

Disability, long-term care, and rehabilitation: emerging questions and data needs^{*}

Vicki A. Freedman
University of Medicine and Dentistry of New Jersey

Robert F. Schoeni
University of Michigan

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Abstract

This paper provides an overview of emerging research and policy questions on disability, long-term care, and rehabilitation and suggests ways of enhancing the National Long Term Care Survey to address these issues. We identify six priority areas: understanding the causes and consequences of declines in disability and disparities therein; identifying interventions to promote disability decline in the future; describing and evaluating settings in which individuals with chronic disability live; monitoring changes in the provision of care and implications for care givers and recipients' well-being; illustrating the cost and cost-effectiveness of various long-term care and rehabilitation strategies; and understanding how a variety of behaviors influence disability pathways. Although we recognize the value of emphasizing continuity in data collection efforts, we argue that over the past 25 years the world's understanding of disability, the continuum of long-term care, the breadth of technologies available, the field of rehabilitation sciences, the demographic and socioeconomic composition of the older population, and public policies regarding disability and long-term care have changed dramatically, making the need to consider new content areas at this time more compelling than ever. We conclude that while some of the questions we identify could be addressed by adding onto other existing national surveys, enhancing the National Long Term Survey may be preferable because existing surveys do not – and mostly likely cannot – devote enough interview time to fully and accurately unpack the disability, long-term care, and rehabilitation processes for the full spectrum of care settings.

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I. Introduction

In the coming years, increased attention to disability and long-term care will be fueled by larger numbers of adults reaching late life and by concerns about possible increases in disabilities among the working age population. Projections suggest that the costs of long-term care for older adults with disabilities will increase dramatically in the coming decades, even if rates of late-life disability continue to decline. One set of projections (CBO 1999) suggests long-term care expenditures will almost triple from \$123 billion in 2000 to \$346 billion in 2040. These projections exclude the costs of informal care from family and friends, the costs of technological accommodations and modifications of homes to create supportive living environments, as well as the less tangible costs to older adults and their families in terms of well-being and quality of life. Clearly, the benefits of enabling all Americans to live independently and to participate in society, irrespective of their age or ability are potentially enormous.

Over the last few decades the world has undergone a transformation in its understanding of disability. The classic medical approach to understanding disability has given way to an ecological framework that recognizes disability exists in a social and environmental context and is malleable to intervention. Conceptual approaches developed in the 1990s by the Institute of Medicine (IOM, 1991; IOM 1997) and by the World Health Organization (WHO 2002), for example, emphasize environmental factors in the disablement process. WHO's International Classification of Functioning, Disability and Health (ICF) has underscored the broader goal of participation in daily life by people of all ages and abilities (WHO 2002). Moreover, the fluidity of disability has been recognized by models in rehabilitation science, which emphasize the *enabling* process—"the process by which physical, sensory, and mental capacities are restored or developed (IOM, 1997, p. 3)."

There also has been a growing array of support systems and technological innovations to help people with disabilities participate in school, work, and leisure activities and to live independently. Living options have expanded beyond nursing homes to include new forms of supportive residential care environments for people who need assistance but who do not require 24-hour skilled nursing care. The number and types of assistive devices to accommodate disability has expanded dramatically as well. These products include portable aids such as electric scooters and canes, modifications to the environment such as stair glides and chair lifts, and universal design options such as lower light switches and adjustable counter tops for the kitchen. Advances in rehabilitation have made it possible for increasing numbers of older adults to regain functioning following debilitating events, such as strokes or fractures. And, promising new strategies for preventing disability—through, for example, pre-rehabilitation, fall prevention, chronic disease management, engaging seniors in volunteer programs—have been developed to prevent functional decline of older adults living at home.

Demographic and socioeconomic factors that have been linked to disability and care in late life are also evolving. The numbers of oldest old are increasing dramatically and the older population is becoming more racially and ethnically diverse. Over the last four

decades poverty declined more among the elderly than any other demographic group and increases in educational attainment have been dramatic. The share of single elderly who live by themselves has risen dramatically over this same period; among widows 65 and older, the share living alone was roughly 40% in the 1950s and now stands at around 65%. Finally, the first cohorts that experienced the large rise in divorce in the 1960s and 1970s are just now entering older ages. It is unclear how this social change will influence support provided to older adults with disabilities, who typically rely most heavily on their spouse and children for care.

