EXTENDED ABSTRACT

Reconciling Divergent Evidence on US Trends in Late-Life Disability: An Update

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Reconciling Divergent Evidence on Trends in Old-Age Disability

The decline in the prevalence of late-life disability observed between the mid 1980s and the early 2000s has been viewed as a one of the most highly significant advances in the health and well-being of Americans in the past quarter century (Schoeni, Freedman, and Martin, 2008). Analyses of more recent data, however, suggest that declines in activity limitations at older ages may have either leveled off (Federal Interagency Forum on Aging-Related Statistics 2010; Seeman, Merkin, Crimmins, and Karlamangla 2010; Lubitz 2007) or continued, but at a slower pace (Martin et al., in press). Notably this pattern is seen even in the National Long Term Care Survey, the data source most associated with early detection of the downward trend in ageadjusted disability prevalence (Spillman 2010). Knowledge of the direction of trends and changes in direction continues to be an urgent need for projections of health and delivery system needs of the older population. Thus it is critical to carefully examine available evidence and, where evidence from different sources diverges, to understand the reasons for inconsistent findings.

For this study, we have assembled a team of researchers to examine five major national surveys and determine whether they provide consistent findings with regard to the direction of functional trends since the early 2000s, after taking various methodological differences into account. The study design follows that of earlier similar efforts, the most recent of which involved many of the same researchers as the current study and examined trends in severe disability through the early 2000s. After establishing a common protocol for estimates, collaborators analyzed the Health and Retirement Study (HRS), the Medicare Current Beneficiary Survey (MCBS), the National Health Interview Survey (NHIS), the National Long

1

Term Care Survey (NLTCS), and the National Health and Nutrition Examination Survey (NHANES) to examine the following research questions:

- Has disability prevalence among the older population continued to decline, stagnated, or reversed course in the first decade of the 21st century?
- Do trends differ by disability measure, i.e., for limitations in personal care activities, domestic activities, and upper and lower body impairments?
- Do trends differ across age groups pre-retirement (60-64), young old (65-74), old (75-84) and oldest old (85+)?

Previous Attempts to Reconcile Trends.

Several previous attempts to reconcile trends have been undertaken following (in some cases years after) the publication of inconsistent findings. At the request of the National Institute on Aging, the Committee on National Statistics of the National Research Council held a workshop to review the data and methods used to determine trends in disability at older ages (Freedman and Soldo 1994) and found modest declines in the proportion of older persons with limitations in instrumental activities of daily living (IADLs) such as shopping, managing money, and doing laundry but inconsistencies across surveys in trends in more severe disabilities in activities of daily living (ADLs), such as bathing, dressing, and eating. In their comprehensive review of subsequent studies, Freedman and colleagues (2002) found remarkable consistency in declines in IADLs and in functional limitations (e.g., difficulty bending, reaching, and stooping) but inconsistent findings with respect to trends in ADL disability.

In September 2002, the National Institute on Aging provided support for a technical working group to examine and if possible resolve apparent inconsistencies in old-age trends in the prevalence of ADL limitations across five national surveys (Freedman et al. 2004). Although the evidence was mixed for the 1980s, and it is difficult to pinpoint when in the 1990s the decline began, during the mid- and late 1990s, the panel found consistent declines on the order of

1%–2.5% per year for two commonly used measures in the disability literature: difficulty with ADLs and help with ADLs. Evidence was mixed throughout the period for a third measure: combined use of either help or equipment with ADLs. In comparing findings across surveys, the panel found that the period, definition of disability, treatment of the institutionalized population, and age standardizing of results were important to consider.

Given that since these last efforts, estimates from at least some of the same surveys are showing a potential change in the downward trend in either IADLs or ADLs, the TRENDS Disability Research Network (http://trends.psc.isr.umich.edu/) received funding from NIA¹ to undertake the current collaborative project in which we investigate more recent trends in IADLs, ADLs, and functional limitations, again taking into account the role of survey design features, with a particular emphasis on differences in question wording and measure, for example having difficulty with ADLs versus receiving help.

Data and methods

To examine more recent trends in prevalence, we selected four surveys that historically have been the primary the primary sources of self-reported disability information for the US population age 65 or older and have been extensively used in disability trends-related studies: HRS, the MCBS, the NHIS, and the NLTCS. The fifth survey selected, NHANES, distinct in its combination of survey information and actual physical examination of participants, is designed to monitor trends in disease and disease risk factors and has more limited self-reported information on functioning. We included NHANES in the analysis primarily to capture experience in the pre-retirement population age 60-64 for comparison with the HRS and NHIS, which, unlike NLTCS and MCBS, extend to younger ages. Including evidence for this group is important to provide insight into future trends. The NHANES also is distinct in its rolling

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design, which requires combination of several years of data in order to accumulate sufficient sample size for prevalence estimates. All included surveys provide representative samples of the community-residing population; the MCBS and the NLTCS also providing representative samples of the facility-residing population.

