caucasians, African Americans also show a higher prevalence of deficits in activities of daily living, the conventional measure of everyday functional (as opposed to purely cognitive) limitations (Leon and Lair 1990).

Efforts to respond to the foregoing problems require attention if we are to gain a more focused picture of the incidence and prevalence of ADRD across our multiethnic society. The challenge for clinical and epidemiological researchers is to develop a dementia research technology that transcends ethnic and cross-cultural differences and appropriately distinguishes between the person actually suffering from a dementing disease and the individual who tests in the impaired range because of a cultural heritage that is incongruent with the instruments or procedures used to evaluate ADRD or cognitive impairment. Until this impasse is resolved, both clinical and epidemiological studies of ADRD will be suspected of embodying cultural biases in their cognitive testing, diagnostic, and/or other research procedures, and we will not be able to determine with accuracy the incidence and prevalence of ADRD in our multicultural society.

Ethnic Populations and ADRD Care and Services

Similarities and Differences in Understanding ADRD

Ethnic populations exhibit both similarities to, and differences from, the majority population in their recognition and understanding of the symptoms and facts about ADRD. In part, the special approach of any ethnic group to ADRD can be traced both to culture-bound understanding of the diseases and disorders that produce cognitive impairment or dementia in late life and to long-held beliefs, attitudes, and practices about the best ways to identify and care for persons evidencing such changes.

Because of an "acculturation dynamic" (Valle 1988-89, 1989a, 1989b), members of any individual ethnic group, to a greater or lesser degree, may come to share concepts and attitudes about ADRD held by the larger society. Some members may adopt fully the ADRD knowledge base and diagnostic/treatment conventions that have been developed by the research community, the Alzheimer's Association, and other organizations. In contrast, other members of the particular ethnic group may rely on culture-specific constructs in which the disease may be viewed as a normal part of aging, to be expected in people's later years, or an abnormality or punishment brought about by prior behavior deemed culturally inappropriate. However, attitudes will vary along the acculturation continuum, depending in large part upon the degree to which assimilation has been achieved or, indeed, even desired.

A number of investigators of various ethnic populations have observed that early signs and symptoms of elders' loss of memory or other cognitive function may evoke relatively little concern; the elder and other family members may not perceive the cognitive decline or may not feel disturbed about it even though family members may have recognized the subtle and insidious cognitive changes found in ADRD in their elders many years prior to seeking assistance (Valle et al. 1989; Zhong et al. 1990). At present, data are not available that allow conclusions as to whether lack of concern regarding cognitive changes is actually more frequent in ethnic minority groups than in the majority population. As indicated by a broad survey of service providers, one reason for this lack of concern may be that ethnic minority populations have very little knowledge about dementia as a disorder and often attribute the

changes involved to normal aging (OTA 1990; Valle et al. 1989). Likewise, in the traditional U.S. Black southern culture, which often emphasizes affective aspects of relationships, symptoms of dementia are frequently attributed to various folk illnesses, such as "worra-tion" (worry) or "spells." Common terms used to describe such mental illness include "going off," "having trouble," "not clothed in the right mind," or "not right in the head."

Significantly, these conditions often do not prompt movement toward the formal health care system (Gaines 1988-89). However, disintegration of personality function—a later symptom of ADRD—generally is approached more seriously and often precipitates a search for health care and social support services. Although it has not been established to what extent these ethnic minority patterns differ from those characteristic of the majority population and whether the differences relate to ethnicity, social class, or other factors, what is clear is that many affected ethnic elders come to clinical attention only when they have reached quite advanced stages of the disease.

Thus, our understanding of how Alzheimer's disease is viewed must include a comparison of the knowledge, attitudes, and practices of the overall ethnic group or of individual group members with the viewpoints of the majority society on the dementias. In this way, we can better plan and develop mechanisms to provide education and services that will be useful for that population. Though complex, this perspective is facilitated in research by gathering information about (a) the ethnic group's knowledge, beliefs, attitudes, and practices about aging and dementia and (b) the elder's and significant others' understanding of the disease. These cultural differences in viewpoints must be approached in a value-neutral fashion. Because of lack of research on these particular issues and on the general outcomes of providing formal or informal care to ADRD patients, few empirical data are available to clarify what repercussions either the majority-culture viewpoint or the ethnic minority approach have on the quality of life experienced by individuals with ADRD and their families.

While the need for community education about ADRD in ethnic populations is great, if that information is to be meaningful, it must be couched in appropriate ways, using the language and nuances of that particular culture. Experience in support group contexts has shown that complex technical information about ADRD can be both understood and integrated by non-English-speaking members of

traditional ethnocultural groups when presented in a manner attuned to the ethnic group's core body of knowledge, attitudes, and practices and built upon this base (Valle 1990).

Help-Seeking and Help-Accepting Behavior

Whether or not AD is a uniform biophysical process across cultures, responses to the illness vary, particularly with regard to help-seeking and help-accepting behaviors. Differences in the help-seeking and help-accepting behaviors typically shown by cognitively impaired elders and family caregivers in the various U.S. ethnic groups may well be related to the health maintenance behaviors characteristic of their cultures of origin as well as to characteristics of the U.S. health care delivery system. As Kleinman (1977) has suggested, the response to illness must be distinguished from the disease entity itself.

Little or no literature has been produced bearing on the use of traditional, culture-specific forms of health care for ADRD treatment by ethnic populations, such as reliance on medicine men and women by American Indians and Alaska Natives, herbalists by Chinese Americans, spiritual healers or root doctors by African Americans, or curanderos by Mexican Americans. There is, however, considerable need for empirical data to validate the knowledge, attitudes, and practices regarding traditional treatments that characterize various minority groups, relative to those attributed to them in the emergent literature on this topic.

Information about the help-seeking and help-accepting patterns of ethnic groups with respect to ADRD, unfortunately, has not been widely reported in the research literature. An emerging area of study that centers around caregiver response to the disease process, however, appears to suggest certain salient features in care-seeking and accepting behavior among the four core ethnic populations. For example, African American caregivers appear to emphasize religiosity as a coping mechanism; they report higher use of internalizing or cognitive coping strategies (Segall and Wykle 1988-89; Wykle and Segall 1991). Furthermore, African Americans tend to maintain large caregiver households and to use a wide range of informal social supports (Neighbors and Jackson 1984; Taylor and Chatters 1986; Wood and Parham 1987).

Hispanic populations report greater utilization of informal support systems than traditional health care providers (Greene and Monahan 1984). Caregivers in some American Indian groups

appear to manage stress by passive forbearance, with relatively little reference to control as a concept (Strong 1984). An analysis of caregiving networks based on data from the 1982 National Long-Term Care Survey and associated Informal Caregivers Survey indicated that, in comparison to the majority population, ethnic frail elderly are more likely to have non-kin primary caregivers (Valle et al. 1989).

Whether or not relatives seek formal care for the demented elderly also depends upon such factors as acculturation, level of education, and literacy (Sakaue 1989). Some studies have suggested that ethnic elders suffering from dementia and significant numbers of their family caregivers tend to have low levels of formal education and minimal operational or working knowledge of services and how best to link themselves to services and formal caregiving systems (Taussig 1991; Valle et al. 1989). Where others might seek services, they generally turn inward for assistance—to themselves and their network of significant others. Their informal caregiving networks seem to involve a greater number of individuals than found in the networks of comparable elders in the majority population (Greene and Monahan 1984; Stone et al. 1987; Valle et al. 1989); the tasks of assisting elders with their activities of daily living are distributed differently within these ethnic networks.

Unfortunately, study of caregiver response in ADRD is limited, not only with respect to the ethnic elderly population but also with respect to any large, representative population bases. Exploration of both the formal and informal networks of care used by ethnic elders suffering from ADRD is critical if we are to better understand how formal services may be structured to meet their individual needs optimally, in a culturally sensitive, empathetic manner. However, rather than either assuming the benefits of formal services or idealizing the informal care patterns observed among ethnic elders with ADRD, we need research comparing the empirical outcomes on such dimensions as the ethnic elder's health, daily functional level, socialization, and quality of life and also on the family's level of stress and burden. If reliance on informal caring networks is associated with detrimental outcomes, such research can also help clarify barriers that impede access to services. Alternatively, should the research show that some informal care outcomes are not altogether negative, the majority culture may have much to learn from the ways in which individuals with dementia are viewed and managed within ethnic subcultures.

Ethnic Group Access to Formal Services

Access to ADRD care by culturally diverse ethnic populations lags behind that of the majority population. Although exceptions may be cited (such as Casa Central in Chicago or On Lok in San Francisco), overall, long-term care services and clinical health care delivery programs are not designed with accessibility for ethnic populations in mind. Much of the overall health care system, and the long-term care system in particular, lacks culturally and linguistically accessible information and referral capacities. Social and health care services for ADRD elders are not always able to incorporate or make use of the informal caregiving networks of culturally diverse ethnic elders. The reliance for caregiving by many ethnic elders not only on the immediate family but also on friends, extended family, and the church is a positive asset but may present a challenge to service delivery organizations when attempting to include such caregivers in planning, patient management, and decisionmaking. Moreover, case management services frequently lack sensitivity to these sorts of cultural issues, whether because personnel lack the ability to communicate with non-English-speaking elderly or because the personnel are not attuned to traditional cultural values held by ethnic elderly clients (Garcia 1985). Financing mechanisms that address the special service eligibility concerns of immigrant and refugee ADRD victims, who are generally not eligible for Medicare or many other programs of assistance, are also lacking.

Thus, it is important to train ADRD service personnel to meet the culturally disparate needs of the ethnic elderly population. With increasing numbers of ethnic elderly, culturally capable long-term care staff should be increasingly available to work with both patients and families (Baker et al. 1990). Most studies in this area reveal the importance of barriers between patient and provider created by differences in language, cultural relevance, needs, and ethnicity. Bilingual ethnic professionals and paraprofessionals will be helpful in working with both newly immigrated elderly and those who have not yet learned fluent English. Use of translators may limit communication between patients and professional personnel, and perhaps limit treatment options as well.* Bilingual, ethnic health care and

* Studies have found that family translators either may impart their own affect into the statements of their non-English-speaking relatives or may be embarrassed to translate candidly. Patients may hesitate to disclose important information when a family translator is used. Professional translators who are not of the patient's native culture may translate too literally to convey the culture-based message behind the words themselves.

social services professionals may share with a patient a common understanding of attitudes and nonverbal communication. While acculturation differs from ethnic elder to ethnic elder, the ability to provide care in an environment sensitive to traditions and the ethos of the native culture is critical, particularly as the numbers of ethnic elders increase.

African Americans and Hispanics use long-term care facilities less than would be expected from their numbers within the population (Lockery 1986). To a large degree, the underrepresentation of ethnic populations within the long-term care system, particularly within nursing homes, may be due to socioeconomic and systemic factors such as poverty, absence of insurance, maldistribution of services, lack of educational opportunity, and behavior patterns reactive to the longstanding experience of having been underserved by the existing social and medical service system (Baker 1980; Hobart 1974; Holmes et al. 1979; Torres-Gil and Fiedler 1986-87; Valle 1989b). Cultural factors obviously also influence the participation of ethnic elders in such facilities (Chee and Kane 1979; Novak 1974; Wykle and Segall 1991). Differences in language, attitudes, expectations, or tolerance for particular ADRD symptoms may make it more difficult for certain ethnic populations to adjust to nursing home or other formal care settings. Outreach and followup with such individuals by culturally sensitive social workers, home health nurses, and others involved in the health care and social services systems could begin to remove many obstacles that may be keeping formal care from being accessible for ethnic elders.

The absence of substantial numbers of ethnic group members within nursing homes and related long-term care services is also associated with the tendency for family members and others who provide informal support to maintain the caregiving function for a longer period, though the direction of causality in this association is unclear (Eribes and Bradley-Rowles 1978; Espino et al. 1988; Greene and Monahan 1984). Since this dynamic has been reported in the caregiver literature with respect to many ethnic groups, more comparative cross-cultural research may help to elucidate the factors involved, in particular, whether socioeconomic or cultural factors more strongly govern this pattern.

One of the most significant barriers to formal care for the ethnic elderly lies in the screening instruments used to detect both ADRD and the cognitive impairments found in these disorders. Variations in culture, education, and literacy profoundly affect these assess-

ments; formidable problems have arisen in efforts to control for these influences in research protocols. Before ADRD treatment and research can move forward on behalf of ethnic minorities, it is necessary to validate the efficacy of existing screening instruments and, as necessary, to develop improved instruments or alternative techniques to detect dementia across ethnically and educationally different subpopulations.

Because few evaluative instruments have been validated directly with ethnic populations, both research and clinical work have relied on instruments and techniques that have been normed only on the Nation's majority population. Such methodology is inadequate both for resolving scientific questions regarding the incidence and prevalence of the cognitive deficits associated with ADRD in these populations and for undertaking individual clinical evaluations of the ethnic elderly. For example, test items based on orientation to time may be less relevant to certain ethnic subpopulations. Rather, what may be more salient is an understanding of kinship terms or power relationships (as in the Chinese and African American populations) or seasons (as in some Mexican and Mexican American groups) or knowledge of clans (as in some American Indian groups). By failing to determine the relevant, culturally based expressions of cognition, findings regarding functional capacity and cognitive ability may be distorted.

Rogler (1989) has suggested that research and clinical work in ADRD and in other areas of mental illness must be made "culturally sensitive." The process through which this occurs extends far beyond translating a screening instrument into another language or applying nomenclature of one society to another. Rather, it requires extensive immersion in the culture of the study or treatment group, evaluating whether the concepts underlying the proposed test instruments fit the constructs of the study group itself. Only after such a fit is achieved should the translation of specific items begin. During the process of translation, care and attention must be given to ensuring that the instrument reflects the ways in which the population expresses itself. Only with this information in hand should final development of instruments begin. The process is complex, time-consuming, and expensive, but is necessary to ensure the requisite mesh between cultural components of the population and either the research intent or the clinical process.

Several factors in combination are likely to facilitate access to services by ethnic populations in need of long-term care assistance

(Valle 1989b). First, the program (whether providing only patient care or combining care with research) ideally should be located within the target ethnic community.

Second, professional and technically competent personnel who are ethnically and culturally compatible with (or specially sensitive to) the patients to be served should be employed at all levels of the system. Thus, culturally capable geriatricians, internists, neurologists, neuropsychologists, psychiatrists, nurses, social workers, and other professionals and paraprofessionals should be working as part of the ADRD clinical intervention or research team. Since, as noted above, inadequate numbers of culturally capable specialists are now available, special training in cultural sensitivity must be emphasized in professional and paraprofessional education.

Third, the provision of social and health care services and the conduct of research on ADRD in ethnic minority populations should be accompanied by sustained, culturally relevant outreach and community-wide education. Specialized personnel, again, should be located and trained to facilitate this effort.

Fourth, screening instruments used to establish cognitive impairment as the first steps in the ADRD diagnostic process should be "culture-fair," that is, responsive to the particular culture-based belief systems, acculturation level, education, and ethos of the individuals being assessed.

Fifth, research data gathering must increase and must focus on documenting the ethnic group dynamics surrounding the disease, and the clinical and family outcomes experienced as a result of the forms of care rendered, as well as on probing the disease process itself. When formal services have been structured to fit the target ethnic group's knowledge, attitudes, and expectations regarding help-seeking and help-accepting behaviors, ethnic group members generally have shown a greater willingness to make use of these services.

A recent initiative by the Administration on Aging (AOA) to fund special projects on minority access to ADRD services generated a large number of applications and demonstrated that service providers in many localities are concerned about and attempting to address this issue. Three grants to develop new materials and methods for informing ethnic elders with dementia and their caregivers about available services, and for helping connect them to needed services, were awarded by AOA during 1990 to the Executive Office on Aging in Honolulu, Hawaii; the Morehouse School of

Medicine in Atlanta, Georgia; and the Institute for Community Research in Hartford, Connecticut.*

The context in which health care is provided to elderly American Indians and Alaska Natives living on reservations differs from that of other ethnic elders. Virtually all health care services for reservation-based American Indian elders are coordinated by the Indian Health Service (IHS), either directly or through contracts with tribes. While historically little attention has been paid to specifically geriatric issues for these elders, the recent establishment of an advisory IHS Workgroup on Aging concerned with the delivery of services to elders on reservations may lead to changes in the quality and availability of community care, home care, and other ADRD-relevant services for this subpopulation. Stronger linkages between the services provided and outside research investigators, if facilitated as a part of these changes, would also be a positive development.

Biomedical Science and Cross-Cultural Research in ADRD

Cross-cultural and cross-ethnic research has the unique potential to clarify the effects of cultural diversity on the presentation and diagnosis of Alzheimer's disease. The scientific value of multicultural research as well as its importance for sociopolitical purposes must not be overlooked.

Cognitive Screening Procedures

As noted earlier, the efficacy of existing cognitive screening instruments in accurately detecting cognitive impairment in the ethnic elderly of various origins has been questioned. For example, the high level of cognitive impairment found among African Americans and Hispanics by Holzer and colleagues (1984) when administering the Mini-Mental State Examination may be valid or may be an erroneous finding based on an instrument lacking cultural sensitivity or plagued by other problems, such as the influence of respondents' educational status, interviewer characteristics, or poorly understood difficulties of administering the instrument in the field.

* In addition, a demonstration project recently funded by HCFA is allowing the State of Arizona to provide long-term care services, through community contracts, to Arizona residents, including American Indians.

Research is already under way in New York, San Diego, Los Angeles, and San Antonio to validate screening instruments for Hispanic and African American populations. Preliminary findings from the work in New York comparing African American, Hispanic, and non-Hispanic white populations on five cognitive screening procedures suggests that a different procedure was most sensitive for each ethnic group (Gurland 1991). A task force of the multicenter Consortium to Establish a Registry for Alzheimer's Disease (CERAD) has been working to validate a brief neuropsychological battery for use with Hispanics and African Americans (Pirozzolo and Valle 1989). In international research, the Blessed Dementia Rating Scale and the Mini-Mental State Examination have been tested with a Chinese population, as have components of a neuropsychological battery (Katzman et al. 1988). Norms for these various populations have not yet been established, since many of the data are still being collected and analyzed.

The screening procedures that emerge from this ongoing research will have been validated for cultural fairness relative to the specific ethnocultural populations studied, meeting the culture-fair challenge inherent in earlier reports (Bird et al. 1987; Escobar et al. 1986). Various studies are also attempting to resolve the effects that education and literacy appear to have on screening instruments and other assessments of cognitive function (Anthony et al. 1982; Bird et al. 1987; Escobar et al. 1986; Holzer et al. 1984). A number of studies suggest that the current cognitive screening procedures (particularly the Mini-Mental State Examination) require a certain degree of educational attainment; even when the norms are scaled downward, existing items on such instruments may not be sufficient to measure cognitive impairment accurately or yield accurate diagnoses among those of lower educational attainment (e.g., less than ninth-grade education). Rather, additional items may be necessary to tap into various dimensions of cognitive impairment among those with very limited or no formal education. This idea is evident from the diagnostic study of AD in Shanghai by Katzman et al. (1988; Zhang et al. 1990) in which the study population contained a large percentage of persons without any formal education. Twenty-six percent of the sample classified as illiterate also demonstrated exceptionally high levels of cognitive impairment on the Mini-Mental State Examination.

Researchers presently have great difficulty adequately screening nonliterate and semiliterate people for dementia, regardless of

their culture, and can do so only by adding on extensive and expensive clinical diagnostic protocols. Several efforts are currently underway in the United States to disentangle the effects of education and low literacy from cultural artifacts in screening procedures. The already mentioned San Diego project with Hispanics (Valle et al. 1991) is seeking to distinguish educational from cultural artifacts in three cognitive screening procedures—the Mental Status Questionnaire (Kahn et al. 1960), Information-Memory-Concentration Test (Blessed et al. 1968) and the Mini-Mental State Examination (Folstein et al. 1975). Research on alternate testing and diagnostic approaches that are less language-based and potentially more culturally fair, such as reaction time procedures (Pirozzolo and Hansch 1981; Teng et al. 1990), also is worth pursuing. Until cognitive screening procedures have been calibrated for nonliterate and semiliterate individuals, not only within linguistically and culturally diverse groups but also in the general population, prevalence studies will continue to report questionable rates of cognitive impairment in community populations, particularly in ethnic groups.

Yet, even the best testing instruments are only as good as the individuals administering them. The research community is in need of professionals who speak the language of the subgroups and who can explain things in terms familiar to the particular ethnic population. People who must communicate in a second language or through translators often appear to be curt and brusque simply because their vocabulary is limited and their knowledge of idiom absent. As noted earlier, translators create problems as well. Family translators restrict the test subject's freedom to speak; professional translators may over- or under-interpret in communications both from and to the interviewer.

Obviously, no resolution has yet been reached about the best testing instruments or about the most clearly efficacious approach to the study of ethnic populations. However, these issues require priority attention. Whether or not the biophysiology of AD may vary across racial and ethnic groups, patient and family recognition of and response to the disease may range widely. The challenge for clinical and epidemiological researchers at this point is to develop a dementia screening technology that transcends educational, ethnic, and cross-cultural differences. Until this impasse is resolved, both clinical and epidemiological studies of ADRD will suffer from cultural and educational biases inherent in their cognitive testing, diagnostic, and/or other research procedures.

Clinical Intervention Studies

Many of the same barriers that limit access by ethnic populations to long-term care services also affect their participation in basic, epidemiological, and clinical ADRD research. It has proven quite difficult for researchers to recruit ethnic population subjects in major clinical trials of psychopharmacological treatments for ADRD and other mental disorders. However, differences in drug metabolism of psychoactive agents are well documented and may extend to drugs being developed for ADRD. Some indications from other areas of psychopharmacological research suggest that physiologic systems vary (Shader 1982), and appropriate medication dosage levels may differ among ethnic groups (Lin et al. 1986). A recently established Center on the Psychobiology of Ethnicity at the Harbor-University of California, Los Angeles, Medical Center has as its goal the study of the ways in which different ethnic groups physiologically process and respond to psychotropic medications (DeAngelis 1991). Findings from this NIMH-supported center's studies may help delineate physiological and sociocultural differences that may influence the appropriate use and dosages for psychotropic medications used in the treatment of disorders collateral to ADRD.

It is particularly important to test the safety and efficacy of drugs in a broad spectrum of patients as early as possible in clinical trials. However, the imperative to develop such drugs should not allow the difficulty in recruiting ethnic ADRD patients into clinical trials to slow the drug development process. Rather, this problem should encourage detailed study of ethnic populations in the later phases of the drug approval process or even postapproval surveillance studies.

Epidemiological and Population Studies

By identifying and subsequently testing variables of potential etiological significance, population studies and epidemiological research have great potential for uncovering causes of ADRD. However, no major etiologically oriented research on ADRD across ethnically diverse populations has been reported in the United States. One recently funded study, however, is beginning to evaluate, for cognitive deficits, a tri-ethnic population in New York City's North Manhattan, including a large group of now-elderly migrants from the Dominican Republic who may be at high risk for neurodegenerative changes because of earlier exposure to pesticides

as field workers. Greater attention needs to be paid to including such ethnic comparisons in ongoing ADRD biomedical research, including autopsy efforts. In an effort to include more ethnic population elders in ongoing ADRD research, NIA has initiated a program of developing additional diagnostic and treatment centers as satellites to its Alzheimer's Disease Research Centers. These satellites expand the ADRC clinical operations to other geographic sites to facilitate the entry of minority, rural, and other underserved populations into AD research and drug trials.

While research has demonstrated convincingly that at least some cases of AD are genetically linked, scientific inquiry has not yet conclusively identified other robust risk factors aside from advancing age. Our ability to search more aggressively and broadly for modifiable risk factors in ADRD demands that the conduct of research extend across cultural boundaries. Comparative research on population groups in various cultures with different environmental exposures and habits may offer clues to the etiology of the disease that are not available from research undertaken within a single culture. These clues may emerge from differences in age-specific incidence and prevalence rates between distinct subpopulations or by acquired characteristics and may lead to new etiological research hypotheses.

With the exception of the epidemiological project conducted in Shanghai (Katzman et al. 1988; Yu et al. 1989), the available literature provides little guidance relative to cross-cultural ADRD population studies. Although research on these important issues has not been adequately supported to date, several recently begun projects reflect growing interest in cross-cultural studies. Ongoing efforts include a World Health Organization multisite study involving Canada, Chile, Malta, Nigeria, and Spain as well as the United States that is developing culturally fair screening instruments and other tests needed as tools for conducting epidemiological comparisons (Amaducci 1991). Another international collaboration is supporting a normative study in the elderly population of Italy of computerized technology developed in the United States for assessing cognitive impairment (Lebowitz and Zappala 1990). Studies of ADRD in Japanese Americans are beginning in Seattle and Honolulu and will include parallel studies in Japan, thereby yielding an opportunity for migration studies (Larson and Teng 1991). Other likely parallel study sites include Taiwan and, possibly, South Korea. U.S. investment in such ADRD studies, though increasing, has been minimal

and needs to be expanded. The scientific value of such research needs to be more broadly recognized and receive greater emphasis. Though costly, the dividends from these studies are potentially great.

Recommendations

The Panel finds that too few existing institutional and community-based long-term care programs have placed sufficient emphasis on service delivery to ethnic and cultural subpopulations suffering from, or at risk of, ADRD. Neither has the existing research base adequately investigated ADRD or ADRD care in these populations. The current limited capacity of both institutional and community-based long-term care systems and the scientific community to address many issues relevant for the ethnic elderly suggest to the Panel that steps should be taken to remedy the low levels of cultural sensitivity and readiness to meet these populations' diverse health and social services needs. Specifically, the Panel makes the following priority recommendations:

- Funds should be allocated for health services research to investigate how to modify and adapt existing long-term care services to more adequately meet the needs of culturally and linguistically diverse ADRD victims, including enhancement of the accessibility and cultural appropriateness of services to ethnic populations, incorporation of the victims' informal caregiving networks, and establishment of linkages with culturally attuned information and referral and case management services.
- Research should be undertaken to examine empirically the relative degree to which social class, ethnocultural, and racial factors influence differences in ethnic elderly subpopulations' access to, and utilization of, formal health care and social services.
- High priority should be given to determining the prevalence of ADRD in the Nation's culturally diverse ethnic populations and documenting the rates at which culturally diverse ethnic group elders with ADRD are found in treatment programs; trends in these statistics over time should be evaluated.