Change has also been reflected in national policies, such as the Americans with Disabilities Act, the Assistive Technology Act, and President Bush's New Freedom Initiative, which have been aimed at enhancing the participation of adults with disabilities in all aspects of society. Although a variety of federal assistance programs have been in place to assist people with disabilities, newer policies and programs emphasize legal protections and the removal of barriers to participation in work, health care, leisure (see Freedman, Martin, and Schoeni, 2004 for an overview of these programs and policies).

With this backdrop, we provide in this paper our view of current and emerging themes in disability, long-term care, and rehabilitation. Our approach is not meant to be exhaustive, but instead to highlight research and policy-related themes that are likely to be particularly relevant in the coming years. Next, we provide suggestions for enhancing content of the National Long Term Care Survey to address these issues. A final section offers our thoughts about tradeoffs and priorities.

II. What are the current and emerging research and policy-related questions on long-term care, disability, and rehabilitation?

To impose some structure on this exercise, we begin with questions that require for the most part descriptive analyses at the population-level that are essential to planning for the care of the population with chronic disabilities. We then go on to suggest a series of questions about individual behaviors that will advance our understanding of how older adults with chronic disability accommodate and/or reverse functional decline. Cross-sectional (and repeat cross-sectional) data may be useful for many of the proposed descriptive analyses; however, panel data with relatively short intervals (e.g., 6 months to 2 years) may be needed in many cases to understand questions about the dynamics of disability and care and to model the future implications of disability and interventions on long-term care and well-being.

What are the causes and consequences of declines in disability? Over the past decade a consensus has emerged that late-life disability is declining. Evidence from several national surveys shows remarkable consistency in declines during the 1990s in limitations in instrumental activities of daily living (e.g., limitations in shopping, cleaning, and going places) and in functional limitations (e.g., difficulty bending, reaching, and stooping) (Freedman, Martin, and Schoeni, 2002); smaller declines appear to have occurred during the 1990s in difficulty and dependence in activities of daily living (Freedman, Crimmins, Schoeni et. al. 2004). And, although not all studies agree

(Rodgers et al. 2003), limited evidence also suggests severe cognitive impairment may be declining as well (add Manton et al. 2005; Freedman, Aykan and Martin 2001). During the same period use of assistive technologies has expanded (Freedman et al. 2006), offsetting the use of personal care. Such shifts have occurred despite apparent increases in the reports of many chronic conditions (Crimmins and Saito 2000; Freedman and Martin 2000).

In these studies, disability is generally measured in terms of difficulty or help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Hence, whether levels of *participation* have changed remains unclear as does the nature and extent of barriers to such participation. Because of data limitations, it remains unclear as to whether underlying physiological health is improving, or if declines are limited to a narrow set of activity limitations.

More importantly perhaps, *why* disability is declining remains a compelling question for study and crucial to anticipating future trends. Cutler (2001) discusses several possible explanations--including medical care improvements, changes in health behaviors such as smoking and diet, increased use of technological aids, shifts in education and work history, reductions infectious disease exposures, and changes in social support—but notes that data to test many of the theories are not available. Also of interest is the extent to which declines can be linked to reductions in age-specific incidence, increases in recovery, or differential changes in the risks of mortality. Do these changes signal a compression of morbidity as Fries has predicted or are we experiencing an expansion of diseases but with lower levels of severity consistent with Manton's theory of dynamic equilibrium?

