

Operational definition of chronic disability in the National Long Term Care Survey: Problems and suggestions

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Abstract

We examine the operational definition of disability as measured by the core disability questions in the National Long Term Care Survey (NLTC), paying particular attention to the interplay between the basic concept of chronic disability as disability lasting more than 90 days and the complex longitudinal survey design. The central piece of this work focuses on the issues of compatibility between slightly different versions of the core disability questions in the two components, the screener and the detailed NLTC surveys. Contrary to the common believe, we find that the design of the NLTC does not allow one to obtain *chronic* disability measures but only measures that are some combination of chronic and short-term disability episodes. We conclude with suggestions for future longitudinal surveys aimed to measure chronic disability.

Key words: Longitudinal, screener survey, activities of daily living, questionnaire design, binary outcomes.

1 Introduction

The National Long Term Care Survey (NLTCS) is designed to address changes in disability among elderly people in the United States through a longitudinal sampling design mechanism. The first wave of the data collection was in 1982, followed by a second wave in 1984 and subsequent waves every five years afterwards. The NLTCS sampling mechanism is described elsewhere [1].

It is evident from several highly visible headlines in scientific journals [2, 1, 3] and in the lay press [4] that the NLTCS provides measurement of *chronic* disability. Although the amount of attention given by these and other publications to the definition of *chronic* disability employed by the NLTCS varies, the interplay between the basic definition (as a disability lasting more than 90 days) and the complex survey design is rarely mentioned. In fact, as we explain in this paper, the NLTCS by design does not unequivocally measures *chronic* disability but rather some combination of chronic and short-term disability episodes.

Measurement of chronic disability in NLTCS is structured around core disability questions that focus on basic activities of daily living (ADL) and instrumental activities of daily living (IADL). A description provided by Manton, Corder and Stallard [2] states that in the NLTCS “disability was defined as the inability to perform ≥ 1 IADL (e.g., cooking, doing laundry) due to health or aging, or the inability to perform at least one ADL (e.g., bathing, dressing) without using personal assistance or special equipment... To be identified as chronically disabled when initially selected for a detailed interview a sample person had to have at least one ADL or IADL disability that had lasted, or was expected to last, >90 days.” Although factually correct, this brusque description does not allow one to fully understand the operational definition of the disability measurement employed by the NLTCS, and gets misinterpreted by some of the most knowledgeable researchers in the field (see [3, 5, 6], for example).

We set out to explore the operationalization of the disability measurement in the NLTCS by examining the design of questionnaires and records on the core disability measures from the 1999 survey wave. Our findings question a commonly accepted notion that the NLTCS provides measurement of *chronic* disability. We indicate several areas for possible improvement in the content and design of the survey as relates to core disability measures.

2 Determination of ADL and IADL disabilities by the screener and the community detailed surveys

The key data in the NLTCS are individual reports of impairments on ADL and IADL measures. Three sources of NLTCS data include (some subset of) ADL and IADL measures: the screener survey, the detailed community survey, and the analytic data files. The original intention of the investigators was to screen the elderly for chronic disability,

possibly accepting “false positives”, and then use the detailed survey to measure disability more accurately [7].

2.1 Analytic data files

It is our understanding that major disability findings obtained by the Duke Center for Demographic Studies used data from the analytic files, which are “the products of specific analyses conducted by the Center for Demographic Studies and thus include various correction factors and consistency checking not included in the standard Census data product” [8]. However, to the best of our knowledge, a thorough description of the survey process which underlies the definition of binary outcomes on the core disability indicators in the analytic file have not been explained in detail in a publication.

We compared records from the 1999 survey wave on core disability questions between the community detailed and analytic data files. The community detailed survey was part of the public use file, from which the analytic file was formed. The records on ADL measures matched completely. The agreement for IADL measures was very good but not perfect; the disagreement was less than 2% on each individual IADL. When inconsistencies on IADLs did appear, it was always the community detailed file giving credit for an IADL and the analytic file not giving credit, and never the other way around. The largest inconsistency was observed for the IADL ‘heavy housework’; the CDS Analytic File Documentation [9], provided with NLTCs utilities, explains this inconsistency.¹

Considering that the disagreement between the community detailed and the analytic data file is minor, we will focus on examining protocols of the screener and the detailed community parts of the survey to understand how the definition of *chronic disability* has been operationalized to result in 0/1 indicators on ADL and IADL measures.

