

# **Cross-Federal Survey Measures of Disability: Making Meaning Out of Chaos**

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## **Abstract**

Prevalence estimates of persons with disabilities are important for public health planning purposes. But it is often difficult to compare estimates derived across data sources due to survey differences: in purpose, scope, and target populations; in data collection processes, including questions and response categories; and in analysis, where specific measures will be constructed post data collection based on the availability of questions.

Because of a desire to include more disability data in the Agency for Healthcare Research and Quality's National Disparities and Quality Reports (NHDR/QR), a process was initiated in 2005 to examine this phenomenon for activity limitations. Activity limitations is an important component of the disability construct and provides a way of systematically looking at this important measurement issue for three national surveys: the Medical Expenditure Panel Survey, National Health Interview Survey, and Medicare Current Beneficiary Survey.

This process culminated in the development of comparable disability measures for the three surveys which measures have been used in the NHDR/QR since 2007. American Community Survey estimates are provided for comparison purposes.

## **1. Introduction**

Prevalence estimates of persons with disabilities are important for public health planning purposes. The U.S. Census and national surveys have been asking about disability in a variety of different ways. Estimates of functional difficulties, activity limitations or impairments, and medical conditions associated with different domains of disability have been produced for many years. But the prevalence estimates found across surveys are often different. Question focus, answer categories, introductory statements, skip patterns, and various other aspects of questionnaire construction combine to reflect different operationalizations of the conceptual components associated with disability definition and thereby produce different estimates.

The International Classification of Functioning, Disability, and Health (ICF) defined four components of disability (Body Functions and Structures, Activities and participation, Environmental Factors, and Personal Factors). Activity limitations (operationalized by the Activities and participation component of the ICF) is considered one of the most important concepts.

Questions in several major surveys, including the Medical Expenditure Panel Survey (MEPS), National Health Interview Survey (NHIS), Medicare Current Beneficiary Survey (MCBS), and American Community Survey (ACS) capture activity limitations. The focus of this paper is to compare activity limitation questions and their estimates from three national surveys (MEPS, NHIS, and MCBS). In addition, we will harmonize the different survey approaches for the MEPS, NHIS and MCBS to examine various disability data for public health purposes. The ACS estimates are provided for comparison purposes.

## 1.1. Background

This work had its origin with activities related to the Agency for Healthcare Research and Quality (AHRQ) *National Healthcare Disparities Report* and *National Healthcare Quality Report* (NHDR/QR). AHRQ has produced the NHDR/QR since 2003 in accordance with legislation enacted by the U.S. Congress. AHRQ is mandated to report national trends in the quality of health care and prevailing disparities in health care delivery as it relates to racial and socioeconomic factors in priority populations, which include individuals with disabilities.

The earliest NHDR/QRs (2003-2006) contained limited sections on disabilities and the production team wanted to include more information about individuals with disabilities in these reports. Because of difficulties in obtaining consensus on the definition and measures of disability and in getting comparable measures of disability across surveys, AHRQ, in conjunction with the Interagency Subcommittee on Disability Statistics (ISDS) of the Interagency Committee on Disability Research (ICDR), brought together an interagency Disability Working Group (DWG) to work with the NHDR/QR Interagency Work Group.

This DWG<sup>v</sup> developed comparable measures of disability for MEPS, NHIS, and MCBS using existing data to report disability information in the NHDR/QR. The ICF (WHO, 2001) was adopted by the DWG to guide the deliberations. The disability measures developed by the DWG have been used in the NHDR/QR starting with the 2007 NHDR/QR.

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<sup>v</sup> The DWG included representatives from the Agency for Healthcare Research and Quality, Administration on Aging, Assistant Secretary for Planning and Evaluation, HHS Office of the Secretary Office on Disability, Centers for Disease Control and Prevention (CDC) National Center for Health Statistics, CDC National Center on Birth Defects and Developmental Disabilities, Centers for Medicare & Medicaid Services, National Institutes of Health (NIH) National Institute on Aging (NIA), NIH National Center for Medical Rehabilitation Research (NCMRR), Health Resources and Services Administration, Substance Abuse and Mental Health Services Administration, Social Security Administration, Department of Education National Institute on Disability and Rehabilitation Research, National Council on Disability, U.S. Census Bureau, and Department of Veterans Affairs.