- Public education and outreach efforts should be targeted specifically to ethnic elders and their families and communities through the development and dissemination of culturally relevant materials emphasizing both the established facts about ADRD and the efficacy of seeking treatment. Care should be taken to ensure that materials respond not only to general cultural differences, but also to the level of acculturation, literacy, and fluency in English. Specialized training should be made available to both formal and informal caregivers of the ethnic elderly; research should examine problems in caregiving that arise specifically among ethnic caregivers as the result of ethnic or culturally based belief systems.
- Professional and paraprofessional training and education should emphasize cultural aspects of health care, in general, and the specific cultural differences among the ethnic elderly suffering from ADRD, in particular. Individuals planning to work in the field of geriatrics and gerontology should be particularly well grounded in specific ethnic and cultural differences among populations. At the same time, special emphasis should be placed on bringing professionals and paraprofessionals of each ethnic population "home" to work within the ethnic community.
- Adequate funding should be identified to develop and validate screening, diagnostic, and treatment methods useful across ethnocultural variations, levels of educational/literacy, and socioeconomic status and to conduct carefully designed and generalizable cross-cultural studies on ADRD issues.
- The budgets of existing Alzheimer's disease research settings should be augmented with funds to facilitate inclusion in research of ethnically and culturally diverse populations that are currently underrepresented within the existing structure of ADRD biomedical research. Ethnic minority subjects should be included in greater numbers in patient registries and ADRD longitudinal studies, in brain banks, basic genetic and other biophysiological research, and in clinical drug trials.

CONCLUSION

This report represents the attention given by the Advisory Panel on Alzheimer's Disease to the four areas of concern that it was charged to address—biomedical research, health services research, health care and social services delivery, and the financing of health care and social services for ADRD patients and their families. As in its 1990 and 1991 reports, the Panel has included an update of its previous discussion of and recommendations for biomedical research, services, and health services research.

The balance of the report, expanding on points mentioned in prior reports, discusses issues of ethnic and subcultural variation that require attention in both biomedical and health services research in ADRD and in the organization and delivery of health care and social services for ADRD patients and their families. Through its consideration of these issues, the Panel has been able to specify steps that must be taken if policymakers are to develop long-term care policies that are sensitive to subcultural differences and if researchers are to expand the scientific knowledge base on ADRD to more adequately reflect the influences of ethnic diversity within the U.S. population. Both focused research and policy changes are required in order to foster the development of a system of services that will be more readily accessible to, and that will appropriately address the special needs of, ethnic minority elders suffering from ADRD and their families.

In broad terms, the Panel's recommendations include the following:

- As in past reports, the Panel urges increased appropriations to support biomedical and health services research that address the needs of the ADRD population, including direct support both for research and for the infrastructure developments necessary for the conduct of scientific inquiry. The Panel highlights the importance of broadened inclusion of ethnically and culturally diverse populations in ADRD biomedical and health services research.

SUMMARY
CHARACTERISTICS OF RESIDENTS OF FACILITIES FOR THE MENTALLY RETARDED
Peter Cunningham and Curt Mueller

This article reports data on residents of facilities for the mentally retarded. The survey is representative of all such facilities in the U.S., except for undercounting very small facilities. In 1987 there were nearly 212,000 residents, of which about 90 percent were diagnosed as mentally retarded. The typical resident is a white male between the ages of 22 and 44 who has at least one living parent and at least one living sibling. Residents of larger facilities, especially state facilities tend to be severely or profoundly retarded. Residents of these facilities typically require help in one or more activities of daily living, and exhibit one or behavior problems. About one-third of the residents have a mental health problem as well.



National Medical Expenditure Survey

Characteristics of Residents in Facilities for the Mentally Retarded

Research Findings 6



Department of Health & Human Services
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Abstract

Findings from the Institutional Population Component of the 1987 National Medical Expenditure Survey are used to describe characteristics of residents of facilities for the mentally retarded. On January 1, 1987, there were 211,712 residents of facilities for the mentally retarded as defined by the NMES sample criteria. Approximately 90 percent of residents had a diagnosis of mental retardation. Almost 9 percent had neither a diagnosis of mental retardation nor another condition associated with developmental disabilities. This report compares the characteristics of residents in State institutions with those in other types of facilities, particularly facilities having fewer than 16 beds. State institutions housed a high proportion of residents with more severe forms of mental retardation, greater difficulty in performing activities of daily living, other handicaps and disabilities, and problem behaviors.

Similar data are presented for residents in facilities eligible for Federal reimbursement as indicated by certification for intermediate care of the mentally retarded as well as for residents in noncertified facilities. The population in these certified institutions comprised principally residents of State and other large facilities. Only 15 percent were in facilities with between 3 and 15 beds. Certified facilities housed a disproportionate number of residents with severe or profound mental retardation, difficulties in performing activities of daily living, and other handicaps and disabilities.

September 1990

DHHS Publication No. (PHS) 90-3468

Background

The 1987 National Medical Expenditure Survey (NMES) continues a series of national health care expenditure surveys, most recently the 1980 National Medical Care Utilization and Expenditure Survey and the 1977 National Medical Care Expenditure Survey. Like these earlier surveys, NMES uses a national probability sample of the civilian, noninstitutionalized population in a Household Survey. NMES includes as well the population resident in or admitted to nursing homes and facilities for the mentally retarded over the course of the survey year.

To provide focused estimates of the provision of long-term care rendered in the community, the Household Survey oversampled population segments known to be at risk of needing or using services for chronic impairments or long-term illness, particularly the elderly and those with difficulties in performing activities of daily living. Because of continuing policy concern with populations having restricted access to the health care delivery system, oversampling was directed also at poor and low-income families and the black and Hispanic minorities. In addition, the American Indian and Alaska Native population living on or near reservations and eligible for services from the Indian Health Service was included in NMES on the basis of a separate household sample.

Together, the major components of the National Medical Expenditure Survey provide measures of health status and estimates of insurance coverage and the use of services, expenditures, and sources of payment for the period from January 1 to December 31, 1987, for the civilian population of the United States. The reports of health care expenditures and insurance coverage obtained in the household surveys are being verified and supplemented by additional surveys. Most important among these are the Health Insurance Plans Survey of em-

ployers and insurers of consenting Household Survey respondents and the Medical Provider Survey of physicians, including osteopathic physicians, and inpatient and outpatient facilities reported as providing services to consenting members of the noninstitutionalized population sample. The Medicare Records Component will provide a record check on 1987 eligibility status and claims information of all sampled Medicare beneficiaries, including those in the institutional population.

Household Survey

The Household Survey was fielded over four rounds of personal and telephone interviews at 4-month intervals, with a short telephone interview constituting the final fifth round. The reference period was calendar year 1987. Baseline data on household composition and employment and insurance characteristics were updated each quarter, and information on all use of and expenditures for health care services and sources of payment was obtained. A long-term care supplement permits the development of estimates of persons with functional disabilities and impairments and their use of formal home and community services, as well as the burden of providing care felt by family and friends.

Survey of American Indians and Alaska Natives

Conducted with the same data collection instruments and interview procedures over the same period, the Survey of American Indians and Alaska Natives provides a basis for comparing the use of health services by the American Indian and Alaska Native population eligible for care through the Indian Health Service. Special attention was paid to measures of access to care, sources of payment for services other than those provided by the Indian Health Service, and the use of traditional medical care.

Institutional Population Component

The survey of persons resident in or admitted to long-term care facilities (nursing homes and facilities for the mentally retarded) at any time in 1987 was conducted to provide data on health care use and expenditures both within the institution and in the community for the survey year. This information and extensive data on health and functional status, demographic characteristics, and living arrangements and insurance coverage at the time of admission were obtained from two primary sources. The Survey in Institutions collected data from facility administrators and designated staff; a Survey of Next of Kin collected data from the respondent's next of kin or other knowledgeable person in the community to obtain additional personal history and related information.

All survey components were designed to provide statistically unbiased national estimates that are representative of the civilian population of the United States in 1987. The Household Survey sample can be characterized as a stratified multi-stage area probability design with a total sample of 36,400 individuals in roughly 15,000 households. Over-sampling of the population subgroups of interest was based on a separate screening interview conducted in the fall of 1986 with a sample of approximately 35,000 addresses. The institutional population sample was based on a three-stage probability design. Facilities were selected in the first two stages. The final stage sampled residents as of January 1, 1987, and obtained a sample of admissions between January 1 and December 31, 1987. Sampling specifications required the selection of a total of 1,500 facilities, 7,000 current residents, and 3,500 new admissions to either nursing homes or facilities for the mentally retarded. The sample frame for facilities in the Institutional Population

Component was derived from the 1986 Inventory of Long-Term Care Places.

Taken in conjunction, these surveys yield comprehensive, population-based estimates that will permit separate and comparative analyses of most population groups of policy interest, including those presently outside the scope of the various public and private financing mechanisms. In contrast to information limited to program or provider statistics, the National Medical Expenditure Survey will permit comprehensive analyses of data on all public and private sources of coverage for health care services and on out-of-pocket payments by individuals and families in the U.S. population. The data base will also enable assessment of the implications of recent and projected changes in public and private health care benefits; in methods of financing both health care and insurance coverage; and in various public and private subsidies, income tax exemptions, and employee compensation arrangements.

The 1987 National Medical Expenditure Survey was guided by the information requirements of the Center for General Health Services Intramural Research, Agency for Health Care Policy and Research. The Survey of American Indians and Alaska Natives was cosponsored by the Indian Health Service. The Health Care Financing Administration, the National Center for Health Statistics, the National Institute of Mental Health, and the Office of the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services provided consultation and technical assistance during the development of the survey instruments. Field work was conducted by Westat, Inc., Rockville, MD, as the primary contractor and by NORC, University of Chicago; the Council of Energy Resource Tribes, Denver, CO; and Stephen R. Braund and Associates, Anchorage, AK. Data processing during the analysis stage is being provided by Social

and Scientific Systems, Inc., Bethesda, MD.

The data were collected and are being edited and published in accordance with the confidentiality provisions of the Public Health Service Act and the Privacy Act. A series of public use tapes is being released to ensure timely access to these data by the research and policy community.

Additional information on the National Medical Expenditure Survey is available from Daniel C. Walden, Director, Division of Medical Expenditure Studies; Steven B. Cohen, Director, Division of Statistics and Research Methodology; Pamela Farley Short, Senior Research Manager; and Renate Wilson, Project Editor; Center for General Health Services Intramural Research, Agency for Health Care Policy and Research; Room 18-A-55, Parklawn Building; 5600 Fishers Lane; Rockville, MD 20857 (301/443-4836).

Characteristics of Residents in Facilities for the Mentally Retarded

Peter J. Cunningham and Curt D. Mueller

Background

State-operated institutions have been the primary source of long-term institutional care for individuals with mental retardation for most of this century. These institutions were commonly perceived as large facilities serving thousands of residents, usually located far from major cities and providing care that was mostly custodial. Objections to large institutions for the mentally retarded began to increase during the 1950s and 1960s. Critics charged that they were overcrowded, often abusive, and failed to provide opportunities for residents to learn skills that would enable them to function in the community (Scheerenberger, 1983). Concepts of care that stressed education, rehabilitation, and community integration began to replace those favoring the custodial model (Wolfensberger, 1972).

As a result, alternatives to institutional care for the mentally retarded have grown; they include group homes, foster homes, board and care homes, and semi-independent living arrangements. These types of facilities offer residential care in settings that are less crowded and restrictive and more integrated with the community. During the late 1960s and 1970s, as the deinstitutionalization movement for the mentally retarded accelerated, large numbers of residents were moved out of State institutions and into the community or other residential care settings. Greater restrictions were placed on admissions to State institutions and some facilities were closed altogether (Scheerenberger, 1987). As a result, more individuals with mental retardation currently reside in facilities other than State institutions and the population of the latter is expected to decrease even further (Lakin and others, 1989a).

While most States continue to operate large institutions that serve individuals with mental retardation and other developmental disabilities, these institutions are now smaller, on average, than in the earlier part of the century (Lakin and others, 1982). They also serve a population that is more often characterized by severe or profound mental retardation, since many of the residents with borderline or mild retardation have been placed in the community or other residential settings (Lakin and others, 1986). Advocates for communi-

ty-based care argue that the depopulation of institutions in recent years has been slowed unnecessarily; others maintain that modified institutional arrangements can provide suitable care to residents with severe impairments (Reiter and Bryen, 1986).

Also, future trends in Federal and State funding for persons with mental retardation will affect the emphasis on care in institutions versus that in smaller residential facilities and other forms of community-based care. The Federal role has greatly increased since 1971 when Congress authorized Medicaid reimbursement for State-operated intermediate care facilities for the mentally retarded (ICF-MR). Under this program, matching funds from the Federal Government could be used to pay for care of Medicaid eligibles in institutions that States had previously run entirely at their own expense.

Although financial participation by the States remained high, advocates for community-based services charged that Medicaid programs tended to support existing practices and did not provide incentives for States to maintain individuals with mental retardation in smaller facilities (Lakin and others, 1989a). Despite the fact that guidelines have been established for certifying small ICF-MR group homes and that a waiver program has permitted States to provide home and community-based services to residents who otherwise would have to be institutionalized, total expenditures for institutions still exceed those for community-based services (Braddock and others, 1990). As a result, large ICF-MR certified facilities house far more of the population with mental retardation and developmental disabilities than do small certified facilities of 15 or fewer beds (Lakin and others, 1989b). Moreover, most small facilities remain uncertified. Recent legislative efforts—including the Medicaid Home and Quality Services Act of 1989—have tried to redress this emphasis on the certification of large institutions and would enable more ICF-MR funds to be used for the development of community-based alternatives, including small residential facilities.

An understanding of the characteristics of residents who are served by different facility types, including detailed information on their physical and mental impairments, is necessary for planning and funding future resi-

dential care. This report presents estimates for the population in facilities for the mentally retarded on January 1, 1987. Data are from phase 1 of the Institutional Population Component (IPC) of the National Medical Expenditure Survey (NMES), which was designed to provide unbiased national estimates for the population in nursing and personal care homes and facilities for the mentally retarded.

The characteristics of residents within sampled facilities were obtained both for persons residing in the facility on January 1, 1987, and for persons admitted between January 1, 1987, and December 31, 1987. For all residents, information on utilization, expenditures, and sources of payment was obtained throughout the survey year. Thus, the NMES IPC will provide a picture of full-year use and expenditures for all persons who spent any time in a residential facility during 1987.

The present report focuses on the personal characteristics and health status of residents and on the distribution of persons with these characteristics. Emphasis is placed on comparing the characteristics of residents in large State institutions with those in other types of residential facilities, particularly those with 3-15 beds. These types of residential facilities in the NMES include group homes, foster homes, semi-independent living arrangements, and other types of facilities, whether publicly or privately owned. Similar estimates are provided for residents in certified intermediate care facilities for the mentally retarded, which are compared with facilities not certified under this program.¹

The technical appendix at the end of this report describes the sample, explains how the estimates were derived, and presents the standard error of these estimates. Future reports will provide information for both current residents and new admissions over the course of 1987 and examine 1987 use of services, expenditures, and sources of payment according to differences in resident characteristics.

Residents by Facility Type and Certification

Comparison of the population resident in MR facilities eligible for Federal funding with those in facilities not benefiting from Federal support indicates that ICF-MR certification has in general served large facilities and State institutions to a greater extent than small facili-

ties. Roughly 60 percent of all residents in ICF-MR certified facilities were in State institutions in 1987, 24 percent were in other residential facilities of 16 beds or more, and 15.3 percent were in small facilities of at most 15 beds (Table 1). Almost all residents of noncertified facilities (96 percent) lived in non-State facilities; over half of these resided in small facilities.

On January 1, 1987, 211,712 persons resided in facilities for the mentally retarded (Table 2). Of these, 81,442 or 38.5 percent were in State institutions and 130,270 in other residential facilities. Just under half of the latter were in facilities with 3-15 beds. In terms of facility certification, 128,908 residents or 61 percent were in ICF-MR certified facilities while 82,805 or 39 percent were in noncertified facilities (Table 3). Of residents in certified facilities, only 15.6 percent were in small facilities.

Persons with mental retardation comprised the vast majority of all residents (90.5 percent). Less than 1 percent of residents had no mental retardation but had conditions associated with other developmental disabilities, including epilepsy, autism, cerebral palsy, and spina bifida (Table 2). The remaining residents (8.7 percent) had neither mental retardation nor other developmental disabilities. These are likely to be people who are elderly or have other mental health problems; some facili-

Table 1. Population of facilities for the mentally retarded by facility type and ICF-MR certification status, United States, January 1, 1987

Facility type	Total population	Population in ICF-MR certified facilities	Population in non-certified facilities ^a
Number	211,712	128,908	82,805
Percent	100.0	60.9	39.1
<u>Percent of residents</u>			
State institutions	81,442	60.6	3.9
Other facilities			
16 beds or more	68,709	24.0	45.6
3 to 15 beds	61,561	15.3	50.5

^aIncludes a small number of facilities certified as intermediate care or skilled nursing facilities.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component, phase 1.

¹In this report, the term "noncertified" refers to facilities that are not certified as intermediate care facilities for the mentally retarded (ICF-MR). It should be noted that a small number of facilities that are not ICF-MR certified but certified as intermediate care facilities (ICF) or skilled nursing facilities (SNF) are included in the noncertified group.

Table 2. Number and percent of residents with mental retardation and other developmental disabilities by type of facility, United States, January 1, 1987

Resident characteristic	Total population	All facilities	State institutions	Other residential facilities		
				All	3-15 beds	16 beds or more
Number	211,712	211,712	81,442	130,270	61,561	68,709
Percent		100.0	38.5	61.5	29.1	32.4
<u>Percent of residents</u>						
Mental retardation	191,712	90.5	99.1	85.2	92.2	79.0
Other developmental disability only ^a	1,550	0.7	0.0	1.2	*0.8	1.5
Neither	18,450	8.7	*0.9	13.6	7.0	19.4

^aIncludes epilepsy, autism, cerebral palsy, and spina bifida.

*Standard error is equal to or greater than 30 percent of the estimate.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey — Institutional Population Component, phase 1.

ties for the mentally retarded do not exclusively serve persons with mental retardation.²

Virtually all residents of State institutions had mental retardation (99.1 percent), but as many as 13.6 percent in other residential facilities and 19.4 percent in large non-State facilities (16 beds or more) had neither mental retardation nor a related condition (see Table 2). (Over 90 percent of these residents were in privately owned facilities; data not shown.) Facilities that do not exclusively serve persons with mental retardation also tend to be noncertified. Only 3.3 percent of residents in ICF-MR certified facilities did not have mental retardation or a related condition compared with 17.1 percent in noncertified facilities (Table 3).

Demographic Characteristics of Residents

Age, sex, and race. The majority of residents were aged 22 to 44. Only 14.4 percent were 21 years of age or younger (Table 4). This compares with 25 percent reported in a 1982 study and 37 percent in 1977 (Hill and others, 1984). The decrease in the number and percent of children and adolescents in facilities for the mentally retarded may well be attributable to policies that require community-based education for young people with mental retardation. However, some variation by age remains across facility types. State institutions housed a higher percentage of persons 22 to 44 years old than other residential facilities and a relatively small percentage of those 45 to 64 years. By contrast, other large facilities

had a higher percentage of elderly than did State institutions (12.7 percent versus 6.7 percent).

Males outnumbered females in all types of residential settings, particularly in State institutions (59.8 percent versus 54 percent in other residential facilities).

Small residential facilities held a higher percentage of whites than State institutions (84 percent versus 77.3 percent); by contrast, blacks were more likely to live in State institutions than in small facilities (16.3 percent versus 10.6 percent). This finding may reflect, in part, the high percentage of blacks among institutionalized residents in the South (48.8 percent; data not shown).

Region. Differences in the regional distribution of residents according to facility type indicate that compared to other regions, there was a disproportionately high percentage of residents in State institutions in the South and a relatively low percentage in other residential facilities (43.2 percent and 21.7 percent, respectively; Table 4). This may reflect a lower level of public funding for community-based services compared to expenditures for State institutions in many Southern States, as observed by Braddock and others (1990). In fact, the South had the smallest proportion of residents in small facilities (18.5 percent).

Regional differences are also reflected in the percent of residents living in ICF-MR certified facilities (Table 5). Compared to large certified facilities, many of which are State institutions, noncertified facilities housed a lower percentage of residents in the South. By contrast, small ICF-MR certified facilities had a higher percentage of residents than large (16 beds or more) facilities in the Northeast. Similarly, noncertified facilities had pro-

²In phase 1 of the NMES IPC, 47 percent of the residents without mental retardation or a related condition were 65 years or older and 66 percent had other mental health problems.

Table 3. Number and percent of residents with mental retardation and other developmental disabilities by facility ICF-MR certification status, United States, January 1, 1987

Resident characteristic	Total	ICF-MR certified facilities			Noncertified facilities ^a
		All	16 beds or more	3 - 15 beds	
Number	211,712	128,908	108,841	20,067	82,805
Percent	100.0	60.9	51.4	9.5	39.1
<u>Percent of residents</u>					
Mental retardation	191,712	96.3	96.0	97.8	81.6
Other developmental disability only ^b	1,550	*0.4	*0.4	*0.3	1.2
Neither	18,450	3.3	3.6	*1.8	17.1

^aIncludes a small number of facilities certified as intermediate care or skilled nursing facilities.

^bIncludes epilepsy, autism, cerebral palsy, and spina bifida.

*Standard error is equal to or greater than 30 percent of the estimate.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey — Institutional Population Component, phase I.

portionately more residents than large certified facilities in the Northeast and the West.

Living kin. Most residents of facilities for the mentally retarded had living parents (68.4 percent); for 41.8 percent, both parents were alive (Table 4). Just under 20 percent of residents had no living siblings. Residents in large non-State facilities were less likely to have living family members than residents in State institutions, possibly due to the higher percentage of elderly in these types of facilities.

Health and Functional Status

Level of retardation. As noted in Table 2, 90.5 percent of residents in facilities for the mentally retarded had a diagnosis of mental retardation. Over half of these had severe or profound retardation (Table 6). However, this proportion varied greatly by facility type and size. More than 80 percent of residents in State institutions were severely or profoundly retarded, compared with 45.2 percent in other large residential facilities and 37.4 percent in small facilities.

Facilities receiving Federal support—as indicated by ICF-MR certification—housed a disproportionately large number of residents with profound mental retardation. This is true especially for large certified facilities, where 54.2 percent had profound mental retardation, compared with 18.4 percent in small certified facilities and 16.3 percent in noncertified facilities (Table 7).

ADL difficulties. Individuals with mental retardation and other developmental disabilities in residential care tend to have relatively high levels of functional limitations that make it difficult to live independently. In 1987, 63.9 percent of all residents had difficulty performing at least one of the major activities of daily living (ADLs); 35.4 percent had difficulty with three or more activities (Table 6).

Considerable variation existed across facility types in the level of ADL difficulties. Residents in State institutions again had the highest levels of functional problems: only 19.6 percent had no ADL difficulty and as many as 53.6 percent had three or more difficulties. Fewer residents in other facilities, especially small facilities, were at such levels of ADL difficulty. Over half of residents in small facilities reported no difficulty with any activity of daily living; only 16.8 percent had three or more difficulties.

As expected, residents in ICF-MR certified facilities more often had multiple ADL difficulties: 74.1 percent had difficulty with at least one ADL; 45.3 percent had difficulty with three or more ADLs (Table 7). By contrast, residents in small certified facilities had comparatively few difficulties with activities of daily living. Just under half (48 percent) had no ADL difficulty and only 18.8 percent had difficulty with three or more. A similar distribution was observed for residents in noncertified facilities.

Table 4. Demographic characteristics of residents of facilities for the mentally retarded by type of facility, United States, January 1, 1987

Resident characteristic	Total population	All facilities	State institutions	Other residential facilities		
				All	3-15 beds	16 beds or more
Number	211,712	211,712	81,442	130,270	61,561	68,709
Percent		100.0	38.5	61.5	29.1	32.4
<u>Percent of residents</u>						
Age in years						
Less than 21	30,446	14.4	13.6	14.8	12.9	16.6
22-44	121,308	57.3	63.6	53.3	58.8	48.4
45-64	40,743	19.2	16.1	21.2	20.0	22.3
65 or older	19,216	9.1	6.7	10.6	8.3	12.7
Sex						
Male	119,121	56.3	59.8	54.0	52.2	55.7
Female	92,591	43.7	40.2	46.0	47.8	44.3
Racial background						
White	170,150	80.4	77.3	82.3	84.0	80.8
Black	29,728	14.0	16.3	12.6	10.6	14.5
Other	11,834	5.6	6.4	5.1	5.4	4.7
U.S. Census region						
Northeast	39,504	18.7	16.6	20.0	25.0	15.5
Midwest	69,629	32.9	26.7	36.8	33.4	39.8
South	63,465	30.0	43.2	21.7	18.5	24.6
West	39,114	18.5	13.5	21.6	23.1	20.2
Living parents						
Both	88,485	41.8	44.4	40.1	41.3	39.1
At least one	56,311	26.6	30.4	24.2	26.3	22.4
Neither	54,635	25.8	19.3	29.8	26.9	32.4
Unknown	12,281	5.8	5.9	5.8	5.5	6.1
Living siblings						
0	39,867	18.8	19.0	18.7	18.5	18.9
1	51,995	24.6	23.4	25.3	24.8	25.7
2 or more	95,891	45.3	47.0	44.3	48.5	40.5
Unknown	23,960	11.3	10.6	11.8	8.3	14.9

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey — Institutional Population Component, phase 1.

Other health problems. In addition to ADL limitations, many residents had vision, speech, and hearing problems. Overall, 19.7 percent had some vision difficulty and 4.1 percent were blind (Table 6). Relatively few residents overall had hearing problems and deafness. The most frequently reported handicap was speech problems, with 58 percent having some difficulty talking and 30.5 percent not being able to talk at all. A higher proportion of residents in both State institutions and large ICF-MR facilities had impaired vision or speech than residents in other facilities (Tables 6 and 7).

Overall, 18.7 percent of residents had at least one chronic physical health problem (Table 6). The three

most common conditions were heart disease (6.5 percent), high blood pressure (7.0 percent), and arthritis (5.1 percent; data not shown). Table 6 also shows that residents in non-State facilities were somewhat more likely to report a physical health problem than those in State institutions. Similarly, residents of noncertified facilities were more likely to have this type of problem than residents in large ICF-MR facilities (Table 7).

Mental and behavioral problems. Roughly a third of residents had at least one mental health problem (Table 8). Of the group as a whole, 12.9 percent had personality or character disorders, 11.1 percent had schizophrenia, and 9.9 percent had anxiety disorders. Although the per-

Table 5. Demographic characteristics of residents of facilities for the mentally retarded by facility ICF-MR certification status, United States, January 1, 1987

Resident characteristic	Total population	ICF-MR certified facilities			Noncertified facilities ^a
		All	16 beds or more	3-15 beds	
Number	211,712	128,908	108,841	20,067	82,805
Percent	100.0	60.9	51.4	9.5	39.1
<u>Percent of residents</u>					
Age in years					
Less than 21	30,446	13.3	14.1	9.0	16.0
22-44	121,308	61.4	60.3	67.1	50.9
45-64	40,743	18.0	17.6	19.8	21.2
65 or older	19,216	7.3	7.9	*4.0	11.9
Sex					
Male	119,121	57.0	57.9	52.2	55.1
Female	92,591	43.0	42.1	47.8	44.9
Racial background					
White	170,150	78.6	78.4	80.5	82.9
Black	29,728	15.2	15.7	12.7	12.2
Other	11,834	6.0	5.9	6.7	4.9
U.S. Census region					
Northeast	39,504	15.1	13.0	26.4	24.2
Midwest	69,629	34.6	34.0	37.6	30.3
South	63,465	37.5	39.8	24.8	18.3
West	39,114	12.8	13.1	11.1	27.2
Living parents					
Both	88,485	43.2	43.6	40.6	39.7
At least one	56,311	28.6	28.4	29.4	23.5
Neither	54,635	22.9	22.6	24.4	30.3
Unknown	12,281	5.4	5.3	5.6	6.5
Living siblings					
0	39,867	18.6	18.9	17.0	19.2
1	51,995	24.9	24.4	27.7	24.0
2 or more	95,891	45.8	45.5	47.7	44.5
Unknown	23,960	10.7	11.2	7.5	12.3

^aIncludes a small number of facilities certified as intermediate care or skilled nursing facilities.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey — Institutional Population Component, phase 1.

cent with at least one problem did not vary greatly across facility types, higher relative rates of depression, schizophrenia, and anxiety disorder were reported in residential facilities that were not State institutions (Table 8) and in noncertified institutions (Table 9).