A related area of importance focuses on the consequences of the disability decline for public programs, such as Medicare and Medicaid, and for the well-being of older adults and their families (Suzman and Haaga, 2005). Using a microsimulation model, for example, Chernow and colleagues (2005) have demonstrated that, compared with population growth and aging, the influence of disability trends on Medicare spending rates appears to be relatively modest. Others have shown that lifetime health expenditures for healthier elderly persons, despite their greater longevity, are similar to those with functional impairments and disability (Lubitz et al. 2003). However, analyses of the influence of disability declines on long-term care use and expenditures are lacking. Suzman and Haaga (2005; p. 26) point out that to understand the economic consequences of the disability decline requires rich panel data that include: “all diagnostic procedures, medical and behavioral interventions, prescriptions, and insurance and out-of-pockets costs, along with measures of health, functioning, and well-being.”

Not all groups appear to be benefiting equally from these trends. Recent evidence suggest that although racial gaps have remained relatively constant, groups of lower socioeconomic status have experienced much smaller declines in the need for help with IADLs – and in some cases *increases* in the need for help with ADLs (Schoeni et al. 2005). Consequently, gaps by education and income levels have grown over the past few decades. Exploration of the potential reasons for these growing gaps – for example,

differences in medical care, health behaviors, the use of technological aids, work histories and early life exposures, and social support – are key to the design of effective strategies for reducing disparities. In addition, the extent to which differential levels and trends reflect cultural differences across population subgroups in the interpretation and meaning of disability is also of interest and may provide important insights into these gaps.

What interventions are most likely to have the greatest impact in reducing disability in the future? Disability is by its very nature a multi-factor condition— influenced by underlying health conditions, the social and physical environment, other individual-level factors, and the nature of the activities in which an individual wishes to participate. To design effective, multi-component, high-impact interventions requires an understanding of the physical, social, and environmental causes of disability—and the extent to which they co-occur (Freedman, Hodgson, Lynn et al. 2005). Yet studies of the etiology of disability most often emphasize single underlying chronic conditions (e.g., arthritis, cardiovascular disease, injury) as the cause of disability. Consequently, we have little understanding as to the extent to which multiple combinations of chronic conditions underlie disability, the role of the environment in causing disability, and the extent to which disability is remediable or avoidable. Moreover, even when randomized control trials are conducted to test interventions that may reduce disability, such studies often omit measures of disability and generally do not follow individuals long enough to assess the ultimate effects on disability over the remaining lifetime (Freedman, Hodgson, Lynn et al. 2005).

Notably absent from the literature is a comprehensive, nationally-focused assessment of the home environments of older people and the extent to which modifications could alleviate dependence in the older population. The extent of rehabilitation and other treatments (e.g., prescription drugs, alternative medicines, vitamin supplementation) used in this population has also not been well documented. The extent of physical activity and other protective health behaviors among the population with chronic disability is also of interest, as is whether enhancing these preventive measures can slow functional decline or prevent secondary conditions from developing. Such information, when combined with efficacy data from clinical trials, could form the basis for comparisons of population-level effects of various approaches to population-based interventions.

In what settings do individuals with chronic disability live and receive care and how well are their care needs being met? Just a few decades ago, older individuals with disabilities had two relatively discrete alternatives: remain in the community and depend on personal care from family and friends (or less often from agencies, paid for through Medicare or Medicaid’s home health benefit), or enter a nursing home. Yet in the last few decades, the line between community and institution has blurred considerably. Many older adults now live in supportive living environments, which vary in name and the kinds of services provided. “Assisted living” is perhaps the most common name for supportive living environments for people who need assistance but who do not require the 24-hour skilled nursing care available in nursing homes. The definition and terminology varies by state; other names for these kinds of living arrangements include residential care, personal care, adult congregate care, boarding home, and domiciliary

care. At a minimum, assisted living facilities offer 24-hour supervision and assistance, and two to three meals per day in a common dining area. Other common support services include housekeeping and laundry services, medication reminders and/or help with medications, help with personal care activities including bathing, toileting, dressing, and eating, transportation, security, health monitoring, care management, and activities.

The absence of common terminology makes it difficult to estimate the number and characteristics of the residential care population in the United States. Moreover, surveys use different approaches to identifying these places and treat some of them as ‘community’ and others as ‘institutions.’ Nevertheless, using three different national surveys Spillman and Black (2006) recently found that about 6.5 percent of persons age 65 or older—about 2.2 million persons—live in some type of residential care setting (including nursing homes); of these, one-third (about 750,000) live in alternative residential care settings such as assisted living facilities.