2.2 Chronic disability measurement

Table 1 provides examples of binary outcomes determination for ADL and IADL measures by the screener and the community detailed surveys; Appendix A details the exact process.

In order to be classified as screened-in impaired by the NLTCs screener survey, an individual must have a problem (coded with a binary indicator of 1) with at least one

¹“The ‘Heavy Housework’ IADL is not used to determine disability on the Screener questionnaire. It is only assessed on the Community questionnaire. This condition required CDS to implement a consistency check in calculating its disability group variables. If ‘Heavy Housework’ was the individual’s only disability measure, ADL or IADL, and they were a member of the survey subgroup that automatically received a detailed questionnaire, they were considered “non-disabled.” Had they received a screener, they would not have been asked about heavy housework and would, as far as anyone can know, been considered non-disabled, and not have been selected. However, if the individual was part of the group that received a screener questionnaire, and was selected for a detailed interview because they scored as disabled at the time of the screen, they were considered “IADL only.””

Table 1: Examples of ALD/IADL disability determination (binary): A comparison between the screener and the detailed NLTCS surveys

Screener Survey	Detailed Survey
ADL-Eating	ADL-Eating
The following question is asked:	The following 3 questions are asked:
1. Do you have any problem eating without the help of another person or special equipment?	1. During the past week ... did anyone help you eat? 2. Did you use special equipment to help you eat? 3. Did someone usually stay by just in case you might need help with eating?
If question 1 was answered yes, the individual is ADL-disabled on eating. Otherwise, no disability is recorded.	If any of questions 1-3 were answered yes, the individual is ADL-disabled on eating. In addition, if the individual did not eat at all (a third response category from question 1), the individual is ADL-disabled on eating. Otherwise, no disability is recorded.
IADL-Managing Money	IADL-Managing Money
The following 2 questions are asked:	The following 3 questions are asked:
1. Are you able to manage money without the help of another person or special equipment? 2. Does a disability or health problem keep you from managing money?	1. Do you usually manage money by yourself? 2. If you had to manage money on your own, could you do it? 3. Is the reason you cannot manage your own money because of disability or a health problem?
If question 1 was answered no, and question 2 was answered yes, the individual is IADL-disabled on managing money. Otherwise, no disability is recorded.	If questions 1 and 2 were answered no, and question 3 was answered yes, the individual is IADL-disabled on managing money. Otherwise, no disability is recorded.

ADL² or with at least one IADL³ that had lasted, or was expected to last, 3 months or longer. Note that the screener survey first determines whether there is a problem performing each ADL at the present time (see Table 1 for an example), and then, if at least one problem was found, asks a set of general ADL-problem duration questions (not ADL-specific)⁴; the IADL process is similar.

The detailed survey employs a more complicated process with several triggering questions to determine binary outcomes on ADL and IADL measures (see Table 1 for examples). Questions in the detailed survey that result in binary ADL and IADL determination ask about *current* difficulties.⁵ The detailed survey does record the length of impairment⁶ for ADL; however, that information does not factor into the determination of binary outcomes on ADL measures. The detailed survey does not record the length of impairment for IADLs. Since the detailed survey is believed to provide proper screening of “false positives”, the overall measurement of disability must be done using mainly records obtained from the detailed survey, checked against the screener for consistency¹.

From the description above, it is clear that disability measurement in NLTCs is only indirectly related to the basic definition of chronic disability (as disability lasting or expected to last 90 days or longer) through the mechanism employed by the screener survey. Impaired individuals who screen-in have at least one problem with either basic or instrumental ADLs, where the actual or expected duration is 90 days or longer. These individuals can be classified as chronically disabled *at the time of the screener survey*. Subsequent disability measurements by the detailed surveys address more short-term disability (see Table 1 for examples and Appendix A for more detail).