## 1.2. Objective

It is often difficult to compare estimates derived across data sources. These difficulties arise from data collection and analysis. Collected data elements will reflect the purpose, scope, and target population of the survey. In addition, the overall focus of the collection (health, housing, economic issues) may influence how respondents answer any specific set of queries. To reduce respondent burden, surveys often use “screener” questions so that respondents are screened out of question series from which a “low yield” of positive responses is expected. Post collection, analysts will construct specific measures based on the availability of questions.

Because of all these factors, estimates for similar questions in general and specifically for disability may yield disparate estimates. This paper examines this phenomenon for activity limitations, an important component of the disability construct, and provides a way of systematically looking at this important measurement issue.

People have examined this issue before (Wiener, et al., 1990; Federal Interagency Forum on Aging-Related Statistics, 2010); our paper develops a protocol for harmonizing the different survey approaches. We present an in-depth analysis of the disability survey questions, response options, and prevalence estimates for the common domains of disability for MEPS, NHIS, and MCBS.

In addition, we suggest reasons differences exist, and develop a protocol for harmonizing the different survey approaches to examine disability data from various sources for public health purposes. In order to harmonize the different survey approaches, we studied domain estimates by different severity levels (determined by the survey questions/responses for that domain) to determine which provided the closest match within domains.

This paper's method of harmonizing different survey approaches for measuring disability resulted in a disability measure that has been used in the analysis of disability data in the NHDR/QR since the 2007 reports.

At the time of this study, efforts were also in progress in the development and implementation of the current ACS disability questions (introduced starting with the 2008 ACS), and in the recommendation of these questions as a standardized core measures of disability across surveys. At that time, the ACS disability questions were not part of MEPS, NHIS, or MCBS.

### **1.3. Measurement of disability**

There is no uniform standard on how to measure or define disability or more specifically activity limitations. The ICF uses the term "disability" as an umbrella term for impairments, activity limitations, or participation restrictions (WHO, 2001). The first criterion of the Americans With Disabilities Act defines a person as having a disability as one who has a physical or mental impairment that substantially limits one or more "major life activities" (U.S. DHHS, 2005).

Among the more common approaches are to identify individuals who have problems performing everyday functions such as seeing, hearing, communication, self-care, mobility, learning, and behavior; have difficulty with complex activities such as working; or meeting eligibility criteria for important income maintenance or training programs (e.g., SSDI [Social Security Disability Income] or vocational rehabilitation) (NHDR, 2008). Many researchers (Nagi, 1965; Granger, 1984; LaPlante, 1991; Altman & Bernstein, 2008) dichotomize "major life activities" into two levels, though this approach is by no means universal. Most use the same building blocks to focus on – the domains of disability or chapters in the Activities and participation component of the ICF (WHO, 2001).

Using the ICF as guidance, the DWG examined the MEPS, NHIS, and MCBS disability questions; identified commonalities among their estimates; and developed paired measures based on those commonalities for adoption in the NHDR/QR. These disability measures use a broad definition of disabilities that captures relevant elements of the Americans with Disabilities Act (U.S. DHHS, 2005) and recent guidance from the Institute of Medicine (IOM, 2007). The two measures of disability for adults for use across MEPS, NHIS, and MCBS that were agreed on were:

1. A measure of basic activities that represents *limitations in basic activities* at the person level; and
2. A measure of *complex activities* that represents limitations encountered when the person attempts to participate in community life.

*Limitations in basic activities* in this context focuses on problems with mobility and other physical functioning and includes the following domains: mobility, self-care (activities of daily living, or ADLs), domestic life (instrumental activities of daily living, or IADLs), and activities that depend on sensory functioning (limited to people who are blind or deaf).

A second component of the measures produced by the comparisons focuses on *limitations in complex activities* and includes: questions that address limitations in work, and limitations in community, social and civic life activities that are influenced by both individual limitations and facilitators or barriers experienced in the environment.

