

This article reports research and analysis undertaken by a very successful collaborative, federal interagency work group on disability, convened by the Office of Management and Budget and charged with the development of a short set of disability questions for Census 2000. The process that culminated in the final disability questions on Census 2000 is described, along with a discussion of the complexities of defining and measuring disability.

* Michele C. Adler is with the Division of Disability Research, Office of Research, Evaluation, and Statistics, Office of Policy, Social Security Administration; Robert F. Clark is retired from the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services; Theresa J. DeMaio, Louisa F. Miller, and Arlene F. Saluter are with the U.S. Census Bureau, Department of Commerce.

Note: An earlier version of this article was presented at the Seminar on Interagency Cooperation, sponsored by the Council of Professional Associations on Federal Statistics held in Bethesda, Maryland, on November 4-5, 1998. It has undergone a more limited review than official Census Bureau publications.

Collecting Information on Disability in the 2000 Census: An Example of Interagency Cooperation

*by Michele C. Adler, Robert F. Clark, Theresa J. DeMaio,
Louisa F. Miller, and Arlene F. Saluter**

Summary

The United States Constitution requires that an enumeration (or census) of the population be conducted every 10 years to apportion seats in the House of Representatives. Census information is also used to allocate funds and to plan and manage programs. Census 2000 occurs on April 1, 2000, when one-sixth of all American households will be mailed the “long form,” containing disability, demographic, economic, and housing questions.

Although no short set of commonly accepted questions on disability existed, one was developed for Census 2000 by a collaborative, federal interagency work group on disability, convened by the Office of Management and Budget. The work group consisted of staff from the Social Security Administration (SSA), the Department of Health and Human Services, the U.S. Census Bureau, and other agencies. They reviewed questions initially proposed by the Census Bureau, developed an alternative proposal, tested both versions in the Census Bureau’s cognitive questionnaire lab, and on the basis of testing, derived a consensus version for Census 2000.

In many ways, the six questions now contained on Census 2000 are an improvement over previous efforts. Disability is ascertained for children as well as for adults, and information will be collected separately for several domains of disability (for example, sensory, mental, physical).

The need for a brief set of disability measures goes beyond Census 2000. If such data were collected regularly on national surveys,

critical policy and program concerns across agencies could be addressed because better information could be gathered on changes in disability prevalence and on the characteristics of persons with disabilities. Other similar efforts include the former Disability Evaluation Study, now known as the National Study of Health and Activity—a national sample survey on working-age disability to be conducted by SSA—and the President’s Task Force on the Employment of Adults with Disabilities (Executive Order 13078).

Introduction: Disability Policy and Program Context

Disability is a critical policy issue facing this country and will become even more important as the population ages. However, it is important to note that the subject of disability is far more complicated than other decennial census topics.

First, the needs, uses, and sponsors for data on disability are more widespread than that for any other decennial topic. Decennial topics (such as age) with a wide variety of uses tend to be quite straightforward. Secondly, no single accepted definition of disability exists, making it very difficult to develop a general multipurpose measure. There are other decennial topics that are not clearly defined, but these other topics tend to have a single focus and a single federal sponsor, such as the commuting data needed by the Department of Transportation. Therefore, it is much easier to derive measures in these instances.

Many federal, state, and local agencies administer programs either for or affecting persons with disabilities. Within the federal government, there are several dozen programs, each with a different purpose. Some programs provide cash income, such as Social Security Disability Insurance (DI), Supplemental Security Income (SSI), and veterans' benefits; some programs cover medical care such as Medicare and Medicaid; and others provide services such as special education and vocational rehabilitation.

Although federal programs have different purposes and thus different criteria, there has been a common perception that disability pertains only to the effects of medical conditions or impairments that a person may have. Indeed, disability has been often referred to as a limitation or an inability to perform age-appropriate activities due to a medical condition or impairment. The Americans with Disabilities Act (ADA), enacted in 1990, guarantees civil rights for persons with disabilities. This increases the relevance of disability topics still further, extending beyond the area of programs and entitlements into the legal arena. With the advent of the ADA, it is now recognized that environment can contribute either positively or negatively to disability. For example, a major factor in defining disability for DI and SSI is the inability to work due to a medically determined impairment(s). Besides disability, accommodations in the workplace, in public transit, and in other areas affect whether or not a person is able to hold a job.

Definitions of disability have widespread implications for programs because estimates of the number and characteristics of persons with disabilities vary so much depending on how disability is defined. This can be seen by looking at the wide range of prevalence rates among the working-age population (18-64) using four common ways to define disability based on the 1994-96 National Health Interview Survey Supplement on Disability (NHIS-D), the first comprehensive, national disability survey ever conducted in this country (Adler 1997).