Such operationalization of the definition of *chronic* disability would be appropriate for a cross-sectional survey if there were no time lags between the screener and the detailed parts of the survey. It would also be appropriate for a longitudinal survey if, in addition, the elderly experienced no transitions from the chronically disabled state back to the healthy state. Unfortunately, both of the above propositions do not hold. First, not all individuals receive ADL and IADL core disability questions in the screener and the detailed survey on the same day (see Appendix B). Some experience time lags between the screener and the detailed survey interviews in the same wave. Others, such as those who had the detailed survey in the previous wave, receive an abbreviated form of the screener in the next wave which doesn’t include core disability questions by design. Second, the elderly do experience back and forth transitions between healthy and disabled states [10,

²An individual has an ADL problem if he/she needs human help or special equipment to perform the activity, or if he/she can’t do it or doesn’t do the activity at all.

³An individual has an IADL problem if he/she is unable to perform the activity without help because of a disability or a health problem.

⁴The duration questions are as follows: Has the problem lasted for 3 months or longer? Do you expect the problem to last for the next 3 months or longer? From beginning to end, will the problem have lasted 3 months or longer?

⁵The time references are “during the past week” for ADL questions and “usually” for IADL questions.

⁶Response categories on the length of impairment question are: < 3 months, 3-6 months, 6-12 months, 1-5 years, and >5 years.

11, 12, 13]. Thus, the notion that the NLTC measures *chronic* disability seems flawed.

3 Empirical comparison of ADL and IADL measures in the screener and the detailed surveys

The original survey design idea was to have the screener survey be less stringent in assessing disability, therefore allowing “false positives” to be screened-in, and then detecting “false positives” with the detailed survey. Differences in wording between the core disability questions in the screener and the detailed surveys (Table 1, Appendix A) essentially mean that it is impossible for an empirical investigation to conclude with certainty whether the screener and the detailed surveys have the intended relationship. With this in mind, we attempt to compare outcomes on core disability measures using records from the 1999 wave.

Note that in addition to differences in wording (see Table 1 for examples and Appendix A for more detail), the overlap in ADL and IADL measures between the screener and the detailed surveys is less than perfect (Appendix C). While the screener survey lists 9 ADLs and 7 IADLs, the detailed (community) survey has 6 ADLs and 10 IADLs. ‘Getting in and out of chair’ and ‘continence’ ADLs are in the screener survey but are not in the detailed survey, while the screener ADL ‘outside mobility’ is considered as an IADL by the detailed survey. The additional 3 IADLs in the detailed survey that are not in the screener survey are: ‘heavy housework’, ‘travel’, and ‘outside mobility’ (although the latter is considered as an ADL by the screener survey).

Next, we carry out an empirical comparison of binary records on ADL and IADL measures between the screener and the detailed surveys for persons who have both sets of records in 1999. We use 6 ADLs and 8 IADLs that overlap between the screener and the detailed survey.

3.1 Subset receiving core disability question in the screener and detailed surveys

There were 5,147 individuals in 1999 who have received the detailed survey, community or institutional, in 1999. All of these individuals were administered a version of the screener survey, but only about 40% (1,988) had screener data for ADL and IADL measures.⁷ The remaining individuals, who were either in the detailed survey in the previous wave or were institutionalized in 1999, received an abbreviated form of the screener which did not include core disability questions.

From those individuals who had records on core disability questions in the detailed and screener surveys, 41% (811) received the screener and detailed interviews on the same

⁷Most of the individuals who had screener records on the core disability question in 1999 had not received the detailed survey in any previous wave, however 14, 15 and 22 of them were in the 1982, 1984, and 1989 detailed surveys respectively.

day.⁸ Other individuals in this group experienced various time lags between the screener and the detailed surveys; the time lag averaged 24 days for those who did not receive the screener and the detailed interviews on the same day.

3.2 Analysis of records on core disability questions

We extracted ADL and IADL data from the screener and the detailed surveys in 1999 for 1,988 individuals who had ADL and IADL records in both survey components. We used the analytic file records for the detailed data, since it uniquely included the IADL for taking medicine.⁹ Recall that the differences between the analytic file and public use file were small.