These paired measures of basic and complex activity limitations are conceptually similar to the way others have dichotomized disability (LaPlante, 1991; IOM, 2007; Altman and Bernstein, 2008) and are consistent with the ICF division of activity limitations and participation restrictions (WHO, 2001). These two categories are not mutually exclusive. People often have limitations in

both basic and complex activities; however, on occasion where the basic activity limitation is not captured in the questions set, the measures of complex activity will capture many of those respondents. Sometimes the activities listed under complex activities limitations (work, social activities) are analyzed as dependent variables. For example, employment status can be analyzed by disability status with any dataset that has both disability and employment information. Such datasets include the ACS, Current Population Survey (CPS), Survey of Income and Program Participation (SIPP), MEPS, and NHIS (Brault, 2010; U.S. Department of Labor, 2010).

#### **1.4. Survey background and methods**

MEPS is designed to provide nationally representative annual estimates at both the individual and family level of health care use and expenditures, access to care, patient satisfaction, health status, and insurance coverage for the U.S. civilian noninstitutionalized population. MEPS allows the identification of persons with disabilities, including those with activity limitations, and allows for analyses of the health care interactions that characterize them over a 2-year period. The primary sponsor of MEPS is AHRQ. For our analyses, 2003 MEPS data are presented for persons ages 18-44, 45-64, and 65 and over.

NHIS's primary purpose is to monitor the Nation's health. It is designed to provide nationally representative annual estimates at both the individual and family level of health status, health care use, and insurance coverage for the U.S. civilian noninstitutionalized population. The primary sponsor of NHIS is the National Center for Health Statistics, Centers for Disease Control and Prevention. For our analyses, 2003 NHIS data are presented for persons ages 18-44, 45-64, and 65 and over.

MCBS is designed to determine health insurance coverage, expenditures, and sources of payment (including copayments and deductibles) for all services (including noncovered services)



used by Medicare beneficiaries. It is a nationally representative sample of the Medicare population sponsored by the Office of Strategic Planning of the Centers for Medicare & Medicaid Services. For our analyses, 2002 MCBS data are restricted to those age 65 and over living in the community to ensure comparisons across surveys using similar population groups.

ACS generates data used to help determine how to distribute Federal and State funds and to help communities plan investments and services. It is an ongoing nationally representative survey that provides annual and multiyear estimates of demographic, housing, social, and economic characteristics for all States, as well as for all cities, counties, metropolitan areas, and population groups of 65,000 or more. After its full implementation in 2005, ACS replaced the long-form questionnaire that had been part of the Decennial Census. For our analyses, 2010 ACS data are presented for persons ages 18-44, 45-64, and 65 and over.

As a first step, we undertook a crosswalk of the different survey disability questions with the ICF. Questions and response categories were carefully reviewed for consistencies and discrepancies in measurement of the major domains of disabilities in the ICF. After we determined domains with survey questions for each survey, we compared estimates for these domains by severity level across surveys to determine which provided the closest match.

Section 2, Results, provides estimates by severity level for MEPS, NHIS, and MCBS, and for ACS for the different domains of disability in the order of the ICF Activities and participation component chapters. Appendix A contains the actual survey questions, their relationship to the ICF, and how the severity levels within a domain were created. Appendix B contains the ACS disability questions and the Washington Group on Disability Statistics (WGDS) disability questions that are discussed in the Conclusion. ACS estimates are also provided in Appendix B.

## **2. Results**

The following topics are presented in the order of the corresponding chapter of the ICF

Activities and participation section:

- Seeing activity limitations: Chapter 1, Learning and applying knowledge
- Hearing activity limitations: Chapter 1, Learning and applying knowledge
- Mobility activity limitations: Chapter 4, Mobility
- Self-care activity limitations: Chapter 5, Self-care
- Domestic life activity limitations: Chapter 6, Domestic life
- Major life areas activity limitations: Chapter 8, Major life areas
- Community, social and civic life activity limitations: Chapter 9, Community, social and civic life

### **2.1. Seeing activity limitations**

As indicated in Table A.1 (Appendix A), MEPS, NHIS, and MCBS all ask about seeing activity limitations while the person is wearing glasses or contacts if they wear them. However, the actual seeing activity limitations that people are asked about differ among the three surveys. MEPS asks about any difficulty and level of difficulty seeing in terms of being able to read newspaper, recognizing people two or three feet away, or being blind. NHIS asks about any trouble seeing and whether the person is blind or unable to see at all. More similar to the NHIS questions, the MCBS questions ask respondents to quantify their trouble seeing in terms of no trouble, a little trouble, a lot of trouble, or no usable vision.