According to the NHIS-D, approximately 25.7 million persons reported a functional disability, defined as one or more limitations in certain mental or physical functions or activities due to a long-term medical condition or impairment. Of these, about 11.6 million reported more severe functional disabilities, defined as activities of daily living (ADLs), in which the help of another person or an assistive device is needed in order to perform basic activities (for example, bathing, dressing). Approximately 16.9 million persons reported a "work disability," defined as either limitations in or the inability to work; 9.1 million reported receiving disability benefits or pensions from either DI, SSI, the Department of Veterans' Affairs, or other public or private sources; and 11.1 million reported that they either perceived themselves or others perceived them as having a disability.

Besides prevalence, characteristics of persons with disabilities also vary greatly depending on how disability is defined. For example, according to the NHIS-D, when disability was defined functionally, 63.1 percent of men and 48.3 percent of women were employed either full- or part-time in 1994 (Adler

1997). But when disability was defined as needing long-term care, only 31 percent of men and 30.5 percent of women were employed. It is important to know how many working-age persons with disabilities are employed in order to assess the impact of the ADA and the role of accommodations for the disabled in the workplace, among other issues. Therefore, the definition of disability can have a major impact on policy and programs.

Section I: Development of Overall Content

The road to Census 2000 content was both challenging and long, beginning during the Content Reinterview Survey phase of the 1990 Census when it became clear that certain questions did not perform optimally (Miller 1997). Official discussions in the federal government began in December 1992 when the Office of Management and Budget (OMB) began to solicit information from federal agencies about specific subjects to be included as part of their Census 2000 data needs.

It is critical to understand the climate under which the Census Bureau was operating. Concerns about cost and coverage led to intense and continuing pressure by Congress to reduce the length of the "long form" or to eliminate it altogether for Census 2000. Some members of Congress expressed concern that some of the questions on the 1990 census were asked for the benefit of the private sector and were not needed by the federal government. As a result, the Census Bureau scrutinized content for Census 2000 very rigorously.

The Census Bureau began by carefully reviewing the text of the underlying laws authorizing federal programs using census data. A legal typology was used, under which subjects were classified as mandatory, required, or programmatic. A subject was classified as *mandatory* if there was a federal law that actually mandates the use of decennial census data on the subject. A subject was classified as *required* if there was either a federal law that requires the use of data on this subject or if the data were needed for case law requirements imposed by the U.S. federal court system. Finally, a subject was classified as *programmatic* if a federal agency told the Census Bureau that it needed the data for program planning, implementation, or evaluation but there was no explicit legal requirement. Only mandatory and required subjects are included on Census 2000. Disability was determined to be a *required* subject based on laws pertaining to certain programs in the Department of Education.

The Census Bureau had an extensive formal content development process for Census 2000. Very briefly, the steps followed for developing disability questions included:

- Reviewing material from the Interagency Policy Committee of the Task Force for Designing the Year 2000 Census and Census Related Activities for 2000-2009 (comprised of the major federal agency decennial census data users and cochaired by OMB and the Census Bureau), which had gone out of existence before the work group's creation;

- Devising an extensive testing program including both cognitive and field tests; and
- Soliciting input from federal agencies and from the nonfederal sector.

Section II: Development of Disability Questions

Disability items have been included on the decennial census since 1830 (although not included on every census). Every 10 years, the Census Bureau asks agencies for topics to include on the decennial form and for justification of their need on the decennial census. Federal agencies again requested that disability be included on Census 2000, as was the case for the 1990 census, which reflects the urgent need for disability data. The programmatic landscape and policy implications of disability issues had changed since 1990, because of the advent of the ADA and increases in SSA's disability rolls. The magnitude of these changes affected the content of the questions and focused more attention on the process used to determine questions for the Census.

The version proposed by the Census Bureau for Census 2000 was designed with the assistance of the Interagency Committee on Disability Research (Subcommittee on Disability Statistics) through meetings and mailings to subcommittee members. The Census Bureau version was presented at a fall 1996 meeting of this group, and further input was solicited. Additional input was provided by representatives of the President's Commission on Employment of Persons with Disabilities and other interested researchers. As a result, the 1990 census question on whether a respondent was prevented from working by his or her disability was dropped based on the Commission's strong arguments that such a question was out of date. The Commission's concerns were that the questions did not allow work environment and employment accommodations to be factors influencing an individual's ability to work. However, ability to work is a critical factor in eligibility for many disability programs, such as DI and SSI.