To obtain an overall indication of consistency in core disability measures, we calculated the average number of mismatches on records for the 6 ADL and 8 IADL variables between the screener and the detailed (analytic version) surveys for each individual (Table 2). The average number of mismatches for those who had both interviews on the same day

Table 2: Average measures of consistency of core disability questions in the screener and the detailed surveys: The number of mismatches and the difference in totals

	mismatches (st.dev.)	differences (st.dev.) screener-detailed
<u>zero-lag (N=811)</u>		
ADL (6)	1.13 (1.41)	-0.76 (1.50)
IADL (8)	1.96 (1.84)	-0.15 (1.58)
<u>full subset (N=1988)</u>		
ADL (6)	1.16 (1.39)	-0.63 (1.54)
IADL (8)	2.02 (1.86)	-0.09 (1.72)

was 3.09, composed of 1.13 average for ADL and 1.96 average for IADL records. The average of 3.09 mismatches out of possible 14 is quite high, considering that it only reflects qualitative differences in wording of questions used for the screener and the detailed surveys. It is only slightly lower than the average number of mismatches for the full subset of 3.18, which includes individuals who experienced time lags.¹⁰ This indicates that influence of differences in operational definitions of disability between the screener and the detailed surveys is much greater than potential influence of time lags. Consistently, further analyses (not shown here) indicated that the number of mismatches in ADL/IADL variables was not related to the length of the time lag.

⁸From a total 5,147 individuals who were administered detailed surveys in 1999, 37% (1,916) received the screener and the detailed surveys on the same day.

⁹There was no variable in the community detailed survey that represented the taking medicine IADL

¹⁰There were 15 individuals overall who varied on all 6 ADLs and 7 different individuals who varied on all 8 IADLs.

To examine the direction of changes, we obtained average differences in the total number of ADL and IADL problems detected by the screener and the detailed surveys (Table 2). Negative differences indicate that binary disability indicators in the detailed survey represent greater amounts of disability than those in the screener survey. For the full subset of 1,988 individuals, the total number of disabilities recorded on the detailed survey (average 4.23) was significantly higher than the corresponding number on the screener survey (average 3.51); a 2-sample t-test for paired data obtained the 95% confidence interval for the difference of -0.72 to be (-0.83,-0.61). Similarly, the differences were significant for ADL ($p < 0.001$) and IADL ($p = 0.0175$) measures separately.

Since the major NLTCs findings were based on the classification into five mutually exclusive groups defined in Manton and Gu [1], we obtained a similar comparison of records on core disability questions based on the same disability classifications (Table 3). Note that the detailed survey classified almost twice as many people in the two most

Table 3: Counts of individuals by the five disability categories

	non- disabled	IADL- disabled	1-2 ADLs	3-4 ADLs	5-6 ADLs
rank-category	0	1	2	3	4
<u>zero-lag (N=811)</u>					
screener	214	238	205	74	80
detailed	224	99	212	136	140
<u>full subset (N=1988)</u>					
screener	497	603	545	172	171
detailed	561	275	540	324	288

disabled groups (3-4 ADLs and 5-6 ADLs), whereas the screener survey classified more than twice as many people in the IADL-only group. The detailed survey also classified slightly more people in the mysteriously healthy group.¹¹ Excluding the healthy group, it is clear that the detailed survey was more lenient in classifying individuals into disability groups than the screener survey.

To examine changes on a within-individual level, first note that the five disability groups defined in Table 3 are logically ordered from least to most disabled. As a rough measure of this scale, we assign the numeric rankings from 0 to 4. Table 4 provides a summary of individual changes in ranks. Based on the numeric ranking, we see again that the screener survey is more stringent in measuring disability than the detailed survey. The average change in rank for the entire group of 1,988 individuals between the screener and the detailed survey was -0.29; a 95% confidence interval for the mean difference obtained

¹¹Of 497 non-disabled individuals who were assigned rank 0 by the screener survey, 280 were part of the healthy supplement, 86 were coded as institutionalized and 131 non-institutional were coded as screened-in impaired and hence were administered the detailed survey for reasons unknown to us.

by a 2-sample t-test for paired data was (-0.33,-0.25). The time lag did not appear to be an influence.

Table 4: Distribution of individual changes in ranks for the five disability categories

change in rank screener - detailed	-4	-3	-2	-1	0	1	2	3	4
<u>zero-lag</u> (N=811) count	0	12	75	218	429	57	16	2	2
<u>full subset</u> (N=1988) count	0	33	169	519	1000	181	74	7	5

Overall, we found that differences in wording on ADL and IADL questions in the screener and the detailed surveys have an impact on the binary outcomes. The amount of disability recorded is higher on the detailed survey than on the screener survey for both measures that we examined, the disability classifications by Manton and Gu [1] and the total number of disabilities. Note that the above analysis is based on binary indicators for ADL and IADL measures, whereas the primary outcome of the screener survey (the decision whether someone can be classified as screened-in impaired) is based on a check for disability duration ≥ 90 days.