Prevalence estimates for seeing activity limitations by severity level are shown in Table 1 for persons ages 18-44, 45-64, and 65 and over.<sup>vi</sup> Information on how the severity levels were determined is in Appendix A, as well as the actual survey questions and their relationship to the ICF. Comparisons across estimates among persons age 65 and over are made since that is the only category that allowed observations for comparable populations from all three surveys.

Because of the different approaches to determining how well a person sees, the survey estimates based on severity level vary quite a bit. Among those age 65 and over, MEPS showed a wide range indicating problems: 12.4 percent with any difficulty seeing; 3.9 percent who cannot read newsprint; 1.2 percent who cannot read newsprint and cannot recognize people; and 0.7 percent for those who are blind. The NHIS estimates by severity level for persons age 65 and over range from 16.6 percent for any trouble seeing to 1.1 percent for blind or unable to see at all. MCBS, which asks about level of trouble seeing, has estimates by severity level for persons age 65 and over that range from 32.7 percent with a little trouble, a lot of trouble, or no usable vision to 7.8 percent for those with a lot of trouble or no usable vision and 0.8 percent for those with no usable vision. The ACS estimate for blind or serious difficulty seeing for 2010 is 6.9 percent, within the severity ranges for each of the other surveys.

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<sup>vi</sup> For our purposes, MCBS data are restricted to those age 65 and over living in the community to ensure comparisons across surveys are using similar population groups.

**Table 1. Seeing activity limitations—concepts and estimates**

[Highlighted cells indicate measure included for cross-comparison purposes.]

Survey	Concept	Ages 18-44		Ages 45-64		Age 65+	
		Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>
MEPS <sup>1</sup> (2003)	Family-style question Any difficulty seeing (with glasses, contacts)	3.80	0.25	8.6	0.44	12.4	0.69
	Cannot read newsprint (with glasses, contacts)	0.69	0.09	1.9	0.19	3.9	0.39
	Cannot read newsprint and cannot recognize people (with glasses, contacts)	0.21	0.05	0.6	0.10	1.2	0.19
	Blind (with glasses, contacts)	0.1	0.03	0.3	0.07	0.7	0.15
NHIS <sup>2</sup> (2003)	Any trouble seeing (with glasses, contacts)	5.2	0.24	10.6	0.37	16.6	0.61
	Blind or unable to see at all	0.2	0.04	0.4	0.06	1.1	0.15
MCBS <sup>3</sup> (2002)	A little trouble, a lot of trouble, or no usable vision (with glasses or contacts)	-	-	-	-	32.7	0.71
	A lot of trouble, or no usable vision (with glasses or contacts)	-	-	-	-	7.8	0.26
	No usable vision (with glasses or contacts)	-	-	-	-	0.8	0.08
ACS (2010)	Blind or serious difficulty seeing even when wearing glasses	1.0	±0.02	2.6	±0.02	6.9	±0.06

**Note:** Seeing activity limitations correspond to ICF Activities and participation Chapter 1, Learning and applying knowledge.

<sup>1</sup> The family-style screener asks whether anyone in the family has any difficulty seeing (with glasses or contacts). There are three additional questions: whether the person cannot see anything at all, that is, blind; (with glasses or contacts) can see well enough to read ordinary newspaper print; (with glasses or contacts) can see well enough to recognize familiar people if they are two or three feet away.

<sup>2</sup> Sample adult and sample child each have two questions: whether they have any trouble seeing even when wearing glasses or contact lenses; whether they are blind or unable to see at all.

<sup>3</sup> The person is asked to select the statement which best describes their vision (while wearing glasses or contacts): no trouble seeing, a little trouble, a lot of trouble, or no usable vision.

- Data are not presented. For our analysis, data are restricted to age 65 and over.

<sup>†</sup> The margin of error (MOE) at the 90 percent confidence level are provided for the ACS.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey; Centers for Disease Control and Prevention (CDC) National Center for Health Statistics, National Health Interview Survey; Center for Medicare & Medicaid Services, Medicare Current Beneficiary Survey; U.S. Census Bureau, American Community Survey.