This set of disability questions, along with the rest of the questions planned for the U.S. Census 2000 Dress Rehearsal were sent out to the former Interagency Policy Committee in the spring of 1997 for comment and, hopefully, concurrence. The Census Bureau proposed dropping the ADL question, which had appeared on the 1990 census (chart 1). Feedback from the former Interagency Policy Committee made it clear that dropping the ADL item and the general complexity of disability meant that further development was needed. Thus, another group

(the Work Group on Disability), convened by OMB was formed in June 1997 and chaired by Nancy Kirkendall of OMB. The purpose of the collaborative effort was to design a set of disability questions that would satisfy the needs of federal agencies. There were severe time constraints because a modified set of questions had to be designed and tested by the end of the summer to be included on the U.S. Census 2000 Dress Rehearsal conducted in 1998.

The work group met very intensively over the summer, with subgroups meeting outside of the full group meetings. It was critical that certain ground rules were followed, namely that—

- Questions must meet the needs of the laws for which census disability data were required (that is, laws from the Department of Education requiring disability items);
- An alternative proposal could be developed by the work group;
- The alternative proposal could not take up more space on the form nor could it include more than the six questions on the version initially proposed by the Census Bureau (chart 2);
- Questions must meet the Census Bureau's minimum pretest requirements, including testing in the cognitive questionnaire lab;¹ and
- Questions must not jeopardize the other questions on the form, for example, by adding complex skip patterns, and so forth.

Since the development of the disability questions for the 1990 census, years of careful methodological work had been devoted to developing measures for the NHIS-D, particularly for persons under age 65. The work group took advantage of methodological work in designing the NHIS-D (including work

Chart 1.—1990 Census questions

18. Does this person have a physical, mental, or other health condition that has lasted for 6 or more months and which—
- a. Limits the kind or amount of work this person can do at a job?
 Yes No
- b. Prevents this person from working at a job?
 Yes No
19. Because of a health condition that has lasted for 6 or more months, does this person have any difficulty—
- a. Going outside the home alone, for example, to shop or visit a doctor's office?
 Yes No
- b. Taking care of his or her own personal needs, such as bathing, dressing, or getting around inside the home?
 Yes No

in the cognitive questionnaire lab). However, different circumstances prevailed for Census 2000. The NHIS-D was totally devoted to disability. Many items needed in order to ascertain the full extent and severity of disability were included in the NHIS-D, because disability can affect so many activities and result from so many origins (for example, sensory, physical, mental, emotional, cognitive). Altogether, about 50 questions were used to measure disability among adults and another 50 for children. The work group had a six-question limit for both children and adults.

Information on the best way to compress the many items in the NHIS-D would have been very useful, but the data were not yet available. The work group decided that the next best approach was to identify broad domains of disability and fit them into the six-question limit imposed for Census 2000. Three domains that reflect the broad classifications of health conditions and impairments resulting in disability were identified as (1) sensory impairments (seeing, hearing); (2) physical impairments (walking, lifting, climbing stairs, reaching, carrying); and (3) mental/emotional/cognitive impairments (learning, remembering, concentrating).

In addition, three specific types of functioning needed for program and policy concerns were included. The first two measures refer to more severe loss of functioning and the third to the ability to work. All three could have sensory, physical, mental, cognitive, or emotional origins. These items include:

- Activities of Daily Living (ADLs)—dressing, bathing, getting around the house;

- Instrumental Activities of Daily Living (IADLs)—going outside to visit a doctor's office or going shopping; and
- Working at a job or business.

Other Issues

Other general conceptual issues that were addressed and resolved included:

Combination items.—To meet the six-question limit, it was clear that multiple items would need to be grouped within a single question. The challenge was to develop these questions so that they would be understandable.

Duration or length of disability.—To distinguish between short-term and long-term (or acute and chronic) disabilities, only disabilities with at least 6 months duration were included.

Work accommodations.—The importance of work accommodations was prompted by the passage of the ADA. This is a new area and very little literature or survey experience exists. Some work accommodation items did appear in the NHIS-D, but those data had not yet been released. The work group developed and tested a question on work accommodations, but the question failed, because the severe time constraints did not allow the magnitude of developmental work needed. A description of the work accommodation question is contained later in this article. However, since work accommodation is of such great interest, the Survey of Income and Program Participation (SIPP) was offered as a possible research vehicle for future work on question design.

ADLs and IADLs.—Questions on ADL and IADL limitations were included in the 1990 census in order to derive prevalence rates for individuals with the most severe disabilities. Since the ADL question did not perform well in the Census Bureau's own validity tests, serious consideration was given by the Census Bureau to dropping that item entirely from Census 2000. However, opposition from other agencies was strong. The next section describes the issues around the inclusion of both ADL and IADL items on Census 2000.

