

# Perspectives on the Recent Decline in Disability at Older Ages

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A decline has been found in the prevalence of disability among the older U.S. population during the 1980s and 1990s. One source of evidence for this decline is data from the National Long-Term Care Survey (NLTC). This article investigates possible ambiguities in measuring disability using large-scale household surveys, illustrating the consequences of such problems with new analyses of NLTC data. The reanalysis suggests a more gradual decline in disability than that found in prior research. The article also discusses three societal trends in areas other than health or functioning that might contribute to declines in disability levels: a reduced supply of informal care, changes in the technology of self-care, and changes in the definition and perception of both “ability” and “disability.”

**Key Words:** Disability, trends, measurement.

**R**ECENT FINDINGS OF A DOWNWARD TREND IN THE prevalence of disability at older ages have attracted a great deal of interest. The most recent results from the National Long-Term Care Survey (Manton and Gu 2001), for example, show a steady—and, in the most recent period, an accelerating—downward trend in disability among those 65 and older. Manton and Gu found that the prevalence of chronic disability declined by 6.5 percentage points, from 26.2 percent in 1984 to 19.7 percent in 1999, a statistically significant change. Moreover, disability rates were found to have fallen by an average of

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0.26 percent annually, 0.38 percent annually, and 0.56 percent annually for the periods 1982–89, 1989–94, and 1994–99, respectively. These findings prompted front-page coverage in the *New York Times* (Freudenheim 2001) and have been enthusiastically embraced in the academic community as well (Cutler 2001).

Some interpret the decline in disability as indicating an improving general health status among the older population (Singer and Manton 1998). Better health, in turn, presumably results from some combination of behavioral and lifestyle factors—smoking, nutrition, and exercise, for example—and health care—treatments, therapies, medication, and other interventions. However, disability trends could reflect many underlying factors besides improved health status, including new behavioral adaptations to chronic conditions, environmental changes, or social or attitudinal trends that mediate external responses to potentially disabling conditions. We address several such factors in this article. Whatever the causes, falling disability rates have important political and policy implications. Not only do they imply improvements in public health and quality of life, they may also indicate a more optimistic picture of future health and long-term care expenditures for Medicare, Medicaid, and other public programs in the United States.

The results of the National Long-Term Care Survey (NLTC) have received much attention in the scholarly and policy communities. Some have cautioned that the declines observed in the 1980s and 1990s may not last into the future (e.g., Freedman, Martin, and Schoeni 2002; Wolf 2001). The results also have prompted additional research, including reanalysis of the NLTC, comparisons with other data sources, methodological investigations, and attempts to project future trends and their fiscal implications (Freedman et al. 2004b; Spillman 2004; Waidmann and Liu 2000). The review by Freedman, Martin, and Schoeni (2002) placed the attempts to explain the downward trends in old-age disability into two categories: compositional change in the older population, and health care and treatment. Spillman (2004) suggested a third category, environmental change, including the spread of services like direct bank deposits (e.g., of Social Security benefit checks), electronic bill-paying, and other technological innovations that could reduce the prevalence of less severe disability.

We reexamine this decline in disability from two perspectives. First, we consider several technical issues: how well, and how consistently, responses to typical survey questions produce measures of disability.

Because surveys do not generally ask whether respondents are “disabled,” it is necessary to determine how both the wording of surveys and the procedures elicit conceptually relevant responses. We look at several methodological issues that arise when trying to map the concept of disability to an operational measure and address some of those issues with our own reanalysis of NLTCS data.

Second, we address a range of possibilities regarding the factors underlying recorded responses to the survey questions, arguing that several societal trends may be implicated in the observed declines in disability among the older population. We discuss social change—in arenas other than disability or health, as usually construed—that might contribute to the reported decline in disability at older ages. One such arena is the family, which remains the principal source of assistance with disability-related needs. Another is technological progress that changes either the context in which older individuals function or their ability to function in that environment or both. Finally, we examine the disability rights and independent living movements, two examples of cultural or normative changes that may have both redefined and changed self-perceptions of “ability” and “disability.” These other societal changes, in turn, suggest a number of possible interpretations about the reasons for, and the possible continuation of, the downward trends in old-age disability. In particular, reductions in disability may not be the result of better health or of health care and should not necessarily lead to optimism about the future of costly public programs like Medicare and Medicaid.

The different perspectives from which we view the prevalence of declining disability have in common their concern with issues of *measurement*. Disability is a construct with numerous and diverse observable manifestations. One aspect of the measurement problem is devising survey questions that faithfully and consistently elicit appropriate responses. Another aspect is posing those questions to large national samples. Comparing these measures over time creates additional issues. A change in apparent disability may reflect social or environmental trends rather than “internal” changes. And to those affected by it, the meaning attached to “disability” and its manifestations may change over time as well. While our investigation of these issues suggests that disability has indeed declined, we question how large and how rapid those declines have been and urge caution regarding the likely continuation of such trends in the future.

## A More Detailed Look at the Trends

While it is possible to treat disability as a binary distinction between being “disabled” or “nondisabled,” a closer examination of the literature on disability trends reveals a more complex picture. With respect to severity, Manton and Gu’s (2001) results indicate differing patterns of change over time across several groups of older people. For example, among the noninstitutionalized population, the most dramatic declines were found for those who were *least* disabled, namely, those with limitations only in instrumental activities of daily living (IADL) (such as shopping, housework, and travel). After rising slightly from 5.7 percent to 6.2 percent of the over-65 population from 1982 to 1984, the prevalence of disability fell by almost half, to 3.2 percent, by 1999. A qualitatively similar, but less dramatic, pattern can be seen for those with limitations in one or two (out of six) activities of daily living (ADL) (such as eating, bathing, dressing, and using the toilet). These rates rose from 6.9 to 7.0 percent of the over-65 population from 1982 to 1984 and fell steadily to 6.0 percent in 1999. The prevalence of persons with three or four ADL limitations actually rose, from 3.0 percent of the over-65 population in 1982 to 3.5 percent in 1999, despite a single period of decline from 1989 to 1994. The prevalence of institutionalized persons over 65 and of noninstitutionalized persons over 65 with numerous (five or six) ADL limitations also fell between 1982 and 1999.