4 Conclusion

Analyzing 1999 screener and detailed survey data on core disability questions, we observed a large impact of the differences in the operational definitions employed in recording binary ADL and IADL outcomes between the screener and the detailed parts of the survey. In addition, the ADL and IADL lists in the two survey components overlap but are not identical. Finally, time lags between the screener and the detailed interviews, various skip patterns that result in no ADL/IADL questions asked by the screener, and substantial chronic disability recovery rates make it problematic to accept the disability measurement in the NLTCs as the measurement of *chronic* disability.

The operational definitions of disability measurement employed by the NLTCs have their roots in the historic development of the survey at the early waves. They incorporate an interplay between the lower bound of 90 days on the disability duration and the complex longitudinal structure of the survey. Key published sources for the NLTCs disability measurement provide only brusque descriptions [1, 2, 10]. Thus, it is not surprising that the nature of the NLTCs disability measurement gets misinterpreted toward oversimplification by even some of the most knowledgeable researchers in the field. For example, it is often assumed that the NLTCs provides measures of chronic disability prevalence [5, 6], where chronic disability is defined as one which lasts or is expected to last more than 90

days. Findings in another recent publication, which points to an overestimation of chronic disability by the NLTCS [3], are based entirely on this overly simplistic interpretation of the NLTCS measurement protocol.

As we have shown in this paper, the NLTCS uses chronic and short-term disability measurements in different parts of the survey (in the screener and the detailed part of the survey, respectively). We also showed that the two measurement protocols produce outcomes that are significantly different, precluding therefore any construction of a comprehensive *chronic* disability measurement based on the NLTCS data.

4.1 Suggestions for the future

Ideally, a longitudinal survey composed of a screener and detailed survey that aims to measure chronic disability based on the results of the detailed component should:

1. Include core disability questions that result in binary ADL and IADL outcomes each time the screener survey is administered.
2. Keep core disability questions that result in binary ADL and IADL outcomes consistent between the screener and the detailed surveys.
3. Administer disability duration questions in the screener and the detailed surveys in the same way.

These requirements will assure proper tracking of *chronic* disability status of the elderly. In addition, such data collection will be more efficient in that those individuals who have the screener and the detailed parts of the survey on the same day only need to answer one set of the ADL/IADL questions. Moreover, compatibility between the screener and the detailed survey will provide researchers who are interested in studying transitions in disability with additional longitudinal records obtained for those who experience time lags between the screener and the detailed surveys.

Considering the importance of keeping the survey structure intact as it relates to the need for core disability questions to be consistent with prior waves, there is not much improvement that can be done with the future NLTCS waves to fully accommodate the above concerns. However, closer compatibility between the screener and the detailed surveys can be achieved by possibly including a few additional questions.

Appendices

A Determination of binary outcomes on ADL and IADL measures

The existing document listing all the triggering questions for ADL/IADL determination on the detailed survey, although accurate, is difficult to follow from a logical perspective [14]. For example, many of the triggering questions involve length-of-time related measures, however, these temporal measures do not factor into the determination of binary outcomes on ADL and IADL measures for a particular task. This appendix lists the exact process that is used for ADL and IADL binary outcomes determination. The process is common among some ADLs (or separately, among some IADLs), but differs to varying extents among other ADLs (and IADLs).

A.1 Screener Survey

Those aged 65 and over and non-institutionalized qualify to receive the full version of the screener survey. The screener survey does have questions relating to all 6 individual ADLs and 8 of the 10 individual IADLs (all except heavy housework and going places outside of walking distance). Note that on the screener survey, the function of getting around outside is considered a seventh ADL rather than an IADL. Also note that, unlike the detailed survey, the screener survey does indeed measure chronic disability due to the 3 month requirement (see below) for at least one ADL/IADL for an individual to be screened-in. The main purpose of the screener survey, though, is to either screen people in or out for inclusion in the detailed survey, and in doing so, the ADLs and IADLs are considered in aggregate, rather than on an individualized basis. Below is the process that is followed in making this determination.