Section III: ADL and IADL Questions

The ADL and IADL limitations are widely used measures of functional status and disability in survey research, clinical settings, and public programs, with the most frequent application being among the elderly (aged 65 or older). ADL limitations tend to focus on basic personal self-care activities, while IADL limitations

Chart 2.—Version initially proposed by the U.S. Census Bureau

6. Mark the category that best describes this person's usual ability to perform the following activities:

	No difficulty	Some difficulty	Great difficulty or unable
a. Perform mental tasks such as learning, remembering, concentrating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Dress, bathe, and get around inside the home without help from another person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Answer if person is 16 YEARS OLD OR OVER—

c. Go outside the home alone to shop or visit a doctor's office	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
---	--------------------------	--------------------------	--------------------------

7. Does this person have any of the following long-lasting conditions—

	Yes	No
a. Blindness or a severe vision impairment?	<input type="checkbox"/>	<input type="checkbox"/>
b. Deafness or a severe hearing impairment?	<input type="checkbox"/>	<input type="checkbox"/>
c. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?	<input type="checkbox"/>	<input type="checkbox"/>

pertain to more sophisticated activities, often involving activities in the outside world, like going outside. Like other disabilities, ADL and IADL limitations can result from many different kinds of conditions or impairments, but generally ADL limitations tend more to have physical and sensory origins, while IADLs tend towards mental and/or cognitive origins.

Questions on long-term difficulties in performing ADLs and IADLs have been used in national surveys to establish chronic disability prevalence rates for the elderly. ADL questions in more extensive disability-oriented surveys include such activities as eating, bathing, dressing, toileting, transferring (going from bed to chair), getting around inside, and getting around outside. IADL questions include such activities as doing heavy work around the house, doing light work around the house, doing laundry, preparing meals, shopping for groceries, managing money, and using the telephone. While there exists no “gold standard” for the measurement of disability, questions on ADLs and IADLs have been found to be significant predictors of nursing home admission, living arrangements, use of physician services, insurance coverage, and mortality.

The 1990 census contained ADL and IADL questions similar to the ones in the U.S. Census 2000 Dress Rehearsal questionnaire. The 1990 question reads as follows:

19. Because of a health condition that has lasted for 6 or more months, does this person have any difficulty—
 - a. going outside the home alone, for example, to shop or visit a doctor’s office?
 - b. taking care of his or her own personal needs, such as bathing, dressing, or getting around inside the home?

The Census Bureau used results from the 1990 Content Reinterview Survey (CRS) to evaluate the performance of the 1990 census questions. In the CRS, a sample of households that had received the 1990 “long form” was re-asked those and other questions. The 1990 census, like all others, was answered by filling out a questionnaire received in the mail. However, the CRS was conducted by telephone about 6 weeks later than the 1990 census. There was no attempt in the CRS to reach every household member. For the most part, only one person in each household participated.

In comparing results between the 1990 census and the CRS, the IADL question (going outside the home) worked reasonably well, whereas the ADL question (personal needs) did not. The 1990 census estimate was more than twice as high as the CRS estimate for both age groups. Among persons aged 65 or older, 9.1 percent of respondents reported an ADL difficulty in the 1990 census, compared with only 4.1 percent for the CRS. Among persons aged 16-64, the proportions were 2.9 percent in the 1990 census, compared with 1.3 percent in the CRS. In contrast, the IADL difficulty question on “going outside” showed more similar responses. Among persons aged 65 or older, 11.9 percent of respondents to the 1990 census indicated an IADL difficulty, compared with 11.8 percent from the CRS. Among persons aged 16-64, the proportions were 2.3 percent in the 1990 census, compared with 2.1 percent for the CRS.

Based on these findings, the Census Bureau initially proposed dropping the ADL question entirely and deriving the prevalence of ADL limitations using a model-based approach. Essentially, the probability that a person had ADL difficulty would be generated using the IADL variable (going outside) along with other variables (such as age and sex) in conjunction with a set of more specific limitations given on the CRS. The resulting estimate would then be adjusted through a raking procedure to keep it in conformity with estimates independently generated from the SIPP.

The Census Bureau proposal had undeniable face validity. The IADL question worked well, while the ADL question did not. However, such an indirect approach to ADL measurement caused discomfort among the policy research communities in disability and aging. Since the ADL and IADL items refer to such different activities, it did not make sense to derive estimates of ADLs (disabilities that are largely physical or sensory in origin) based on data from IADLs (disabilities that are largely mental or cognitive in origin).

Five arguments were put forward to retain a direct ADL question in Census 2000. *First*, there is value in having data from the same or a similar question at more than one point in time, even if the question is not perfect. Since the question in a slightly altered form appeared on the 1990 census, it should be considered a strong candidate for Census 2000.