Information about the residential care sector is critical to understanding the evolving long-term care delivery system and to monitor the quality of that care. Emerging issues related to these expanding forms of supportive living environments include: What are the breadth and quality of services offered by these supportive living environments? How does intensity of use within these settings vary? How well do such environments meet the needs of older adults with disabilities? What are the optimal and most effective arrangements for various levels of disability, particularly those caused by cognitive impairments? Can these environments effectively substitute for more expensive nursing home care? What role does technology and environmental features play in these supportive living environments? What factors determine demand for the various types of arrangement?

A parallel set of questions relates more specifically to rehabilitation therapies, including physical therapy, occupational therapy, and speech pathology, which are available in a variety of settings, including the home, outpatient centers, skilled nursing facilities, and hospitals. These post-acute services experienced rapid growth during the 1990s (Haffey, et al. 1995), a trend which appears to have continued despite the implementation of post-acute prospective payment systems (McCall et al. 2003).

Such services are critical to understand because they play a key role in restoring the functioning and independence of individuals experiencing strokes, hip fractures, Parkinson's disease, osteoporosis, and other chronic debilitating conditions. As the number of people needing such services increases, questions of how best to meet their needs will inevitably continue to arise. In particular, it remains unclear what types of treatments are received across settings, whether there are disparities across groups in use and effectiveness of rehabilitation services, and how individual and provider characteristics combine to predict who will regain their ability to carry out daily activities and participate in daily life.

Who will provide care? Family members—most often spouses and children—have traditionally provided the vast majority of long-term care to older persons. A recent

report suggests their role may be more important than ever, in light of declines in paid care that occurred between 1994 and 1999 (Spillman and Black 2005a). Declines in formal care are likely linked in part to changes in Medicare's home health benefit enacted in the late 1990s in order to contain the skyrocketing costs of home health care, but whether they will continue is unclear.

Projections suggest there will be an imbalance between the future demand for care and the supply of informal and direct care workers in long-term care settings. The baby boom generation has a lower completed fertility than their parents and greater percentage are childless (Wolf 2004). At the same time, by 2050 only a slight increase is expected in the supply of workers who have traditionally filled low-pay, physically demanding direct care worker jobs (ASPE 2003).

Tracking how the face of informal care giving is changing to meet the needs of new cohorts of elderly is critical to formulating informed policy responses. We have already seen some shifting; for example, caregivers today are older than they were in the past, and they are more likely to be men (Center on an Aging Society 2005). And as IADL disability rates have fallen the type of care provided has also changed (Friedland 2004). Tracking the costs of such care – both in terms of time and well-being of caregivers – continues to be important as does identifying how care givers can best avoid negative outcomes. To that end, studies exploring the role of technology in minimizing the time costs of disability and maximizing care giver and care recipient well being are of interest.

On the formal care side, States are undertaking new efforts to recruit and retain direct care workers. How these efforts will influence the face of care giving and the well being of care recipients has yet to be assessed.

What is the cost of long-term care and rehabilitation and who pays? Not only is it critical to understand the living and care arrangements of older adults with chronic disabilities, and the extent to which rehabilitation services are improving their well being, but also how much is spent on such care and by whom. The last decade has seen changes in public financing of post-acute care, notably Medicare's home health, inpatient rehabilitation facility and skilled nursing home benefits. At the same time Medicaid funding continues to tighten as States and the Federal government seek ways to reign in this growing entitlement.

One set of important questions relates to whether outcomes and costs differ for elderly patients depending on the setting. With respect to rehabilitation, for example, prior studies suggest that older adults who have experienced strokes receive more expensive but also more effective treatment in rehabilitation hospitals (Kramer et al. 1997). These differences were not observed for patients with hip fractures however. Similar questions can be asked about outcomes and costs of managing long-term care needs at home, in residential care, and in nursing home care.