Our first task was to catalog the distinct characteristics of each data source along several key dimensions to identify any threats to comparability and to inform our interpretation of comparisons and potential methodological reasons for any observed disagreement among surveys. These dimensions included periodicity, which broadly ranges from annual to every five years; demographic composition for common years; and survey design features, such as overall response rates, proxy response rates, and loss to follow-up. To focus on potential changes in trends previously observed for the 1990s, we examined all available years from 1989 to the present. (For the preliminary estimates reported here, the most recent year available was 2006, but we are in the process of adding more recent years now available.)

Most important, of course, was identification of disability measures available in each survey and for which specific ADLs, IADLs, or functional impairments they were available. Summary comparisons are shown in Table 1. We used more detailed examinations of differences in question wording and other aspects of how measures were collected that underlie the table in our interpretations of results. We then established common protocols to guide team members in production of comparable prevalence estimates for each survey, including such factors as the treatment of missing data and groupings of activities common across sets of surveys for each disability definition. In the end, we examined prevalence estimates for groupings of four and six ADLs, two and four IADLs, and five and six functional limitations. Disability definitions used for each ADL and IADL grouping were difficulty, needs help, has

4

	Survey					
Definition	HRS	MCBS	NHIS-	NHIS-	NLTCS	NHANES
			family	adult		
ADLs						
1. Has difficulty	\checkmark	\sqrt{a}				\sqrt{a}
2. Needs help from another person			\checkmark		\checkmark	
3. Has difficulty/problem and gets help	\checkmark	\sqrt{a}			\checkmark	
IADLs						
1. Has difficulty	\checkmark	\sqrt{a}				\sqrt{a}
2. Needs help from another person			\checkmark			
3. Has difficulty/problem and gets help	\checkmark	\checkmark				
4. Is unable/can't do/doesn't do b/c of	,/b	,/b			al	, /a,b
health	N	N			v	N ¹
FLs						
1. Has difficulty	\checkmark	\checkmark		\sqrt{a}	\checkmark	\sqrt{a}
2. Is unable/can't do/ doesn't do b/c of health	\checkmark	\checkmark		\sqrt{a}		\sqrt{a}

 Table 1. Summary of Definitions of Disability for 5 National Surveys

^a by yourself and without special equipment/use of aids

^bresponse to "difficulty" question

difficulty and gets help, plus unable to do for IADL groupings; and difficulty and unable to do for functional limitations. To inform our interpretations, all feasible estimates across the two dimensions of activity groupings and disability definition were produced even in cases where estimates were available from only one survey.

Disability prevalence estimates were produced for the community population across all surveys. Estimates for the combined community and facility-residing population were produced from the MCBS and the NLTCS, which include both populations. All estimates were produced for the population age 60-64, 65-74, 75-84, and 85 or older to examine whether either prevalence trends or consistency in trends across surveys differed by age group.

The next step as we complete this study is to specify a consistent methodology for testing the statistical significance of the trends seen for each survey as well as for changes over discrete periods. Testing methodology will need to account for panel designs (HRS, NLTCS, and MCBS) and for the unique rolling design of the NHANES. We will also identify additional analyses that may be needed to understand where the impacts of differences in methodology need to be explored further.

Preliminary results

According to our preliminary results, evidence across all surveys examined appears to indicate that disability in ADLs and IADLs may have continued to decline for persons age 85 or older as a whole, although the trend appears to be far less steep than observed in the previous two decades. The trend among community residents age 85 or older appears flat likely because of recent trends in disability care from "facility" to community settings, including both private residences and assisted living. This pattern is illustrated in Figure 1 for a disability definition of having difficulty/problem with and receiving help for any of 4 ADLs (eating, bathing, dressing, and walking or indoor mobility) common to the HRS, MCBS, and NLTCS. Among 65-84 year



Figure 1. Has Difficulty and Receives Help with Any of 4 ADLs Age 85+

olds, however, trends appear to have flattened substantially, both overall and within the community-residing population. Figure 2 illustrates this pattern in the age 75-84 population, also using a disability definition of receiving help with any of 4-ADLs. Finally, among those approaching later life (ages 60-64), ADL and IADL prevalence rates appear to have been flat or to have increased slightly since 2001, depending on the measure and survey, but remain quite low relative to older age groups. Estimates for the prevalence of functional limitations for all ages appear to yield less consistent results both within and across surveys, with different directions in the trends for difficulty and inability to do the examined groups of activities, respectively.



Figure 2. Has Difficulty and Receives Help with any of 4 ADLs Age 75-84

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