Second, the achievement of similar estimates between the census and the CRS may be unrealistic due to differences in interviewing modes between the two (mail-out versus telephone) and to greater opportunities for proxy respondents in the CRS. Furthermore, actual changes in ADL status can and do occur over even short periods of time, as individuals become more and less functional due to rehabilitation, changes in medical conditions or impairments, and the impact of assistive devices.

Third, no independent body of research establishes a correlation between IADL limitations (in this instance the ability to “go outside”) and performance on ADLs. This issue was looked into for elderly persons in a preliminary way based on the 1994 National Long-Term Care Survey (NLTC). As shown in table 1, of the 1.3 million persons needing help with ADLs, 53 percent received help getting around outside (an IADL measure), while 47 percent did not. Of the 1.2 million persons receiving help getting around outside, 58 percent received help in one or more ADLs, while 42 percent did not. Thus, there did not appear to be a correlation between help with ADLs and help with going outside the home. This is not surprising considering the difference in broad groups of health conditions that typically result in ADL and IADL limitations.

The 1990 census estimates that of the 3.5 million persons aged 65 or older reporting a self-care limitation (the ADL question), 62 percent also had a limitation in going outside (the IADL question) and 38 percent did not. Conversely, of the 4.6 million elderly persons reporting a limitation in going outside, 47.5 percent also reported a self-care limitation (the ADL question) and 52.5 percent did not.

Thus, while overall estimates of ADL and IADL limitations in

the 1990 census were smaller than estimates from those derived from other national surveys, no clear and direct correlation between ADL and IADL status was seen. This is because, as most researchers believe, ADLs and IADLs measure the capacity to perform functions based on an underlying etiology of disease, including both physical and cognitive dimensions. It is not uncommon among elderly populations for cognitively impaired individuals to have high levels of physical functioning. Indeed, this is often the case for persons with Alzheimer's disease. Agency members of the work group concluded that both the ADL and IADL items were required on Census 2000 in order to achieve the soundest models and support the kinds of discrete multivariate approaches needed to produce more robust results.

Fourth, a great deal of methodological research has been performed on ADL measures among the elderly. The work group consulted with many of these researchers who all concluded that the ADL question should be retained on Census 2000.

ADL measures can consist of up to nine separate activities; but six (that is, walking across the room, bathing, dressing, eating, transferring from bed to chair, and using the toilet) are commonly used. Rodgers and Miller (1997) concluded that summary measures such as the 1990 census item are sound even after complications such as the following were considered: differences in sampling frames, question wordings, scaling effects (for example, level of difficulty), proxy reporting, interviewer effects (for example, influence of personal characteristics of the interviewer), interview mode effects (in-person, mail, telephone), and durations of disability. In their study, ADL questions from various surveys were compared and summary measures were developed; results were compared from Wave 1 of the Asset and Health Dynamics (AHEAD) Survey, the 1984 Supplement on Aging (SOA) to the NHIS, and the 1982 NLTCS. In addition to ADL questions on AHEAD, three random samples of AHEAD respondents were also asked ADL ques-

tions from the SOA, the NLTCS, and the 1990 census. In the SOA comparison, the two sets of questions had similar results on specific ADL limitations, except for eating.² More importantly for this comparison, a summary measure covering all six ADLs improved the similarity of the results. Thus, SOA showed 6.7 percent of respondents receiving help on one or more of six ADLs, compared with 9.1 percent of the AHEAD respondents. Similar results were seen when another sample of AHEAD respondents was asked a series of specific ADL questions from the NLTCS. Even with a great deal of variation between surveys on individual ADL results, the authors concluded that a summary ADL measure appeared to have construct validity.

A sample of AHEAD respondents was also asked the ADL question from the 1990 census. The prevalence of ADL limitations from the 1990 census question was much smaller (6 percent) than those reporting an ADL limitation in AHEAD (25 percent), SOA (28 percent), or the NLTCS (23 percent). However, one encouraging fact is worth noting—all AHEAD respondents who reported a limitation in response to the Census question also reported a limitation on at least one of the AHEAD core ADL questions. The Census question did not elicit affirmative responses that were not matched anywhere else.