Another set of questions relates to equality of access. Some have suggested that nursing homes have evolved into two tiers: low-quality institutions that serve the poor

and higher-quality institutions that serve mainly individuals who have the means to pay privately (Mor et al. 2004). Others have pointed out similar bifurcation in the assisted living industry (Hawes et al. 2003) consisting of a high privacy/high service and low privacy/low service models. In the area of rehabilitation, geographic variation in practices has been noted that may translate into access issues in some areas of the country (Lee et al. 1996). Exploring disparities in the use and quality of long-term care is critical to developing strategies to ensure equity regardless of race, ethnicity, socioeconomic status, or geographic boundaries.

The costs of disability and long-term care are not restricted to financial outlays. Forgone earnings and effects on health status and well being of both adults with disabilities and their care givers are important to consider in any comprehensive assessment.

How do care needs and accommodations change over individuals' lives and what behaviors influence these pathways? Because of the evolving understanding of disability and the growing array of settings and technologies to accommodate functional decline, there has emerged a new set of questions about the experience of disability at the individual level. For example, the research community is just beginning to investigate the role of environmental risk factors, including neighborhood quality, in the onset of disability. Others are interested in understanding the typical course of disability and whether clearly defined and predictable physiological trajectories can be identified.

Another set of questions relate to the use of assistive technologies and whether they forestall the use of personal care and if so, if they are equally effective in facilitating activities and participation and promoting well-being of older adults and their caregivers. With respect to settings, there are questions about what triggers individuals' moves across levels of the long-term care continuum and where are they optimally served. There are also emerging questions about the dynamics of acute, post-acute, and long-term care and how older individuals with disabilities move across these systems over the course of a chronic illness or injury.

Both the quality and costs of end of life care remain of interest, in part because expenditures in the last year of life account for a disproportionate share of an individual's lifetime medical care expenditures (Hogan et al. 2001). Distinct end of life trajectories have been suggested that vary by the length of functional decline (Lynn 2001), but whether prospective predictors of such trajectories can be identified and whether interventions can effectively alter individuals' paths remain important questions to be resolved (Freedman, Hodgson, Lynn et al. 2005).

III. What new or modified content is needed to address current and emerging questions?

To address the set of questions discussed above requires consideration of new content. Here we suggest five key areas for enhancement: unpacking and expanding disability measurement; expansion of measures of underlying disease processes and

treatments; assessment of well-being; systematic identification of long-term care settings and services; and expanded linkages to administrative data.

Unpacking and expanding disability measurement. Currently measures of late-life disability vary across national surveys, but almost all surveys—including the NLTCs—include some version of activities of daily living, instrumental activities of daily living and functional limitations. These measures were initially developed for various clinical purposes during the 1960 and 1970s, and became widely adopted as self-reported items in national surveys during the 1980s and 1990s. Surveys that have maintained identical question wording from year to year—like the NLTCs—have been able to provide two decades worth of evidence on trends in the prevalence of late-life disability. Still, a number of recent advances in the measurement of disability and its underlying components provide new opportunities for national surveys (Freedman and Waidmann 2005; Freedman, Spillman, and Waidmann 2005).

The addition of **physical performance measures** could further our understanding at the individual level of the physiology of functional loss and recovery. Physical performance measures involve an individual performing a movement or task according to a standardized protocol and a trained observer rating the performance using objective, predetermined criteria. Batteries have been developed to measure the basic components of functioning (strength, balance, coordination, flexibility, endurance) as well as physical movements (e.g., walking speed) and goal-oriented functions (e.g., ADLs and IADLs). NHANES, for example, includes performance measures of balance and strength in its mobile exam center protocol. HRS has also added performance measures for a subsample of respondents. Designers may also want to consider the measures of functioning embedded in the Functional Independence Measure (FIM) and their translatable to a national survey.

The expansion of measures of **assistive technology and the physical environment** would allow analysts to more fully understand the reasons for population-level changes in disability prevalence, and could further understanding at the individual level of the accommodation process and interventions to enhance independence and participation. New batteries of questions about assistive technology and the environment have recently been developed and tested (Freedman, Agree, and Cornman 2005); others have developed items to measure the environmental components of mobility disability (for example, distance, ambient conditions, terrain characteristics) (Shumway Cook, 2003;2005). The HRS has included an experimental module to measure environmental features and modifications in its 2006 wave.