Spillman’s (2004) reanalysis of the NLTCs used different definitions and a different set of sampling weights and omitted the 1982 data (which did not obtain responses from institutionalized sample members). Spillman concluded that the percentage of the over-65 population who were considered nondisabled did not increase from 1984 to 1994 and rose only slightly between 1994 and 1999. Furthermore, while there was a clear downward trend in the disabled, over-65 population overall, within that population there was a drop in the use of human assistance and a rise in the use of special equipment and assistive devices. The apparent inconsistency of the trends in the percentage of nondisabled (no increase) and disabled (a decline) is explained by the presence of a third, intermediate, group, those with slight disabilities and those formerly but not currently classified as disabled, who “may be in poorer health and at a higher risk of future chronic disability” (Spillman 2004, 163). Finally, Spillman pointed out that most of the downward trend in the receipt of human assistance occurred among persons over 65 with IADL

disabilities only, which is consistent with Manton and Gu's findings (2001).

Most recently, Freedman and colleagues (2004b) reported findings from a coordinated study of five different survey data sources with the same definitions, coding schemes, and analytic techniques. As did the studies just cited, Freedman and colleagues (2004b) found a consistent pattern of declining ADL disability, from 1 to 2.5 percent per year, in the proportion of the community-based population considered disabled. These trends were found when using either reported difficulty with activities or the receipt of help with activities as the criterion for classifying people as disabled.

Over the same time period, other indicators of health have shown trends in some cases parallel to, but in other cases in contrast to, the trends in disability. For example, Freedman, Aykan, and Martin (2001, 2002) reported that survey-based measures of severe cognitive impairment dropped substantially among older people between 1993 and 1998. In fact, their findings suggest that *relative* declines in cognitive limitations were considerably larger than those for functional disability reported by Manton and Gu (2001) and others. Liao and colleagues (2000) also reported findings on cognitive improvements in comparisons of data from the National Mortality Followback Survey from 1986 and 1993, and Manton, Stallard, and Corder (1998) reported declines in dementia using NLTCs data for 1982 to 1994. Although these survey-based measures of cognition are not equivalent to a clinical diagnosis of dementia, they might reflect a diminishing prevalence of dementia in the older population. The findings regarding trends in cognition were not, however, uniform across studies. Rodgers, Ofstedal, and Herzog (2003) found little improvement in cognition using data from the same source as that used by Freedman, Aykan, and Martin (2001). Sauvaget and colleagues (1999), analyzing data from two consecutive nine-year cohort studies, found rising dementia incidence rates for men in several age groups but falling rates for women in some age groups. A drop in cognitive disability paralleling that in physical disability would be important for several reasons. First, reduced cognition contributes directly and independently to the need for care; indeed, in their more serious forms (e.g., Alzheimer's disease), cognitive impairments lead to intense and effectively unceasing care needs. In addition, reduced cognition has been found to interact with chronic conditions to produce lower levels of functioning (Fultz et al. 2003), further exacerbating care needs.

In contrast to the reported trends in disability and at least some of the available research on cognition, other studies (Crimmins 2004; Crimmins and Saito 2000; Freedman and Martin 2000) showed that in recent decades, the prevalence of several chronic diseases and health conditions has *increased* among the older population. Among the conditions for which significant increases have been reported over this time period are osteoporosis, hip fractures, stroke, cancer, diabetes, heart disease, arthritis, obesity, and glaucoma. In view of the close association between many of these medical conditions and the need for, or receipt of, care, the coincidence of rising disease prevalence but falling disability prevalence seems paradoxical. Freedman and Martin (2000) suggest a number of explanations for these contrasting trends among older people: some conditions may have become less debilitating over time, thanks to progress in disease management; better and earlier detection and diagnosis over time may have caused the average severity of reported conditions to fall; and improvements in behavioral risk factors may have counteracted the adverse trends in the presence of the chronic conditions. For some other conditions closely associated with disability—in particular, vision and hearing problems—the available evidence indicates an absence of trends, either upward or downward, during the 1980s and 1990s (Desai et al. 2001; Lee et al. 2004).

## A Conceptualization of Disability

A widely accepted depiction of the “disablement process” (Verbrugge and Jette 1994) emphasizes the progression along the “main pathway” *pathology* → *impairment* → *functional limitation* → *disability*. The first stage, *pathology*, refers to biochemical or physiological conditions that may be a consequence of disease but could also result from injury or developmental abnormalities. Pathology may be latent; when detected, it is typically reported using diagnostic language. *Impairments*, in contrast, are “dysfunctions and significant structural abnormalities in specific body systems” (Verbrugge and Jette 1994, 3) such as musculoskeletal, cardiovascular, or neurological systems. Impairments typically do not involve the entire organism. *Functional limitation* refers to restrictions on one’s capacity for physical or mental actions or “work.” For example, the destruction or wastage of certain tissues may give rise to painful or restricted joint movement, which, in turn, hinders grasping, rising, or climbing stairs.

The final stage of the disablement process, *disability*, refers to the context-specific consequences of functional limitations: disability is “experienced difficulty doing activities in any domain of life . . . due to a health or physical problem” (Verbrugge and Jette 1994, 4). The domains most often measured with respect to the older population are ADLs and IADLs. Disability assessment tools (including surveys, scales, and screening instruments) frequently reveal functional limitations (or “physical functioning”) as well, including musculoskeletal tasks (e.g., stair climb, chair rise, or timed walk) and sensory levels (e.g., vision and hearing). Particularly important is that whereas pathologies, impairments, and functional limitations reside wholly within the individual (i.e., they are “internal”), disabilities are defined with respect to the interaction between the individual and his or her environment. Moreover, there are many ways to react to, adapt to, or accommodate a person’s functional limitations.

