Online Resource 1

Trends in Late-Life Activity Limitations in the United States: An Update From Five National Surveys

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This appendix provides a broad overview of each data set analyzed in the research note. Table 1 presents details of question wording for IADLs and ADLs and identifies which activities are available on each survey.

The Heath and Retirement Study (HRS) began in 1992 as a panel study of people who were 51 to 61 years old and lived in the community. Its sister survey, the Asset and Health Dynamics of the Oldest Old study (AHEAD) began in 1993 with an initially community-based sample ages 70 and older.[1] In 1998 the two surveys merged and expanded to include Americans ages 51 and older in that year. Follow-up interviews have been conducted every other year. Since 1998, the measures of activity limitations have been asked in a consistent way and have included difficulty because of a health or memory problem and help with 6 IADLs and 6 ADLs. We focus on the population age 65 and older in the years 2000-2008 (N= approximately 10,000 each survey wave). Response rates have been steady at approximately 87%-88% and loss to follow-up around 5%, whereas proxy rates have slowly declined from nearly 10% to less than 7% over the 2000 to 2008 period.

The Medicare Current Beneficiary Survey (MCBS) is a continuous panel survey of Medicare beneficiaries (including those living in the community and in long-term care and other facilities) that began in 1991. Respondents are interviewed up to three times a year. During the

[1] Both surveys followed respondents into institutions, but we include only community-residing respondents in analyses to preserve comparability across waves.

fall round of interviews, respondents are asked a series of questions about difficulty because of a health or physical problem and use of personal help with 6 IADL and 6 ADL activities. For survey participants in institutions, information about the level of assistance from another person for a subset of IADL activities and for all 6 ADL activities is gathered from medical records and staff. We rely on the 2000-2008 Access to Care files, which include individuals who were enrolled in Medicare on January 1 and survived roughly nine months to the fall interview when disability questions are asked.[2] Approximately 14,000 beneficiaries ages 65 and older are included in each year (community and institutional samples combined). Response rates have been approximately 70% and proxy response rates 7% to 8% over the 2000 to 2008 period (loss-to-follow-up rates have not been available).

The National Health Interview Survey (NHIS) is an annual cross-sectional survey of the non-institutionalized population. Since the early 1980s, NHIS has included two global items on need for help, one for personal care activities (ADL) and the second for routine activities (IADL), followed by questions about the conditions that cause the need for help. Beginning in 1997 the NHIS altered the global questions slightly and added six additional follow-up items on the need for help with specific ADLs. For consistency with earlier analysis, in the estimates presented here, we include reports of need for help only from those who say that the need resulted from having a chronic condition.[3] For the initial comprehensive disability estimates in

[2] This "always enrolled" Access to Care sample is not quite representative of a cross-section of enrollees age 65 or older because it does not include persons who become eligible and enroll. More pertinent for this study, sample weights do not adjust survivors to the fall interview to represent a cross-section. Because deaths are more likely at advanced ages and among persons with disabilities, estimates may slightly underestimate both age and disability relative to a cross-section.

[3]For the 1997-2001 period, the percentage needing help with personal care activities such as eating, bathing, dressing, or getting around the house as the result of a chronic condition and the percentage responding that they need help to perform one or more activities as part of a series of

Figure 1, we combine the global IADL and ADL measures of need for help. We use the more detailed follow-up ADL items (asked if there is a positive response to the global ADL question) in our analysis of a more consistent definition across studies (discussed below). These questions are asked in the family core component of the NHIS where one person generally provides reports for all household members, so proxy reports are higher than in the other studies (approximately 36% each year). Sample sizes ranged from approximately 8,000-11,000 for the 65 and older population, depending on the specific year. Survey response rates have declined slightly from 87% to 85% over the 2000 to 2008 period.

The National Long Term Care Survey (NLTCS) is a nationally representative panel study of the Medicare population age 65 or older living in the community or institutions that began in 1982 and was repeated at approximately five-year intervals between 1984 and 2004, the survey's final year. The sample was replenished in each wave to maintain cross-sectional representation. Initially respondents were screened to determine if they had a "problem" with any ADL or inability to perform any IADL activity that had lasted or was expected to last for at least three months. Those reporting any such chronic problems or inabilities were asked detailed questions about limitations and accommodations for 6 ADLs and 9 IADLs. After once screening in, sample members are added to the longitudinal sample and receive detailed questions in all subsequent waves. The estimates we include focus on help with ADLs and inability to perform IADLs. We include estimates for only the last two survey waves, 1999 and 2004, which occurred within our study period.[4] Sample sizes are approximately 16,000 to 17,000 in each

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six follow-up questions to the global item (no chronicity imposed) were substantially similar (Freedman et al. 2004).