Steps Relating to ADL-disabled Classification

1. Do you have any problem [insert ADL] without the help of another person or special equipment?
2. If the previous question was answered yes or "can't/don't do at all" for at least one ADL, the following question was asked (Otherwise, the individual was classified as not ADL-disabled).
3. Have you had this problem for 3 months or longer, do you expect that this problem will last for the next 3 months or longer, or altogether, from beginning to end, will this problem have lasted 3 months or longer?

4. If and only if the previous question was answered yes (in any part), the individual was classified as ADL-disabled.

Steps Relating to IADL-disabled Classification

1. Are you able to [insert IADL] without the help of another person or special equipment?
2. If the previous question was answered no for at least one IADL, the following question was asked (Otherwise, the individual was classified as not IADL-disabled).
3. Does a disability or health problem keep you from [insert IADL]?
4. If the previous question was answered yes for at least one IADL, the following question was asked (Otherwise, the individual was classified as not IADL-disabled).
5. Have you had a problem with this activity for 3 months or longer, do you expect that this problem will last for the next 3 months or longer, or altogether, from beginning to end, will this problem have lasted 3 months or longer?
6. If and only if the previous question was answered yes (in any part), the individual was classified as IADL-disabled.

Screening Decision If an individual has been either classified as ADL-disabled or IADL-disabled (or both), he/she becomes screened-in, and henceforth eligible to receive the detailed survey. Note a subtle difference in interpretation between the ADL and IADL portions of the screener survey. For the ADL portion, if one does not perform a certain task, they are asked the question about the length of time they have had a problem with the task, regardless whether they are able to do the task or not. However, for the IADL portion, if one does not perform a certain task, but is able to do the task, they will not be flagged as having difficulty with the task, and will never be asked the length-related question if they are not flagged on any of the other IADL tasks either. Now, if we are not as interested in the screening decision, but just want to know where the individual ADL and IADL measurements arise at the screener level, we simply look to the first question in the ADL subsection, and the first two questions in the IADL subsection. Repeated here for clarity, they are:

1. Do you have any problem [insert ADL] without the help of another person or special equipment?
2. Are you able to [insert IADL] without the help of another person or special equipment?
3. Does a disability or health problem keep you from [insert IADL]?

If and only if the first question, asked for each ADL, is answered yes, the individual is classified as ADL-disabled on that ADL. If and only if the second question, asked for each IADL, is answered no, and the third question, asked for each IADL in which the second question was answered no, is answered yes, the individual is classified as IADL-disabled on that IADL. Note the difference in how the first two questions, one pertaining to ADLs and the other to IADLs, are framed.

A.2 ADLs from Detailed(Community) Survey

Eating

1. During the past week ... did anyone help you eat?
2. Did you use specific utensils or special dishes to help you eat?
3. Did someone usually stay by just in case you might need help with eating?

If any of these questions were answered yes, the individual was ADL-disabled on eating. Also, if the person did not eat at all (a third response category from the first question), the individual was ADL-disabled on eating. Otherwise, no disability was recorded.

Getting In or Out of Bed Identical process to eating. Note that if a person did not get out of bed at all, he/she was automatically coded as being ADL-disabled on getting around inside and dressing, as well as IADL-disabled on heavy housework, light housework, laundry, cooking, shopping, outside mobility, and travel.

Getting Around Inside Identical process to eating, except for additional question below.

4. During the past week ... did you get out of bed at all?

If the last question was answered no, the individual was also considered ADL-disabled on getting around inside. Note that if a person did not get around inside at all, he/she was automatically coded as being IADL-disabled on heavy housework, light housework, laundry, cooking, shopping, outside mobility, and travel.

Dressing Identical process to getting around inside, except that having the dressing ADL does not qualify an individual as being IADL-disabled on any IADL (like it does for getting around inside).

Bathing Identical process to eating.

Toileting Identical process to eating.