One possible adaptation to functional limitation is to reduce the frequency, intensity, or scope of participation in an activity or to eliminate it from one’s life altogether. Such adaptations would almost certainly be accompanied by a decrease in the quality of life, but they do illustrate the possibility that there can be functional limitation *without* disability. Other ways in which limitations can be accommodated are changing routines, reducing the speed with which activities are carried out, using assistance from other people or from special equipment, or modifying one’s environment through, for example, a change of residence, remodeling, or the installation of assistive devices.

## Measurement Issues

The measurement—that is, the *operational* definition—of “disability” originated in clinical assessments of individuals. In the assessment, a trained professional, such as a physician, nurse, or social worker, evaluates a person’s capabilities and needs, based on direct observation, health history, and other idiosyncratic information. Often these evaluations are for developing care plans or determining eligibility for programmatic benefits. There may be a considerable variation in assessment criteria across time, space, and programmatic setting. For example, Adler and Hendershot (2000) noted the existence of 43 different programmatic definitions of disability just for federal programs in the United States. However, when the goal is to characterize health or disability at the

*population* rather than the individual level, practical considerations rule out professional assessments as well as fine-grained programmatic details. Instead, standard, closed-end questions for use in large-scale surveys must be devised, to which respondents are expected to self-report their capacities and their limitations in—it is hoped—a uniform way. As earlier sections of this article showed, many such population surveys have dealt with disability, and a great deal of methodological research has been conducted on topics related to disability surveys. We discuss here three problem areas: the wording of questions, the administration of surveys, and the use of proxy respondents.

### *The Wording of Questions*

Several studies have demonstrated the sensitivity of estimating the prevalence of disability to various wordings of survey questions (Freedman 2000; Rodgers and Miller 1997; Wiener et al. 1990). A particularly important distinction is between survey questions that ask respondents about their *difficulty* performing tasks and those that ask whether they *receive help* with those tasks.

When using data from a survey that asks respondents whether they have *difficulty* with ADL or IADL tasks, it is logical to equate a report of difficulty with the presence of disability. This approach to measuring disability, however, can produce downward-biased estimates of disability prevalence. “False negatives” may result when a respondent with some sort of functional limitation (as defined in the disablement process) has adapted to that limitation, developing a strategy for performing the task without perceived “difficulty.” For example, Pine, Gurland, and Chren (2002) analyzed data from a population-based sample of older Manhattan residents and found that 7 percent of those reporting “no difficulty walking” either indoors or outdoors nevertheless used a cane, suggesting the presence of an underlying functional limitation. Elsewhere, Pine, Gurland, and Chren (2000) reported that among a subset of the same Manhattan sample, nearly half those reporting no difficulty walking indoors had in fact slowed their walking speed during the preceding ten years. Again, the reduction in walking speed may reflect some deterioration in functioning despite the respondent’s belief that he or she could walk without difficulty. Surveys thus often adopt a more refined approach, asking respondents whether *because of a health or physical problem* they have difficulty with specified tasks. But this approach



still leaves open the possibility of “false negative” responses. Williamson and Fried (1996) reported that 20 percent of a sample of older Baltimore residents stated that “old age” (rather than a health condition) was the reason for their reported disabilities. Nevertheless, those who attributed their difficulties to old age had significantly higher levels of arthritis, heart disease, and hearing loss than did those who reported disabilities but did not attribute them to old age.

In contrast, survey questions that ask whether respondents *receive help* with ADL or IADL tasks may produce an opposing bias. “False positives” can occur if respondents receive help with tasks that they could perform without help but possibly with some degree of difficulty. Jette (1994) provides evidence for this phenomenon. He used data from a sample of older New England residents (age 70 and over) who were asked separately whether they had difficulty performing each of several ADL activities because of a health or physical problem, whether they received help from another person or used equipment to perform the activity, or whether they were unable to perform the activity. Jette’s Table 3 (p. 940) reports, for each of seven ADL tasks, the percentage reporting difficulty and getting help and also the percentage reporting no difficulty but nevertheless getting help. From each pair of percentages it is possible to compute the percentage reporting *no* difficulty *given* that they receive help. These percentages range from a low of 3.7 percent (for transfer) to a surprisingly high 32 percent (for eating). These findings suggest that the “false positives” problem embedded in the “get help” questions may be substantial. Few surveys, however, ask those who report no “difficulty” any questions about whether they “get help.” Another example is Bootsma-van der Wiel and colleagues (2001), whose analysis of data for the 85-and-older population of Leiden, Netherlands, reveals that about 9 percent of persons getting help with ADL tasks could do those tasks, without help, with “no difficulty.”

### *Interview Mode*

Surveys containing questions about disability use in-person as well as telephone-based data collection, and sometimes a mix of both. Health (and other) information obtained from these two modes of questionnaire administration tends, on average, to be different, but this could be attributed to a variety of selection effects as well as mode effects. Much less is known about the effects of interview mode while holding constant

one's health or disability status, although a recent review of the existing evidence on disability decline in the older population maintained that a switch between in-person and telephone reporting constituted a design weakness (Freedman, Martin, and Schoeni 2002).

The design of the longitudinal Asset and Health Dynamics of the Oldest-Old (AHEAD) survey specified a switch from a telephone to an in-person mode when respondents reached age 80. The researchers introduced into the survey a randomized trial of mode effects, randomly switching half the age-appropriate respondents (i.e., those aged 78 to 81) in wave 2 and half in wave 3. An analysis of the possible effects of the interview mode on reports of cognitive functioning using these data found no such effects (Herzog and Rodgers 1999), although we should point out that the narrow age range, and therefore the modest number of cases used in the test, tends to favor the null hypothesis. Rodgers (2003, personal communication) also reported an absence of mode effects on other disability measures (including ADL and IADL difficulties and the receipt of help) of this age group. Nevertheless, despite the lack of experimental evidence supporting the claim of in-person versus telephone biases in self-reports of disability, a professional discomfort with the mixing of modes prevails.

### *Self-Reported versus Proxy-Reported Disability*

Finally, research has shown that proxy respondents tend to overreport disability, especially when reporting on older people (Andresen et al. 2000; Santos-Eggimann, Zobel, and Bérod 1999; Todorov and Kirchner 2000). Surveys like the NLTCS have no choice but to solicit proxy responses in certain situations, particularly when the sample individual exhibits sufficiently severe cognitive limitations. But if the mix of proxy and self-reporting respondents changes over time or if there are within-subject changes between the proxy and self-report status in panel surveys, spurious changes in the apparent prevalence of disability might appear.