[4] Our NLTCS estimates were produced using new cross-sectional weights developed at Battelle, Inc., under contract to the Department of Health and Human Services (HHSP233200-45006XI). They are intended to improve consistency of weighting methodology and avoid potential

survey year for the community and institutional samples combined. The survey response rate was 91% in 1999 and fell to 86% in 2004, and the loss-to-follow-up rate increased from 9% to 13% over this period. Proxy rates fell from nearly 20% to below 16%.

The National Health Examination Survey began in the late 1950s as a series of periodic surveys that focused on various health topics and specific population sub-groups. In 1971, the survey added components on nutrition and was renamed the National Health and Nutrition Examination Survey (NHANES) with a focus on the health and nutritional status of all adults and children in the United States. In 1999, the study adopted a continuous survey design. NHANES includes a nationally representative sample of about 5,000 persons per year. Although respondents reside in counties across the country, approximately 15 locations are included in the sample each year. Our estimates are based on data from two consecutive years to produce sample sizes for the 65 and older population of approximately 1,400-1,500 per 2-year period for 1999-2000 through 2007-2008. Activity limitations, which were asked for individuals ages 60 and older, are determined by whether respondents report difficulty with any of 3 IADL or any of 4 ADL activities. The interview response rate for NHANES declined over this period from 82% in 1999/2000 to 78% in 2007/2008.[5]

Characteristics of the 65 and older population from each of the data sources are shown in Table 2. On the whole, the data sources showed similar levels of characteristics, with a few exceptions: the NLTCS produces a lower estimate than other studies of the percentage Black, the NHANES produces a higher estimate of the percentage with 8 or fewer years of education and a

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distortions from between-wave changes in methodology for weights historically provided with the NLTCS. The new weights are now distributed with the NLTCS data by the National Archive of Computerized Data on Aging (http://www.icpsr.umich.edu/icpsrweb/NACDA).

[5] Proxy respondents were allowed in the NHANES but information on rates was not available.

higher percentage married in 2000, and the MCBS produces a higher estimate of the percentage with 13 or more years of education. In addition, across all samples the percentage Hispanic[6] and the percentage with 13 or more years of education increased, whereas the percentage with 8 or fewer years of education declined.

[6] For NHANES the percentage Mexican-American is shown.

Table 1. ADL and IADL Activity Limitation Items by Survey

Activity	HRS	MCBS-community	MCBS-Institution	NHIS*	NLTCS-community	NLTCS-institution	NHANES
ADL Stem	**Because of a health or memory problem, do you have any difficulty…; Does anyone ever help you…**	**Because of a health or physical problem, do you have any difficulty… [by yourself and without special equipment]; Do you receive help from another person with…**	**Level of self-performance in (activity)**	**Because of a physical, mental, or emotional problem, do you need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around inside this home? Do you/Does ____} need the help of other persons with …**	**After screening in because of a chronic problem with an ADL or IADL: During the past week, did any person help you… or did you not…? Did you use special equipment like … to …? Did someone usually stay nearby just in case ... might need help with …? Do you need help with …?**	**During the past week, did any person help you… or did you not…? Did you use special equipment like … to …?**	**By yourself and without using any special equipment, how much difficulty do you have…**
Bathing	bathing or showering	bathing or showering	level of self-performance on bathing	bathing or showering	bathe	bath or shower	--
Dressing	dressing including putting on socks and shoes	dressing	dressing	dressing	dressing, that is getting and putting clothes on	dressing, that is getting and putting clothes on	dressing yourself, including tying shoes, working zippers, and doing buttons
Eating	eating such as cutting up your food	eating	eating	eating	eat/eating	eat	eating like holding a fork, cutting food or drinking from a glass
Transferring	getting in our out of bed	getting in or out of bed or chairs	transferring (e.g., in and out of bed)	getting in or out of bed or chairs	get in or out of bed	get in or out of bed	getting in or out of bed
Toileting	using the toilet including getting up and down	using the toilet	toilet use	using the toilet, including getting to the toilet	get to the bathroom or use the toilet	get to the bathroom or use the toilet	--
Walking	walking across a room	walking	locomotion on unit	getting around inside this home	get around inside	get around indoors	walking from one room to another on the same level

(continued)

Table 1. ADL and IADL Activity Limitation Items by Survey (continued)