Addendum Note that, for each of the above 6 ADLs, even if a person was classified as not disabled on a particular ADL, they were still asked the follow up question: Do you need help with [insert ADL]? However, if this question was answered yes, the individual was still classified as not being ADL-disabled on this particular ADL. Also note that there is no mention of the 90-day limit often required for chronic disability in the ADL triggering questions. There are questions (for ADLs only) that do address the length of disability, but they do not factor into ADL determination for any of the 6 ADLs. These questions are listed below:

1. About how long have you needed help or used special equipment to [insert ADL]?
2. About how long have you been unable to [insert ADL]?

Each of these questions has 5 possible response categories: less than 3 months, 3 to 6 months, 6 to 12 months, 1 to 5 years, and 5 years and over. The individual is asked at most one of these two questions per ADL, based on their responses to the ADL-specific triggering questions listed in earlier sections. However, their categorical response regarding length of disability is, once again, not used to determine ADL status for any of the 6 ADLs on the detailed survey. It will be mentioned later that the length of disability is used, though, to determine ADL status, on an aggregate basis, on the screener survey.

IADLs from Detailed(Community) Survey

Light Housework

1. Do you usually do light housework around the house...?
2. If you had to do light housework around the house, could you do it?
3. Is the reason you cannot do light housework around the house because of disability or a health problem?
4. During the past week ... did you get out of bed at all?
5. During the past week ... did you get around inside at all?

If the first two questions are answered no, and the third question was answered yes, the individual was classified as IADL-disabled on light housework. Also, if either of the last two questions were answered yes, the individual was classified as IADL-disabled on heavy housework. Otherwise, no disability was recorded.

Heavy Housework Identical process to light housework. Note that if either of the first two questions were answered yes, an individual was automatically coded as being not IADL-disabled on light housework as well.

Laundry Identical process to light housework.

Prepare Meals Identical process to light housework.

Shop for Groceries Identical process to light housework.

Gets Around Outside

1. Do you get around outside at all, either with or without help?
2. When you go outside, does someone usually help you get around?
3. When you go outside, do you use special equipment ... to help you get around?
4. Is the reason you cannot get around outside because of disability or a health problem?
5. During the past week ... did you get out of bed at all?
6. During the past week ... did you get around inside at all?

There are four possible pathways for IADL-disability to be recorded for getting around outside. First, if the first and second questions was answered yes (then, the third and fourth questions would be skipped), the individual was classified as IADL-disabled on getting around outside. Second, if the first and third questions were answered yes (then, the fourth question would be skipped), and the second question was answered no, the individual was classified as IADL-disabled on getting around outside. Third, if the first question was answered no (then, the second and third questions would be skipped), and the fourth question was answered yes, the individual was classified as IADL-disabled on getting around outside. Finally, if either of the last two questions were answered yes, the individual was classified as IADL-disabled on heavy housework. Otherwise, no disability was recorded. Note that if the first question was answered no, an individual was automatically coded as being IADL-disabled on going places outside of walking distance (different from getting around outside), even if the reason he/she could not get around outside was not because of a disability or health problem.

Goes Places Outside of Walking Distance

1. How do you usually go places outside of walking distance?
2. Does someone usually help you go places outside of walking distance?
3. If you had to go places outside of walking distance by yourself, could you do it?
4. Is the reason you cannot go places outside of walking distance by yourself because of disability or a health problem?

5. During the past week ... did you get out of bed at all?

6. During the past week ... did you get around inside at all?

If the first question was answered any way except for "did not travel at all", the second and fourth questions were answered yes, and the third question was answered no, the individual was classified as IADL-disabled on going places outside of walking distance. Also, if either of the last two questions were answered yes, the individual was classified as IADL-disabled on heavy housework. Otherwise, no disability was recorded. Note that anyone who does not travel at all is automatically coded as not being IADL-disabled on going places outside of walking distance, regardless of whether they are able to perform this function or not.

Manages Money Identical process to light housework, except that questions 4 and 5 are not asked, and thus do not figure into whether an individual is IADL-disabled on managing money.

Takes Medicine

1. Does someone usually help you take medicine?

If the above question was answered yes, the individual was classified as IADL-disabled on taking medicine. Otherwise, no disability was recorded. Also, if the person does not take medicine at all (a third category from the above question), the individual was not IADL-disabled on taking medicine.