## Measurement Issues in the NLTCS

The methodological issues reviewed in the preceding sections suggest several questions about the evidence on trends in disability prevalence based on NLTCS data. Most important, the NLTCS uses two key survey

elements, a “screeener” interview used when sample members are initially contacted, and a “detail” interview that provides extensive follow-up information. The screener interview is brief, and its default mode of administration is by telephone. In it, respondents are asked a series of ADL “difficulty” questions, as follows: “First, I’d like to ask about [your] ability to do everyday activities without help. By help, I mean either the help of another person, including people who live with [you], or the help of special equipment. Do [you] have any problem . . . eating without the help of another person or special equipment? . . . getting in or out of bed without help? . . . getting in or out of chairs without help?” (and so on). These are followed by a series of questions concerning the respondents’ ability to do, without help, a series of IADL tasks.

If a respondent does have “any problem” with any of the ADL tasks or, “because of a disability or health problem,” is unable to do any of the IADL tasks *and* if any such problems have lasted, or are expected to last, for at least three months, then the respondent “screens in”—he or she meets the NLTCs’s criteria for being classified as disabled and is scheduled to receive the longer, in-person, “detail” interview. A comparatively short form of the detail interview is used for institutionalized respondents, and a longer version is used for community-dwelling respondents (the exception being in 1982, when institutionalized sample members were not interviewed).

The ADL questions in the detail questionnaire are of the “gets help” type. For example, the first such question is “During the past week . . . did any person help [you] eat? [If not], did [you] use special utensils or special dishes to help [you] eat?” If the respondent got no help and used no special equipment, he or she is asked, “Did someone usually stay nearby just in case [you] might need help?” Respondents who got no help, whether active or standby, and used no equipment, are asked, “Do [you] *need* help with—?” Thus, the NLTCs mixes screener questions whose wording may prompt “false negative” reports with follow-up questions more likely to foster “false positive” reports. Within an interview year, the net effect of these features may be a downward bias in the apparent overall level of disability. Some respondents who screen out and are therefore classified as nondisabled might report using an assistive device or special equipment (such as a cane) if they were asked the detail questions and would therefore be classified as disabled. However, the data to test this possibility are unavailable because of the nature of the design of the NLTCs questionnaires.

From a longitudinal perspective, more complex possibilities arise. The NLTCS design dictates that respondents who have *previously* screened in must *automatically* screen in for subsequent waves of interviewing. Respondents who have been determined to automatically screen in are not asked the disability questions normally included in the screener interview. Thus, previously disabled individuals who have recovered some or all their functional capacity will not be asked the “difficulty” questions. Such respondents fall into the intermediate group included in Spillman’s (2004) classification scheme. This design feature increases the opportunity for upward-biasing “false positive” reports of disability. For example, there is some evidence that people who show functional improvements do not proportionally reduce their use of ADL and IADL assistance (Freedman et al. 2004a).

Furthermore, although the NLTCS design has remained essentially fixed throughout, changes in the population can interact with the design to produce changes in the de facto design. For example, findings concerning declines in the prevalence of dementia suggest that fewer proxy respondents will be needed in successive waves of the NLTCS, thereby changing the mix of upward-biased and (possibly) downward-biased reports of disability among proxy respondents and self-respondents, respectively. Paradoxically, genuine improvements in population cognitive health might contribute to overstating the improvement in physical functioning.

Our review of NLTCS instrument design and field procedures pointed to a number of potential sources of bias in the reporting of individual disability. Some of these sources can be expected to bias upward the reported level of disability, while others are likely to bias the reports downward. Moreover, the relative importance of these biases could change over time, affecting our estimates of time trends in disability prevalence. The net effect of these influences is not clear. An empirical investigation designed to isolate and remove these influences does, however, seem warranted.

### *Findings from the Reanalysis of the NLTCS*

There is only one subgroup of NLTCS respondents for whom the effective design of the survey is constant over time, and that is people aged 65 to 69, that is, those newly “aged in” in the follow-up interviews. All these respondents are asked the full set of screener disability

questions, permitting an analysis of trends in the prevalence of responses to the screener's "any problem" questions. Even for this group, there are some qualifications. First, the 1984 respondents cannot be used, since only those aged 65 and 66 were in the "age in" group that year. Second, in-person interviewers were instructed, for purposes of the screener interview, to code the disability questions "yes" (the respondent has a problem), without asking, if "apparent by observation" in 1989, 1994, 1999, but not in 1982. And although the design and field procedures otherwise did not change over time, the relative use of proxy and self-report, as well as in-person and telephone modes, could still vary over time for any number of reasons, including purely random factors.

We analyzed the prevalence of two binary indicators of disability—any ADL disability (whether or not accompanied by IADL disability), and any (i.e., ADL or IADL) disability—for 1982, 1989, 1994 and 1999, among those aged 65 to 69. Our disability indicators used responses to the screener questions *only*. Also, our coding scheme did not use the respondents' reports about whether the reported problems had lasted, or were expected to last, for a period of three or more months; in this regard, we departed from the practice followed by Manton and colleagues. As with most other survey data on disability, however, our approach produces point-in-time prevalence estimates. We also stratified our screener-only measures according to *respondent status* (self-versus proxy-reported) and *interview mode* (telephone versus in-person administration).