Roughly 70 percent of residents were reported to have some kind of behavioral problem (Table 8). The most frequently occurring problems were getting upset or yelling, not avoiding dangerous things, and injurious behavior, whether towards oneself or others. The highest percentage of residents with three or more problem behaviors was found in State institutions (34.3 percent);

the highest percentage without such problems was found in other residential facilities (34.2 percent). Residents in ICF-MR certified facilities were more likely to have three or more problem behaviors than residents in noncertified facilities (Table 9).

Summary

Findings from the first phase of the NMES Institutional Population Component indicate that facilities for the mentally retarded serve a diverse population. Most, but not all, residents have mental retardation. Residents without mental retardation included the elderly and

Table 6. Health and functional status of residents of facilities for the mentally retarded by type of facility, United States, January 1, 1987

Resident characteristic	Total population	All facilities	State institutions	Other residential facilities	
				3-15 beds	16 beds or more
Number ^a	211,712	211,712	81,442	61,561	68,709
Percent		100.0	38.5	29.1	32.4
<u>Percent of residents</u>					
Level of retardation^b					
Borderline/mild	41,046	21.4	8.6	32.1	29.2
Moderate	40,099	20.9	11.0	30.6	25.6
Severe	39,263	20.5	20.3	22.5	18.7
Profound	71,305	37.2	60.1	14.9	26.5
Difficulties with activities of daily living					
Bathing	125,853	59.5	77.2	41.7	54.4
Dressing	112,210	53.0	72.4	36.2	45.0
Using toilet	68,698	32.5	49.4	14.3	28.7
Does not use the toilet at all	19,042	9.1	15.4	1.9	8.2
Transferring	43,109	20.4	31.9	6.3	19.3
Does not transfer at all	9,630	4.6	6.1	*1.0	*5.9
Feeding self	47,925	22.6	35.7	8.8	19.5
Does not feed self at all	13,453	6.4	11.0	*1.2	5.6
Walking	50,141	23.7	34.8	9.8	22.9
Does not walk at all	27,488	13.0	20.7	2.6	13.2
No ADL difficulties	76,578	36.2	19.6	52.0	41.7
One or two ADL difficulties	60,268	28.5	26.8	31.2	28.0
Three or more ADL difficulties	74,866	35.4	53.6	16.8	30.3
Handicaps and disabilities					
Epilepsy	56,903	27.1	40.6	17.3	19.8
Cerebral palsy	22,239	10.6	11.6	7.5	12.0
Autism	6,792	3.2	2.5	3.2	*4.1
Spina bifida	--	--	--	--	--
One or more conditions	74,026	35.0	46.8	24.4	30.5
Difficulty seeing	41,005	19.7	26.8	14.7	15.7
Blind	8,723	4.1	6.3	2.4	3.1
Difficulty hearing	24,780	11.8	13.3	11.4	10.5
Deaf	3,229	1.5	2.2	*1.4	*0.9
Difficulty talking	122,645	58.0	74.8	48.0	46.8
Does not talk at all	64,518	30.5	49.8	14.6	21.8
Physical health problem^c					
None	172,098	81.3	85.4	79.0	78.5
One or more	39,614	18.7	14.6	21.0	21.5

^aIncludes residents with unknown ADL, handicap, and health problem status.

^bExcludes persons without mental retardation.

^cIncludes heart disease, high blood pressure, arthritis, cancer, arteriosclerosis, rheumatism, and emphysema.

*Standard error is equal to or greater than 30 percent of the estimate. --The number of cases is too small for a valid estimate.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey — Institutional Population Component, phase 1.

those with mental disorders, as well as a small number with developmental disabilities other than mental retar-

dation. Residents varied considerably in terms of the level of retardation and included many with borderline.

Table 7. Health and functional status of residents in facilities for the mentally retarded by facility ICF-MR certification status, United States, January 1, 1987

Resident characteristic	Total population	ICF-MR certified facilities			Noncertified facilities ^a
		All	16 beds or more	3-15 beds	
Number ^b	211,712	128,908	108,841	20,067	82,805
Percent	100.0	60.9	51.4	9.5	39.1
<u>Percent of residents</u>					
Level of retardation^c					
Borderline/mild	41,046	15.1	11.8	33.0	32.9
Moderate	40,099	15.4	13.8	24.1	31.0
Severe	39,263	20.9	20.2	24.5	19.8
Profound	71,305	48.6	54.2	18.4	16.3
Difficulties with activities of daily living					
Bathing	125,853	70.5	75.0	46.4	42.3
Dressing	112,210	63.2	67.5	39.5	37.2
Using toilet	68,698	41.3	46.4	13.4	18.7
Does not use the toilet at all	19,042	12.3	14.4	*0.9	4.2
Transferring	43,109	26.6	30.8	*3.8	10.7
Does not transfer at all	9,630	5.1	6.0	*0.5	3.7
Feeding self	47,925	30.0	33.6	10.5	11.2
Does not feed self at all	13,453	9.1	10.7	*0.2	2.2
Walking	50,141	30.3	34.5	7.6	13.4
Does not walk at all	27,488	17.3	20.3	*1.1	6.3
No ADL difficulties	76,578	25.9	21.8	48.0	52.2
One or two ADL difficulties	60,268	28.8	28.0	33.2	27.9
Three or more ADL difficulties	74,866	45.3	50.2	18.8	19.9
Handicaps and disabilities					
Epilepsy	56,903	32.7	35.7	16.7	18.2
Cerebral palsy	22,239	12.7	13.7	6.9	7.2
Autism	6,792	2.5	2.5	*2.5	*4.4
Spina bifida	--	--	--	--	--
One or more conditions	74,026	41.1	44.4	23.3	25.4
Difficulty seeing	41,005	22.9	24.4	14.5	14.8
Blind	8,723	5.3	5.7	*2.8	2.3
Difficulty hearing	24,780	11.6	12.1	8.7	12.2
Deaf	3,229	1.7	1.8	*1.5	*1.2
Difficulty talking	122,645	66.4	69.2	51.3	44.7
Does not talk at all	64,518	39.7	43.7	17.8	16.2
Physical health problem^d					
None	172,098	83.7	84.2	80.6	77.6
One or more	39,614	16.3	15.8	19.4	22.4

^aIncludes a small number of facilities certified as intermediate care or skilled nursing facilities.

^bIncludes residents with unknown ADL, handicap, and health problem status.

^cExcludes persons without mental retardation.

^dIncludes heart disease, high blood pressure, arthritis, cancer, arteriosclerosis, rheumatism, and emphysema.

*Standard error is equal to or greater than 30 percent of the estimate. --The number of cases is too small for a valid estimate.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey — Institutional Population Component, phase 1.

Table 8. Mental and behavioral problems of residents in facilities for the mentally retarded by type of facility, United States, January 1, 1987

Resident characteristic	Total population	All facilities	State institutions	Other residential facilities	
				3-15 beds	16 beds or more
Number ^a	211,712	211,712	81,442	61,561	68,709
Percent		100.0	38.5	29.1	32.4
<u>Percent of residents</u>					
Mental health problems					
Depressive disorders	17,481	8.3	3.1	11.8	11.4
Schizophrenia	23,296	11.1	6.5	11.0	16.7
Other psychoses	15,126	7.2	7.6	6.0	7.8
Anxiety disorders	20,680	9.9	5.0	13.4	12.6
Personality/character disorders	27,066	12.9	12.2	12.9	13.7
Other	19,154	9.1	13.9	5.4	6.8
No mental health problems	136,144	64.3	64.9	65.8	62.3
One or more mental health problems	75,568	35.7	35.1	34.2	37.7
Problem behavior					
Injurious behavior	47,072	22.2	28.0	19.3	18.0
Getting upset/yelling	106,675	50.4	55.0	48.2	47.1
Dressing inappropriately	37,736	17.9	16.5	20.8	16.9
Crying for no reason	26,265	12.4	12.0	13.4	12.0
Hoarding	28,553	13.5	9.7	17.5	14.5
Getting lost	31,061	14.7	17.5	13.8	12.3
Not avoiding dangerous things	49,480	23.5	32.3	18.8	17.3
Stealing	33,034	15.7	17.3	15.1	14.2
Problem sexual behavior	26,343	12.5	14.6	11.8	10.6
No problem behaviors	63,177	29.8	25.5	30.7	34.2
One or two problem behaviors	84,474	39.9	40.2	38.6	40.7
Three or more problem behaviors	64,062	30.3	34.3	30.7	25.1

^aIncludes residents whose mental health or behavioral problems are unknown.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey — Institutional Population Component, phase 1.

mild, and moderate retardation. While residents in facilities for the mentally retarded tended to have a high level of ADL difficulties, roughly one-third had no difficulty in performing the major activities of daily living. Levels of vision, hearing, and speech problems were high, as were mental and behavioral disorders. However, these conditions were by no means prevalent across the entire residential population.

The findings show that the severity of impairment was especially high among residents of State institutions. The majority in these facilities had severe or profound mental retardation and over half had difficulty with three or more activities of daily living. In addition, three-fourths had some difficulty talking and over one-fourth had impaired vision. Three-fourths of residents in State institutions had at least one behavioral problem and one-third had three or more.

Despite the severity of impairments among residents of State institutions in general, the findings indicate that a substantial number of persons with less severe impairments continue to reside in these institutions. For example, 19.6 percent of State institution residents had borderline, mild, or moderate retardation; the same percentage had no difficulty with activities of daily living; and 25.5 percent had no behavioral problem.

The majority of residents in non-State facilities tended to have less severe impairments, especially those in facilities with 3-15 beds. Over 60 percent in these small facilities had borderline, mild, or moderate retardation, and over half had no difficulty with activities of daily living. Nonetheless, there were residents with severe impairments even in small facilities, including almost 15 percent with profound retardation and almost 17 percent with difficulty in performing three or more activi-

Table 9. Mental and behavioral problems of residents in facilities for the mentally retarded, by facility ICF-MR certification status, United States, January 1, 1987

Resident characteristic	Total population	ICF-MR certified facilities			Noncertified facilities ^a
		All	16 beds or more	3-15 beds	
Number ^b	211,712	128,908	108,841	20,067	82,805
Percent	100.0	60.9	51.4	9.5	39.1
<u>Percent of residents</u>					
Mental health problems					
Depressive disorders	17,481	5.5	4.8	9.2	12.8
Schizophrenia	23,296	7.6	7.8	6.4	16.6
Other psychoses	15,126	7.6	8.1	*4.3	6.7
Anxiety disorders	20,680	7.1	6.4	11.3	14.2
Personality/character disorders	27,066	12.7	12.6	13.1	13.2
Other	19,154	11.4	12.6	*4.4	5.7
No mental health problem	136,144	66.0	65.2	70.2	61.7
One or more mental health problem	75,568	34.0	34.8	29.8	38.3
Problem behavior					
Injurious behavior	47,072	25.1	25.9	20.4	17.9
Getting upset/yelling	106,675	53.4	53.9	50.4	45.8
Dressing inappropriately	37,736	18.4	17.5	22.8	17.2
Crying for no reason	26,265	13.5	13.4	13.8	10.8
Hoarding	28,553	12.2	11.6	15.5	15.6
Getting lost	31,061	16.4	16.7	15.1	12.1
Not avoiding dangerous things	49,480	28.1	29.3	21.8	16.2
Stealing	33,034	17.1	17.4	15.5	13.4
Problem sexual behavior	26,343	13.6	13.8	12.7	10.8
No problem behaviors	63,177	27.1	27.3	26.3	34.0
One or two problem behaviors	84,474	39.6	39.1	42.1	40.4
Three or more problem behaviors	64,062	33.3	33.6	31.5	25.6

^aIncludes a small number of facilities certified as intermediate care or skilled nursing facilities.

^bIncludes residents whose mental health or behavioral problems are unknown.

*Standard error is equal to or greater than 30 percent of the estimate.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey — Institutional Population Component, phase 1.

ties of daily living. These findings may reflect efforts by some States to make community placement available specifically to those residents with severe disabilities (Lakin and others, 1989a).

Most residents in facilities eligible for Federal funding under the ICF-MR program were in large establishments. They included almost all residents of State institutions as well as a substantial number of residents in other large facilities. Thus, there was a high concentration of residents with severe impairments in certified facilities. In contrast, residents of small facilities—a large percentage of whom had less severe impairments—comprised only 15.3 percent of all residents in certified

facilities and 50.5 percent of all residents in noncertified facilities.

While there is growing and clear support for community-based alternatives to institutional care, the relative costs of maintaining individuals with very low levels of functioning in such facilities are largely unknown at the national level. Future reports from NMES will provide detailed analyses of both expenditures and sources of payment for residential care. Included will be direct expenses incurred at the facility as well as those for various support and medical services utilized over the course of the year. Payment sources examined will include private and public payers.

Technical Appendix

Data Sources and Methods of Estimation

The data in this report are from phase 1 of the Institutional Population Component (IPC) of the 1987 National Medical Expenditure Survey (NMES). The IPC was designed to provide unbiased national estimates at two levels: for the U.S. civilian population in nursing and personal care homes and facilities for the mentally retarded and their characteristics; and for the facilities and a range of their characteristics.

Data were collected in three phases with four interviews. The estimates in this report are based on 677 facilities for the mentally retarded and 3,618 facility residents as of January 1, 1987. Of 730 sampled facilities for the mentally retarded, 94.7 percent responded and 99.1 percent of responding facilities permitted sampling. In these facilities, data were obtained for 96.8 percent of sampled residents, all of whom resided in their respective facility on January 1, 1987. The estimates in this report thus refer to a sample of current residents and do not include admissions over the survey year.

Data on facilities were obtained from a facility questionnaire administered to administrators or designated staff. The facility reference period is the date of interview (February-May, 1987). Resident data were obtained from a baseline questionnaire for which the reference point was January 1, 1987. For these, respondents were direct care staff (caregivers) or others designated by the facility. The phase 1 data underlying the estimates in this report are preliminary and subject to revision as more information from other parts of the survey becomes available. For a detailed description of data collection methods and the instruments used, see Edwards and Edwards (1989).

Eligible Facilities

The sampling frame for the Institutional Population Component was the Inventory of Long-Term Care Places (ILTCP), a census of nursing and personal care homes and facilities for the mentally retarded compiled for NMES in 1986 by the National Center for Health Statistics and the Bureau of the Census. The listing of facilities for the mentally retarded was obtained by updating the 1982 National Census of Residential Facilities (Hauber and others, 1984). Facilities for the mentally retarded were eligible for NMES if they met at least one of the following conditions:

- Certified as an intermediate care facility for the mentally retarded (ICF-MR) by Medicaid.
- Licensed or under contract by the State to provide living quarters for mentally retarded persons.
- Had at least three beds for clients who resided there, provided either personal care (assistance with one or more activities or instrumental activities of daily living) or protective oversight (24 hours-a-day, 7 days-a-week supervision), and was not a licensed hospital except a hospital for the mentally retarded and not a family providing services exclusively to one or more relatives.

In the case of an MR unit within a hospital, only the MR unit was eligible. The ILTCP eligibility criteria are described in detail in Potter, Cohen, and Mueller, (1987). Final facility eligibility was established during the first phase of NMES data collection using the facility questionnaire. Facilities failing to meet the eligibility criterion or serving any group or groups other than the mentally retarded or developmentally disabled were considered ineligible for NMES as facilities for the mentally retarded.

Resident Population Estimates

Estimates of the total population in facilities for the mentally retarded were based on weighted counts from the final sample of facilities and residents. The NMES total of 211,712 residents is well below estimates reported elsewhere. A 1987 study by the Center for Residential and Community Services at the University of Minnesota reported a census of approximately 256,000 residents nationwide; another national census in the 1988 Study of Public Spending for Mental Retardation and Developmental Disabilities by the University of Illinois-Chicago reported 263,000 residents (Lakin and others 1989b; Braddock and others, 1990).

Several reasons may account for these differences. Apart from population differences that are due to the fact that the current estimates are based on a sample, NMES excluded one- and two-bed facilities, in contrast to the studies by Lakin and Braddock. Furthermore, the design of the NMES IPC required assignment of the total facility sample and associated residents into two mutually exclusive categories (nursing and personal care homes on the one hand and facilities for the mentally retarded on the other). The IPC assigned to the nursing home sample some long-term care facilities which could have qualified for the MR sample; for example,

this was the case for a nursing home also certified as an ICF-MR facility.

Facility Data

Facility type. Facility administrators were asked to classify their facilities as either State institutions for the mentally retarded/developmentally disabled or as group residences, foster homes, semi-independent living arrangements, or some other kind of place for the mentally retarded. In the respective tables, the category "other residential facilities" includes all privately and publicly owned facilities that were not reported to be State institutions.

Facility size. Facility administrators were asked the total number of beds in their facility regularly maintained for residential use. For six facilities, the number of beds was not ascertained and was imputed based on the number of residents listed for sampling and occupancy rates for similar facilities. For seven facilities, the sampled facility was actually an administrative office serving several facilities and the reported bed size was the combined number for all facilities under its administration. In these cases, bed size for the sampled facility was obtained by dividing the total number of beds in all units by the total number of units. In another 40 cases, the sampled facility was actually a unit of another facility or hospital. Here, bed size reflects that of the larger facility rather than the individual unit.

ICF-MR certification. Facility administrators were asked whether or not any beds in the facility were certified for Medicaid reimbursement under the intermediate care facilities for the mentally retarded (ICF-MR) program.

Resident Characteristics

Race. Classification by racial background was based on information reported for each resident. Caregivers were asked if the racial background of residents was best described as American Indian or Alaska Native; Asian or Pacific Islander; black, white, or other. Data from a personal history questionnaire that formed part of a next-of-kin survey (Edwards and Edwards, 1989) were used to validate the responses for race.

Living family members. Data were also obtained on whether or not the sample person had any living parents or siblings. Facility respondents were asked if the resident's mother and father were alive. Residents were grouped into those with both parents living, those with at least one living parent (the other parent was not alive or

status unknown), those with neither parent living, and those for which the status of neither parent could be ascertained. Respondents were also asked whether or not the resident had any living brothers or sisters. Residents were grouped into those who had no living siblings (including those who never had brothers or sisters), those with one living sibling, those with two or more living siblings, and those for whom information on living siblings could not be ascertained. Data from the personal history questionnaire were used to validate the responses on living family members.

Level of retardation. Level of retardation was reported by the caregiver, as indicated in the medical record (the facility respondent consulted the patient record in 94 percent of cases). Level of retardation was reported in one of five categories, which correspond to the ICD-9-CM classification: borderline (IQ 69-84), mild (IQ 52-68), moderate (IQ 36-51), severe (IQ 20-35), and profound (IQ 19 and below). Level of retardation was not ascertained for 70 residents. For 18 of these residents, level of retardation was imputed based on a primary or other diagnosis associated with the admission date. Weighted sequential hot-deck imputation was used to replace the remaining 52 cases (Iannachione, 1982). This procedure imputes data for individuals with complete information to individuals with missing data but similar characteristics that are good predictors of the variable to be imputed. Individuals who had complete information on activities of daily living, other handicaps, and level of retardation were used to form groups of donors. Similar groups of recipients were identified for individuals with missing information on level of retardation. Within such groups, data were assigned from donors to recipients, taking into account the weights associated with each person in the complex survey design.

Activities of daily living. Caregivers were asked to indicate whether residents had difficulties performing one of the activities of daily living because of a physical or mental health problem. Activities include bathing or showering, dressing, using the toilet, getting in or out of bed or chair (transferring), and feeding oneself. Caregivers were also asked to indicate whether the resident experienced difficulty walking. The summed estimates of ADL difficulties in Tables 6 and 7 include difficulty walking. Separate estimates are shown for residents who were reported to be entirely unable to perform specific ADL tasks, with or without help. The level of missing data was less than 1 percent for all of these items; missing data were considered as "no" responses for the purpose of constructing the summed variable.

Other physical and mental health problems. Caregivers were first asked whether certain problems or conditions were indicated in the resident's records, and then recorded each yes/no response on questionnaire checklists. Problems elicited included epilepsy, cerebral palsy, autism, spina bifida, hypertension, arteriosclerosis, heart disease, rheumatism, arthritis, emphysema, diabetes, and cancer. The extent of vision, hearing, and speech impairments was also elicited, although these conditions may not have been recorded. Mental health problems elicited were coded to indicate depressive disorders, schizophrenia, other psychoses, anxiety disorders, and personality/character disorders. The level of missing data was less than 1.5 percent for all of these items; missing data were considered as "no" responses for the purpose of constructing the summed variables.

Behavioral problems. Caregivers were asked to indicate whether a resident gets upset and yells, tries to hurt himself (herself) or others, dresses inappropriately, cries for long periods of time, hoards or hides things, gets lost or wanders, is unable to avoid dangerous things, steals from others, or exhibits problem sexual behaviors while in the sampled facility. The level of missing data was less than 1 percent for all of these items; missing data were considered as "no" responses for the purpose of constructing the summed variables.

Sample Design and Standard Error Estimates

The IPC target population included all persons who in 1987 spent at least one night in a nursing or personal care home or a facility for the mentally retarded. The sample was designed to yield unbiased national and regional estimates of health care parameters at the facility and resident level. At both levels, the information is classified as to the type of institution; that is, nursing and personal care homes and facilities for the mentally retarded.

The sample was selected according to a stratified three-stage probability design, with facility selection in the first two stages. The Inventory of Long-Term Care Places served as the facility sampling frame. The final stage of selection consisted of a sample of residents as of January 1, 1987, and a "rolling" sample of persons admitted during the year. Thus, persons residing in sampled facilities on January 1 were included in the sample, as were persons admitted at any time during 1987, up to and including December 31. For a summary description of the survey design and of sampling, estimation, and adjustment methods, including weighting

for nonresponse and post-stratification, see Cohen, Flyer, and Potter (1987).

Reliability of Estimates

Since the statistics presented in this report are based on a sample, they may differ somewhat from the figures that would have been obtained if a complete census had been taken. This potential difference between sample results and a complete count is the sampling error of the estimate.

The chance that an estimate from the sample would differ from a complete census by less than one standard error is about 68 out of 100. The chance that the difference between the sample estimate and a complete census would be less than twice the standard error is about 95 out of 100.

Tests of statistical significance were used to determine whether differences between facility estimates exist at specified levels of confidence or whether they simply occurred by chance. Differences were tested using Z-scores having asymptotic normal properties, based on the rounded figures at the 0.05 level of significance. Unless otherwise noted, only statistically significant differences between estimates are discussed in the text.

Rounding

Estimates presented in the tables have been rounded to the nearest 0.1 percent. The rounded estimates, including those underlying the standard errors, will not always add to 100 or the full total.

Standard Errors

Standard errors for the statistics in this report were approximated, by interpolation where necessary, using a curve smoothing procedure developed by Cohen, (1979). The statistical tests in this report, however, are based on direct estimates of standard errors using the Taylor Series linearization method.

Relative standard errors of totals. Where the statistics of interest are total estimates (T) of the population, an estimate of the standard error, SE , can be obtained by multiplying the relative standard error, $RSE(T)$, expressed as a percent of the respective total (T), by T and then dividing by 100. Thus,

$$SE(T) = \frac{T(RSE(T))}{100}$$

For estimated population totals for individuals, the approximate relative standard errors expressed as percents are as shown in Table I.

- Example—An estimate of 101,322 whites in ICF-MR certified facilities (128,908 x .786, Table 5) has a relative standard error of between 3.4 and 2.8 (Table I) or, by interpolation, a relative standard error of about 3.4 percent. The standard error of this estimate, then, is

$$SE(T) = \frac{101,322(3.4)}{100} = 3,445$$

Direct standard error estimates. When the statistic of interest is expressed as a percent of the number of persons, direct estimates of standard errors have been derived for ease of calculation. For the estimated percent of residents in facilities for the mentally retarded, approximate standard errors expressed as a percent are as shown in Table II.

Table I. Approximate relative standard errors

Estimated population totals for individuals	Relative standard error (percent)
1,000	28.8
2,500	18.3
5,000	13.0
10,000	9.3
25,000	6.0
50,000	4.5
100,000	3.4
200,000	2.8
211,712	2.7

- Example — The estimate of 70.5 percent of the population in ICF-MR certified facilities with difficulty bathing is based on a population total of 128,908 (Table 7). This estimate, by interpolation, has a standard error of approximately 1.2 percent (Table II).

Table II. Approximate direct standard errors

Persons in the base of the percent	Estimated percent						
	2 or 98	5 or 95	10 or 90	20 or 80	30 or 70	40 or 60	50
1,000	4.0	6.3	8.6	11.5	13.2	14.1	14.4
2,500	2.5	4.0	5.5	7.3	8.3	8.9	9.1
5,000	1.8	2.8	3.9	5.1	5.9	6.3	6.4
10,000	1.3	2.0	2.7	3.6	4.2	4.5	4.5
25,000	.8	1.3	1.7	2.3	2.6	2.8	2.9
50,000	.6	.9	1.2	1.6	1.9	2.0	2.0
100,000	.4	.6	.9	1.1	1.3	1.4	1.4
200,000	.3	.4	.6	.8	.9	1.0	1.0
212,712	.3	.4	.6	.8	.9	1.0	1.0

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SUMMARY
A PROFILE OF NURSING HOME USERS UNDER AGE 65
Tamra Lair

About one of ten persons in a nursing home is under age 65. These individuals fall into two groups: (1) the mentally ill; and (2) those with severe physical disabilities, often resulting from disorders of the central nervous system. By contrast to elderly nursing home users, almost 80 percent of the care for the non-elderly is paid from public funds. Institutions for the mentally retarded are not included in this analysis.

Agency for Health Care Policy and Research

Center for General Health Services Intramural Research

National Medical Expenditure Survey

A Profile of Nursing Home Users Under Age 65

Research Findings 13



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Abstract

The Institutional Population Component of the 1987 National Medical Expenditure Survey includes a nationally representative sample of current residents and new admissions to nursing and personal care homes which, taken together, constitute the population of nursing home users in 1987. This report focuses on the nursing and personal care home user population under 65 years of age (reported separately for those ages 18 to 54 and those ages 55 to 64) and contrasts this group with the more typical elderly population of nursing home users. Demographic characteristics, prevalent medical diagnoses, and degree of functional and mental health problems are presented. In addition, national estimates of prior residence, expenditures and sources of payment for nursing home care, and overall length of institutionalization are compared. The findings indicate that 10.3 percent of those residing in a nursing or personal care home for 1 or more nights in 1987 were under age 65 and that they were more likely to be black, male, and never married. They tended to suffer most commonly from mental illness or other disorder of the central nervous system. Nearly 80 percent of expenditures for their care came from Federal or State funds, in contrast to 48.6 percent of monies for elderly nursing home users. Implications of these findings are discussed.