Makes Phone Calls

1. Is there a telephone in the house/apartment?

2. Do you usually make your own telephone calls without the help of another person?

3. If you had to make your own telephone calls, could you do it?

4. Is the reason you cannot make your own telephone calls because of disability or a health problem?

There are two possible pathways for IADL-disability to be recorded for making phone calls. First, if the first and fourth questions was answered yes, and the second and third questions were answered no, the individual was classified as IADL-disabled on making phone calls. Second, if the first and third questions were answered no (then, the second question would be skipped) , and the fourth question was answered yes, the individual was classified as IADL-disabled on making phone calls. Otherwise, no disability was recorded.

Addendum Also note that, for each of the above 10 IADLs, except for making phone calls, even if a person was classified as not disabled on a particular IADL, they were still asked the follow up question: Do you need help with [insert IADL]? However, if this question was answered yes, the individual was still classified as not being IADL-disabled on this particular IADL. Also note that there is no mention of the 90-day limit often required for chronic disability in the IADL triggering questions either. In fact, the IADL portion of the survey does not have any questions that address the length of IADL-related disability whatsoever.

B Appendix B: Interview times

For 1999, we compared the start of the detailed interview (*date_condtns*) with the start of the screener survey (*date_screener*). Out of 5,147 individuals who have received detailed surveys in 1999, 63% of people had delayed interviews. The amount of delay varied between -25 and 126 days. The average and the median lag times were 26.3 and 12 days respectively. Excluding same-day interviews, the mean time lag between the screener and the detailed interview was about 42 days, and the median time lag was 41 day.

From those individuals who had records on core disability questions in the detailed as well as in the screener surveys, 41% (811) received the screener and detailed interviews on the same day. Other individuals from this group experienced various time lags between the screener and the detailed surveys; the time lag averaged 24 days for those who did not receive the screener and the detailed interviews on the same day.

Note that screener survey times are available across all waves, whereas detailed survey times are only available for the 1999 wave. Only start dates in the control card (demographic) portion of the survey were recorded over all the waves.

Variables that record time of the main survey components in NLTCs are:

date_int – sets start date of the entire interview process at point of first contact, before the screener, control card, or detailed survey has commenced - available for 1999 only.

date_screener – sets start date of the screener survey; available for all years.

date_condtns – sets start date of the detailed (community) survey; available for 1999 only.

date_select – sets end date of the detailed (community) survey; available for 1999 only.

date_cc – sets start date of the control card survey; available for all years.

C Appendix C: List of ADL/IADL variables

The screener, public use file, and analytic data file variables names are given for each ADL/IADL. If an ADL/IADL does not appear in the survey, it is noted as ‘[blank]’.

ADL/IADL	screener name	public use file name	analytic file name
eating ADL	<i>prob_eating</i>	<i>adl_eat</i>	<i>adleat</i>
dressing ADL	<i>prob_dressing</i>	<i>adl_dress</i>	<i>adldress</i>
inside mobility ADL	<i>prob_inside</i>	<i>adl_inside</i>	<i>adlin</i>
toileting ADL	<i>prob_toilet</i>	<i>adl_toilet</i>	<i>adltoi</i>
getting in and out of bed ADL	<i>prob_bed</i>	<i>adl_bed</i>	<i>adlbed</i>
bathing ADL	<i>prob_bathing</i>	<i>adl_bath</i>	<i>adlbath</i>
laundry IADL	<i>disab_laundry</i>	<i>iadl_laundry</i>	<i>idllaun</i>
cooking IADL	<i>disab_prepmeals</i>	<i>iadl_prepmeals</i>	<i>idlcook</i>
light housework IADL	<i>disab_lighthw</i>	<i>iadl_lightwk</i>	<i>idllite</i>
shopping IADL	<i>disab_shop</i>	<i>iadl_shop</i>	<i>idlshop</i>
making phone calls IADL	<i>disab_phone</i>	<i>iadl_phone</i>	<i>idlphon</i>
taking medicine IADL	<i>disab_takemed</i>	[blank]	<i>idlmeds</i>
managing money IADL	<i>disab_money</i>	<i>iadl_money</i>	<i>idlmoney</i>
outside mobility IADL	<i>prob_outside</i>	<i>iadl_outside</i>	<i>idlout</i>
heavy housework IADL	[blank]	<i>iadl_heavywork</i>	<i>idlhvy</i>
travel IADL	[blank]	<i>iadl_travel</i>	<i>idltravl</i>

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