Fifth, there was a strong push by policymakers and researchers in and out of government to retain an ADL question in Census 2000 so that local area estimates could be produced, particularly those involving health, aging, disability, and long-term care issues. Local area estimates are required more often by policymakers and researchers because of increased involvement of states and local areas in health and long-term care policy and programs. While national surveys can provide more in-depth descriptions than decennial census on levels and types of disability, decennial censuses are often the only source of local area estimates. The inclusion of an ADL question on Census 2000 would allow analysts to develop

Table 1.—Number and percent of persons aged 65 or older who get help with one or more ADLs,¹ by whether or not they receive help getting around outside

[Numbers in thousands]

Help with ADLs	Total		Receives help getting around outside (an IADL) ²		Does not receive help getting around outside (an IADL) ²	
	Number	Percent	Number	Percent	Number	Percent
Total.....	5,828.8	100.0	1,195.8	100.0	4,633.0	100.0
Receives help in one or more ADLs.....	1,322.3	22.7	696.7	13.5	625.6	13.5
Does not receive help in one or more ADLs.....	4,506.5	77.3	499.1	86.5	4,007.4	86.5

¹ Activities of Daily Living (ADLs) consist of eating, getting in and out of bed, getting dressed, bathing, and using the toilet.

² Instrumental Activities of Daily Living consist of going outside, going shopping, preparing meals, using the telephone, and managing money.

Source: 1994 National Long-Term Care Survey/Community File.

models based on responses to the Census 2000 ADL question and other more detailed items on nationally representative sample surveys. The experience of researchers on the HRS and AHEAD team³ to improve modeling capability using national survey data has been encouraging.

Section IV: Cognitive Questionnaire Lab Testing

The initial version of disability questions proposed by the Census Bureau (referred to as the Census version) and the alternative proposal (developed by work group members outside the Census Bureau) were reviewed by members of the former Interagency Policy Committee, and cognitively tested by the Census Bureau. The Census Bureau version included an attempt to collect information on severity, by asking respondents to differentiate between “no difficulty,” “some difficulty,” and “great difficulty or unable” rather than asking all “yes” and “no” questions.

As noted previously, the first three questions in the alternative proposal focused on different types of disabilities resulting from three broad domains of conditions and impairments: sensory, physical, and mental; emotional; and cognitive. The second three questions focused on certain functional limitations: those in ADLs, IADLs, and ability to work. Although space for only six questions was available on Census 2000, an additional question (8) was tested to try to identify persons with a need for work accommodation. The plan was to use either question 8 or question 6d, but not both.

The Census Bureau tested the two proposals in their cognitive questionnaire lab to see how well they worked. Cognitive testing involved small-scale, one-on-one interviews to probe how people interpret the questions, formulate their responses, and in a self-administered form, such as the decennial census, navigate through the questionnaire. This technique was designed to give quick, qualitative information about problems with the terminology and concepts contained in the questions, the reference period, and the respondent’s ability to provide the information. However, the respondents did not constitute a representative sample, and the results were not generalizable to any larger population.

Census Bureau staff conducted 20 cognitive interviews in August 1997, interviewing 10 people with each form. The questions were tested on a wide range of people. Interviews were conducted with persons with disabilities, persons who could report for disabled household members, and persons without disabilities. Subjects included both children and adults with a wide range of disabilities including diabetes, epilepsy, multiple sclerosis, back injuries, blindness, severe hearing impairments, severe learning disabilities, mental retardation, cerebral palsy, and attention deficit disorder.

The results of the testing indicated that there were problems in both the Census Bureau and the alternative version. The response scale associated with question 6 caused one of the major problems with the Census Bureau version (chart 2). The question stem is not in the form of a question, but rather a

statement: “Mark the category that best describes this person’s usual ability to perform the following activities.” Respondents found this confusing, since the response scale did not match up exactly with the question. Some respondents understood the question to be asking if they could do an activity. They were expecting “yes” and “no” response options. However, since those options were not there, they had to translate their yes or no response into something that matched the scale. This proved difficult for respondents, many of whom kept changing their answers. Respondents were also asked to interpret the meaning of response categories. Their answers suggested that they could not easily differentiate between response categories. In addition, there did not seem to be consistency in the meaning of each category across respondents. It seemed easier for respondents to just be able to report that they either had or did not have difficulty in performing the activity.

The formatting of the response options in question 7 also proved problematic for respondents. The “yes” boxes in question 7 were in a perfect line down the column from the “some difficulty” boxes in question 6. Some people answered the “yes” box while saying aloud “some difficulty.”

Another problem with this question series was that the dimensions of the response categories were reversed in questions 6 and 7. There were persons who reported in question 6 that they had “no difficulty” when it was contained in the left-most column, but did not report “no difficulty” when it was in the right-most column, as in question 7. Problems were created when respondents learned the pattern of responses in question 6 and wanted to continue it in question 7, even though the pattern was different. Some misreporting occurred because of this reversal of categories.