For comparison, we also reported—for the same subsample of NLTCS respondents—the percentages of disabled using the same disability classifications (ADL disability and any disability) but based those classifications on variables found in the "analytic file" prepared at Duke University's Center for Demographic Studies (see [http://www.cds.duke.edu/pdf/82-99\\_Analytic\\_File\\_Data\\_Dictionary.pdf](http://www.cds.duke.edu/pdf/82-99_Analytic_File_Data_Dictionary.pdf)). The latter variables are identical to those used in Manton and Gu's analysis (2001) and were derived from responses from both the detail and screener interviews. Our calculations were weighted with the same weights as those found in the Center for Demographic Studies file. We computed standard errors using Manski and Lerman's formula (1977) for weighted maximum-likelihood estimates. Significant differences, where noted, were based on determinations that 95 percent confidence intervals did not overlap. Because we confined our analysis to individuals who newly joined the sample each

TABLE 1  
 Sample Size and Screener Mode, NLTCS Respondents 65–69 Years Old,  
 1982–1999

	Year			
	1982	1989	1994	1999
Full sample size	5370	4636	3489	4583
% missing values	1.6	3.2	1.2	4.5
Number in analysis	5286	4489	3447	4379
% self-respondents	85.7	87.2	92.3	85.8
% screened by telephone	77.1	84.1	80.3	— <sup>a</sup>
% telephone self-respondents	67.2	73.6	74.9	—

<sup>a</sup>Data not available.

interview year (i.e., those who “aged in”), we eliminated the analytic problems associated with repeated measures.

Table 1 shows the sample sizes used in our analysis and indicates that very few cases were lost because of missing values on the disability, mode, or proxy variables. The percentage of respondents interviewed in person (versus by telephone) and by proxy (versus by self-report) varied from year to year but showed no consistent patterns. The 1999 NLTCS public-use data file does not, unfortunately, include an indicator of screener interview mode.

Table 2 presents several different estimates of disability prevalence and of the rate of change of disability prevalence for persons aged 65 to 69, between 1982 and 1999. Estimates based on the analytic file data are labeled “CDS,” and our screener-only variables are labeled “Screener.” Our results indicate a substantial sensitivity of both disability level and trend estimates to several measurement issues. The “CDS” and “Screener, All” measures differ in two important ways: the former relied on screener as well as follow-up interview items for their operationalization of “disability” while also requiring that reported disabilities last for three (or more) months’ duration, and the latter used the screener items only and imposed no minimum-duration requirement. Our prevalence estimates (from the “Screener, All” rows of the table) are higher than those derived from Manton and Gu’s (2001) variables, a difference that presumably was driven principally by the three-month duration criterion. Respondents whose disability was reported by proxies appear to be considerably more

TABLE 2  
Prevalence of Alternative Disability Indicators, NLTCS Respondents  
Age 65–69, 1982–1999

	Prevalence				Average Annual Change	
	1982 %	1989 %	1994 %	1999 %	82–94	82–99
Any ADLs <sup>a</sup>						
CDS <sup>b</sup>	6.5	5.4	5.7	4.8 <sup>d</sup>	–0.07	–0.10
Screener <sup>c</sup>						
All	8.3	7.1 <sup>d</sup>	7.2	6.1 <sup>d</sup>	–0.10	–0.13
Respondent status						
Self	7.2	6.2	6.6	5.8	–0.06	–0.09
Proxy	15.4 <sup>e</sup>	13.3 <sup>e</sup>	14.0 <sup>e</sup>	8.3	–0.12	–0.42
Interview mode						
Telephone	8.1	6.6	7.0	–	–0.09	–
In person	9.1	10.0	7.6	–	–0.13	–
Respondent + mode						
Self & telephone	7.2	5.7 <sup>d</sup>	6.5	–	–0.06	–
Any disability						
CDS	10.1	8.1 <sup>d</sup>	8.5 <sup>c</sup>	6.6 <sup>d</sup>	–0.14	–0.21
Screener						
All	10.7	9.0 <sup>d</sup>	8.9 <sup>c</sup>	7.7 <sup>d</sup>	–0.15	–0.18
Respondent status						
Self	9.2	7.9	7.9	7.1	–0.11	–0.12
Proxy	20.5 <sup>e</sup>	16.5 <sup>e</sup>	21.5 <sup>e</sup>	10.9	0.09	–0.56
Interview mode						
Telephone	10.3	8.2 <sup>d</sup>	9.1	–	–0.11	–
In person	11.7	13.1	8.4	–	–0.28	–
Respondent + mode						
Self & telephone	9.1	7.1 <sup>d</sup>	7.9	–	–0.10	–
n	5286	4489	3447	4379		

<sup>a</sup>ADL: Activities of Daily Living.

<sup>b</sup>CDS: Center for Demographic Studies coding of disability.

<sup>c</sup>Screener: authors' coding of disability as described in text.

<sup>d</sup>Percent disabled is significantly different from 1982 percentage.

<sup>e</sup>Percent disabled for proxy respondents significantly different from self-respondents.

disabled than were those who self-reported, with most of the differences in prevalence being statistically significant. Based on the research cited earlier, these differences undoubtedly reflect a combination of true differences and proxy-response bias. In-person reports also produced higher

prevalence levels than did telephone reports, although none of the latter differences was statistically significant.

With respect to changes in disability prevalence over time, both the CDS measure and our “ Screener, All ” indicator showed significant declines from their 1982 levels. But when we controlled for respondent status or for interview mode, the differences in prevalence over time were not significant. Regarding average annual change, the most telling findings are those in the “ Any disability ” portion of the table. Our screener-only coding scheme produced estimates of the rate of improvement in disability that are closer to zero than those based on Manton and Gu’s coding scheme. For the full period shown, 1982 to 1999, our estimated rate of change was  $-0.18$  percentage points per year, about 14 percent lower than the estimates using Manton and Gu’s variables ( $-0.21$  percentage points per year). The difference was even larger for self-respondents only: our estimate of  $-0.12$  percentage points per year is about 43 percent lower than Manton and Gu’s estimates. The patterns over time were rather erratic for the much smaller group of proxy-reported respondents. The available evidence suggests that for responses obtained by telephone (or, more narrowly, self-reporters interviewed by telephone, the only combination of *respondent status* and *interview mode* that produced adequate sample sizes), there was no clear pattern. But the absence of 1999 data on interview mode limited our ability to make such comparisons. Finally, we found steeper downward trends in the “ Any disability ” than in the “ ADL disability ” indicator, consistent with both Manton and Gu’s (2001) and Spillman’s (2004) analyses of NLTCS data.