Background

This report from the Division of Medical Expenditure Studies presents results from the 1987 National Medical Expenditure Survey (NMES). The survey provides extensive information on health expenditures by or on behalf of American families and individuals, the financing of these expenditures, and each person's use of services. The National Medical Expenditure Survey is a research project of the Center for General Health Services Intramural Research, Agency for Health Care Policy and Research.

Since the 1970s the intramural research program has given particular emphasis to studies of the use and financing of health services. The first series of studies (NMES I) employed data collected in the 1977 National Medical Care Expenditure Survey. These studies produced information on a broad range of issues such as the number and characteristics of the uninsured and the underinsured, the tax implications of excluding employer-paid premiums for health insurance from employee income, and the differences among socioeconomic and demographic groups with respect to the use of health services.

A new series of studies (NMES II) was initiated in the 1980s. These studies also involve a major data collection effort—the 1987 National Medical Expenditure Survey. Like its predecessor, NMES II provides information about the noninstitutionalized population. In addition and in contrast to the earlier studies, NMES II also provides extensive information on the population residing in or admitted to nursing homes and facilities for the mentally retarded.

The NMES II Household Survey is based on a national probability sample of the civilian, noninstitutionalized population living in the community. The sample is designed to provide a larger representation of population groups of special policy interest to the Federal Government than would have been obtained from a random sample. These groups include poor and low income families, the elderly, the functionally impaired, and black and Hispanic minorities. A Survey of American Indians and Alaska Natives

(SAIAN) includes a separate sample of American Indians and Alaska Natives living on or near Federal reservations and eligible to receive care provided or supported by the Indian Health Service. The Institutional Population Component includes a sample of persons residing in or admitted to nursing and personal care homes and facilities for the mentally retarded during 1987. A separate Medicare Records Component provides claims data on all Medicare beneficiaries included in the household and institutional samples.

Together, the major components of NMES II contain information to make national estimates of health status, use of health services, insurance coverage, expenditures, and sources of payment for the civilian population of the United States during the period from January 1 to December 31, 1987. Oversampling of population groups of special interest makes possible in-depth studies of these groups. The data base can also be used to assess the implications of recent or proposed changes in public or private health care benefits, methods of financing both health care and insurance coverage, various public and private subsidies for health care, and employee compensation arrangements.

Household Survey

Each family in the Household Survey was interviewed four times over a period of 16 months to obtain information about the family's health and health care during calendar year 1987. Baseline data on household composition, employment, and insurance were updated at each interview, and information was obtained on illnesses, use of health services, and health expenditures for each family member. A fifth round of interviews was conducted in the spring of 1988 to obtain information on the tax filing status and medical deductions of each household. A long-term care supplement was administered during the first and fourth rounds of interviewing to permit estimates of persons with functional disabilities and the use of formal services or long-term care provided by family or friends.

In order to verify and supplement the information provided by household

respondents, the household component of NMES II included two additional surveys. A Medical Provider Survey obtained information from the physicians, hospitals, outpatient clinics, emergency rooms, and home health agencies used by the household sample during 1987. A Health Insurance Plan Survey obtained information on the private insurance of persons in the household sample, including premiums paid by all sources and the provisions of coverage.

Survey of American Indians and Alaska Natives

This survey was conducted with the same data collection instruments and interview procedures as the Household Survey and covered the same reference period — calendar year 1987. SAIAN also included followup surveys to medical providers and health insurers. Consequently, the data can be used to make comparisons between American Indians and Alaska Natives eligible for care from the Indian Health Service and the general U.S. population with regard to issues such as health status, use of health services, and access to care. Information was obtained on services provided outside the Indian Health Service and on other sources of health care financing available for persons eligible for IHS care.

Institutional Population Component

The Institutional Population Component of NMES II included persons resident in or admitted to nursing and personal care homes and facilities for the mentally retarded at any time in calendar year 1987. This survey provides information on the functional status, use of services, and health expenditures of the institutionalized population. A Survey in Institutions collected data from facility administrators and designated staff on the characteristics of facilities and charges. A Survey of Next of Kin obtained data from the respondent's next of kin or other knowledgeable persons in the community on the financial status, insurance coverage, and personal history of the institutionalized person.

Survey Samples

All survey components were designed to provide statistically unbiased estimates. The Household Survey sample is representative of the civilian noninstitutionalized population of the United States in 1987. It is a stratified, multistage area probability design with a total sample of roughly 35,000 individuals in 14,000 households who completed all rounds of data collection. Oversampling of the population subgroups of special policy interest was based on a separate screening interview conducted in the fall of 1986 with a sample of 36,000 addresses.

The Survey of American Indians and Alaska Natives adopted a multistage area probability sample design. It used an IHS constructed frame of counties with individuals eligible for services provided or supported by the Indian Health Service and living on or near federally recognized reservations or in Alaska. An initial screening interview was completed in approximately 13,700 dwelling units to identify the eligible sample, yielding 1990 responding households in round 1. Approximately 6,500 SAIAN respondents responded for their entire period of eligibility in 1987.

The institutional population sample was based on a three-stage probability design. The first two stages were used to select facilities; the final stage sampled facility residents as of January 1, 1987. These facilities were also used to obtain a sample of admissions between January 1, 1987, and December 31, 1987. Based on sampling specifications, the Institutional Population Component includes a total of 1,500 facilities, comprising 800 nursing homes and 700 facilities for the mentally retarded. Counting both residents and new admissions, this sample yielded approximately 10,100 persons, of whom 5,700 were in nursing homes and 4,400 were in facilities for the mentally retarded. The sample frame for facilities was derived from the 1986 Inventory of Long-Term Care Places.

Taken in conjunction, the NMES II surveys yield comprehensive, population-based information that will support studies of most population groups of policy interest, including those presently

outside the scope of various public and private financing mechanisms. In contrast to information obtained from program or provider statistics, NMES II data can be used to analyze all public and private sources of coverage for health care services and out-of-pocket payments by individuals and families.

The Agency for Health Care Policy and Research sponsored the NMES II data collection activities. A substantial part of the support for the Survey of American Indians and Alaska Natives was provided by the Indian Health Service. The Health Care Financing Administration, the National Center for Health Statistics, and the Office of the Assistant Secretary for Planning and Evaluation provided extensive technical assistance during the development of the survey design and instruments. Interviews were conducted by the primary contractor, Westat, Inc., Rockville, MD and by the National Opinion Research Center at the University of Chicago; the Council of Energy Resource Tribes, Denver, CO; and Stephen R. Braund and Associates, Anchorage, AK. Data processing during the analysis stage of the project is being provided by Social & Scientific Systems, Inc., Bethesda, MD.

The data were collected under the authorities of the Public Health Service Act and are being edited and published in accordance with the confidentiality provisions of that act and those of the Privacy Act. Public use tapes from NMES II are being released on a continuous basis to ensure timely access to the data.

Alan Monheit, Ph.D., and Renate Wilson, Ph.D., are editors of the NMES II publications series. Additional information on NMES II is available from Daniel C. Walden, Ph.D., Director of the Division of Medical Expenditure Studies; Center for General Health Services Intramural Research, Agency for Health Care Policy and Research; 2101 East Jefferson Street, Suite 500; Rockville, MD 20852 (301/227-8400).

A Profile of Nursing Home Users Under Age 65

Tamra J. Lair

Recent events have drawn national attention to the appropriate use of nursing homes. For example, the Omnibus Budget Reconciliation Act of 1987 (Public Law 100-203) established screening procedures for all residents of Medicaid-certified facilities to determine, through a combination of mental illness and physical health criteria, whether residents should be "outplaced" or reassigned to other facilities more appropriate to their needs. It has also been argued that Federal financing arrangements encourage the use of nursing homes when other types of care may be more appropriate (Rivlin and Wiener, 1988). Because Medicaid does not pay for home care or household chore services or for modifications to a home or special equipment that would allow a disabled individual to live independently, many individuals are forced into skilled care facilities such as nursing homes when such a level of care and supervision may not be needed.

A notable example in this debate is the case of younger residents of nursing homes who have mental or physical disabilities but find themselves in settings not appropriate to their age or social needs. Although these younger residents of nursing homes draw particular attention to the limitations of current financing arrangements for the disabled, the appropriateness of nursing home placement over other options is a perennial debate in long-term care. However, little is known about these populations, most notably those under age 65.

While the appropriate care debate continues, the number (although not necessarily the proportion) of nursing home residents under age 65 is expected to grow for several reasons. The parents of disabled persons born during the baby boom of the 1940s and 1950s are aging and may no longer be able to provide the informal care required by their disabled offspring. Individuals born with developmental disabilities or those who have experienced serious trauma are surviving because of medical advances: as a result, they will increasingly require long-term care (Mechanic, 1987). Finally, individuals with acquired immunodeficiency syndrome (AIDS) will increasingly require long-term care services as the course of the disease becomes more protracted.

This report uses data from the Institutional Population Component (IPC) of the 1987 National Medical Expenditure Survey to characterize persons under age 65 who spent at least 1 night in a nursing home in 1987. Previous findings (Lair and Lefkowitz, 1990) on the

mental health and functional characteristics of residents of nursing and personal care homes on January 1, 1987, are supplemented and expanded. Detailed information is provided on the complex nature of the health status and related characteristics of nursing home users ages 18-54 and 55-64. Estimates for elderly residents (ages 65 and older) illustrate differences and similarities between this more typical user population and those under age 65.

The NMES Institutional Population Component is composed of national, representative samples of residents of nursing and personal care homes and facilities for the mentally retarded. The estimates in this report are based on findings from the nursing and personal care home sample, which consists both of persons residing in nursing and personal care homes on January 1, 1987, and of persons admitted to a nursing or personal care home during 1987. The inclusion of estimates of the entire user population over the course of the year is important. A strict sampling of January 1 residents is more highly representative of long-stay residents (Liu and Palesch, 1981), while a nursing home user sample which includes admissions over the course of a year represents people with various lengths of stay and their characteristics.

For each age group, national estimates are presented for selected demographic characteristics. Estimates of the most prevalent medical diagnoses are provided to describe a major axis of the health status of the nursing home user population. The elderly in nursing homes typically suffer from a constellation of physical and mental health problems which combine to result in functional limitations. By contrast, younger residents are expected to have either severe functional limitations resulting from physical trauma or congenital anomalies, or chronic mental disorders that are not necessarily accompanied by functional limitations. By extension, they are expected to have either severe levels of functional difficulty or none at all. Estimates representing the intersection between mental disorders and functional limitation are, therefore, presented by age as well.

Other characteristics of the nursing home user population include place of residence prior to admission for the last continuous stay extending into 1987 and the overall time since admission to a nursing or personal care home. Summary estimates of expenditures and sources of payment for basic nursing and personal care home services

are presented to indicate variations among the age groups shown. Finally, since the age distribution of the nursing home population may vary by type of facility, selected facility characteristics are presented according to the age of users. These include ownership, size, and certification status. Information on the derivation of all estimates, on sampling procedures, and on the standard error estimates that must be considered in assessing the confidence level of the national estimates is included in the technical appendix.

Demographic Characteristics

Roughly 231,000 users of nursing and personal care homes in 1987 were under age 65, representing 10.3 percent of the total nursing home population (Table 1). Nearly 5 percent were between ages 18 and 54, and 5.6 percent were ages 55 to 64. The number of men and women in nursing and personal care homes in these age groups was evenly distributed (Table 2); this is in contrast to the population ages 65 and older, where nearly three-quarters (71.8 percent) were women. Among the younger age groups, the distribution by sex was more a reflection of the distribution in the noninstitutionalized population than in the group ages 65 and older, where women were disproportionately represented relative to the elderly living in the community (59 percent female and 41 percent male according to NMES household data for this population; Leon and Lair, 1990).

In 1987 about 1 in 5 nursing home users between ages 18 and 54 was black. Blacks in this age group were over-represented relative to their proportion in the general population (11.8 percent; Cornelius, Beauregard, and Cohen, 1991). In the older age groups, the proportion of black nursing home users declined; they represented 10.8 percent of the group ages 55 to 64 and 6.4 percent of those ages 65 and older. However, in these cases, both

the trend and the proportion of blacks were consistent with their representation in the noninstitutionalized population.

More than 56 percent of nursing home users ages 18 to 54 had never been married; this may partly be due to the type of health problem that led to institutionalization. Another 26.8 percent were no longer married and 14.3 percent were married. By contrast, among those ages 55 to 64, fully one-quarter were married and two-fifths had been married but were now widowed, separated, or divorced. Only about a third had never been married, compared to more than half in the younger age group. The vast majority of nursing home users ages 65 and older (68.8 percent) were no longer married. Only 12.5 percent of these elderly residents had never been married.

The regional distribution of nursing home users differed by age as well. The age group 18 to 54 was evenly divided between the Northeast (28.6 percent), the Midwest (28.9 percent), and the South (29.2 percent), while relatively fewer nursing home users in this age group were found in the West (13.2 percent). This disparity in the distribution of nursing home users ages 18 to 54 is not fully accounted for by variations in their regional distribution in the general population; relative to other regions of the country, the proportion of noninstitutionalized people 18 to 54 in the West was higher than the proportion found in nursing and personal care homes. This finding may reflect differences in both the availability of nursing home beds and in program incentives in the West such as MediCal, which encourage disabled individuals to remain in the community. The West has fewer nursing home beds per capita than other regions of the country (National Center for Health Statistics, 1986).

The distribution of nursing home users in the age group 55 to 64 showed a higher proportion of residents in nursing and personal care homes in the Midwest (30.9 percent) and the South (29.5 percent) than in the Northeast (20.5 percent) or the West (19.0 percent). A similar regional distribution prevailed in the elderly user population.

Table 1. Persons in nursing and personal care homes, by age, United States, 1987

Age in years	Number (in thousands)	Percent
Total population	2,235	100.0
Under 65	231	10.3
18 to 54	106	4.7
55 to 64	125	5.6
65 and older	2,004	89.7

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component.

Physical Health, Mental Health, and Functional Status

More than 36 percent of nursing home users 18 to 54 years of age had disorders of the central nervous system such as multiple sclerosis, cerebral palsy, paralysis, and epilepsy (Table 3). Over 34 percent in this age group

Table 2. Selected demographic characteristics of persons in nursing and personal care homes: Percent by age, United States, 1987

Demographic characteristic	Ages 18 to 54	Ages 55 to 64	Ages 65 and older
Total population (in thousands) ^a	106	125	2,004
	Percent of users		
Sex			
Male	50.0	46.5	28.2
Female	50.0	53.5	71.8
Racial background			
White	77.4	86.4	92.0
Black	19.8	10.8	6.4
Marital status			
Married	14.3	25.5	18.0
No longer married ^b	26.8	41.1	68.8
Never married	56.5	30.9	12.5
Census region			
Northeast	28.6	20.5	22.3
Midwest	28.9	30.9	31.4
South	29.2	29.5	29.1
West	13.2	19.0	17.3

^aIncludes all other racial groups and persons of unknown marital status.

^bWidowed, separated, or divorced.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component.

suffered from psychoses, including organic brain disorders. Nonpsychotic mental disorders such as neurotic disorders or personality disorders afflicted 33.9 percent of this age group and 23.5 percent had a diagnosis of mental retardation.

Diseases of aging were apparent among nursing home users ages 55 to 64. For example, ischemic heart disease, which was not among the five most prevalent diagnoses for the youngest users, was experienced by nearly one-quarter of nursing home users in the age group 55 to 64. Similarly, 26.3 percent of this group had hypertensive disease. Although still prevalent among nursing home users ages 55 to 64, disorders of the central nervous system were experienced by a smaller percentage of people (21.1 percent) than in the youngest age group. At 37.4 percent for each, psychoses and nonpsychotic mental disorders were the most prevalent conditions in the age group 55 to 64; this rate is similar to that among the youngest users.

Among nursing home users ages 65 and older, nearly 45 percent suffered from psychoses. While the diagnostic categories for the youngest residents were most likely to include schizophrenia, autism, and affective psychoses such as major manic depression, psychoses experienced by elderly residents were most likely to be de-

mentia (data not shown). Diagnoses of nonpsychotic mental disorders were found at similar rates among elderly users and among other age groups (roughly a third). Elderly nursing home users also suffered from diseases of the arteries (37.5 percent), including atherosclerosis, aneurysms, and thrombosis, as well as from arthropathies (31.9 percent), which include both rheumatoid arthritis and osteoarthritis.

Table 4 shows nursing home users by age and several combinations of mental health and functional status. The age group 18 to 54 was almost evenly divided between those with four or five difficulties in activities of daily living (ADLs) but no mental disorders or mental retardation (25.9 percent); those without ADL limitations but one or more mental disorders or mental retardation (22.8 percent); and those with both a high number of ADL limitations in addition to mental disorders and/or mental retardation (24.2 percent). A similar proportion (20.8 percent) in this age group had one to three ADL difficulties, most in combination with mental disorders (16 percent).

In the group ages 55 to 64, over 14 percent had only a mental disorder and no evidence of ADL difficulties. Just under one-third suffered from low to moderate levels of ADL limitations, either without mental disorders

Table 3. Five most prevalent diagnostic categories among persons in nursing and personal care homes: Percent by age, United States, 1987

Diagnostic category ^a	Total population (in thousands)	Percent
Ages 18 to 54	106	
1) Other disorders of the central nervous system (such as multiple sclerosis, cerebral palsy, paralysis, epilepsy)		36.3
2) Psychoses (includes dementias and other organic brain disorders)		34.1
3) Neurotic disorders, personality disorders, and other nonpsychotic mental disorders		33.9
4) Mental retardation		23.5
5) Symptoms (such as coma, convulsions, hallucinations)		18.6
Ages 55 to 64	125	
1) Psychoses (includes dementias and other organic brain disorders)		37.4
2) Neurotic disorders, personality disorders, and other nonpsychotic mental disorders		37.4
3) Hypertensive disease		26.3
4) Ischemic heart disease		24.3
5) Other disorders of the central nervous system (such as multiple sclerosis, cerebral palsy, paralysis, epilepsy)		21.1
Ages 65 and older	2,004	
1) Ischemic heart disease		49.3
2) Psychoses (includes dementias and other organic brain disorders)		44.9
3) Diseases of arteries, arterioles, and capillaries		37.5
4) Neurotic disorders, personality disorders, and other nonpsychotic mental disorders		33.1
5) Arthropathies and related disorders		31.9

^aDiagnostic categories from the *International Classification of Diseases, 9th Revision, Clinical Modification*. People can be in more than one category.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component.

or mental retardation (9.8 percent) or in combination with them (19.8 percent). By contrast, most elderly nursing home users had high levels of ADL limitations (63.4 percent), many in combination with mental disorders (36.7 percent).

Prior Residence and Length of Institutional Stay

About a third (32.4 percent) of nursing and personal care home users between the ages of 18 and 54 had been admitted to their 1987 facility of residence from independent living in the community (Table 5). Another 15.6 percent had been transferred from another nursing home or facility for the mentally retarded and 40.3 percent from a hospital or other health care facility. The

remaining 11.7 percent came from places such as retirement homes, group houses, boarding houses, or the street. Roughly a quarter of nursing and personal care home users ages 55 to 64 came from their home, but more than half came from a hospital or other health care facility (53.2 percent). For users ages 65 and older, there was an even split between independent living in the community (44 percent) and a hospital (40.5 percent) as the last place of stay prior to admission to the nursing or personal care home. In fact, elderly users were most likely among the three age groups to have come from their home to the nursing facility.

In general, nursing home users ages 18 to 54 had been institutionalized longer than residents ages 65 and older (Table 6). Counting length of institutional stay from the

Table 4. Mental health status of persons in nursing and personal care homes, by number of limitations in activities of daily living and age, United States, 1987

Mental health status	Total population (in thousands)	Number of ADL limitations ^a		
		0	1-3	4-5
Percent of total				
Ages 18 to 54	106	29.1	20.8	50.1
No mental retardation or mental disorders		*6.3	*4.8	25.9
Mental retardation and/or any mental disorder ^b		22.8	16.0	24.2
Ages 55 to 64	125	19.9	29.6	50.5
No mental retardation or mental disorders		5.4	9.8	26.2
Mental retardation and/or any mental disorder ^b		14.5	19.8	24.3
Ages 65 and older	2,004	8.3	28.4	63.4
No mental retardation or mental disorders		4.6	13.2	26.7
Mental retardation and/or any mental disorder ^b		3.7	15.2	36.7

^aIncludes limitations in bathing, dressing, transferring from a bed or chair, toileting, and feeding.

^bIncludes at least one of the following: chronic or organic brain syndrome, depressive disorder, schizophrenia, other psychoses, anxiety disorder, personality or character disorder, and other mental disorders.

*Relative standard error equal to or greater than 30 percent.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component.

last day of continuous community residence to December 31, 1987 (or the date of discharge during 1987, as applicable), the age group 18 to 54 had, on average, been institutionalized for 2,293 days, or well over the average of 1,763 days for users ages 65 and older. (The mean number of days for the age group 55 to 64 was not statistically different from either of the other age groups.)

The distribution of the length of time from the last residence in the community to the most recent admission was similar for the two age groups under age 65. Elderly nursing home users exhibited a different pattern. Over 26 percent had resided in institutions for periods of more than 1 to less than 3 years since their last continuous community residence, compared with roughly 20 percent in the younger age groups. By contrast, just over 10 percent of elderly users had been institutionalized for 10 years or more; this compares to nearly 20 percent of the group ages 18 to 54.

Expenditures and Sources of Payment

Table 7 reports aggregate expenditures and mean expenditures per person for basic nursing and personal care home services in 1987, and the distribution of these expenditures by various sources of payment. Expenditures for nursing home users ages 18 to 54 were an aggregate \$1.65 billion in 1987, compared to \$26.1 billion for elderly users. Also, the youngest age group spent roughly \$4,000 more per person than those ages 55 to 64 (\$15,654 versus \$11,654). The mean expenditure of el-

derly nursing home users was not significantly different from that of the other two age groups. Nearly half of aggregate nursing home expenditures for elderly nursing home users was paid by the elderly themselves or through family support. Younger residents paid less from their own resources or with family assistance: 20 percent of aggregate expenditures was paid out of pocket by those ages 18 to 54 and 27.4 percent by those ages 55 to 64.

Of the \$1.65 billion in total expenditures for nursing home users ages 18 to 54, almost three-quarters (71.6 percent) was paid by Medicaid. This compares with 53.2 percent for users ages 55 to 64 and with 45.2 percent for those ages 65 and older. The Department of Veterans Affairs paid 7.6 percent of nursing home expenditures for users 55 to 64 years of age, in contrast to roughly 1 percent for both of the other age groups.

Facility Characteristics

Facility ownership characteristics (Table 8) did not differ across the three age groups of nursing and personal care home users shown. There were some differences for facility bed size and certification status. For example, compared to their older counterparts, the youngest nursing home users were more likely to reside in large facilities of 150 beds or more (40.8 percent) and less likely to be in moderately sized facilities of 50 to 99 beds (16.4 percent). Also, nursing and personal care home users ages 18 to 54 were more likely to be found in non

Table 5. Place of residence of persons in nursing and personal care homes prior to admission, by age of user, United States, 1987

Place of residence	Ages 18 to 54	Ages 55 to 64	Ages 65 and older
Total population (in thousands)	106	125	2,004
	Percent of users		
Independent living in the community	32.4	27.5	44.0
Facility for the mentally retarded or nursing home	15.6	11.2	10.5
Hospital/health care facility	40.3	53.2	40.4
Other ^a	11.7	8.1	5.1

^aIncludes retirement homes, boarding houses, group houses, correctional facilities, training centers, or the street.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component.

Table 6. Time since last continuous community residence for persons in nursing and personal care homes, with standard errors (SE), by age, United States, 1987

Time since institutionalization ^a	Ages 18 to 54	Ages 55 to 64	Ages 65 and older
Total population (in thousands)	106	125	2,004
Mean number of days (SE)	2,293 (256)	2,351 (308)	1,763 (60)
	Percent of users		
1 to 90 days	14.8	17.0	16.3
91 to 365 days	16.5	21.3	17.6
More than 1 to less than 3 years	19.1	20.6	26.4
3 to less than 5 years	11.1	9.1	13.8
5 to less than 10 years	18.8	14.2	15.5
10 or more years	19.7	17.7	10.4

^aDefined from the last date of continuous residence in the community through December 31, 1987, or the date of discharge from the current facility, disregarding possible interruptions for hospitalizations. May reflect institutionalizations in one or more long-term care facilities.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component.

certified facilities than older users (22.9 percent compared to less than 15 percent for the two older age groups).

Summary

Nursing and personal care home users ages 18 to 64 made up just over 10 percent of the nursing home population in 1987. Although nursing home users ages 18 to 54 differed markedly from their elderly counterparts on many dimensions examined in this report, those in the age group 55 to 64 resembled elderly users in some respects and were more like younger users in other ways. The youngest users (ages 18 to 54) were more likely to be male, black, and never married than were those 65 and older; there were proportionately more young black nursing home users than their noninstitutionalized counterparts of the same age. The racial distribution of

nursing home users in the other age groups reflects more closely the age-specific proportions of blacks in the noninstitutionalized population. Men were also more likely to be young and institutionalized than women; nearly 17 percent of all men in nursing homes were under age 65, compared with only 7.7 percent of all women in nursing homes. These disparities by sex and race may reflect differences in the prevalence of the types of medical conditions that are likely to result in institutionalization. For example, both men and blacks are at higher risk for serious accidents that may result in spinal cord injury or head trauma (Baker, O'Neill, and Karpf, 1984; Wishner and others, 1991). In addition, because of current Medicaid financing arrangements, the younger poor who are severely disabled may more often find themselves institutionalized than their more affluent counterparts who can afford alternative types of care.

Table 7. Annual expenditures, with standard errors (SE), and sources of payment for basic nursing and personal care home services, by age of user, United States, 1987

Expenditure and source of payment	Total	Ages 18 to 54	Ages 55 to 64	Ages 65 and older
Total population (in thousands)	2,235	106	125	2,004
Total nursing home expenditures ^a (in thousands)	\$29,253,000	\$1,654,000	\$1,464,000	\$26,135,000
(SE)	(555,000)	(203,000)	(76,000)	(482,000)
Mean expenditure per user	\$13,091	\$15,654	\$11,654	\$13,045
(SE)	(249)	(1,922)	(602)	(241)
Percent distribution of expenditures				
Source of payment				
Own income or family support	46.8	20.0	27.4	49.5
Federal programs				
Medicare	1.3	*0.6	*0.8	1.4
Medicaid	47.1	71.6	53.2	45.2
Supplemental Security Income	0.7	*1.5	1.8	0.6
Department of Veterans Affairs	1.3	*1.2	7.6	0.9
State/local government	0.9	*4.0	*4.0	0.5
Private health insurance ^b	1.5	*1.0	*5.1	1.4
Other	*0.4	*0.1	*0.2	*0.5

^aAll expenditure estimates are for basic nursing and personal care home services. Excludes expenditures for ancillary items billed separately by the facility.