The conceptualization most similar for all three surveys is being blind or having no usable vision, in which the estimates from the three surveys are about the same (0.7 percent for persons age 65 and over based on MEPS, 1.1 percent based on NHIS; and 0.8 percent based on MCBS). This then became the basis for the measure of seeing activity limitations for the cross-survey use of that domain.

## **2.2. Hearing activity limitations**

Table A.2 (Appendix A) provides hearing activity limitation questions from MEPS, NHIS, and MCBS. One difference among the surveys is that MEPS and MCBS ask about hearing activity limitations while the person is wearing a hearing aid, while NHIS asks about hearing activity limitations without a hearing aid. MEPS asks differently about hearing activity limitations than NHIS and MCBS. MEPS asks about any difficulty hearing and level of difficulty quantified by whether the person can hear any speech at all (whether he or she is deaf), hear most of the things people say, or hear some of the things people say. NHIS and MCBS ask about trouble hearing. The NHIS categories are: good, a little trouble, a lot of trouble, or deaf. The MCBS categories are: no trouble hearing, a little trouble, a lot of trouble, or deaf.

**Table 2. Hearing activity limitations—concepts and estimates**

[Highlighted cells indicate measure included for cross-comparison purposes.]

Survey	Concept	Ages 18-44		Ages 45-64		Age 65+	
		Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>
MEPS <sup>1</sup> (2003)	Family-style question Any difficulty hearing (with hearing aid)	2.4	0.20	8.6	0.39	21.0	0.75
	Cannot hear most of the things people say (with a hearing aid)	0.2	0.06	1.0	0.14	3.0	0.32
	Cannot hear some of the things people say (with a hearing aid)	0.2	0.05	0.5	0.10	1.3	0.21
	Cannot hear any speech at all, that is, deaf (with a hearing aid)	0.2	0.05	0.5	0.10	1.2	0.21
NHIS <sup>2</sup> (2003)	A little trouble, a lot of trouble, or deaf (without a hearing aid)	6.9	0.25	17.7	0.51	37.6	0.79
	A lot of trouble, or deaf (without a hearing aid)	0.9	0.09	1.8	0.21	10.5	0.52
	Deaf (without a hearing aid)	0.1	0.03	0.2	0.04	1.0	0.15
MCBS <sup>3</sup> (2002)	A little trouble, a lot of trouble, or deaf (with a hearing aid)	-	-	-	-	36.4	0.74
	A lot of trouble, or deaf (with a hearing aid)	-	-	-	-	7.3	0.28
	Deaf (with a hearing aid)	-	-	-	-	0.2	0.05
ACS (2010)	Deaf or serious difficulty hearing	1.0	±0.2	3.5	±0.04	15.1	±0.08

**Note:** Hearing activity limitations correspond to ICF Activities and participation Chapter 1, Learning and applying knowledge.

<sup>1</sup> The family-style screener asks whether anyone in the family has any difficulty hearing (with a hearing aid if they use one). There are three additional questions: whether the person cannot hear any speech at all, that is, deaf; (with a hearing aid) can hear most of the things people say; (with a hearing aid) can hear some of the things people say.

<sup>2</sup> Sample adult and sample child are asked to select the statement which best describes their hearing without a hearing aid: Good, a little trouble, a lot of trouble, or deaf.

<sup>3</sup> The person is asked to select the statement which best describes their hearing without a hearing aid: no trouble hearing, a little trouble, a lot of trouble, or deaf.

- Data are not presented. For our analysis, data are restricted to age 65 and over.

<sup>†</sup> The margin of error (MOE) at the 90 percent confidence level are provided for the ACS.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey; CDC National Center for Health Statistics, National Health Interview Survey; Center for Medicare & Medicaid Services, Medicare Current Beneficiary Survey; U.S. Census Bureau, American Community Survey.

As indicated in Table 2, the hearing activity limitations estimates by severity level from MEPS (stipulated to be with a hearing aid) for persons age 65 and over range from 21.0 percent for those who have Any difficulty hearing to 3.0 percent for those who cannot hear most of the things people say, to 1.3 percent for those who cannot hear some of the things people say, and to 1.2 percent for those who cannot hear any speech at all, that is deaf.