We cannot directly compare our results with other published analyses of the same data, because neither Manton and Gu (2001) nor Spillman (2004) isolated the particular five-year age group used here. Our goal, however, was not to supplant prior estimates of either the levels or the dynamics of disability among the older population; rather, we wished to point out the problems with reaching conclusions about these phenomena using even what are arguably the best available data on the subject. Our results do, in fact, provide further evidence of a downward trend in prevalence of disability, albeit for a narrow, and comparatively healthy, age group. Yet by holding constant the wording of the questions, as well as illustrating other possible methodological biases, we have cast doubt on previous findings regarding the speed with which any such decline is taking place.



## Do Reductions in Disability Reflect Improvements in Health?

The disablement process model discussed here rests in part on a distinction between functional health conditions, as commonly understood, and disability. Thus, trends in reported disability may reflect underlying trends in non-health-related domains. Here we consider several possible domains in which changes over time might lead to changes in reported disability.

### *The Supply of Caregivers*

In our discussion of the possibility of “false positive” reports of disability, we cited evidence that survey respondents occasionally receive help for activities that they could perform without help, with little or no difficulty. This phenomenon, along with evidence from other studies that older people with more children have more helpers (Dwyer and Coward 1991; Wolf, Freedman, and Soldo 1997) and that informal helpers provide more hours of help than do paid helpers, holding the severity of care needs roughly constant (Wolf 2004), indicates that the receipt of help—and therefore the *appearance* of disability—may be at least partially driven by supply.

Spillman’s (2004) findings indicate that the decline in the prevalence of disability among the older population in general is mainly driven by IADL. The prominence of diminishing IADL disability, in combination with the fact that family members are the principal providers of IADL assistance for elderly people (Wolf 2004), raises the possibility that any trend toward reduced availability or the willingness of family members to provide services could partly explain the downward trends in disability. In other words, over time, as a greater percentage of the older population faces a diminished supply of caregivers, the chances of “false positive” reports of disability based on the receipt of help might fall. For disability measures based on “difficulty,” there could be a contrary trend: people who, owing to the diminished supply of assistance, do not receive care may notice limitations that in the past they would not have noticed because of the assistance they received. Thus, a declining supply of care may encourage “true positives.”

Research based on the NLTCs has shown that over time, family members have, in fact, become a relatively less prominent source of elder care.

Among all helpers identified in the 1982 data, for example, 35.5 percent were spouses and 37.4 percent were children, a total of 72.9 percent (Stone, Cafferata, and Sangl 1987). By 1999 these percentages had fallen to 24.4, 33.8, and 58.2 percent (Wolf 2004). From the perspective of the care recipients, a similar story emerges: in 1982, 73.6 percent relied exclusively on informal caregivers, but by 1994 only 64.3 percent did (Liu, Manton, and Aragon 2000). Spillman and Pezzin's (2000) comparison of assistance received by 1984 and 1994 NLTCS respondents also led them to conclude that family members had become less prominent as caregivers. The *relative* decline of informal care could, however, be the result of greater access to other forms of care, especially formal care, during this time. In order to argue that declines in disability are driven by the supply side, we must demonstrate an *absolute* decline in the availability or willingness of family members to provide care. Here we examine three indicators of the effective supply of family caregivers over time.

Table 3 presents the marital status distribution of NLTCS respondents for survey years 1984–1999 (figures for 1982 are not available because in that year the marital status of respondents who “screened out” was not ascertained). Figures by the respondents' sex and by institutional status are shown separately. For men, the percentage of married respondents fell slightly, which could in turn produce a slight decline in the availability of spousal caregivers. For women, the percentage of married respondents rose, although by a very small amount. But the percentage of divorced men and women rose by several percentage points. Several studies have shown that parental divorce diminishes the quality and quantity of parent-child interactions and relationships, especially for fathers (Lye et al. 1995; Cooney and Uhlenberg 1990), including less likelihood of parent and child living together (Aquilino 1990). Thus, the rising divorce rate of the 65-and-older population during the 1980s and 1990s might have helped reduce the children's provision of care. Indeed, Pezzin and Schone (1999) found that for older men, being divorced was associated with fewer hours of informal help received from children.

Two other social trends that might have lowered the supply of care services from adult children, especially daughters, are women's rising participation in the labor force and later childbearing, both of which could create conflict with the caregiver's activities. Stone, Cafferata, and Sangl (1987) showed that about 63 percent of caregiving daughters (in 1982) fell into the 45-to-64 age group. From 1980 to 2000, labor force participation among women aged 45 to 54 rose from 59.9 percent to

TABLE 3  
Marital Status of NLTCS Respondents, by Year

	Survey Year			
	1984	1989	1994	1999
Noninstitutionalized				
Men				
Married (%)	78.1	78.2	76.6	75.7
Widowed	13.3	12.9	13.6	14.8
Divorced	4.6	5.3	6.2	6.3
Never married	4.0	3.7	3.7	3.2
Women				
Married	39.7	41.1	41.6	40.4
Widowed	50.2	47.3	47.3	48.2
Divorced	4.8	6.5	7.3	7.6
Never married	5.3	5.0	3.9	3.8
All				
Men				
Married (%)	76.6	76.6	75.4	74.6
Widowed	14.2	14.0	14.2	15.5
Divorced	4.7	5.5	6.3	6.5
Never married	4.5	4.0	4.0	3.4
Women				
Married	37.7	38.9	39.5	38.8
Widowed	51.7	49.2	49.1	49.7
Divorced	4.8	6.5	7.1	7.5
Never married	5.8	5.4	4.3	4.0

76.8 percent, a very large relative increase. During the same period, labor force participation rates for women aged 55 to 64 also rose, from 41.3 to 51.8 percent (U.S. Bureau of the Census 2002). Similarly, the average age of women giving birth to children each year has risen steadily since 1974 (Mathews and Hamilton 2002). Birthrates among women aged 30 to 34 have been rising since 1975, and for women aged 35 to 44 they have been rising since the early 1980s (Martin et al. 2002). Thus, among the women whose age places them at the greatest risk of providing parent care services, trends under way during the 1980s and 1990s were increasingly raising barriers to the provision of such care. This suggests, but does not prove, that women did in fact cut back their provision of care services during these years, but we are not aware of any research that addresses this question directly.