^bOnly payments made directly to the nursing or personal care home. Includes prepaid care through life care communities.

*Relative standard error equal to or greater than 30 percent.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component.

The youngest nursing home residents described in these estimates suffer from both severely disabling physical and mental conditions. Chronic and severe conditions of the central nervous system, either as a result of major trauma or from unknown causes, are common among nursing and personal care home users in this age group. At rates similar to their older counterparts, the youngest users also suffer from a host of mental disorders, including both psychoses and neurotic and personality disorders. It is likely, however, that the psychoses experienced by the young differ in type from those suffered by elderly residents because dementias are closely correlated with age. Psychoses experienced by the youngest residents are more likely to be schizophrenic disorders, autism, and affective psychoses such as major manic depression. In addition, nearly one-quarter of all nursing home users ages 18 to 54 had a diagnosis of mental retardation. With this constellation of physical and mental problems, both in nature and degree, it is clear that these younger nursing and personal care home users are a population requiring a range of long-term care services.

A comparatively large proportion of nursing and personal care home users ages 55 to 64 experienced diseases of aging and in this respect were similar to elderly nursing home users. These chronic disease groups, such as ischemic heart disease and hypertension, require less skilled care to maintain patient functioning when they are experienced in isolation. However, with increasing age, multiple chronic disabling conditions become more likely and combine to limit the individual to varying degrees.

Even in the face of severely limiting medical conditions, aggregate expenditures of nursing home users in the youngest age group were proportional to the size of the population. It may be that the nature, extent, or volume of ancillary services required by this group go significantly beyond those reflected in the estimates for basic services presented here. However, under current reimbursement schemes, the sources of payment for both basic and other expenditures are likely to stay relatively constant regardless of the type of service considered. In 1987, Federal and State program dollars paid for a significantly higher proportion of the bill for younger nurs-

Table 8. Distribution of nursing home users according to characteristics of nursing and personal care homes, by age of user, United States, 1987

Facility characteristic	Ages 18 to 54	Ages 55 to 64	Ages 65 and older
Total population (in thousands) ^a	106	125	2,004
	Percent of users		
Facility ownership			
For profit, independent	22.3	22.6	24.3
For profit, chain	45.0	50.2	44.7
Nonprofit, independent	*13.0	7.7	15.5
Nonprofit, chain	*8.2	8.3	7.4
Public	11.4	11.2	8.2
Bed size			
3-49	15.1	12.6	9.8
50-99	16.4	27.2	25.6
100-149	27.8	27.7	33.0
150 or more	40.8	32.6	31.5
Certification status			
Skilled nursing and intermediate care facility	41.8	39.3	44.6
Skilled nursing facility only	17.6	21.4	24.2
Intermediate care facility only	17.4	25.5	21.2
Not certified	22.9	13.6	10.0

^aIncludes all other facility types not shown separately.

*Relative standard error equal to or greater than 30 percent.

Source: Agency for Health Care Policy and Research. National Medical Expenditure Survey—Institutional Population Component.

ing home users than for elderly users. Nearly 80 percent of basic nursing home charges for users ages 18 to 54 was paid by Federal and State programs (including Medicaid), compared with 48.6 percent of the charges for the elderly.

Probably due to a combination of medical conditions and age, the youngest group of residents averaged just above 6 years of institutionalization since their last period of continuous residence in the community, compared with 4.8 years for elderly nursing home users. This longer period of institutionalization, combined with the fact that the bulk of their care was paid for from public funds, suggests that the costs of care for this population may have important implications for the Federal and State role in the overall financing of long-term care.

It is clear that the younger nursing and personal care home users, particularly those ages 18 to 54, present the long-term care system with a different set of challenges than the typical elderly user. This is due to the severity and nature of the illnesses afflicting young residents, coupled with different age-specific social and psychological needs. Also, it is likely that the size of this population will grow. Given both the nature and variability of

the nursing home population by age and on other dimensions, further research is needed to inform policy regarding the expected demands and special needs of institutionalized people of all ages.

Technical Appendix

Data Sources and Methods of Estimation

The data in this report are from the Institutional Population Component (IPC) of the 1987 National Medical Expenditure Survey (NMES). The IPC was designed to provide national and regional estimates for the population in nursing and personal care homes and facilities for the mentally retarded as well as estimates of these institutional facilities and a range of their characteristics. The findings in Tables 1-8 are based on data from the nursing and personal care home component of the IPC, which comprised two samples, one consisting of persons residing in sampled nursing and personal care homes on January 1, 1987, and the other including all persons admitted to sampled nursing and personal care homes at some time during 1987. The union of these two population samples represents the population in

nursing and personal care homes at any time during 1987 (Cohen, Flyer, and Potter, in preparation).

Data were collected in three phases and four interviews. Persons for whom data were provided for at least one-third of their period of institutionalization in 1987 were considered IPC person-level respondents. The estimates in this report are derived from 781 nursing and personal care homes and 5,056 persons 18 years of age and older who spent at least 1 night in one of these facilities in 1987. Overall, the response rate for January 1, 1987, residents in a sampled facility was 89.5 percent (.946 facility-level response rate x .946 resident-level response rate). For those sampled as admissions, the overall response rate was 81.2 percent (.891 facility-level response rate x .911 admission-level response rate).

Instruments

Facility data were obtained from a facility questionnaire. Respondents were facility administrators or designated staff. The reference period was the date of the interview, conducted during the period February-May 1987. Data on resident characteristics were obtained from a baseline questionnaire administered to staff responsible for direct patient care (caregivers) or other designated staff. Information on facility use and expenditures was collected in an institutional use and expenditure questionnaire, which was collected several times during the year, depending on the time of sampling. Respondents for the expenditure information were generally persons connected with the billing office of the facility. The reference period for these instruments began on January 1, 1987, for residents as of that date, or the time of admission to the sampled facility. Residents who moved from a sampled facility were followed to collect all institutional expenditure data for calendar year 1987. (For detailed information on data collection instruments and procedures, see Edwards and Edwards, 1989.)

Definition of a Nursing Home

A facility is considered a nursing or personal care home if the facility was certified by Medicare or Medicaid as a skilled nursing facility (SNF) or intermediate care facility (ICF) or was a separate place or unit of another institution licensed or officially recognized by a State, with three or more beds for patients and which provided patients with personal care assistance. Excluded are noncertified facilities licensed as hospitals and residential facilities that limited care exclusively to persons with specific physical, mental, and emotional conditions. Personal care assistance is defined to be

nursing or medical care, supervision of medications, help with bathing, dressing, walking, eating, correspondence, or shopping. All SNF- or ICF-certified units of licensed hospitals are considered "nursing homes."

Data on Nursing and Personal Care Home Users

Racial background. Classification by racial background was based on information reported for each nursing home user. Next of kin and facility staff were asked if the racial background of the user was best described as American Indian or Alaska Native, Asian or Pacific Islander, black, white, or other. Next-of-kin responses were given preference in the case of inconsistent answers. The present report is limited to separate estimates for two categories (white and black) because of the small number in other racial groups. These groups are included in the population totals, however.

Marital status. Facility respondents were asked if, on the reference date, the sampled person was married, widowed, divorced, separated, or had never been married. These responses were validated with next-of-kin survey data, where possible (see Edwards and Edwards, 1989, for details). In cases where the facility and next of kin reported marital status inconsistently, next-of-kin data were preferred, provided that time could be ruled out as a factor for the difference in status. For cases where no facility data were available, next-of-kin data were used. For approximately 3 percent of cases, marital status was logically imputed. Marital status was collapsed into three categories for the purposes of this report: married, never married, and no longer married (a combination of widowed, divorced, and separated).

Census region. Classification by region of the country was determined by the location of the sampled facility. Region was defined in terms of the categories developed by the U.S. Bureau of the Census.

Activities of daily living (ADLs). Respondents were asked to indicate whether the resident had difficulty performing personal care activities commonly known as activities of daily living (Katz and Akpom, 1976), a measure widely used in both institutional and community settings to characterize an individual's ability to function independently and without physical limitation resulting typically from a complex of conditions. Five activities are included in the summary ADL measure: bathing, dressing, transferring from a bed or chair, toileting (getting to and from the toilet and physically using the toilet), and feeding oneself. Residents were considered to have difficulty with a specific activity if they received personal assistance or supervision in performing

the task or could not perform the activity at all. Any missing data (no more than 1.5 percent) on any of the source variables were imputed, using a regression-based approach.

Medical diagnoses. Two primary questionnaire items were sources of information on the medical conditions of the sampled person. First, an open-ended question regarding the primary and other diagnoses of the sampled person was asked. Referring to the medical record, the facility respondent provided a list of all conditions. Each of these conditions was coded using the *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM) coding system. Coding was performed by trained medical coders who maintained an error rate no greater than 1.5 percent as verified by supervisors and nosologists. As many as 10 conditions could be coded in this section of the baseline questionnaire for each respondent.

Second, facility respondents were asked to indicate, according to the medical record, whether the resident had any of a series of medical conditions. The questions were in list format and included hypertension, arteriosclerosis, rheumatism, emphysema, arthritis, diabetes, cancer, and heart disease. Missing values, in all cases less than 1 percent of the total, were imputed. A range of ICD-9-CM codes was then associated with each condition in the checklist. This range was used to search the codes already assigned to the sampled person. If the facility respondent had not provided this type of condition in the answer to the question on primary and other diagnoses but gave a positive response in the checklist for this condition, then an additional ICD-9-CM code representing this condition was assigned to the sampled person. Uniformly, this additional ICD-9-CM code was the most general code within each broad disease category; for example, cancer was assigned a recoded value of 290 (neoplasm of an unspecified nature).

On completion of coding, conditions were grouped into categories based on the ICD-9-CM scheme of disease types within body systems or by major disease categories. The level of detail used in this report is the first subclass in the ICD-9-CM within a major body system or disease category. For example, ischemic heart disease is a second-level disease category under diseases of the circulatory system summarizing conditions coded 410 through 414 in the ICD-9-CM.

Mental disorders and mental retardation. Again, two primary questionnaire items were used. First, the open-ended question regarding the primary and other diagnoses for the sampled person provided by the facility respondent elicited answers indicating diagnoses of

mental disorders. Second, respondents were specifically asked to indicate, according to the medical record, whether the resident had any of a series of mental disorders (the medical record was consulted in 97 percent of the interviews). The questions were in list format and included senile dementia/chronic or organic brain syndrome; depressive disorders; schizophrenia; other psychoses; anxiety disorders; personality/character disorders; and any other mental disorders. Missing values on the mental disorder checklist, consistently less than 1.5 percent of the total, were imputed. The mental disorders reported here are the union of the two sets of responses after removing duplicate conditions reported on both lists by the process described above for medical conditions more generally.

In addition to the information collected on mental disorders, a question was asked about whether the respondent had a diagnosis of mental retardation. This item was handled as described above with respect to the free-recall condition question. After recoding was conducted, multiple conditions were grouped into two categories: 1) no mental disorders and no mental retardation; or 2) mental retardation and/or one or more mental disorders.

Place of residence prior to admission to the sampled facility. Place of residence was determined using a series of questions in the baseline questionnaire, the personal history questionnaire, and the community use and expenditure questionnaire. Place of residence was determined using items from these questionnaires in a hierarchical fashion, accepting the first nonmissing location in the hierarchy. Missing locations were then imputed using a weighted sequential hot-deck procedure. Once prior residence was determined for all sampled persons, it was collapsed into a four-level variable: independent living, nursing home or facility for the mentally retarded, hospital, or other. "Other" includes retirement homes, boarding houses, correctional facilities, training centers, or the street.

Time since the last continuous community residence. Time since institutionalization was defined as beginning on the last date of continuous residence in the community through December 31, 1987, or the last date of discharge from a primary sampled facility in 1987, ignoring discharges and admissions entirely related to the hospital care of patients previously in the facility (Short, Cunningham, and Mueller, 1990). This time span, measured in days, could encompass periods of institutionalization in one or more long-term care facilities. If the first and only admission to an institution occurred in 1987, this variable was calculated based on the

first admission of the year to the primary sampled facility until date of discharge or December 31, 1987, as applicable.

Expenditures for basic nursing home services. Data on facility charges and sources of payment were collected for each billing period in the facility where a person was institutionalized. Expenditures for basic nursing home services as reported here refer to the facility's basic daily charge, as limited by the amounts allowed by third-party payers such as Medicare, Medicaid, and private health insurers. Additional expenditures for ancillary items (such as special supplies and services) billed separately by the facility are not included. The services provided by facilities that do not customarily charge for their care (because, for example, they are public institutions financed by government budgets) are valued according to the daily expenditures of similar patients in otherwise similar facilities.

Daily expenditures were imputed where missing for all billing periods in a facility or assigned in facilities without charges by means of a weighted sequential hot-deck procedure. This procedure, which was employed for less than 3 percent of all billing periods in 1987, imputed data from individuals with expenditure information to individuals with missing information but similar characteristics. Groups of similar individuals were formed according to region, sources of payment, average daily Medicaid payments in the State, first admission to a nursing home in 1987, and number of ADL limitations. Daily expenditures for persons missing data for some but not all billing periods in a facility were assigned from the nonmissing data.

In a similar fashion, sources of payment for persons missing data for some but not all billing periods in a facility were assigned from the nonmissing data. The procedure for the remaining cases was first to identify or impute coverage under Part A of Medicare and then to assign all other sources of payment (including, if necessary, the party responsible for Medicare copayments after the 20th day of a Medicare stay).

The NMES design provided for linkage with Medicare claims records for all residents for whom Medicare claim numbers could be obtained. For residents with a valid claim number and billing periods with missing data, the Medicare claims data were used to determine if Medicare had paid for any care during the billing period. If so, both the Medicare payment and total expenditures from the claim record were assigned to the IPC record. There were only 65 residents without a valid claim number and with missing data for billing periods who potentially met the requirements for Medicare coverage (that

is, the person was enrolled in Medicare, the facility was certified by Medicare, and there was a prior hospital stay). A hot-deck imputation was used to randomly select a small number of stays that were assigned the median number of Medicare days per episode and Medicare payment in the Medicare skilled nursing facility claims for the NMES sample.

After these procedures were implemented, there remained less than 1 percent of billing periods with missing data to be assigned to other payers. These payers were imputed with a hot-deck procedure, where groups of similar cases were formed according to the payers for prior or subsequent stays in other facilities, length of stay, Medicaid and Supplemental Security Income status as ascertained elsewhere in the IPC, veteran status, 1986 family income and home ownership, and facility ownership. The latter variable was used to identify care financed through the budgets of State and local or non-profit facilities.

Facility Characteristics

Ownership. Facility respondents reported which ownership type best described their facility: for profit (individual, partnership, or corporation), private non-profit (religious group, nonprofit corporation), or one of four types of public ownership (city/county government, State government, Department of Veterans Affairs, or other Federal agency). Respondents also reported whether their facility was part of a chain or group of facilities operating under one general authority or ownership. Facilities with a negative response were classified as independently owned.

Facility size. Facility size was determined by the number of beds in the facility regularly maintained for residents. Beds used by staff or for day care patients were excluded. In the case of a unit in a larger facility, only the unit beds were included.

Certification status. Respondents were asked whether their facility had "any beds certified by Medicare as SNF beds?"; had "any beds certified by Medicaid as SNF beds?"; and had "any beds certified by Medicaid as either ICF (intermediate care facility) beds or ICF-MR (intermediate care facility for the mentally retarded) beds?" For the purposes of this report, facilities were assigned to mutually exclusive categories based on the responses to those questions. Facilities responding affirmatively to both the SNF and to the ICF questions were classified as SNF- and ICF-certified facilities. Facilities responding positively to the ICF-MR question and negatively to SNF Medicare, SNF Medicaid, and

ICF Medicaid questions were classified as "not certified."

Sample Design and Standard Error Estimates

The IPC sample was selected according to a stratified three-stage probability design, with facility selection in the first two stages. The Inventory of Long-Term Care Places served as the facility sampling frame. The final stage of selection consisted of a sample of residents as of January 1, 1987, and a rolling sample of persons admitted during the year. Thus, persons residing in sampled facilities on January 1 were included in the sample, as were persons admitted at any time during 1987 to a sampled facility, up to and including December 31. The sample used in this report represents all people who spent at least 1 night in a nursing or personal care home during calendar year 1987. For a detailed description of the survey design and of sampling, estimation, and adjustment methods, including weighting for nonresponse and poststratification, see Cohen, Flyer, and Potter (in preparation).

Reliability of Estimates

Since the statistics presented in this report are based on a sample, they may differ somewhat from the figures that would have been obtained if a complete census had been taken. This potential difference between sample results and a complete count is the sampling error of the estimate.

The chance that an estimate from the sample would differ from a complete census by less than one standard error is about 68 out of 100. The chance that the difference between the sample estimate and a complete census would be less than twice the standard error is about 95 out of 100.

Tests of statistical significance were used to determine whether differences between estimates exist at specified levels of confidence or whether they simply occurred by chance. Differences were tested using Z-scores having asymptotic normal properties, based on the rounded figures at the 0.05 level of significance. Unless otherwise noted, only statistically significant differences between estimates are discussed in the text.

Rounding

Estimates presented in the tables have been rounded to the nearest 0.1 percent or to the nearest thousand for population estimates or the nearest million for expenditure estimates. The rounded estimates, including those

underlying the standard errors, will not always add to 100 or the full total.

Standard Errors

Standard errors for the totals and percents in this report were approximated, by interpolation where necessary, using a curve smoothing procedure developed at the National Center for Health Services Research (Cohen, 1979). The statistical tests in this report, however, are based on direct estimates of standard errors using the Taylor series linearization method.

Relative standard errors of totals. Where the statistics of interest are total estimates (T) of the population, an estimate of the standard error, SE , can be obtained by multiplying the relative standard error, $RSE(T)$, expressed as a percent of the respective total (T), by T and then dividing by 100. Thus,

$$SE(T) = \frac{T(RSE(T))}{100}$$

For estimated population totals for individuals, the approximate relative standard errors expressed as percents are presented in Table I.

- Example—An estimate of 900,000 nursing and personal home care users ages 65 and older suffering from psychoses ($2,004,000 \times 0.449$; Table 3) has a relative standard error of between 4.6 and 3.8 percent (Table I) or, by interpolation, a relative standard error of about 4.0 percent. The standard error of this estimate, then, is

$$SE(T) = \frac{900,000(4.0)}{100} = 36,000$$

Direct standard errors for percent of population.

When the statistic of interest is expressed as a percent of the number of persons, direct estimates of standard errors have been derived for ease of calculation. For the estimated percents of the nursing and personal care home user population by selected characteristics, approximate standard errors expressed as a percent are as shown in Table II.

- Example—The estimate of 19.8 percent of the black nursing and personal care home population ages 18-54 is based on an estimated population total of 106,000 (Table 2). This estimate has a standard error of approximately 3.2 percent (Table II).

Direct standard errors for percent of expenditures.

Direct estimates of standard errors have been derived for statistics expressed as a percent of total expenditures by source of payment for basic nursing and personal care

home services. Approximate direct standard errors for these estimates, expressed as a percent, are presented in Table III.

- Example—The estimate of 49.5 percent of the nursing and personal care home expenses for users ages 65 and older paid from their own income or with family support is based on an expenditure total of \$26,135,000,000 (Table 7). This estimate has, by interpolation, a standard error of approximately 1.1 percent (Table III).

Tables 6 and 7 provide selected direct estimates of standard errors. Standard error estimates for mean days since the last continuous community residence are presented in Table 6. Table 7 provides estimates of standard errors for total expenditures and mean expenditure per user.

Table I. Approximate relative standard errors for population totals

Estimated population totals for individuals (in thousands)	Relative standard error (in percent)
25	16.3
50	11.7
100	8.5
250	5.8
500	4.6
1,000	3.8
1,500	3.5
2,300	3.3

Table II. Approximate direct standard errors for percent of population estimates

Persons in the base of the percent (in thousands)	Estimated percent						
	2 or 98	5 or 95	10 or 90	20 or 80	30 or 70	40 or 60	50
25	2.3	3.5	4.8	6.4	7.4	7.9	8.1
50	1.6	2.5	3.4	4.6	5.2	5.6	5.7
100	1.1	1.8	2.4	3.2	3.7	3.9	4.0
250	0.7	1.1	1.5	2.0	2.3	2.5	2.5
500	0.5	0.8	1.1	1.4	1.7	1.8	1.8
1,000	0.4	0.6	0.8	1.0	1.2	1.2	1.3
1,500	0.3	0.5	0.6	0.8	1.0	1.0	1.0
2,300	0.2	0.4	0.5	0.7	0.8	0.8	0.8

Table III. Approximate direct standard errors for percent of expenditure estimates

Dollars in the base of the percent (in thousands)	Estimated percent			
	2 or 98	5 or 95	25 or 75	50
500,000	2.2	3.4	6.7	7.8
2,000,000	1.1	1.7	3.4	3.9
10,000,000	0.5	0.8	1.5	1.7
30,000,000	0.3	0.4	0.9	1.0

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SUMMARY

CHANGES IN THE USE OF PERSONAL ASSISTANCE AND SPECIAL EQUIPMENT FROM 1982 TO 1989: RESULTS FROM THE 1982 AND 1989 NLTCs

Kenneth G. Manton, Larry Corder, and Eric Stallard

Trends in disability rates are extremely important to projections of the future cost of long-term care. This article analyses recent data on the disabled elderly and concludes that there has been a decline in disability requiring the use of personal assistance. This decline has occurred among virtually all of the subpopulations. There has been an increase in the use of special equipment to help the disabled.

Analysis of data from the 1982, 1984 and 1989 National Long-Term Care Surveys suggests that long-term care use is changing. Between 1982 and 1989, equipment use by persons with light physical impairment, or to supplement personal assistance for the severely disabled, increased. Over this same period, there was a decline in the use of personal assistance as the sole modality to deal with chronic impairments. Since equipment costs are nonrecurrent, whereas personal assistance costs are recurrent, this finding has implications for long-term care policy.

Key Words: Chronically disabled, Long-term care, Activities of daily living

Changes in the Use of Personal Assistance and Special Equipment from 1982 to 1989: Results from the 1982 and 1989 NLTCs¹

Kenneth G. Manton, PhD,² Larry Corder, PhD,² and Eric Stallard, BS²

The oldest old (85+) form the fastest growing U.S. age group with the highest per capita long-term care (LTC) needs. Growth is due both to the larger size of cohorts entering old age and to improved survival (e.g., mortality over age 85 declined 8.6% from 1988 to 1991 [National Center for Health Statistics, 1992]). Given this growth, there is concern about meeting future long-term medical, social, and rehabilitative service needs. In addition to the growth of the elderly population, several current trends will affect — some positively, some negatively — the amount and type of LTC services used.

A positive trend is that the average educational and economic status of future elderly cohorts has been, and is projected to continue, increasing (Myers, Manton, & Bacellar, 1987). Higher income and education are associated with reduced mortality (Feldman et al., 1989), reduced institutionalization (Manton, Stallard, & Singer, 1992), and improved functioning (Manton, Corder, & Stallard, in press; Maddox & Clark, 1992). Therapeutic and preventative strategies show promise in modifying the natural history of some chronic diseases causing disability. In contrast, the availability of informal LTC may decrease due to smaller family size, changes in residential patterns, and increased labor force participation by women — the latter a special concern for elderly African-Americans dependent on family LTC sources (Headen, 1992, in press).

Also affecting U.S. LTC needs, but less well documented than population growth and health change, are changes in the types of services used by elderly persons to cope with chronic disability. We exam-

ined, using the 1982 and 1989 National Long Term Care Surveys (NLTCs), changes in the use of equipment and housing modifications (defined by the technology available in 1982) and active personal assistance, specific to age, gender, disability level, and ADL and IADL impairment.

Data

The NLTCs were designed to measure a) the 1982, 1984, and 1989 prevalence of chronic disability and institutionalization in the U.S. elderly Medicare-enrolled population (97% or more of the U.S. population 65+, U.S. Department of Health and Human Services [USDHHS], 1988); and b) changes (both improvement and decline) in chronic disability (and institutionalization) in individuals. The NLTCs samples in each year represent the Medicare-enrolled population 65+, with data collection focused on chronically disabled community residents (defined by screening) and, in 1984 and 1989, in institutions.

The sample for the 1982 NLTCs was drawn from Medicare enrollment files. The goal was to conduct 6,000 interviews with chronically disabled community residents. Given that chronic disability prevalence, as defined by survey criteria, was not known before field work started, a sample of 55,000 was drawn to insure that 6,000 chronically disabled community residents could be found. The survey started by screening 15,000 persons to estimate the chronic disability rate, which was then used to project the number of persons (35,789) needed to be screened to identify 6,000 disabled persons. Of 35,789 persons sampled, 781 had died or moved out of sample areas by April 1, 1982. Of the 35,008, a further 489 were identified as dead by the screen. A total of 34,012 persons completed a screening interview, a re-

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sponse rate of 98.5% among the 34,519 confirmed alive on the screen.

Of the 34,012 persons screened (80% by phone; 20% in person), 6,393 reported at least one chronic (i.e., lasting, or expected to last, 90 days or more) disability (respondent is unable to perform an activity or to perform the activity without personal assistance or use of equipment, due to a physical or mental impairment or health problem) on seven questions on Instrumental Activities of Daily Living (IADL; Lawton & Brody, 1969) and nine questions on Activities of Daily Living (ADL; Katz & Akpom, 1976). The screening interview also identified 1,992 institutional residents and 25,627 nondisabled community residents (5.9% and 75.3% of 34,012). Between the screening interview and the attempt to deliver a detailed interview, of 6,393 disabled persons, 67 died and 58 were institutionalized, leaving 6,268 in place, alive, and eligible when the household interview was attempted. Of the 6,268 chronically disabled, community residents, 6,088 (97.1%) were interviewed about health, function, social, economic, family, household, and other factors. Of completed community interviews in 1982, 23.0% were done with proxy respondents representing 19.8% of the disabled population. Though institutional residence was identified on the screen, no institutional interviews were done in 1982. Analyses of Medicare files for 1982 showed that 57 of the 1,992 institutional residents died prior to the screen interview attempt. This balances the 58 persons institutionalized between the screen and detailed interview attempt from the 6,393 identified as disabled on the screen.