Since the wording of the alternative disability questions was new, particular attention was paid to how well respondents understood the intent of the questions (chart 3). For example, in the lead-in to question 6, it was important to ascertain whether respondents understood that the scope of the question included physical, mental, and emotional conditions. When asked to paraphrase question 6 back to the interviewer, it was clear that respondents were considering all three kinds of conditions. Respondents also correctly understood the time frame used—that only conditions lasting 6 months or more should be reported. Respondents noted that broken legs and things of that temporary nature should not be included.

Another concern was whether respondents would understand that only one of the three different types of activities listed in questions 6a and 6b had to be problematic in order to answer “yes”; in other words, did they correctly interpret the “or” term. The interviews showed that respondents were comfortable responding “yes” to an item, even if they only had difficulty with one of the multiple activities listed.

Some of the content, however, was problematic. Question 6b was difficult and confusing for most of the respondents who wore glasses. The phrase “with glasses” had multiple interpretations; some thought it meant “difficulty seeing with their glasses on,” others thought it meant “difficulty seeing and

needed glasses.” Many respondents who wore glasses reported that they had difficulty with this activity because they wore glasses. However, this was not the intended interpretation.

This item also did not work correctly for persons who had difficulty talking. This question had problems on several fronts. Two respondents (one with epilepsy and one with a brain injury from a fall) did not report difficulties with their speech that seemed quite apparent to the interviewers. Also, a parent reported that her child had no difficulty, and then later noted that he visited a speech therapist because of his slurred speech.

The other question in this series that caused problems of interpretation was question 8—“Does this person need special work arrangements for people with disabilities? For example: special equipment, accessible bathrooms, changes in work schedule or assignment, personal attendant, wheelchair ramps.” Although the question was about work arrangements, it was not always interpreted that way. Some people thought it could refer to accommodations for school or getting around the home.

A major problem with the work accommodation question was that it was asked of the entire population aged 15 or older, encompassing people in a wide variety of circumstances. For example, retired persons without disabilities were not sure whether or how to answer this question since they did not

work, and in some cases had not worked in quite a while. Persons with disabilities who did not work had difficulty with this question. A working-age respondent with physical disabilities reported that he did not need special accommodations because he was not currently working. Although he might be able to hold a job, he did not think the question applied to him. From the point of view of good question design, respondents should be able to interpret the question properly. A “yes” response should mean that a person needs special accommodations to work and a “no” response should mean that a person does not need such accommodations. That did not happen with this question.

Section V: Final Consensus

After results from the cognitive questionnaire lab were presented, the work group fully acknowledged and completely understood the difficulty in measuring disability in a brief, but comprehensive way. For the questions to be used in the U.S. Census 2000 Dress Rehearsal and Census 2000. Therefore, elements from both proposals were incorporated into recommendations for the U.S. Census Dress Rehearsal and Census 2000, thus improving the final product and contributing to the success of the whole enterprise (chart 4). The following points were considered:

- Both proposals had good points and problems (DeMaio and Wellens 1997).
- The format and response categories in the Census Bureau proposal to measure severity caused misreporting. The recommended version of the questions adopted the “yes or no” response categories from the alternative proposal.
- Unclear wording in the alternative proposal was dropped.
- The general two-question structure of the Census Bureau proposal was used, but the more simplistic wording in the alternative proposal was used in cases where the wording was not problematic.
- The ADL question was retained.
- The question on work accommodations was dropped, but an item on “working at a job or business” was included.

Chart 3.—Alternative proposal

6. Because of a physical, mental, or emotional limitation lasting 6 months or more, does this person have any difficulty in doing any of the activities listed below?

	Yes	No
a. Learn, remember or concentrate	<input type="checkbox"/>	<input type="checkbox"/>
b. Talk, see (with glasses), or hear	<input type="checkbox"/>	<input type="checkbox"/>
c. Walk 3 blocks or lift a bag of groceries	<input type="checkbox"/>	<input type="checkbox"/>

Answer if person is 16 YEARS OLD OR OVER—

d. Work or keep house	<input type="checkbox"/>	<input type="checkbox"/>
e. Go outside the home alone to shop or visit a doctor's office	<input type="checkbox"/>	<input type="checkbox"/>
f. Dress, bathe, or get around inside the home	<input type="checkbox"/>	<input type="checkbox"/>

7. When was this person born?

Born on or before August 10, 1982

Born after August 10, 1982 → *Skip to 9*

8. Does this person need special work arrangements for people with disabilities? (For example: special equipment, accessible bathrooms, changes in work schedule or assignment, personal attendant, wheel chair ramps.)

Yes No

Conclusion

Disability is a notoriously hard concept to define and measure. Yet disability programs and policy are so

critical that attempts must be made to do both. The summary measures in Census 2000 present big steps towards the development of more widely accepted measures. However, constraints faced in Census 2000 were greater than those found in most other national surveys, perhaps the largest constraint being the six-question limit. Furthermore, because Census 2000 is for the most part administered by mail, more widely tested techniques used for in-person or telephone surveys could not be used.