*Technology of Care, Medical Procedures,  
and Treatments*

A number of changes in what might be called the “technology of self-care” have enhanced the ability of persons with functional limitations to live and care for themselves independently. These factors could cause reported rates of disability to fall even in the absence of any change in health, chronic disease, or functional capacity. One such factor is the use of assistive technology (AT), such as canes, wheelchairs, and hearing aids. The assistive technology market has been growing steadily over the same period that disability rates have been falling among the older population. In 1994, 7.4 million people of all ages living in the community used mobility devices; 4.6 million used anatomical devices such as back braces or artificial limbs; 4.5 million used hearing devices; and 0.5 million used vision devices. The rate of use of any such assistive technology was 65.4 per 1,000 persons of all ages (Russell et al. 1997). Furthermore, the number of users of assistive technology grew at a much faster rate than did the overall population (which grew by 19.1 percent between 1980 and 1994). For example, the use of canes grew by 65.5 percent, the use of walkers by 107.7 percent, and the use of wheelchairs by 117.2 percent. While part of this growth is due to the aging of the population, even age-adjusted use rates rose much more quickly than did the overall population. The age-adjusted growth for canes, walkers, and wheelchairs was 37.0 percent, 70.1 percent, and 82.6 percent, respectively.

Various research studies indicate that assistive technology is used disproportionately by people who report IADL problems (Agree 1999; Allen, Foster, and Berg 2001; Verbrugge and Jette 1994), the group that in most studies has shown the largest decreases in disability rates. Findings by Verbrugge, Rennert, and Madans (1997) also suggest that people who use assistive technology only (without supplemental help from formal or informal caregivers) show the greatest improvements in functioning over time. Another study reported that approximately 1.4 million disabled Americans have mild impairments that can easily be ameliorated by assistive technology (Elliot 1991).

The reason that the growing use of assistive technology can lower rates of reported disability is that some people who function well using these devices may perceive that they no longer are disabled and so answer the survey questions accordingly. These feelings of independence may

lead the respondents to answer disability questions in a very literal way. For example, if asked about trouble “getting in and out of a bathtub,” a respondent might answer “no” if he or she has handrails in the tub that assist entry and exit. Similarly, hearing aids may lead people to say that they do not have a hearing impairment, and motorized scooters may lead people to feel they do not have trouble moving around.

In fact, research by Agree and Freedman (2003) indicates that a substantial number of people—although by no means a majority—who rely on AT exclusively are able to accomplish ADLs acceptably. For example, 25 percent reported that bathing is not “very tiring,” and 30 percent reported that transferring is not “very tiring.” One study suggested that the likelihood of reporting residual needs for care was almost 1.5 times higher for people who used personal help only and three times more likely for those using both personal help and equipment, compared with those using equipment only (Agree 1999). Again, it is very possible that these people were answering survey questions in such a way that they were not classified as disabled.

Assistive devices are not the only form of technology that might affect a person’s perceived disability status. Advances in medical treatment for many types of chronic conditions emphasize a larger role for “self-care” (Wagner, Austin, and Von Korff 1996), thereby empowering patients to contribute to their overall treatment plan. This emphasis on self-care could easily change the perceptions about needing help in some people with medically oriented disabilities.

Housing arrangements represent another form of “technology” for addressing care needs. The growing number of people in assisted living housing may not even notice that they are getting assistance with mobility, bathing, or food preparation. Assisted living changes lifestyle in a way such that limitations are handled as an everyday part of life: limitations are commonplace, expected, and treated as the norm rather than as exceptional. Bishop (1999) noted that the growth in assisted living and other forms of retirement communities coincided with the declining rates of nursing home use. Whereas most statistics assume that every person in a nursing home has some type of disability, this is surely not the case when a comparable person decides to live in the community or at an assisted living center.

The positive outcomes associated with assistive technology, better chronic condition management, and the increased use of specialized retirement housing such as assisted living represent a true reduction in

disability. Referring back to the disablement process, these are interventions that mediate between underlying (or intrinsic) difficulties in functioning and the performance of activities in a social context. But, these technological interventions do not prevent or ameliorate the underlying functional limitation; thus (context-sensitive) “disability” can decline while (intrinsic) “ability” fails to improve. In particular, reduced disability is not necessarily accompanied by better health. A second important point is that many of these technological interventions, especially those involving computers, remote monitoring, or robotics, are costly. Thus, to the extent that technology deserves credit for downward trends in the prevalence of old-age disability, those trends should not be viewed as a softening of pressure on publicly funded programs such as Medicare and Medicaid.

### *Social Perceptions of Disability*

Earlier we discussed the potential for “false negative” responses based on asking respondents whether they have *difficulty* with ADL or IADL tasks. One factor that might contribute to the presence of false negatives is the evolving social perception of ability and disability. Over the past several decades, individual perceptions of disability may have changed, along with expectations regarding self-care and care from others. During these years the “independent living” movement empowered individuals with disabilities and changed how they shaped their identities. These changing perceptions may also have influenced survey results regarding the prevalence of disability. Individuals who may have answered questions about limitations affirmatively 20 or 30 years ago may answer them negatively today. It is important to consider whether the trends in disability are driven in part by changing self-perceptions of physical and cognitive limitations.

The independent living movement grew out of advocacy efforts on behalf of persons with disabilities that started in the United States during the early 1970s, on the heels of a number of improvements in disability policy. The independent living movement is based on the idea that the barriers confronting people with disabilities are less related to individual impairment and more related to social attitudes, interpretations of disability, architectural barriers, legal barriers, and educational barriers (Braddock and Parish 2001). A key achievement of this movement is that people with disabilities no longer view themselves as “broken”; rather,

it is society that is “broken” and needing fixing (McDonald and Oxford 2002).