Features were added to the 1984 NLTCs to track functional change. All persons surviving to 1984 who, in 1982, reported chronic disability on the screen and were alive at the time of the detailed interview (6,268, of whom 5,107 [81.5%], survived to 1984) or who were identified as institutional residents and were alive at the screen attempt (1,935, plus the 58 who changed status in 1982, of whom 1,226 survived to 1984) were automatically eligible for a detailed interview in 1984. For these persons the selection of the household or institutional questionnaire (developed in 1984) was made at the time of the interview. Thus, the rates at which persons became nondisabled (or noninstitutionalized) or died (specific to disability level, age, and gender) between 1982 and 1984 are estimable (Manton, 1988). In addition, a 12,100-person subsample of the 26,623 (45.45%) community residents in 1982 not institutionalized, or eligible for a detailed interview, were selected to be rescreened in 1984. Of 11,892 persons confirmed alive (out of 12,100) at the 1982 screen date, 11,151 survived to 1984 to be screened for disability or institutional residence. A new sample of 4,916 persons passing their 65th birthday by April 1, 1984, was drawn from Medicare files; 4,864 were confirmed alive at the screen date. The total number of sample persons alive (given the subsample of nondisabled persons) on the 1984 screen date was 22,348, of whom 98.1% were screened (80% by telephone; 20% in person); 8,100 were scheduled for detailed interviews and 14,248 were not chroni-

cally disabled or institutionalized. Between the screen and detailed interviews, 154 died, leaving 7,946 in place. Detailed interviews were completed with 7,662 (96.4% of those eligible and alive at the interview date) — 5,934 community and 1,728 institutional. Thus the 1984 NLTCs provides estimates of 2-year changes in chronic disability, institutionalization, and mortality for a nationally representative sample of the Medicare eligible population 65+ and, by supplementing the sample with 65- and 66-year-olds, prevalence estimates of disability and institutional residence of the total 1984 U.S. Medicare eligible population 65+ (Manton, 1988).

The 1989 NLTCs was designed to estimate disability and institutionalization rates for 1984–1989 and to provide 1989 national prevalence estimates. For these two tasks, separate population definitions and sample weights were used. All persons who were institutionalized, or eligible to receive a detailed community interview in either 1982 or 1984, and survived to 1989, were automatically selected for a detailed community (3,928) or institutional (651) interview based on residence at the time of the interview. Then, 4,907 persons passing their 65th birthday between survey dates were selected from Medicare files and screened for disability (4,869 were confirmed alive at the screen date in 1989). A subsample of 14,248 persons 65+ who had been *not* chronically disabled on the screen in 1984 were rescreened in 1989, of whom 12,660 were alive in 1989. Of the nondisabled sample selected, 97.9% were screened (84% by telephone and 16% in person). Income and assets questions from the Survey of Income and Program Participation (SIPP) were added to the 1989 community and institutional surveys. Six-month follow-ups of institutional residents and informal caregivers were done. The total number of sample persons alive at screen date in 1989 was 22,146, with 6,296 scheduled for detailed interviews. Between the screen and detailed interviews, 199 died, leaving 6,099 eligible persons alive at the interview attempt. Interviews were completed with 5,817 (95.4%) — 4,463 in the community, 1,354 in institutions. Twenty percent of the community detailed interviews were done with proxies in 1989 representing 17.6% of the community disabled population. A fourth NLTCs is being designed for 1994.

In each survey year, large samples ($N \approx 2,000$) of the oldest old (85+) were obtained. The detailed community, institutional, and screening interviews are 100% linked to Medicare service use files from 1982 to January 1992 (i.e., all cases [including nonrespondents and persons who died] were Medicare enrollees, and followed for changes in residence, Medicare service use, and date of death). Because the goal of longitudinal analyses is to determine changes in the health and functioning of the elderly chronically disabled and nondisabled populations, mortality is an important response or endpoint (e.g., Manton, Corder, & Stallard, in press). Response rates among survey-eligible persons alive at the interview date (i.e., cross-sectional response rates) are over 95% in all three surveys. The three surveys used

the same field methods, nonresponse and mortality adjustments, and "case" definitions. Longitudinal weights were calculated using exact date of death and adjusted for changes in the proportion screened (i.e., due to automatically interviewing persons previously institutionalized or chronically disabled; Manton, Corder, & Stallard, in press). These weights were based on Medicare files 1982 to 1991, which provide complete mortality experience for the 1982, 1984, and 1989 interview periods. Longitudinal follow-up of the sample is continuing and linkage to Medicaid files for 26 states is being carried out.

Chronic disability among the elderly is a complex physical and mental state difficult to measure and quantify. It is suggested that there is no "gold standard" against which to compare disability measures, so one must examine "predictive validity," that is, the ability to predict acute health care use, institutionalization, or death (Reuben, Siu, & Kimpau, 1992). An analysis of disability measures from the 1982, 1984, and 1989 NLTCs showed they strongly predict the amount of Medicare service used and the risk of death (Manton, Stallard, & Singer, 1992). A Department of Health and Human Services task force examining the quality of disability reporting on national surveys found, for a set of five ADLs that were comparably worded in a number of surveys, that the 1987 National Medical Expenditure Survey (NMES) and the 1982 and 1984 NLTCs gave comparable results. Reports of disability among the institutionalized were comparable for the 1987 NMES, the 1985 National Nursing Home Survey (NNHS), and the 1984 NLTCs. Thus, measurements of disability in several surveys, including the NLTCs, were replicable and consistent (Wiener et al., 1990), in addition to having excellent predictive validity. In addition, self-reports of disability were found to be more accurate (and to show less disability) than proxy reports (Dorevitch et al., 1992). Thus, increases in proxy reporting (as the population ages) may upwardly bias disability estimates over time. In fact, the proxy response rate declined suggesting a decline in severely disabled elderly persons.

Methods

Disability Measures

The detailed community interviews in 1982, 1984, and 1989 elicited information on persons identified on the screen as chronically disabled (i.e., having a disability that lasted, or was expected to last, at least 90 days) on nine ADL and seven IADL questions. The nine ADL questions cover the six basic ADLs (Katz & Akpom, 1976), with three questions asked about ADL components (e.g., chairfastness). The seven IADL questions on the screen (and one in the ADL section on mobility) represent the same range of IADL impairments as on the detailed questionnaire because some items imply the presence of other limitations (e.g., difficulty getting around outside implies difficulty going places outside walking distance). Disability is defined as an inability to perform an activity

without help or use of equipment, due to health or age.

On the detailed questionnaire, the six ADLs were: eating, getting in or out of bed, getting around inside, dressing, bathing, and getting to the bathroom or using the toilet. If a person did not get around inside, it was ascertained whether the person was totally immobile or wheelchairbound. Questions were asked about details of activity limitation. For example, for dressing, it was determined whether someone helped the person change pajamas or gown. For bathing it was ascertained, if the person did not use bathroom facilities, whether they received bed baths (personal assistance). For toileting, equipment use (e.g., bed pan, portable toilet/commode, special underwear/diapers, catheter or colostomy bag) was queried, as was personal assistance with catheter or colostomy care. The three supplementary ADL screen questions (i.e., getting in and out of chairs, going outside, and incontinence) were asked on the household interview.

The IADL questions asked on the household interview were about difficulty, due to health or age, with heavy housework (e.g., moving furniture, scrubbing floors, window washing); light housework (e.g., light cleaning, washing dishes); laundry; meal preparation; grocery shopping; getting around outside; getting to places outside of walking distance; money management and keeping track of bills; using the telephone; and taking medications. Taking medications, and the "heavy housework" item (not on the screen), were not used to define disability but were assessed for persons disabled on other items. All persons were probed for chronic limitations in each activity due to physical or mental impairment or health problems.

Measures of Service Use

Four service categories were defined. The first is the use of only *active personal assistance* from an informal or paid caregiver to help a person cope with one or more chronic IADL or ADL limitations. The second is the *use of equipment* (e.g., raised toilets, rubber mats, hand rails, or housing features such as elevators or ramps) to help carry out ADLs or IADLs. Different equipment and personal assistance questions were asked for each ADL and IADL. Third, "*standby*" help was defined for ADLs when persons report only performing a task if another person is available to provide assistance. Thus, standby help is distinct from personal assistance and is classified with the fourth category, *no service*, as explained below.

Assessing the level of services used is complex because equipment use, active help, standby help (for persons with ADL impairments), or no services to accomplish each ADL and IADL with limitations is recorded in detail. There are eight combinations of types of services (or lack of services) for each ADL and IADL limitation. There are 30 types of equipment, many of which are used for more than one ADL or IADL (see Tables 2 and 3). To reduce the 240 (8 × 30) combinations, we first determined which ser-

vices a person used for any ADL or IADL. We then combined (except in Tables 2 and 3, where equipment use is present for each ADL and IADL) the 240 categories (over IADLs and ADLs; except Table 7 where we provide estimates by disability level) into: (1) use of no service or just standby help; (2) use of equipment only; (3) use of (active) personal assistance only; and (4) use of both active personal assistance and equipment.

The term *equipment* means the use by a disabled person of a physical aid to help perform an activity without the intervention of another person. In this category of services, we include housing modifications. In order to hold the definition of equipment constant over the three surveys, the list of equipment is restricted to that defined for the 1982 surveys, (i.e., uniform questionnaires were used on each date, 1982, 1984, and 1989, to collect data). Thus, estimates of equipment use change are conservative since new kinds of equipment that became available between 1982 and 1989 were not counted.

Standard Errors

Standard errors of estimates were adjusted for design effects. We used methods developed by the U.S. Census Bureau for the 1989 and 1982-1984 longitudinal NLTCs files (U.S. Bureau of the Census, 1991). The average "design" weight (i.e., a sample weight adjusted for design effects) was 1,315 in 1982 (and 1984) and 1,545 in 1989. The standard error for a proportion $S_{x,p}$ is,

$$S_{x,p} = \sqrt{(b/x)p(1.00-p)} \quad (1)$$

where $b = 1,545$ (1,315 in 1982), x is the sample weighted population count, and p is the proportion for which a standard error is desired. Equation 1 was calculated from a large number of design-effect adjusted variances estimated for the 1989 (and 1982) survey. The b represents an "average" population weight. Thus, b/x adjusts for sample size in a bino-

mial test of proportions. Since b/x is larger than $1/m$ (m = number of respondents), sample size is "downweighted" in Equation 1 to represent "effective" sample size (Potthoff, Woodbury, & Manton, 1992) so as to increase the variance of parameter estimates for design effects. NLTCs design effects are small, with the largest increase in variance (in 1989) being only 10.8% higher than a random sample. Use of Equation 1 smooths design-effect adjusted variance estimates over sample domains where small and unequal numbers (and different response rates) make design adjustments unstable (O'Brien, 1981).

Estimates of the standard error of a difference in two proportions is calculated with S_{x,p_1} and S_{x,p_2} defined in Equation 1,

$$S_{x,p_1-p_2} = \sqrt{S_{x,p_1}^2 + S_{x,p_2}^2 - 2pS_{x,p_1}S_{x,p_2}} \quad (2)$$

where p is the correlation of two proportions. If p is positive, assuming it to be 0.0 produces a conservative test against a null hypothesis of no change. Since a large proportion of the NLTCs sample is followed longitudinally, and there is persistence in functional status, p is positive.

Results

We examined changes from 1982 to 1989 in the use of personal assistance and assistive devices by the chronically disabled, elderly community resident U.S. population. Sample weights (with postweighting to adjust the Medicare estimates to the total U.S. 65+ population distribution using Census data) were used in all calculations to estimate the number of persons in the total U.S. population, age 65+, with the reported characteristics. Significance tests were calculated using design weights to adjust variance estimates. Results are reported for 1982 and 1989 since 1984 was intermediate in value. A consistent gradient between 1982, 1984, and 1989 increased confidence in the overall trends.

Table 1. U.S. Chronic Disability and Institutional Residence Distributions for Persons 65+: Data from the 1982 and 1989 NLTCs

Disability status	1982 population		1989 population		Change (%) from 1982 to 1989
	(000's)	% ± SE	(000's)	% ± SE	± SE
Nondisabled	20,548	76.3 ± .30	23,906	77.4 ± .30	1.1 ± .42*
Total disabled community residents	4,844	18.0 ± .27	5,281	17.1 ± .27	-0.90 ± .38*
1. Adjustment of 1982 disabled community population for:					
a. 14.7% growth in the 65+ population			5,556	18.0*	
b. 17.7% inclusive of growth and using constant disability rates			5,701	18.5*	-1.4* ± .38**
IADLs Only	1,434	5.3 ± .16	1,360	4.4 ± .14	-1.3 ± .21**
1-2 ADLs	1,740	6.5 ± .17	1,993	6.5 ± .17	0.0 ± .24
3-4 ADLs	732	2.7 ± .13	1,079	3.5 ± .13	0.8 ± .17**
5-6 ADLs	937	3.5 ± .16	848	2.7 ± .11	-0.8 ± .17**
Institutional residents	1,532	5.7 ± .16	1,685	5.5 ± .16	-0.2 ± .23
Total	26,924	100.0%	30,871	100.0%	

*Assuming disabled population grows as fast as the total elderly population.

**Assuming that the 1982 age specific rates applied in 1989 and that the population grows as fast as the total elderly population.

Based on Census Bureau definition: about 85% are in certified nursing homes with the remainder in "swing" care hospital beds or in noncertified care facilities with medical services available 24 hours/day.

*α = 0.01; **α = 0.001.

Table 1 includes changes 1982 to 1989 in the community disabled and institutional population. If institutionalization rates increased then decreased, use of personal assistance in the community could be an artifact of the institutionalization of persons previously managed in the community.

The institutionalization rate did *not* increase — it nonsignificantly decreased -0.2% ($t = -0.9$). Changes in disability can affect service use. If persons with 5 to 6 ADLs decline in prevalence, then one might expect less use of personal assistance. The proportion of the 65+ population nondisabled in 1989 increased significantly (Manton, Corder, & Stallard, in press). The prevalence of persons with only

IADL or 5 to 6 ADL impairments declined. The proportion with 1 to 2 ADLs impaired did not change. The proportion with 3 to 4 ADLs impaired increased. Thus, decreases occurred both for lightly (only IADLs) and heavily (5 to 6 ADLs) impaired persons. The population with 3+ ADLs (often 2+ ADLs is used as a threshold to define persons eligible for LTC services) increased from 1.67 million to 1.93 million. This is larger (15.6%) than the increase (14.7%) of the U.S. population 65+ — though because the 85+ population increased 27.9%, the 65+ population itself is aging. The increase in the disabled population necessary, assuming constant age-specific disability rates, to reflect both the population growth and the

Table 2. Estimated Number (000's) of Disabled Community Residents 65+ with an ADL Disability in 1982 or 1989, by Type of ADL and Type of Equipment or Assistance Used; Data from the 1982 and 1989 NLTCs

ADLs	1982	1989	ADLs	1982	1989
Eating	694	648 (-6.6%)	Dressing	1,344	1,314 (-2.2%)
Impaired	688	634	Impaired	1,188	1,154
Incapable	6	14	Incapable	156	161
Assistance			Assistance		
No service	361	318	No service	258	162
Equipment only	34	36	Equipment only	68	60
Personal assistance only	261	252	Personal assistance only	965	1,027
Equipment and personal assistance	38	42	Equipment and personal assistance	52	66
Type of Equipment			Type of equipment		
Special dishes/utensils	73	78	Special clothing	123	125
Get in/out of bed	1,669	1,846 (+10.6%)	Bathing	2,546	2,958 (+16.2%)
Impaired	1,622	1,794	Impaired	2,202	2,701
Incapable	47	52	Incapable	344	257
Assistance			Assistance		
No service	298	244	No service	544	3,743
Equipment only	732	975	Equipment only	744	1,178
Personal assistance only	253	166	Personal assistance only	820	735
Equipment and personal assistance	385	461	Equipment and personal assistance	439	670
Type of equipment			Type of equipment		
Wheelchair	260	429	Shower seat/tub stool	625	1,037
Railing	48	87	Grab bars	691	1,079
Walker	485	675	Hand-held shower	NA	187
Cane	545	665	Walker/cane	NA	154
Crutches	59	44	Rubber mat	NA	402
Bed lift	25	43	Other equipment	138	121
Other equipment	99	127	Toileting	1,422	1,615 (+13.6%)
Get around inside	2,375	2,763 (+16.3%)	Impaired	1,330	1,613
Impaired	2,293	2,652	Incapable	91	1
Incapable	82	110	Assistance		
Assistance			No service	314	129
No service	280	257	Equipment only	592	865
Equipment only	1,490	1,847	Personal assistance only	215	59
Personal assistance only	160	121	Equipment and personal assistance	301	562
Equipment and personal assistance	445	538	Type of equipment		
Type of equipment			Raised toilet	225	558
Railing	45	100	Portable	381	498
Walker	735	1,059	Railing	267	413
Cane	1,219	1,385	Other device	137	91
Crutches	114	112	Bed pan	113	343
Elevator	6	22	Diapers	45	148
Orthopedic shoes	30	31	Catheter/colostomy	91	65
Other device	99	254			
Wheelchair	361	523			

Note. NA = not available.

upward shift in age structure, is 17.7% (i.e., 14.7% due to growth and 2.6% due to aging). Thus, 15.6% is less than the increase needed for the disabled population to keep pace with the growth and aging of the U.S. elderly population.

In Table 2 are estimates of the number and proportion of persons disabled in each of six ADLs. For each ADL we present estimates stratified by a) severity (impaired vs. incapable); b) type of assistance — no service or just standby help, equipment only, active personal assistance only, or both personal assistance and equipment; and c) type of equipment.

The number of persons impaired in eating declined 6.6%; the number with problems dressing declined 2.2%. These declines can be contrasted with the 14.7% increase of the U.S. elderly population and the 17.7% increase (i.e., from 5.28 million observed to 5.70 million projected) expected if age-specific disability rates were constant. Getting in and out of bed (+10.6%) and toileting (+13.0%) also

grew slower than the 65+ population. Bathing (+16.2%) and inside mobility (+16.3%) impairment grew faster than the 65+ population, but less than the rate (17.7%) expected due to aging and growth. There were large increases in the use of certain equipment items, for example, raised toilet (+148%, to 558,000), portable toilet (+30.7%, to 498,000), shower seat/tub stool (+65.9%, to 1,037,000), wheelchair to aid inside mobility (+44.9%, to 523,000), and wheelchair to get out of bed (+65%, to 429,000). In addition to increased rates of equipment use, there are also likely technical improvements (e.g., more sophisticated wheelchairs, sensory aids for telephone equipment) not represented in Table 2.

In Table 3 we present the estimated population and proportions disabled with each of nine IADLs in 1982 and 1989. There are fewer IADLs where equipment is used. The largest category is for outside mobility, where the use of equipment increased 17.2% (to 2.13 million).

Table 3. Estimated Number of Disabled Community Residents 65+ with IADL Disability in 1982 and 1989, by Type of IADL and Type of Assistance or Equipment Used; Data from the 1982 and 1989 NLTCs

IADLs	1982	1989	IADLs	1982	1989
Heavy house work	4,096	4,257 (+ 3.9%)	Outside mobility (continued)		
Impaired	4,011	4,142	Type of equipment		
Incapable	84	115	Cane	1,726	1,957
Assistance			Walker	493	737
No service	372	749	Wheelchair	236	399
Personal assistance only	3,724	3,508	Crutches	107	101
Light house work	1,362	1,360 (- 0.2%)	Orthopedic shoes	22	29
Impaired	1,278	1,245	Ramp	NA	43
Incapable	84	115	Handrail	NA	78
Assistance			Other devices	NA	83
No service	30	133	Travel beyond walking distance	3,082	3,064 (- 0.6%)
Personal assistance only	1,331	1,227	Impaired	2,510	2,415
Laundry	2,320	2,225 (- 4.1%)	Incapable	572	649
Impaired	2,235	2,110	Assistance		
Incapable	84	115	No service	575	652
Assistance			Personal assistance only	2,508	2,412
No service	44	192	Money management	1,411	1,470 (- 4.2%)
Personal assistance only	2,276	2,033	Impaired	1,411	1,470
Mean preparation	1,660	1,621 (- 2.3%)	Incapable	0	0
Impaired	1,575	1,507	Assistance		
Incapable	84	115	No service	11	203
Assistance			Personal assistance only	1,400	1,268
No service	252	363	Phone	990	900 (- 9.1%)
Personal assistance only	1,408	1,259	Impaired	990	900
Grocery shopping	3,116	3,099 (- 0.5%)	Incapable	0	0
Impaired	3,081	2,984	Assistance		
Incapable	84	115	No service	109	77
Assistance			Equipment only	0	0
No service	73	299	Personal assistance only	827	762
Personal assistance only	3,042	2,799	Equipment and personal assistance	54	61
Outside mobility	3,291	3,816 (+ 16.0%)	Type of equipment		
Impaired	2,719	3,167	Special phone	108	124
Incapable	572	649			
Assistance					
No service	574	654			
Equipment only	1,815	2,126			
Personal assistance only	454	393			
Equipment and personal assistance	448	643			

Note. NA = not available.

Table 4. Estimated Number and Percent Distribution of Chronically Disabled Community Residents 65 + in 1982 and 1989, by Type of Assistance Used; Data from the 1982 and 1989 NLTCs

Assistance	1982 population	%	(SE)	1989 population	%	(SE)	Δ (1989-1982) population	% difference	(SE)	t test	Proportional change
No service	81,592	1.7	(± 0.2)	95,103	1.8	(± 0.2)	13,511	0.1	(± 0.31)	$t = .3$	+ 17.0%
Equipment only	313,662	6.5	(± 0.4)	631,206	12.0	(± 0.6)	317,544	5.5	(± 0.7)	$t = 7.9$	+ 101.2%
Personal assistance only	1,509,157	31.2	(± 0.8)	1,118,306	21.2	(± 0.7)	- 390,851	- 10.0	(± 1.0)	$t = 9.6$	- 25.9%
Equipment and personal assistance	2,939,703	60.7	(± 0.8)	3,436,462	65.1	(± 0.8)	496,759	4.4	(± 1.2)	$t = 3.8$	+ 16.9%
Total	4,844,114	100.0		5,281,077	100.0		436,963				- 9.0%

Table 5. Estimated Number and Percent Distribution of Disabled Community Residents 65 + in 1982 and 1989, by Gender and Type of Assistance Used; Data from the 1982 and 1989 NLTCs

Assistance	1982 population	%	(SE)	1989 population	%	(SE)	Δ (1989-1982) population	% difference	(SE)	t test
Equipment only										
Men	96,673	5.8	(± 0.7)	190,819	11.9	(± 1.0)	94,146	6.1	(± 1.2)	$t = 5.1$
Women	216,989	6.8	(± 0.5)	440,387	12.0	(± 0.7)	223,398	5.2	(± 0.8)	$t = 6.2$
Personal assistance only										
Men	551,908	33.2	(± 1.3)	387,327	24.2	(± 1.3)	- 164,581	- 9.0	(± 1.8)	$t = - 4.9$
Women	957,249	30.1	(± 0.9)	730,979	19.9	(± 0.8)	- 226,270	- 10.2	(± 1.2)	$t = - 8.5$
Equipment and personal assistance										
Men	991,435	59.7	(± 1.4)	981,142	61.2	(± 1.5)	- 10,293	- 1.5	(± 2.0)	$t = 0.7$
Women	1,948,266	61.2	(± 1.0)	2,455,320	66.7	(± 1.0)	507,052	5.5	(± 1.4)	$t = 3.9$
Total										
Men	1,661,472			1,602,079			- 59,393			
Women	3,182,643			3,678,998			496,355			

*Total includes persons with no services

The estimated number and percentage distribution in the four service categories is shown in Table 4 for all disabled community residents in 1982 and 1989. There is a large and significant decline of - 10.0% in the proportion of disabled elderly who rely on personal assistance only (i.e., 31.2% to 21.2%; $t = - 9.6$; $p < .0001$), an absolute decrease of 391,000 persons — or a relative decline of 25.9% compared with the increase of 14.7% in the U.S. population aged 65 +, the 9.0% increase in the disabled elderly community resident population, and the 17.7% increase if age-specific rates were constant. If this service category were to keep pace with the growth and aging of the U.S. elderly population (+ 17.7%), there would have been an increase of 658,000 over the 1989 value. Thus, the differences are absolutely and relatively large. These persons now either rely wholly on equipment (an absolute increase of 317,544 persons or 5.5%; $t = 7.9$; $p < .0001$; a relative change of 101.2%) or a combination of personal assistance and equipment (an absolute increase of 496,759 or 4.4%; $t = 3.8$; $p < .0001$; a relative increase of 16.9%). Equipment use increased despite aging of the U.S. elderly population and declines in the rate (- 1.3%; $t = - 6.2$) of persons reporting only IADL impairment.

In Table 5, results are stratified by gender with the small "no services" group (e.g., 1.3% for men and 1.9% for women in 1982) deleted from this and subsequent tables. Proportions are not renormed; totals are not recalculated. There is more decline in the sole use of personal assistance for women (- 10.2%;

$t = - 8.5$) than for men (- 9.0%; $t = - 4.9$), although the female population is older and more impaired. There are significant increases in the sole use of equipment (6.1% and 5.2% for men and women, respectively), and in the use of both equipment and personal assistance for women.

In Table 6 we present the distributions for three age groups. The cross sectional use of equipment only declines with age (from 14.1% to 8.0% in 1989). Its use significantly increased for each age over time from 1982 to 1989 (i.e., - 6.5, + 5.3, and + 5.7%). Likewise, at all ages, there are significant declines in the proportion using personal assistance only (i.e., - 10.6% to - 7.3% from 65-74 to 85+). At each age the use of both equipment and personal assistance increased (i.e., + 3.1%, + 3.5%, and - 1.3%, although only the group aged 75-84 is significant for a two-tailed test).

In Table 7 we disaggregated distributions by disability level. Most persons who use personal assistance only (i.e., 989,909 in 1982 and 810,977 in 1989) have IADL impairments only, that is, those not using any equipment tend to have few impairments. The proportion only using personal assistance declined 9.4% to 6.4% across disability levels; the proportion only using equipment increased significantly at each level with large increases for those with only IADLs (6.2%) and 1 to 2 ADLs impaired (9.7%). Those with 1 to 2 ADLs impaired, the most prevalent (6.5%) group, had a faster increase in the rate of equipment use than other service types. This is important because when community residents age 85+, the fastest

Table 6. Estimated Number and Percent Distribution of Disabled Community Residents 65+ in 1982 and 1989, by Age and Type of Assistance Used; Data from the 1982 and 1989 NLTCs

Assistance	Age	1982	%	(SE)	1989	%	(SE)	Δ (1989-1982)	%	(SE)	t test
Equipment only	65-74	142,573	7.6	(± 0.7)	212,558	14.1	(± 1.1)	69,985	6.5	(± 1.3)	t = 4.9
	75-84	148,661	7.5	(± 0.7)	310,173	12.8	(± 0.8)	161,512	5.3	(± 1.1)	t = 4.9
	85+	22,428	2.3	(± 0.6)	108,475	8.0	(± 0.9)	86,047	5.7	(± 1.1)	t = 5.3
Personal assistance only	65-74	693,208	36.7	(± 1.3)	392,895	26.1	(± 1.4)	-300,313	-10.6	(± 1.9)	t = -5.6
	75-84	601,925	30.2	(± 1.2)	523,911	21.6	(± 1.0)	-78,014	-8.6	(± 1.6)	t = -5.5
	85+	214,024	22.2	(± 1.5)	201,500	14.9	(± 1.2)	-12,524	-7.3	(± 2.0)	t = -3.7
Equipment and personal assistance	65-74	1,006,067	53.3	(± 1.3)	850,629	56.4	(± 1.6)	-155,438	3.1	(± 2.1)	t = 1.5
	75-84	1,211,420	60.8	(± 1.3)	1,557,435	64.3	(± 1.2)	346,015	3.5	(± 1.7)	t = 2.0
	85+	722,216	74.9	(± 1.6)	1,028,398	76.2	(± 1.4)	306,182	1.3	(± 2.2)	t = 0.6
Total*	65-74	1,887,283			1,508,508			-378,775			
	75-84	1,992,145			2,422,954			430,809			
	85+	964,686			1,349,615			384,929			

*Total includes persons with no service.