The collection of **time use** data for older adults, and particularly those with disabilities, would be a useful addition for assessing the impact of disability on older adults' ability to participate in society. The data could also be used to understand the time costs associated with providing care to older adults with disabilities.

The **addition of vignettes** could facilitate comparisons of disability measures across population subgroups that may have different conceptual understandings of disability. Vignettes are a brief description of a hypothetical person. Each respondent is asked to self-report about their own disability and then to rate on the same scale hypothetical

individuals who vary in terms of their levels of severity. The information from the vignettes is then used to standardize rankings across groups so that comparisons are not biased. The Survey of Health, Aging, and Retirement in Europe (SHARE) and HRS have begun using vignettes.

Expansion of measures of underlying disease processes and treatments. Direct measurement of physiology would be valuable for obtaining accurate assessments of various conditions, including the ability to differentiate severity of disease. National surveys typical rely on self reports of conditions (“has a doctor ever told you that you have...”). Access to health care and other factors may influence valid reports of conditions, so direct assessment would be valuable. The addition of physiologic measures, such as height, weight, pulse, respiration, blood pressure, blood sugar, as well as markers of cholesterol, for example, could be helpful in quantifying the severity of a number of chronic conditions. More detailed assessments of cognitive impairment and of frailty (a constellation of symptoms including unintentional weight loss, self-reported exhaustion, weakness, slow walking speed, and low physical activity; see (Fried et al. 2004) should also be considered. A few national studies (e.g., National Survey of Adolescent Health, Wisconsin Longitudinal Survey, the HRS, and others) have begun collecting biological data to address these and other scientific issues.

Also important to track are treatments that influence disability and care needs. Some of these treatments can be identified through linkages to Medicare and Medicaid claims (see below), but the amount of detail may be limited. For example, claims do not provide detailed information on the treatment plan that may occur during rehabilitation or home health visits. Other types of treatments, for example alternative medicines, over the counter remedies, and vitamin supplements, may not be available through administrative linkages. Prescription drug use is also important to collect, and it may be worth investigating whether this can be accomplished through a combination of survey items and eventually administrative linkages to Medicare part D.

Measures of well-being. Assessment of psychological well-being of adults with disabilities and their care givers is another area where measurement development is needed. The literature on well-being has mostly relied on global evaluations of one’s life-as-a-whole or of specific life domains. A typical question in this tradition is, “Taking all things together, how satisfied are you with your life as a whole?” An abundant body of experimental research shows that these evaluations are highly context dependent (Schwarz & Strack 1999). An activity-specific approach was adopted by Juster (1985) who assessed how much people enjoyed different activities of daily life. More recently, using an episodic approach, Kahneman and colleagues (2004) assessed how respondents felt during *particular* episodes of these activities, using the Day Reconstruction Method (DRM). Respondents reconstructed what they did during the previous day, thus reinstating episodic information in memory. Next, they reported for each episode what they did, who they were with, and how they felt at that time. Results from the DRM were dramatically different from Juster et al.’s (1985) results. In sum, measures of well-being, including satisfaction and the hedonic experience of the day, are important components that merit further study within the context of disability.

Systematic assessment of long-term care settings. The identification of residential care settings has posed a unique challenge to the survey research community. Language to describe these places is not uniform across the country nor are the services that are provided. In a recent report to ASPE on the subject, Spillman and Black (2006) recommend several key areas for improvements to identify residential care settings in national surveys. First, they recommend a hybrid approach to identifying settings, in which a broad screen for nontraditional settings is applied, as in the HRS, and then information on both services available and named place type is gathered. Second, they recommend that this approach be applied uniformly across all community and facility settings so that analyses can identify factors related to setting, transitions, and outcomes. Third, they recommend collecting information (like that in the HRS and MCBS) on whether services are included in housing costs or cost extra and whether services are actually used. Finally, they suggest developing a methodology for over-sampling the population in alternative residential care to support reliable estimates.