IADL Stem:	Because of a health or memory problem, do you have any difficulty…; Does anyone ever help you…	Because of a health or physical problem, do you have any difficulty… [by yourself and without special equipment]; Do you receive help from another person with…	Level of self-performance in (activity)	Because of a physical, mental, or emotional problem, do you need the help of other persons handling routine needs such as everyday household chores, doing necessary business, shopping or getting around for other purposes	Do you usually do …? [If no] If you had to do… could you do it? [If no] What is the reason you cannot do… — is that because of a disability or health problem or is there some other reason? [If usually does [IADL] or if could do [IADL], Do you need any help…? If can't do [IADL], does someone usually help you … or do it for you?	—	By yourself and without using any special equipment, how much difficulty do you have…
Light housework	work around the house or yard (help only, not difficulty or inability)	doing light housework (like washing dishes, straightening up, or light cleaning)	--	--	light work around the house such as straightening up, putting things away, or washing dishes	--	doing chores around the house (like vacuuming, sweeping, dusting, or straightening up)
Laundry	--	--	--	--	laundry	--	
Preparing meals	preparing a hot meal	preparing own meals	--	--	prepare own meals	--	preparing own meals
Shopping	shop for groceries	shopping for personal items (such as toilet items or medicines)	shopping for personal items (such as toilet items or medicines)	--	shop for groceries, that is, go to the store, select the items, and get them home	--	--
Managing money	managing your money -- such as paying your bills and keeping track of expenses	managing money (like keeping track of expenses, paying bills)	managing money (like keeping track of expenses, paying bills)	--	manage ... own money by self including things like keeping track of bills or handling cash	--	managing (your/his/her) money (such as keeping track of your expenses or paying bills)
Getting around outside				--	get around outside	--	--

(continued)

Table 1. ADL and IADL Activity Limitation Items by Survey (continued)

Going outside of walking distance				--	go places outside of walking distance	--	--
Taking medications	taking medications			--	take medicine	--	--
Telephoning	making phone calls	using the telephone	using the telephone	--	make … own telephone calls without the help of another person	--	--

* The following questions were used to determine whether help was needed due to a chronic condition: what conditions or health problems caused your limitation? How long have you had this condition?

Table 2. Characteristics of the population ages 65 and older, 2000, 2004, and 2008[1]

	Community Only					Community and Institution	
	HRS	MCBS	NHIS Family Core	NLTCS	NHANES	MCBS	NLTCS
% Age 85 +							
2000	9.8	10.9	9.3	9.6	9.2	12.9	11.6
2004	10.7	12.0	10.7	10.4	10.7	13.8	12.0
2008	12.6	13.2	11.9	--	NA	14.7	--
% Female							
2000	57.9	57.8	57.5	58.6	57.4	58.6	59.3
2004	57.1	57.0	57.6	57.6	56.8	57.8	58.4
2008	56.8	56.3	57.0	--	57.6	56.9	--
% Black							
2000	8.7	8.0	8.2	6.6	7.7	8.0	6.7
2004	7.9	7.9	8.2	7.0	8.4	7.9	7.0
2008	8.2	7.8	8.7	--	8.2	7.9	
% Hispanic[2]							
2000	5.2	6.6	5.8	4.9	2.6	6.5	4.9
2004	5.1	7.3	6.1	5.0	3.2	7.1	5.0
2008	5.8	7.4	7.0	--	3.4	7.2	--
% Educ ≤ 8 Yrs							
2000	15.8	15.8	16.2	—[3]	18.8	16.3	—[3]
2004	12.2	13.2	13.0	13.3	16.0	13.7	13.6
2008	9.7	10.1	11.7	--	13.8	10.6	--
% Educ ≥High School							
2000	34.2	38.6	32.5	—[3]	33.7	37.7	—[3]
2004	36.9	41.5	36.6	38.6	39.4	40.5	38.0
2008	40.6	45.7	40.0	--	42.3	44.7	--
% Married							
2000	54.9	54.8	55.9	54.7	60.4	52.9	52.7
2004	55.2	55.1	56.5	55.1	56.2	53.3	53.5
2008	53.6	55.8	56.5	--	55.9	54.1	--
Total N ages 65+							
2000	10,311	12,838	11,206	16,096	1,392	13,806	17,121
2004	10,627	12,016	10,758	15,110	1,494	12,862	16,080
2008	10,573	11,741	8,478	--	1,556	12,597	--

[1] 2000 estimates are from 1999 for NLTCS and are the average of 1999 and 2000 for NHANES. 2004 estimates for NHANES are the average of 2003-2004, and 2008 estimates are the average of 2007-2008.

[2] For NHANES, percentage Mexican-American is shown.

[3] Not ascertained for full NLTCS population (detailed interview only).