Table 7. Estimated Number and Percent Distribution of Disabled Community Residents 65+ in 1982 and 1989, by Disability Level and Type of Assistance Used; Data from the 1982 and 1989 NLTCs

Assistance	1982	%	(SE)	1989	%	(SE)	Δ (1989-1982)	%	(SE)	t test
Equipment only										
Only IADL	97,368	6.8	(± 0.8)	176,653	13.0	(± 1.1)	79,285	6.2	(± 1.4)	t = 4.5
1-2 ADL	194,223	11.2	(± 0.9)	413,293	20.9	(± 1.1)	219,070	9.7	(± 1.4)	t = 6.8
3-4 ADL	21,153	2.9	(± 0.7)	39,856	3.7	(± 0.7)	18,703	0.8	(± 1.0)	t = 0.8
5-6 ADL	918	0.1	(± 0.1)	1,405	0.2	(± 0.2)	487	0.1	(± 0.2)	t = 0.5
Personal assistance only										
Only IADL	989,909	69.0	(± 1.4)	810,997	59.6	(± 1.7)	-178,912	-9.4	(± 2.2)	t = -4.3
1-2 ADL	313,878	18.0	(± 1.1)	226,789	11.4	(± 0.9)	-87,089	-6.6	(± 1.4)	t = -4.8
3-4 ADL	73,153	10.0	(± 1.3)	38,380	3.6	(± 0.7)	-34,773	-6.4	(± 1.5)	t = -4.4
5-6 ADL	132,216	14.1	(± 1.3)	42,141	5.0	(± 0.9)	-90,075	-9.1	(± 1.6)	t = -5.7
Equipment and personal assistance										
Only IADL	288,688	20.1	(± 1.2)	293,886	21.6	(± 1.4)	5,198	1.5	(± 1.8)	t = 0.6
1-2 ADL	1,210,426	69.6	(± 1.3)	1,336,859	67.1	(± 1.3)	126,433	-2.5	(± 1.8)	t = -1.4
3-4 ADL	638,110	87.1	(± 1.4)	1,000,828	92.8	(± 1.0)	362,718	5.7	(± 1.7)	t = 3.3
5-6 ADL	802,479	85.6	(± 1.3)	804,889	94.9	(± 0.9)	2,410	9.3	(± 1.6)	t = 5.7
Total*										
Only IADL	1,434,044			1,360,227			-73,817			
1-2 ADL	1,740,204			1,993,353			253,149			
3-4 ADL	732,416			1,079,064			346,648			
5-6 ADL	937,449			848,435			-89,014			

*Total includes persons with no service.

growing age group, first manifest chronic disability, it is nearly twice as likely to be with 1 or 2 ADLs impaired than with only IADL impairment (Manton, Corder, & Stallard, in press).

We stratified results by gender and age (not shown; available from authors). Although women are older on average and more disabled, they use more equipment at each disability level than men do. The proportion relying on personal assistance only declined for all disability levels and both genders (e.g., 11.2% and 10.0% with only IADL impairment). Declines are large for those with high levels of impairment at younger ages (e.g., a decline of 12.9% at ages 65 to 74); the decline for those 85+ is 5.0%. Those adding equipment to personal assistance increased at all ages. For lower level impairment (e.g., 1 to 2 ADLs), reliance shifted from personal assistance to equipment.

Discussion

Data on the personal assistance and equipment used by elderly community residents to respond to chronic ADL and IADL disabilities showed consistent trends from 1982 to 1989. Reliance on personal assistance only declined. Dependence on equipment — by itself or in combination with personal assistance — increased. Trends were significant for both genders, over disability level and age. Reliance solely on equipment was most prevalent for persons with either only IADL or 1 to 2 ADL impairments and increased most rapidly in those groups. Reliance on equipment only was higher for women than for men (although women have more disability) and was highest at younger ages.

The results suggest that current and future LTC policies should be examined for incentives or disin-

centives to the existing trends toward increasing equipment use for those with up to 2 ADLs impaired and as supplements to active personal assistance for those with 3 or more ADLs impaired (possibly with compensating reductions in personal assistance). Equipment use increased over a period where institutionalization rates were stable and mortality and chronic disability prevalence rates declined. Thus, these trends do not appear to produce adverse results in aggregate. Incentives for equipment use by the elderly would parallel efforts to help younger disabled persons use equipment to increase their social autonomy.

At higher levels of impairment, either personal assistance only or equipment use only appear insufficient to support individuals in the community. While most persons with 5 to 6 ADLs impaired use personal assistance, services were more often supplemented with equipment in 1989. Thus, equipment is necessary to supplement active personal assistance and could reduce LTC costs by replacing recurrent costs for personal assistance from formal sources by non-recurrent equipment costs. To ascertain whether equipment being exchanged for personal assistance would work for specific individuals (rather than in aggregate) in specific conditions other types of experimental or demonstration studies would be necessary. The need for such a study depends on whether one is considering how to make an intervention for an individual or if one is considering more general financial incentives to allow caregivers and disabled persons to make such a substitution if they deem it appropriate for their condition. In this latter case, the concern is budgetary so long as sufficient resources are available not to enforce an adverse choice.

Changes in equipment use between 1982 and 1989 represent the equipment (and housing modifications) in use in 1982. They do not reflect technical innovations now entering the private market or in development. For example, the development of prostheses and orthotics were identified as promising areas of research and training for improving the function of the young and old alike in a recent NIH conference (Barnes, 1992). Thus, to help provide care for chronically disabled elderly, it may be possible to exploit new equipment technologies and to better target populations able to use such services. Severely physi-

cally disabled persons with higher levels of education may be able to use equipment more readily than less physically impaired persons with little education or with significant cognitive impairment.

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SUMMARY

THE CHANGING PROFILE OF THE ELDERLY: EFFECTS OF FUTURE LONG-TERM CARE NEEDS AND FINANCING Sheila Rafferty Zedlewski and Timothy D. McBride

This article presents projections of the elderly population to 2030 based on a microsimulation computer model. The authors predict that the demand for nursing home care will triple by 2030, far exceeding the expected increase in the elderly population. The elderly population in 2020 is more likely to be living alone and less likely to have family caregivers.

The Changing Profile of the Elderly: Effects on Future Long-term Care Needs and Financing

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DESPITE BROAD SUPPORT FOR LONG-TERM CARE financing reform, it is still not clear what shape reform will take. In 1987 approximately \$33 billion of the nation's health care expenses were devoted to nursing-home care for the elderly (Waldo et al. 1989, 117). The Medicaid program, designed to cover the health care of the financially destitute, paid for more than a third of these expenses (\$12 billion), while private finances covered most of the rest (\$19 billion). Only a fraction of nursing-home expenses was covered through an insurance mechanism (either private or social insurance). The elderly also use significant amounts of in-home long-term care services, and payment for these services is even more heavily dominated by out-of-pocket expenses. As the size of the elderly population and the number requiring long-term care services continue to increase, there is a growing consensus that we need an alternative to a system that requires the elderly to pay for long-term care expenses out of pocket until they are sufficiently impoverished to qualify for Medicaid benefits.

Various groups and studies have called for reform in long-term care financing. Most recently, the Pepper Commission proposed financing long-term care through an integrated program that would include a limited social insurance mechanism guaranteeing subsidized home-care

benefits and three months of nursing-home care for every American, a public program for longer nursing-home stays with a floor of protection that guards against impoverishment, and measures that promote private long-term care insurance (U.S. Bipartisan Commission on Comprehensive Health Care 1990). The commission recommended that the social insurance part of the program be fully financed by the federal government, preferably through a broad-based progressive tax system. A recent study by the American Association for Retired Persons (1989) also endorsed the idea of a social insurance program to pay for long-term care expenses. One of the conclusions of a major study by Rivlin and Wiener (1988) was that a social insurance mechanism is needed along with an expansion of the private insurance market. They based this conclusion on projections indicating that only a minority of the elderly could afford private long-term care insurance.

There is obvious resistance to long-term care financing reform that would require a new social insurance program or even an expansion of Medicaid. Proposals that involve increasing payroll taxes or general income taxes in order to pay for a new benefit for the elderly do not seem feasible in a budget climate that already requires hard choices about reducing current government expenditures. This climate, coupled with some sentiment that the elderly already have more than their fair share of government benefits, is not likely to produce wide support for a new program that covers long-term care expenses. Moreover, a new universal social insurance program covering long-term care expenses would benefit middle- and upper-income elderly persons more than low-income persons because the Medicaid program already covers a large share of the nursing-home expenses of poor elderly persons.

Nevertheless, some significant change in the way that long-term care is financed may be on the horizon. This solution involves the rapidly developing private insurance market for long-term care expenses. The Health Insurance Association of America (1991a) recently reported that, as of December 1989, more than 1.5 million long-term care insurance policies had been purchased, an increase of 400,000 policies (36 percent) over 1988. The number of insurers in the market is also increasing rapidly, and the quality of the product is improving. In contrast to earlier plans, most now offer some inflation protection for rising costs of nursing-home care, cover in-home care expenses, do not require prior hospitalization, and provide coverage for at least four years in a nursing home.

It is still not clear whether private insurance coverage can solve a significant portion of the long-term care financing problem. Recently, most of the elderly were not aware that they are not covered by long-term care services through Medicare, and we know that few elderly can afford today's long-term care insurance premiums (U.S. Bipartisan Commission on Comprehensive Health Care 1990). The future contribution of this financing mechanism will depend on the population's interest in long-term care insurance, as well as their ability to pay for the insurance without sacrificing other basic needs.

This study focuses on whether the profile of the elderly population is likely to change over time, so that long-term care insurance will become a more attractive and feasible option for a broader segment of the elderly population. Specifically, we examine two questions:

- What is the future need for long-term care services likely to be?
- Will long-term care insurance be affordable for a large portion of the future elderly population, or will it remain out of reach for most older Americans, suggesting that other solutions will be required?

The study uses dynamic microsimulation techniques to project the elderly population's characteristics, incomes, and long-term care needs between now and the year 2030. These techniques capture how the interactions among changing demographics, disability levels, and income will determine the future long-term care needs of the elderly. This methodology offers advantages over more traditional static aging techniques, such as those used by the Census Bureau, because a large number of variables are endogenous to the model. Projections of long-term care needs that rely primarily on Census age distributions for some future year lead to an oversimplified picture of the future because nursing-home use is also related to marital status, living arrangements, and the availability of caregivers (see, for example, Liu, McBride, and Coughlin 1990). To the extent that there are significant changes in these determinants of long-term care requirements, the more simplified models will under- (or over-) state the future need for long-term care.

A recent study by Rivlin and Wiener (1988) also used microsimulation techniques to project the future need for nursing-home care. This study differs from theirs in that the behavioral content of the underlying demographic and economic model is more complex, allowing us to

simulate the profile of the elderly population further into the future and to incorporate more completely the effects of recent behavior on the future profile of the elderly. In addition, the estimates presented here incorporate more recent changes in the still evolving long-term care insurance market.

Data and Methods

The Urban Institute's Dynamic Simulation of Income Model (DYNASIM) was used to project the characteristics of the elderly population to the year 2030. DYNASIM is a microsimulation model that incorporates behavioral research on all of the major demographic and economic events that will affect the future profile of the elderly. DYNASIM has its origins in the work of Orcutt and others (1961) and has been under continuous development at The Urban Institute for more than 20 years (Lewis and Michel 1990).

The dynamic projection methodology differs from the static aging techniques used by the Census Bureau and the Social Security Administration in that it stimulates behavior at the personal and family levels. The model starts with a representative sample of the population. It "ages" the population in annual intervals through a series of probabilistic models of the major demographic and economic events that affect the status of the family unit. The microsimulation methodology provides a powerful projection tool because births, deaths, labor force participation, and other economic and social events interact to shape the profile of the population.

The DYNASIM model is fully described elsewhere (see, for example, Orcutt, Caldwell, and Wertheimer 1976; Johnson, Wertheimer, and Zedlewski 1983, 1989; Congressional Budget Office 1986; Hacker and McBride 1989; and Zedlewski et al. 1990). Below we highlight the model's input data and the behavioral functions used to develop a profile of the future elderly population. We also define the aggregate projection assumptions used in this analysis.

Input Data

The starting data set used for this analysis is the "1973 Exact Match File," which includes the March 1973 Current Population Survey (CPS),

actual social security earnings records for each individual with work experience, and 1972 Internal Revenue Service tax return information. We begin the simulation process with this data set because it is the *latest* available public use file that includes a representative sample of the population and their earnings history back to 1951. Historical information is critical for simulating retirement incomes for persons with work experience prior to the date of the input file, because many retirement income sources (e.g., social security and pensions) are based on earnings histories. The DYNASIM model continues to build upon this historical data with each year of simulation. For example, a DYNASIM-aged file representative of 1990 includes an earnings history for each individual from 1951 through 1990, where earnings for 1951-1973 are directly observed from social security records, and earnings for 1974-1990 are simulated.

More recent historical data are also built into the simulation process. Historical trends for each event simulated are used to guide the model's projections and to validate its predictions during the 1974-1988 period. These data include vital statistics on births, deaths, marriages, and divorces, and data from the Bureau of Labor Statistics on labor force participation, hours worked, and real earnings growth.

The drawback of using the 1973 Exact Match File is that we must rely on simulated data for a larger part of the projection period. However, we rely on the DYNASIM model to capture the interactions among these events over the 1973-1990 period. In addition, we use historic aggregate data to benchmark simulation results for the 1974-1990 period. These steps ensure accuracy of aggregate events, while also capturing some expected disaggregated effects.

Behavioral Models

Dynamic aging relies on a set of behavioral functions used to update microunit characteristics year by year. These functions attempt to capture important and stable real world relationships so that the model will generate realistic samples representative of some future date. Thus, the model must capture movements of demographic or economic aggregates (such as fertility, divorce, or female labor force participation) over time, as well as the important cross-sectional features of behavior so that distributional outcomes can be examined. For example, it is not sufficient to simulate secular trends in the probability of divorce over time. The

model must also capture important variations in the incidence of divorce such as higher divorce rates experienced by couples in which the wife's earnings are relatively high compared with the husband's, and by couples in which the wife first married at an early age (Cherlin 1977). Similarly, it is not sufficient to capture increasing female labor force participation over time; the model must also capture differences in participation by marital status, the number and timing of children ever born, and the relative economic returns to work.

Development of realistic behavioral functions has been a major feature of DYNASIM (Wertheimer et al. 1986). DYNASIM's aging process consists of a set of simulations of birth, death, divorce, marriage, educational attainment, labor force status, job change, wage rates, and unemployment. Table 1 lists the essential operating characteristics of DYNASIM along with the variables that are endogenous to each of the outcomes. As shown, the extent of the interactions among social and economic variables that DYNASIM captures is fairly extensive.

As indicated in table 1, to project future retirement incomes, the model applies detailed sets of social security and private pension benefit rules to the simulated earnings and family histories. The sets of rules replicate benefit formulas in use today. In the case of social security they incorporate scheduled future changes. Other pension parameters are indexed with real wages or prices as specified in different plan formulas. Projected marital histories are important to the retirement income simulation because former or deceased spouses' retirement credits and benefits are used to calculate surviving spouses' benefits.

DYNASIM also includes a number of health-related modules. Specifically, the model predicts the number of limitations in activities of daily living (ADLs) that elderly persons "have difficulty performing" as a function of a person's age, sex, current and previous marital status, race, and location, based on data representative of the entire elderly population in 1984 (McBride 1989). In addition, the DYNASIM model predicts nursing-home entry as a function of the elderly's health and demographic characteristics.

Projection Assumptions

The DYNASIM model can also capture the consequences of alternative long-range aggregate assumptions about demographic and economic

TABLE 1
Main Events Simulated by the Dynamic Simulation of Income Model

Event or characteristic	Principal determinants
Demographic	
Birth	Marital status, age, race, education, number of previous live births
Death	Age, race, sex, education, marital status, parity of women, current year
First marriage	Age, race, sex, education, hours worked, wage rate, transfer income, current year, year of birth
Remarriage	Age, sex, marital status (widowed or divorced), current year, year last marriage ended
Divorce	Age, race, disability status, unemployment status of husband, earnings of wife, length of marriage, year of marriage, current simulation year
Education (probability of advancing a grade)	Age, race, sex, education of head of family, number of grades completed
Geographic location (region and size of standard metropolitan statistical area [SMSA])	Age, sex, education, and marital status of family head or single individual, duration of marriage, region and current SMSA size
Labor	
Labor force participation	Age, race, sex, presence of disability, whether participated in previous year, marital status, number and age of children, spouse's earnings, history of participation
Hours of labor supplied	Age, race, sex, education, marital status, age and number of children, expected wage, labor supply in previous year
Hours of unemployment	Age, race, sex, education, marital status, unemployment in previous year, aggregate unemployment rate
Wage	Education, region, marital status, age, race, sex

continued

TABLE 1 continued

Event or characteristic	Principal determinants
Retirement income	
Social security	Earnings and marital history (and current statuses), age, actual program rules
Private and government pensions	Earnings and marital history (and current statuses); age, job history (tenure, industry), representations of actual program rules
Financial assets	Earnings, other retirement income, race, health, location, age, sex, marital status
Health and related variables	
Limitations in Activities of Daily Living (ADLs)	Age, sex, ever married, current marital status, race, location
Nursing-home use	ADLs, age, marital status, sex

events. Aggregate outcomes can be constrained to match "consensus" views regarding the future paths of key demographic or economic events. For these projections we followed the Social Security Administration's 1986 assumptions regarding future births, unemployment, and average real wage growth (see table 2). In the case of mortality, however, we provide an alternative assumption. One mortality path follows Social Security's baseline assumption and the other follows their more optimistic projection. In the optimistic projection, mortality rates decline at historical rates; in the middle-of-the-road projection, mortality rates decline at half this rate.

It must be noted, however, that even though some of DYNASIM's aggregate results may be constrained to match key assumptions regarding future events or sectoral change, the model's internal behavioral functions distribute the incidence of events at the microlevel. For example, we track particular mortality rates (for different sexes), but an individual's relative probability of death will vary according to factors included in the model (e.g., education, marital status, age, sex, race).

TABLE 2
Key Projection Assumptions: Baseline and Optimistic Mortality

Projection year	Baseline mortality		Optimistic mortality		Completed fertility ^b	Real wage growth ^c	Unemployment rate	Interest rate
	Men ^a	Women ^a	Men ^a	Women ^a				
1990	15.1	19.9	15.2	19.8	1.90	1.6	6.5	6.2
1991	15.1	20.0	15.4	20.0	1.90	1.7	6.2	6.1 ^e
1992	15.2	20.2	15.5	20.3	1.91	1.6	5.8	6.1
1993	15.3	20.3	15.6	20.5	1.92	1.5 ^e	5.7	6.1
1994	15.4	20.4	15.8	20.6	1.92	1.5	5.6	6.1
1995	15.5	20.5	15.9	20.7	1.93	1.5	5.5 ^e	6.1
2000	15.7 ^d	20.8 ^d	16.4	21.3	1.96	1.5	5.5	6.1
2010	16.1	21.3	17.2	22.3	2.00 ^e	1.5	5.5	6.1
2020	16.4	21.7	18.0	23.2	2.00	1.5	5.5	6.1
2030	16.8	22.2	18.9	24.2	2.00	1.5	5.5	6.1

Source: U.S. Social Security Administration, 1986.

^a Years remaining at age 65.

^b Completed fertility, number of children per woman.

^c Average growth in real (after inflation) wages.

^d Declines are extrapolated between years shown.

^e Ultimate rates.

What Factors Will Affect the Future Demand for Nursing-home Care?

A variety of changes in the demographic profile of the future elderly population will affect their need for formal, long-term care services in nursing homes (or significant levels of in-home services provided by professionals). Obviously, the life span of the elderly and the proportion who have health limitations will be important because the need for long-term care, in general, increases with age and disabling health conditions. Their living arrangements will also be important, however. If more elderly persons live alone in the future, the demand for formal in-home and nursing-home services will increase (holding constant health and other characteristics) because fewer elderly will be living with family caregivers providing significant levels of informal long-term services.

Changing Demographic Risk Factors

Table 3 highlights expected changes in several key demographic factors that will affect the need for long-term care services in the future. We show the age composition of the elderly population, fertility history of women retiring in the twenty-first century, and their future living arrangements. We refer to these as demographic "risk" factors because the need for *formal* long-term care services is most acute for persons who are very old, have no living children, and are living alone.

These results illustrate that the size of the frail elderly population—persons aged 85 and older—will be very sensitive to mortality trends. If the optimistic mortality assumptions hold, there will be 12 million frail elderly in 2030, compared with 8.7 million in the baseline projection, a difference of 38 percent. Given that Social Security's baseline projections have historically been too pessimistic, policy makers must seriously consider the implications of the more optimistic mortality scenario (Guralnik, Yanagishita, and Schneider 1988).

Table 3 also illustrates that there will be fewer adult children available to care for elderly parents in the future. Among women aged 65 in 2010 (born prior to the baby-boom cohort) only 10.6 percent will be childless, compared with 18.5 percent of women reaching age 65 in 2030 (born in 1965). As shown, the average number of children born to women will be significantly lower for cohorts of women retiring after 1990.

The last demographic risk factor shown, the number of elderly living alone, also leads us to expect far greater growth in the demand for formal long-term care services in the future than the sheer size of this population might indicate. These projections show dramatic increases in the number of elderly living alone in the future (table 3). Almost 26 million elderly persons will live alone in 2030 under the baseline assumptions, compared with 10 million in 1990, an increase far in excess of the general increase in the elderly population.

These projections take into account not only changing marital status patterns among the elderly, but also the increasing propensity of non-married elderly to live alone. The baby-boom cohort has experienced lower marriage rates and higher divorce rates than their predecessors, and fewer of them are likely to be married during retirement, all else being equal (Bloom and Bennett 1985). In addition, the increasingly strong preference of the elderly to live alone, their growing financial independence, the declining availability of children as cohabitants, will increase

TABLE 3
Demographic and Health Characteristics of the Elderly Population: 1990-2030

	2010			2030	
	1990	Baseline*	Optimistic mortality	Baseline	Optimistic mortality
Age composition ^b					
Age 65-74	18.7	21.7	22.4	34.4	36.6
Age 75-84	10.1	12.8	13.8	21.3	23.9
Age 85 or older	3.3	6.8	8.3	8.7	12.0
Total	32.2	41.2	44.6	64.3	72.5
Fertility history of women ^c					
Percent childless	14.0	10.6	10.6	18.5	18.5
Average number of children	2.86	2.49	2.49	1.94	1.94
Number living in the community with ADL limitations ^b					
Unmarried	3.1	4.1	4.3	6.4	7.3
Married	1.5	2.1	2.3	3.3	4.1
Total	4.6	6.2	6.6	9.7	11.4
Living arrangements ^b					
Community-based					
Living alone	10.4	15.1	15.9	25.5	26.9
Living with others	6.0	5.2	5.4	6.5	7.1
Married	14.0	17.9	19.9	28.0	33.4
Nursing homes	1.8	3.0	3.4	4.3	5.3
Total	32.2	41.2	44.6	64.3	72.5

Source: Dynamic Simulation of Income Model (DYNASIM)

* The projection scenarios are defined as follows: baseline scenario (following Social Security Administration intermediate assumptions); optimistic mortality scenario (same as baseline scenario, except for mortality, which is assumed to improve at a rate equal to recent historic trends)

^b Millions of persons

^c Reaching age 65 in projection year

the proportion of unmarried (single, widowed, and divorced persons) persons living alone (King 1988).

Degree of Dependency

The health characteristics of the future elderly population interact with demographic characteristics to determine the need for home

care. Table 3 shows DYNASIM's forecasts of the number of elderly likely to need nursing-home care under the two mortality scenarios, and it shows the number of elderly living in the community with health limitations.

Assuming that recently observed entry patterns continue into the future, the number of elderly persons needing care in nursing homes will increase from about 1.8 million today to 3–3.4 million in 2010 and to 4.3–5.3 million in 2030, depending on the mortality rate assumption. Thus, the need for nursing-home care could nearly triple from 1990 to 2030, despite the fact that the elderly population will only increase by 125 percent over the same period under the optimistic mortality rate projection.

Table 3 also indicates the number of elderly living in the community with health limitations using an index that measures the number of elderly who have difficulty with one or more of the following ADLs: eating, dressing, bathing, going to the toilet, and transferring. The number of unmarried elderly experiencing difficulty with ADLs increases from 3.1 million persons to 6.4 million in 2030, indicating a potentially large increase in the need for in-home services.

We expect that these trends will increase elderly persons' awareness of the risk of needing long-term care support. The *proportion* of the elderly needing nursing-home care will expand most significantly between 1990 and 2010 (from 5.7 percent to more than 7 percent of the elderly population) because the proportion of the elderly who are very old, unmarried, and with health limitations will increase faster during this period. Another 15 percent of the elderly will be living in the community with health limitations, and most of these will not have a spouse to care for them. Furthermore, the *number* of elderly requiring long-term care services will continue to increase after 2010 as the size of the elderly population continues to grow. When the baby boom population reaches their very senior years (in the 2040s, beyond these projections), the *proportion* of elderly needing long-term care services will again increase.

Will More of the Elderly Be Able to Afford Long-term Care?

The ability of the elderly to pay for long-term care will depend crucially on their economic status in the 1990–2030 period, the future cost of

nursing-home care, and the type of mechanisms available to finance care. This section examines expectations about future growth in retirement income of the elderly, and estimates whether the future elderly will be better able than their predecessors to afford the cost of long-term care. Of course, real growth in the incomes of the elderly will have to outpace significantly the growth in the cost of nursing-home care to improve the current affordability picture because the cost of nursing-home care currently exceeds the incomes of most elderly persons.

The Changing Income Profile: 1990–2030

The DYNASIM projections show that real postinflation incomes of the elderly will rise significantly between 1990 and 2030, but income growth will be uneven among subgroups of the elderly population and across time (table 4). Particularly strong growth in retirement income is

TABLE 4
Projected Real Median Income by Marital Status,
Age, and Sex: 1990–2030^{a,b}

Marital categories	Baseline scenario (1988 dollars)			Percentage change	
	1990	2010	2030	1990–2010	2010–2030
Married couples	\$20,800	\$32,700	\$48,900	+57	+50
Age: 65–69	23,600	38,600	54,900	+63	+42
70–79	19,600	31,300	48,200	+60	+54
80+	16,500	21,200	38,100	+28	+80
Unmarried men ^c	\$9,500	\$14,200	\$22,300	+51	+55
Age: 65–69	10,800	18,900	23,500	+76	+24
70–79	10,500	16,200	24,700	+55	+52
80+	7,900	10,600	17,900	+34	+69
Unmarried women ^c	\$7,700	\$10,500	\$16,500	+35	+59
Age: 65–69	9,100	14,500	21,500	+59	+48
70–79	7,600	10,400	16,900	+36	+63
80+	7,100	9,200	14,500	+30	+58

Source: Dynamic Simulation of Income Model (DYNASIM).