We concur with these suggestions and also suggest a short battery of questions be added for administrators of these care settings to answer. By following back to providers, as is done with other types of providers in the Medical Expenditure Panel Survey, more detailed analyses about what places offer, their staffing levels, and the quality of care can be addressed. Linkages to administrative data sets such as the Minimum Data Set, OSCAR

Linkages to claims and other administrative data. Linking survey data to administrative data can increase the value of the survey data for many purposes. For example, from Medicare claims detailed Medicare spending, diagnoses, and procedures received by members of the survey sample can be obtained. Other administrative linkages that would be useful to consider adding to the NLTCs include: the Minimum Data Set, Outcome And Assessment Information Set, the Uniform Data Set for Medical Rehabilitation, Medicaid claims, Area Resource File variables, and Social Security earnings history files. As the Medicare prescription drug program evolves, linkages to Part D claims may become a possibility to explore.[†]

IV. Concluding thoughts about tradeoffs and priorities

There are inevitable tradeoffs between retaining core content and introducing new content areas. Clearly, one of the strengths of the NLTCs has been its attention to continuity, particularly with respect to ADL and IADL items. In particular, this strategy has led to the initial highly significant finding regarding declines in late life disability (Manton et al. 1993). However, other surveys now exist (the Medicare Current Beneficiary Survey, the Health and Retirement Study) or have been redesigned (National Health Interview Survey) that will offer consistent time series for ADL and IADL estimates beginning in the 1990s. During the overlapping period, these studies have found trends consistent with those in the NLTCs (Freedman et al. 2004), making the

[†] The recommendation to expand linkages was also recently ranked as the top priority among an expert technical panel brought together by ASPE to offer recommendations for improvements to caregiving data on the National Long Term Care Survey (Spillman and Black 2005b).

argument for continuity somewhat less compelling. In the meantime since 1982 the world's understanding of disability, the continuum of long-term care, the breadth of technologies available, the field of rehabilitation sciences, the demographic and socioeconomic composition of the older population, and public policies regarding disability and long-term care have changed dramatically, making the need to consider new content areas at this time more compelling than ever. One compromise might be to consider retaining the screener items and then revamping the detailed community and institutional questionnaires.

Tradeoffs also must be considered as to whether some of this content should be added to other existing surveys or incorporated into a renewed effort explicitly designed to understand disability, long-term care, and rehabilitation issues. Most other surveys that have been used to study disability collect data on a wide array of issues: income, wealth, family support, retirement, pensions, etc. Disability and long-term care are not the primary focus of these surveys, with generally 5-10 minutes of the interview time devoted to disability- and care-related measurement. To fully address many of the issues described above, disability needs to be measured in a much more complete way, perhaps requiring 2 to 3 times more survey time than is currently provided in existing surveys. It is quite likely that the interviews in existing data collection efforts cannot be lengthened because of respondent burden. If so, then a free-standing disability survey may be the best vehicle. On a related note, current survey efforts also generally include very small numbers of older adults living in residential care settings (Spillman and Black 2006); to fully address issues for the continuum of care requires a sampling frame that includes over-samples of older adults in these supportive living environments.

In this overview we have identified six priority areas for further study: understanding the causes and consequences of declines in disability and disparities therein; identifying interventions to promote disability decline in the future; describing and evaluating settings in which individuals with chronic disability live; monitoring changes in the provision of care and implications for care givers and recipients' well-being; illustrating the cost and cost-effectiveness of various long-term care and rehabilitation strategies; and understanding how a variety of behaviors influence disability pathways. The data and design requirements are more intensive for some areas of inquiry than others. All but the final set of issues could be addressed in some fashion with enhanced content and relatively minor design changes. Analysis of pathways would require substantially shorter frequency between interviews (currently 5 years). Other potential design enhancements could further our understanding of select issues. For example, follow-back surveys to providers and caregivers could add to our knowledge of care settings and the provision of care. The ultimate design decisions should ideally flow from a prioritized list of the most compelling scientific and policy questions.

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