Both anecdotal and qualitative evidence from the disability studies literature point to changes in the psychology, and the self-definition, of disability. For example, the traditional clinical-pathological or medical model view of deafness suggests that the behaviors or values of individuals who can hear are the norm, and so this view focuses on how those with hearing impairments differ from that norm. The cultural view, in contrast, recognizes a complex set of factors that must be considered when examining the deaf community. According to this view, deaf individuals are part of a community who share the same means of communication, language, and culture (American Deaf Culture 2004). Deaf culturists are strong supporters of the Americans with Disabilities Act (ADA) because they feel that deafness is not a disability that needs fixing but is something for which society should compensate by providing special assistance (Tucker 1997). Batavia and Schriener (2001) discussed the independent living movement’s focus on modifying environments to accommodate the needs of people with disabilities as the appropriate intervention. Disabilities are not inherent in people but are a result of the interaction between individuals and their environment.

Iezzoni and colleagues (2000) provided quantitative evidence regarding perceptions of disability. Using the National Health Interview Survey—Disability (NHIS-D) supplement, these researchers examined the associations between mobility and questions about self- and external perceptions of disability. They found that many people with serious lower-extremity mobility difficulties do not view themselves as disabled. For example, about 30 percent of individuals with major mobility problems did not regard themselves as disabled. Similarly, about 20 percent of individuals who used manual wheelchairs did not view themselves as disabled. Unfortunately, these data do not allow for trend analysis to determine the robustness of these findings and to see whether these numbers have changed over time.

The changing psychology of disability may have influenced estimates of disability prevalence in the United States. It is possible that reports of the declining rate of disability represent not only a change in physical functioning but also a change in how people think of their disabilities. If so, we must be cautious about interpreting past trends in disability as indicators of success in treatments or interventions or as consequences of healthier lifestyles and behavioral patterns.

## Conclusions

The national surveys that have been used to generate evidence on the levels and trends in disability among the older population do not ask respondents whether they are “disabled.” Rather, they ask questions about diseases, conditions, functioning, the performance of various activities, the use of devices, help from others, and other behavioral adaptations. The responses to such questions lead to the respondents’ classification as “disabled” or “nondisabled” in accordance with a conceptualization of the underlying disablement process. Accordingly, issues of survey methodology as well as the meaning and interpretation of survey questions, and of the responses given to them, are central to understanding reported trends in disability.

We examined the reported disability trends from two perspectives. First, we considered the conceptualization and measurement of disability, taking a detailed look at the design of the National Long-Term Care Survey, a leading source of information on old-age disability trends. Our reanalysis of part of the NLTCs data confirms, for the group aged 65 to 69 that we examined, some of the previously reported findings for broader age groups, in particular, that overall disability rates have fallen. However, our findings indicate that ADL, rather than IADL-only, disability rates drove these declines. Moreover, the average annual drop in disability is much smaller here than in other studies.

We discussed several specific elements of the NLTCs design, including the use of separate screening and follow-up survey instruments, the wording of questions, the use of telephone and in-person modes of administration, and the use of proxy responses. Although some of these features are problematic, a few are unavoidable. For example, a survey that tries to cover the entire population, as does the NLTCs, must be prepared to accept proxy responses in view of the severe cognitive limitations suffered by some people in its target population. In addition, the mixing of telephone and in-person modes for the screener and follow-up interviews is a reasonable response to the finiteness of data collection budgets. Yet as a consequence of the design adopted, the principal source of information about the nondisabled population is telephone-reported data (i.e., screener responses from those who “screen out”), whereas the principal source of information about the disabled population is in-person reports (collected from follow-up interviews with those who “screen in”). These two modes of survey administration produce distinctive patterns



of measurement error. Even small errors, especially differential errors over time, can have important implications for detecting changes over time as small as those found for disability prevalence—an average of half, or less, a percentage point per year.

When we held constant the wording of survey questions, confining our analysis to respondents to the NLTCS screener questionnaire, we found smaller declines over time in the prevalence of disability (among persons aged 65 to 69) than in the previously reported research based on those 65 and older. Of course, the rate of disability decline among 65- to 69-year-olds may simply be less than among the older population in general. These questions deserve further inquiry; for now, our conclusions must remain more suggestive than definitive. But we also found that when we held constant both the survey mode and the wording of questions, the annual rate of decline in disability prevalence shrank even further. Thus, our results indicate the importance of survey methodology in the study of disability trends.

We also considered several societal changes that could lead to reports of declining disability in the absence of any changes in underlying functional ability, severity of chronic disease, or other aspects of what would conventionally be viewed as “health.” These societal changes include demographic and behavioral changes that might reduce the supply of informal caregivers, technological changes, and cultural or normative factors that might be manifested in individuals’ self-perceived capacities and independence.

Much of the past research on technology in long-term care focused on assistive devices and housing modifications, discrete innovations that alter an individual’s capacity to perform tasks. But technological change can be construed more broadly, encompassing such things as the involvement of patients in their own care and maintenance and the design of new modes for housing and the conduct of daily life—a use of the term *design* that pertains not only to the built environment but also to the clustering of residential units and the integration of staff, services, and facilities in residential complexes.

A reduction in the underlying levels of functional incapacity or limitation clearly seems to be good for those people who would otherwise be more limited, as well as for society as a whole. It also seems eminently reasonable to view a reduction in *experienced* disability—the context-sensitive translation of functioning into tasks directed at the everyday needs of life—as being good for both individuals and society. But our

analysis suggests that evaluative judgments about the decline of disability must take into account the several factors that might be producing them. To the extent that changes in family structure and activity patterns are implicated in the disability decline, the decline may be a correlate of deteriorating intrafamily relationships (e.g., those that accompany parental divorce) or growing stress due to multiple conflicts of roles, and it may be accompanied by fewer social interactions. A trend toward more capital-intensive means to meet the care and self-maintenance needs of older people may exacerbate inequalities in the quality of life. The empowerment that leads persons with various impairments to reject the label "disabled" may also prompt them to increase their demands for services to which they are already entitled or for new services. Finally, because of the complex and diverse nature of the forces that are likely to contribute to the decline in disability, we recommend against extrapolating recent trends forward into the future.

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