^a Includes entire elderly population (community-based plus institutionalized).

^b Income includes social security benefits, private pensions, government pensions, interest and dividend income, SSI and earnings.

^c The unmarried group for men and women includes persons who were never divorced and widowed persons.

expected for the "young elderly" (persons aged 65 to 69) in 2010. These persons represent the cohort born between 1941 and 1945, the generation just prior to the baby boomers. This cohort benefited from the strong economic growth in the 1960s U.S. economy during the beginning of their careers, and they were well established by the time the economic difficulties of the post-1973 economy began (Levy and Michel 1991). Table 4 shows, for example, that incomes for married couples, aged 65 to 69 in 2010, will be 63 percent higher than the incomes of married couples in 1990. Incomes for unmarried men will increase by 76 percent during this period, and incomes for unmarried women will increase by 59 percent.

Real incomes for married couples and for unmarried men aged 70 to 79 are also significantly higher in 2010 than in 1990 for similar reasons. Real income increases by 60 percent for married couples and by 55 percent for unmarried men. Persons in this cohort, many of whom were parents of the baby-boom generation, economically outperformed succeeding and preceding cohorts, often by substantial margins. In contrast, real incomes for unmarried women in this age group only grow by 36 percent over the 1990-2010 period. This generation of women did not participate in the labor force as fully as their successors and thus did not benefit from the favorable economic and pension conditions as much as men.

Table 4 also shows that the projected increases in income for the young elderly between 1990 and 2010 will have an enormous impact 20 years later when this generation reaches their eighties. For example, real median income for elderly married couples aged 80 and older will be 80 percent higher in 2030 than in 2010; income for unmarried men aged 80 and older will increase by 69 percent, and income for unmarried women aged 80 and older will increase by 58 percent.

After 2010, however, the growth in income for young elderly persons is likely to be slower. Married couples aged 65 to 69 in 2030 will have incomes about 42 percent higher than their predecessors in 2010, and unmarried men's incomes will only be about 24 percent higher. This cohort, born in the early 1960s, entered the labor force after 1973 during years of sluggish growth or at least growth rates not as high as the 1960s. They will also be the first to experience the *full* effects of the 1983 Social Security Amendments, which will gradually increase the age at which full retirement benefits are available. The current retirement age of 65 will be expected to increase in the year 2000 until it reaches age 67 in

2022. Benefits for persons retiring before age 67 are expected to be about 12.5 percent lower than they were for preceding cohorts retiring at the same age (Bernstein 1990). Moreover, the increase in the retirement age is not expected to substantially reduce the proportion of the elderly who retire early (Fields and Mitchell 1984). The DYNASIM projections incorporate these changes and show that the amendments will significantly reduce social security benefits.

The 48 percent growth in retirement income for unmarried women aged 65 to 69 during the 2010-2030 period is still relatively strong, however. The effects of increased labor force participation of women and changes in pension regulations during the 1970s influence these results. That is, more women will retire with substantial pensions and with significantly higher social security benefits because of their increased labor force participation and these effects mitigate the reduction in retirement income due to the 1983 amendments.

Despite the real growth in retirement incomes over the 1990-2030 period shown here, the average rate of income growth for the elderly will, in general, be slower than that experienced by their predecessors. Figure 1 compares these projections to historic patterns. The median income of married couples increased by 3.3 percent per year between 1967 and 1984, compared with 2.9 percent during the 1990-2010 period and 2.5 percent between 2010 and 2030. Average increases for unmarried

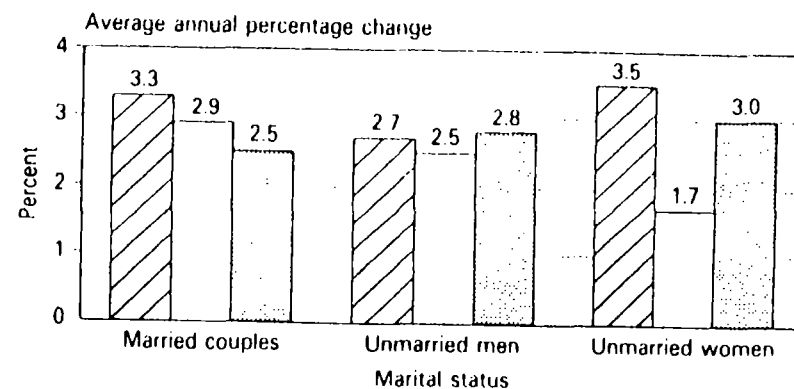


FIG. 1 Average growth in real median income; historical and projected. (Source: Dynamic Simulation of Income Model [DYNASIM].) [Hatched] 1967-1984; [White] 1990-2010; [Dotted] 2010-2030.

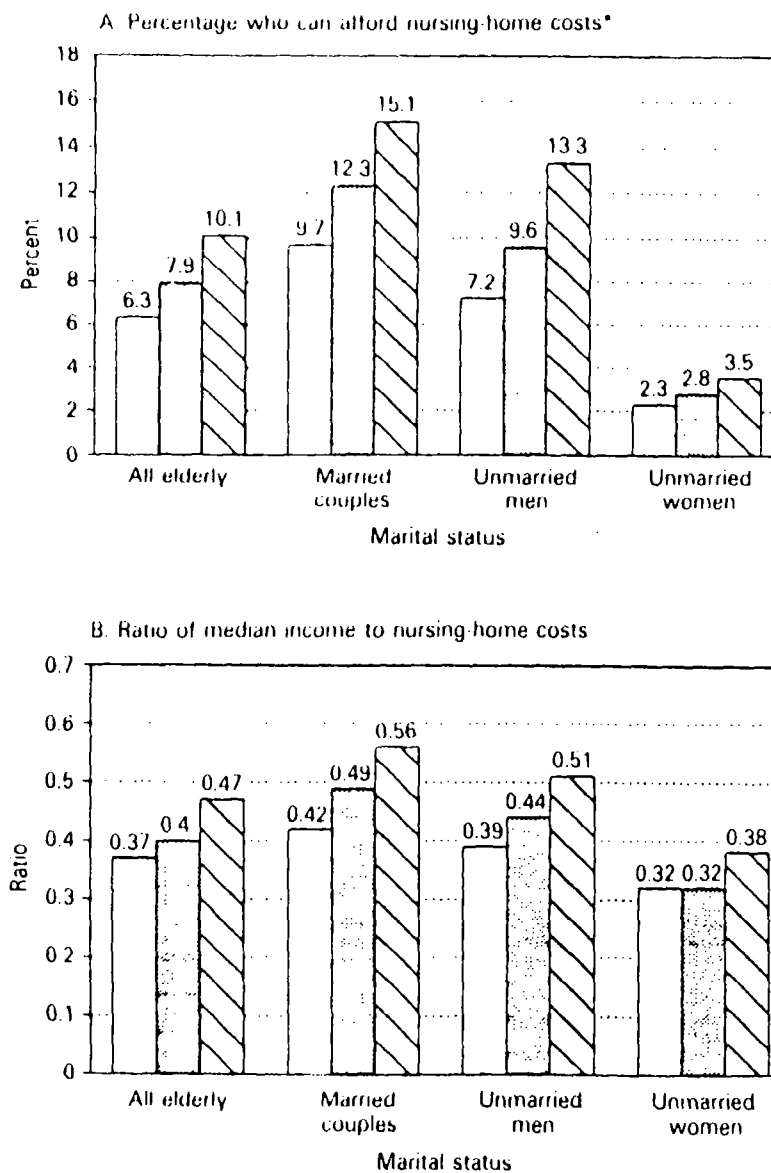
men are very similar to historic increases, however. For women, the pace of growth between 1990 and 2010 is significantly below the historic rates shown, but the rapid rate of income growth for this group is restored in the 2010-2030 period. It must be noted, however, that the growth in income for the elderly during the 1967-1984 period was unusually strong, primarily because of federal policy changes designed to alleviate poverty among the elderly, and a surge in private pension benefits and real interest rates (Burkhauser and Duncan 1988; Zedlewski et al. 1990). Thus, the future growth in income for the elderly would not be expected to match this pattern.

Affordability of Nursing home Care

Although the elderly population will be in a better financial position than their predecessors, it is not clear whether this means that more will be able to afford nursing-home care. The cost of nursing-home care exceeds the incomes of the vast majority of today's elderly. Whether or not the proportion of elderly who can afford to pay for long-term care expenses out of pocket will increase depends on whether the income growth of the elderly will significantly exceed the real increase in the cost of nursing-home care.

In 1990 the estimated annual cost of care in a skilled nursing-home facility was about \$24,300 (American Association for Retired Persons 1989). Assuming that the cost of this care will increase with real wage rates, the average annual cost of nursing-home care (in 1990 dollars) will increase 34 percent between 1990 and 2010 (to about \$32,600 in 2010) and an additional 33 percent between 2010 and 2030 (to about \$43,500 in 2030). Figure 2 compares the per person, real median incomes of the elderly with these projections of nursing-home costs. Despite the substantial growth in income expected for the elderly, only 10 percent of the elderly will be able to finance the cost of nursing-home care out of their incomes in 2030 (figure 2A). However, the percentage of nursing-home costs that could be financed out of the incomes of the elderly will increase. In 1990, for all elderly the ratio of median income to nursing-home costs was only 0.37, but by 2030 the ratio will increase to 0.47 (figure 2B).

These projections suggest that most of the future elderly will not escape the financial risk of long-term care. The problem will be especially



*Percentage whose income exceeds 100 percent of costs.

FIG. 2 Affordability of nursing home care; 1990-2030. (Source: DYNASIM projections) □ 1990; ▨ 2010; ▩ 2030

acute for unmarried women, whose median income will cover barely one third of nursing-home costs. Many of the elderly will continue to be forced to spend down assets until they can qualify for means-tested government coverage of long-term care services. Those who live in states without medically needy programs may find themselves unable to qualify for Medicaid because many are likely to have real incomes above their states' income eligibility limits. In summary, the financial catastrophe that long-term care presents today will not be eliminated on the basis of a change in the income picture of the future elderly.

Affordability of Long-term Care Insurance

Although increasing real income will not enable most of the elderly to finance nursing-home care out of pocket, it would improve their ability to finance a larger share of these expenses. More important, increasing real incomes, coupled with growing awareness of the potential financial catastrophe of long-term care expenses, may increase their interest in other financing mechanisms. Specifically, more may consider the advantages of risk pooling and purchase long-term care insurance. Of course, the viability of long-term care insurance as a financing option will depend on the ability of the elderly to pay for insurance premiums.

Current long-term care insurance premiums can be projected and compared with incomes of the elderly to assess the affordability of long-term care insurance. This requires making assumptions about the cost of long-term care insurance premiums and the "affordability" of long-term care insurance. That is, how much of their incomes could the elderly be expected to devote to long-term care insurance? It is important to note that these projections do not assume that the elderly will consume their assets in order to pay for long-term care insurance. However, this would be an unlikely scenario if the future elderly conserve their assets during retirement like their predecessors (Hurd 1987). Moreover, for reasons discussed earlier, many analysts expect that the future elderly population, particularly the baby-boom generation, will own considerably fewer assets in real terms than their parents (Levy and Michel 1991).

To project insurance affordability, we use a composite of the 15 most popular long-term care insurance policies sold today, as described in the survey by the Health Insurance Association of America (HIAA 1991a). These plans can be characterized as follows:

1. *Type of policy:* The plan covers the cost of a nursing-home bed (at a cost of \$80 per day in 1990 dollars and at least some inflation protection) for up to four years, and in-home services for up to eight years.
2. *Cost of coverage at age 65:* The 1990 cost of this type of policy, purchased individually at age 65, was \$1,400, and \$1,100 if the coverage was purchased through a group policy (HIAA 1991a). We assume that premiums for persons reaching age 65 in subsequent years will increase because nursing-home costs will rise as real wages in the economy increase. Real wage growth (shown in table 2) will increase premiums by 34 percent between 1990 and 2010 and by 33 percent between 2010 and 2030.
3. *Purchase age:* In these simulations, we assume that each individual would evaluate the purchase of insurance at age 65. Long-term care insurance premiums are assumed to remain constant over an individual's life span, but "affordability" is reevaluated during the retirement period. Real income and, therefore, insurance affordability, can decline during retirement because not all sources of income are fully indexed. (Note that affordability estimates are not provided for persons aged 70 and older in 1990 because coverage of the type described here was not available when they reached age 65.)
4. *Affordability:* We assume the elderly can afford long-term care coverage if the premium is less than or equal to 5 percent of income. To allow for sensitivity analysis, however, we also present two alternative income thresholds: 2.5 percent and 7.5 percent.

To project affordability, we compute the ratio of the assumed premium for the policies described above to the incomes of the elderly in the 1990–2030 period. We take for granted that the long-term care insurance policy is affordable only if the resulting ratio is less than the assumed affordability ratio (e.g., 2.5 percent, 5 percent, or 7.5 percent). Note that we do not assume that individuals will necessarily purchase these policies; we only provide estimates of the percentage of elderly who could *afford* to purchase a policy.

Table 5 shows the simulation results using the 5 percent affordability threshold and two premium assumptions: purchase of insurance individually, and purchase through group policies. In 1990 only 6 percent of the elderly in the 65–69 age category could afford individual sur-

chased long-term care insurance. The proportion of this age group who can afford such insurance using 5 percent of their incomes almost doubles between 1990 and 2010 – from 6 to 11 percent – the obvious result of rapid increases in income expected for this group during this period. The slowing of income growth for this group in the 2010–2030 period, however, results in only a 3-percentage point increase in the proportion of the population that will be able to afford long-term care coverage.

As would be expected from the income disparities discussed earlier, long-term care insurance is more affordable for married couples than for singles (even though married couples must purchase two policies). However, differentials in affordability narrow between 2010 and 2030 because the incomes of single elderly persons are expected to rise faster than the incomes of their married counterparts. Whereas women make

TABLE 5
Long-term Care Insurance Affordability: 1990–2030^{a,b}

Characteristics	Individually purchased premium			Group-purchased premium		
	1990 ^c	2010	2030	1990 ^c	2010	2030
(Thousands of persons)						
All elderly	— ^d	3,090	6,400	—	5,320	11,560
By age:						
65–69	620	1,340	2,380	990	2,430	4,090
70–79	—	1,240	3,070	—	2,160	5,510
80+	—	520	950	—	730	1,970
Married couples, total	—	2,130	4,040	—	3,460	6,940
Age 65–69	490	1,030	1,770	770	1,760	2,920
Age 70–79	—	860	1,830	—	1,370	3,280
Age 80+	—	230	430	—	340	740
Unmarried men, total	—	550	1,460	—	1,000	2,620
Age 65–69	—	270	510	—	510	1,080
Age 70–79	—	—	300	—	—	1,200
Age 80+	—	130	310	—	190	630
Unmarried women, total	—	420	900	—	860	2,000
Age 65–69	70	140	300	120	370	590
Age 70–79	—	130	400	—	300	810
Age 80+	—	150	210	—	200	600

continued

TABLE 5 continued

Characteristics	Individually purchased premium			Group-purchased premium		
	1990 ^c	2010	2030	1990 ^c	2010	2030
(Percentage of total persons)						
All elderly	—	7.5%	9.9%	—	12.9%	18.0%
By age:						
65–69	6.0	10.6	13.3	9.6	19.1	22.8
70–79	—	7.8	10.7	—	13.6	19.2
80+	—	4.1	5.4	—	5.8	11.1
Married couples, total	—	11.9	14.4	—	19.4	24.7
Age 65–69	7.9	13.3	16.7	12.3	22.5	27.5
Age 70–79	—	11.6	13.9	—	18.4	24.9
Age 80+	—	8.9	10.2	—	12.9	17.5
Unmarried men, total	—	9.2	13.7	—	16.7	24.7
Age 65–69	5.1	12.8	11.6	9.9	23.2	21.5
Age 70–79	—	11.2	17.9	—	22.7	30.5
Age 80+	—	5.4	9.5	—	7.9	19.1
Unmarried women, total	—	2.4	3.5	—	5.0	7.8
Age 65–69	2.4	3.8	6.4	3.8	10.2	12.7
Age 70–79	—	2.1	2.7	—	4.7	7.5
Age 80+	—	2.0	2.0	—	2.6	5.9

Source: Dynamic Simulation of Income Model (DYNASIM).

^a Percent who can afford insurance with less than 5 percent of income.

^b Both policies include coverage for four years in a nursing home, eight years of home care, and an inflation-adjusted payment for nursing home costs (\$80 per day in 1990 dollars).

^c Because this type of policy was not available in the mid-1980s, when persons aged 70 and older retired, calculations were not made for 1990 for persons aged 70 and older.

^d Dash denotes cells where the sample size is too small to report results separately.

some gains in their ability to pay for long-term care insurance premiums, under the individually purchased premium assumption this type of insurance is still unaffordable for most of them.

The lower-cost group-insurance premium assumption portrays a rosier picture for financing long-term care through a private insurance mechanism. The percent of the young elderly who can afford group premiums with no more than 5 percent of their incomes rises to 19 percent in 2010 and to 23 percent in 2030 from about 10 percent in 1990. Just a

quarter of all elderly married couples and single men would be able to afford group long-term care insurance in 2030. The extent to which this scenario presents a realistic picture of the future will depend on either increasing worker demand for group policies or declining insurance premiums as insurers' risks become spread over a larger participating group. A more mature long-term care insurance market could also result in lower premiums if more insurers compete in the market.

It is also important to consider alternative affordability thresholds. Some elderly may be willing to spend a higher proportion of their incomes on insurance, whereas others may consider 5 percent a burden on their family budget. In fact, the 5 percent assumption represents a relatively high budget share for insurance. For example, in 1987, middle-income (\$15,000 to \$30,000) families headed by a retired individual aged 62 to 74 spent about 9 percent of their incomes on all health care spending, including about 4 percent for health insurance (Moehrle 1990).

Table 6 shows the results using alternative income affordability thresholds. The first shows the percentage of elderly whose insurance premiums cost less than 7.5 percent of income, and the second shows the percentage of elderly whose insurance premiums cost less than 2.5 percent of income. The higher budget share results show that over 26 percent of the elderly could individually purchase long-term care insurance in 2030. A significantly higher percentage—44 percent—would be able to afford the lower-cost group premium for long-term care insurance. On the other hand, the lower budget share results (less than 2.5 percent of income) show that only about 4 percent of the elderly could afford insurance in 2030, even assuming the insurance would be available at the lower-cost group premium price.

Conclusions

Demographics, health, and income trends will interact to increase the demand for nursing-home care faster than many now realize. Whereas the number of elderly will increase by 100 to 125 percent by 2030, the number requiring nursing-home care will triple during the same period. Marital patterns and fertility histories of recent generations of Americans will shape a future elderly population that is more likely to be living

TABLE 6
Percentage of Elderly That Can Afford Long-term Care Insurance
(1990–2030): Comparisons of Affordability Assumptions^a

Affordability threshold characteristics	Individually purchased premium			Group-purchased premium		
	1990 ^b	2010	2030	1990 ^b	2010	2030
Less than 2.5% of income						
All elderly	—	2.3%	2.3%	—	3.2%	3.6%
By age:						
65–69	1.8	2.7	3.3	3.1	4.2	5.1
70–79	—	1.9	2.4	—	2.9	3.8
80+	—	2.3	1.4	—	2.7	1.9
Married couples		3.5	3.8	2.5	5.0	5.8
Unmarried men	0.8	2.8	2.6	1.2	3.9	4.2
Unmarried women	—	0.9	0.7	—	1.2	1.1
Less than 5% of income						
All elderly	—	7.5	9.9	—	12.9	18.0
By age:						
Age 65–69	6.0	10.6	13.3	9.6	19.1	22.8
Age 70–79	—	7.8	10.7	—	13.6	19.2
80+	—	4.1	5.4	—	5.8	11.1
Married couples	4.5	11.9	14.4	6.7	19.4	24.7
Unmarried men	1.7	9.2	13.7	3.5	16.7	24.7
Unmarried women	0.8	2.4	3.5	1.2	5.0	7.8
Less than 7.5% of income						
All elderly	—	18.9	26.4	9.5	30.6	44.3
By age:						
Age 65–69	13.0	28.6	32.1	22.5	45.9	52.6
Age 70–79	—	19.6	27.7	—	31.7	45.0
Age 80+	—	8.1	18.6	—	13.9	34.9
Married couples	8.9	28.3	35.0	14.6	42.9	55.7
Unmarried men	4.9	24.0	34.8	9.2	37.7	52.1
Unmarried women	2.0	7.4	13.6	4.2	15.6	28.8

Source: Dynamic Simulation of Income Model (DYNASIM).

^a Both policies include coverage for four years in a nursing home, eight years of home care, and an inflation-adjusted payment for nursing home costs (\$80 per day in 1990 dollars).

^b Because this type of insurance was not available in the mid-1980s when persons aged 70 and older retired, calculations were not made for persons aged 70 and older in 1990.

alone and less likely to have family caregivers. Thus, more will require formal, professional long-term care services to substitute for substantial family caregiving services.

The need to find alternative long-term care financing arrangements will be acute. Our baseline projections of the number of elderly requiring nursing-home care, and relatively conservative assumptions about the cost of nursing-home care in the future, imply that annual expenditures for nursing-home care will increase from about \$44 billion in 1990 to \$98 billion by 2010 and to \$187 billion by 2030. Thus, although the number of elderly in nursing homes will increase by two-thirds between 1990 and 2010 (from 1.8 to 3.0 million, as shown in table 4), nursing-home expenses will more than double (from \$44 billion in 1990 to \$98 billion in 2010). These estimates imply faster increases in nursing-home spending than those reported by Rivlin and Wiener (1988), primarily because the DYNASIM methodology projects a faster increase in the population at risk for nursing-home use. Over the 1990-2030 period, the need for nursing-home care will increase by 138 percent (4.3 million persons compared with 1.8 million in 1990), but nursing-home expenditures will increase by 325 percent (to \$187 billion) because the real cost of nursing-home care will also be increasing.

Current prospects for the financing of long-term care through alternative public sector programs seem bleak. After a decade of large budget deficits, many feel it is unlikely that policy makers will consider increasing public expenditures by the amounts projected here. Given this situation, it is likely that private-sector solutions for long-term care financing will continue to receive attention.

However, this study suggests that private financing of long-term care through the types of insurance mechanisms available today will be difficult. These projections confirm an emerging picture that, although the economic status of the elderly will improve over the next four decades (see, for example, Easterlin, MacDonald, and Macunovich 1990), private financing of nursing-home care will still not be a viable option for many of the elderly. Very few of the elderly will be able to personally finance nursing-home care out of pocket, and the type of long-term care insurance policies prevalent today—privately purchased insurance with four years of coverage for a nursing-home stay—will not be a viable option for most of the elderly. Its viability is restricted because the expected cost of premiums will still represent a significant proportion of the incomes of the future elderly. Using our best-educated guesses

about the course of future events, we estimate that only about 10 percent of the elderly will be able to purchase a fairly generous individual long-term care insurance policy at a cost of less than 5 percent of their incomes in 2030. Under more optimistic assumptions that the expansion of the long-term care insurance market will lead to lower premiums or that lower-priced group insurance policies will become more common, the proportion of the elderly who could afford insurance only rises to 18 percent.

These findings generally seem to confirm those reported by Rivlin and Wiener (1988) using a microsimulation technique. Although results are not directly comparable (the Rivlin and Wiener projections focus on four-year average profiles rather than single-year projections and the forecast periods of the two studies differ), we can make some general comparisons. The DYNASIM projections suggest that the future elderly population, especially persons aged 80 and older, will be better-off economically than the Rivlin and Wiener study. For example, Rivlin and Wiener (1988, 39) project a median income of \$8,000 for persons aged 85 and older in 2016-2020 (in 1987 dollars), whereas the DYNASIM median income projection for persons aged 80 and older is \$20,800 in 2030 (in 1988 dollars). However, the 1990 premiums used in this study are significantly higher than those used in the Rivlin and Wiener simulation. Both studies reach the conclusion that the type of privately marketed comprehensive long-term care insurance policy available today will be affordable only for upper-income elderly persons (using a 5 percent of income affordability assumption).

Thus, policies that reduce the cost of long-term care insurance are urgently needed. These policies might include tax incentives that would effectively reduce the cost of long-term care insurance to individuals and businesses. Insurance regulation that would require insurers to provide partial protection to those who have to drop policies during retirement may also be needed to increase the number of elderly willing to purchase these policies. Increased participation should reduce the cost of premiums as the risk for long-term care is spread over a larger segment of the elderly population. And policies that make the insurance option more attractive for the elderly may also decrease the age at which premiums are purchased, thereby reducing the annual cost of premiums during the retirement period. Policies that focus on alternatives to our current long-term care service delivery system may also be helpful. For example, more efficient and less expensive home care services at

would substitute for nursing-home care could reduce insurers' expected payouts, thereby reducing the cost of insurance premiums. In short, the viability of private long-term care financing will depend on innovative policies that reduce the cost of long-term care insurance because only a minority of elderly persons will be able to afford the types of comprehensive policies marketed today.

Limitations of This Study

The projections presented here provide our best estimates of the number of elderly who could afford to purchase insurance coverage for long-term care. However, it is important to note that these estimates are based on a simulation model predicting 40 years into the future. The obvious limitations to these types of models serve as a caveat to the results presented here. For example, we noted earlier that nursing-home entry is predicted on the basis of recently observed entry patterns. Thus, the projections implicitly assume that the supply or demand for nursing-home care will be constant over time, given an individual's demographic and health profile. To the extent that the entry into nursing homes can be delayed through more in-home services or alternative living arrangements, these projections will overstate the number in nursing homes. Even in this case, however, it is likely that significant financial resources will still be required to maintain the elderly in alternative settings.

Microsimulation model results provide estimates of the implications of current demographic and economic trends on the future needs of the elderly, assuming a continuation of current policies affecting long-term care. As such, future changes in the delivery and financing of long-term care would affect the affordability estimates provided here. More study is needed to understand the evolving market for long-term care insurance. Although these policies have improved in recent years, policies may become more restrictive and premiums may increase considerably when insurance companies are forced to provide benefits for current policy holders. Moreover, little is known about the decision to purchase long-term care insurance by the elderly. Whereas our study provides projections of the number of elderly who *could* afford to purchase insurance, we need to understand what types of people are likely to purchase coverage before an assessment of the viability of private options for fi-

nancing long-term care can be made. Finally, more research is needed to assess whether the elderly will be able to use their assets to pay for long-term care in the future. Although it is not clear at all whether the asset position of the elderly will improve in the future, it is even less clear how the elderly use their assets to pay for their long-term care needs.

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