Since the work group ended in 1997, the disability questions in Census 2000 have also been included on the Behavioral Factor Risk and Surveillance Surveys conducted in stages by the Centers for Disease Control. The Census 2000 will also be included in the pilot study of the National Study of Health and Activity (NSHA)⁴—a national sample survey.

A major goal of the NSHA, a contract awarded by the Social Security Administration to study disability among the working-age population, is to develop a short set of disability questions. As part of the NSHA, the Census 2000 items along with other disability measures will be evaluated and tested. In addition, the President's Task Force on the Employment of Adults with Disabilities, created by Executive Order 13078, requires the Bureau of Labor Statistics, Department of Labor, in conjunction with other federal agencies, to develop an accurate and reliable methodology for measuring disability in order to determine employment patterns for persons with disabilities. Finally, a consistent summary disability measure could be used on many other data collections (for example, the National Crime and Victimization Survey, the American Housing Survey) regardless of whether or not they pertained to disability.

One thing is certain. Disability questions will again be needed by federal agencies in Census 2010. But the procedure should be easier because more methodological work on disability will have been done and more attention will have been paid to this most important topic. First, data from Census 2000 will be available. Secondly, the NSHA will have been completed and the results will be used to develop summary measures based on a variety of ways to collect disability information: from self-reports in surveys, medical examinations, and performance tests. Finally, as seen in the development of Census 2000 questions, it is now almost universally accepted that cognitive questionnaire labs play a central role in disability measurement. In fact, cognitive questionnaire labs are used in designing the NSHA. Cognitive questionnaire labs insure that not only disability researchers, but persons with disabilities are included in determining how disability can be measured. For a topic as complex as disability, that is the only sensible way to proceed.

Notes

¹ Cognitive questionnaire labs are standard survey design tools. A variety of techniques including "think aloud" procedures are used to ascertain how respondents interpret and answer survey questions.

² Only 0.8 percent of SOA question respondents reported help with eating, compared with 2.6 percent of the AHEAD question respondents, which represents a statistically significant difference.

³ The Health and Retirement Survey and AHEAD are two parts of a larger survey effort (the HRS/AHEAD Survey Team) being conducted by the University of Michigan.

⁴ The National Study of Health and Activity, perhaps the most ambitious national study of disability among the working-age population (18-69) will be fielded in early 2001. Comprehensive disability data will be collected from many sources, including self-reported survey interviews, medical examinations, and medical records. More information can be found on-line at: <www.ssa.gov/policy>.

References

- Adler, Michele. 1997. Unpublished tabulations from the National Health Interview Survey Supplement on Disability. Social Security Administration.
- DeMaio, Theresa and Tracy Wellens. 1997. "Cognitive Evaluation of Proposed Disability Questions for the 1998 Dress Rehearsal." Unpublished report. U.S. Bureau of the Census (September 22).

Chart 4.—Census 2000 questions

16. Does this person have any of the following long lasting conditions:	Yes	No
a. Blindness, deafness, or a severe vision or hearing impairment?	<input type="checkbox"/>	<input type="checkbox"/>
b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?	<input type="checkbox"/>	<input type="checkbox"/>
17. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities:	Yes	No
a. Learning, remembering, or concentrating?	<input type="checkbox"/>	<input type="checkbox"/>
b. Dressing, bathing, or getting around inside the home?	<input type="checkbox"/>	<input type="checkbox"/>
c. (Answer if this person is 16 YEARS OLD OR OVER.) Going outside the home alone to shop or visit a doctor's office?	<input type="checkbox"/>	<input type="checkbox"/>
d. (Answer if this person is 16 YEARS OLD OR OVER.) Working at a job or business?	<input type="checkbox"/>	<input type="checkbox"/>

Keller, Donald M. (No date). "Activities of Daily Living: A Guide to the Literature." Working Paper Series No. 42. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Health Statistics.

Miller, Louisa. 1997. "The Road to Census 2000 Content." *American Statistical Association 1997 Proceedings on the Section on Government Statistics and Section on Social Statistics*, pp. 78-87.

Rodgers, Willard and Baila Miller. 1997. "A Comparative Analysis of ADL Questions in Surveys of Older People." *Journal of Gerontology: Series B*, 52B (Special Issue), pp. 21-35.

Wiener, Joshua; Raymond Hanley; Robert Clark; and Joan Van Nostrand. 1990. "Measuring the Activities of Daily Living: Comparisons Across National Surveys." *Journal of Gerontology: Social Sciences*, Vol. 45, S229-S237.