Because NHIS and MCBS both ask about trouble hearing, their estimates by severity level are more similar even though NHIS asks about trouble hearing without a hearing aid and MCBS asks about trouble hearing with a hearing aid. According to NHIS, an estimated 37.6 percent of those age 65 and over have a little trouble, a lot of trouble, or are deaf. The MCBS estimate is 36.4 percent. A possible reason that two of the three MCBS estimates are statistically significantly lower than the comparable NHIS estimates is that the MCBS questions are with a hearing aid and the NHIS questions are without a hearing aid. The ACS estimate for deaf or serious difficulty hearing for 2010 is 15.1 percent, about in the middle of the severity ranges for each survey.

The hearing category that is most similar for all three surveys once again is the most severe category of being deaf, where the estimates are: 1.2 percent from MEPS; 1.0 percent from NHIS; and 0.2 percent from MCBS. Based on the closeness of the MEPS, NHIS, and MCBS estimates among the measures that reflected the most severe hearing limitations, this measure was included for cross-comparison purposes.

### **2.3. Mobility activity limitations**

The mobility questions for MEPS, NHIS, and MCBS are provided in Table A.3 (Appendix A) as is the relationship of these questions to the ICF. The mobility questions themselves are relatively similar in that they all ask about difficulties for specific activities: MEPS first has a

family-style screener question and then asks about 8 activities, in addition MEPS asks of persons identified with difficulty whether they expect to have difficulty for at least three months; NHIS asks about 9 activities of the sample adult; and MCBS asks about 5 activities. For NHIS, estimates are also provided for difficulty with at least 1 of the 8 items where the NHIS push or pull large objects item was not included since it is not in the other surveys.

The differences in survey estimates may be partially explained by differences in questions and also differences in response options. The MEPS response options for the 8 activities include *four* categories: no difficulty, some difficulty, a lot of difficulty, completely unable to do it. The response options for degree of difficulty for the 9 NHIS mobility activities include *six* categories: not at all difficult, only a little difficult, somewhat difficult, very difficult, can't do at all, do not do this activity. The response options for MCBS include *five* categories: no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, and not able to do it. The range of difficulty is broader with NHIS and MCBS because of the inclusions of response categories reflecting only minor difficulties (“only a little difficult” in NHIS and “little difficulty” in MCBS). Also, NHIS has the “Do not do this activity” category complication which was excluded from both the numerator and denominator for NHIS estimates.

Estimates for mobility activity limitation by severity level are shown in Table 3 for MEPS, NHIS, and MCBS. For persons 65 and over, the MEPS estimates ranged from 35.4 percent of persons reported as having difficulties by the screener question to 35.1 percent for those who additionally had at least some difficulty in at least 1 of the 8 separate items. When the difficulties are expected to last at least three months, the respective MEPS estimates were 33.2 percent and 33.1 percent.



**Table 3. Mobility activity limitations —concepts and estimates**

[Highlighted cells indicate measure included for cross-comparison purposes.]

Survey	Concept	Ages 18-44		Ages 45-64		Age 65+		
		Estimate (%)	Standard Error†	Estimate (%)	Standard Error†	Estimate (%)	Standard Error†	
MEPS <sup>1</sup> (2003)	Family-style question Difficulties walking etc.	4.3	(0.23)	14.4	(0.54)	35.4	(0.99)	
	Family-style and expect difficulties for at least three months	3.6	(0.20)	12.9	(0.51)	33.2	(1.02)	
	1 of 8 (some difficulty, a lot of difficulty, or completely unable to do)	4.0	(0.21)	14.1	(0.53)	35.1	(1.02)	
	1 of 8 (some difficulty, a lot of difficulty, or completely unable to do) and expect difficulties for at least three months	3.5	(0.20)	12.8	(0.51)	33.1	(1.02)	
NHIS <sup>2</sup> (2003)	1 of 9, only a little difficult, somewhat difficult, very difficult, or can't do at all	17.0	(0.37)	37.4	(0.65)	63.1	(0.80)	
	1 of 9, somewhat difficult, very difficult, or can't do at all	11.0	(0.30)	27.3	(0.58)	52.4	(0.81)	
	1 of 9, very difficult or can't do at all	5.9	(0.21)	18.3	(0.48)	40.3	(0.82)	
	Without “push or pull large object w/o special equipment”							
	1 of 8, only a little difficult, somewhat difficult, very difficult, or can't do at all	16.7	(0.37)	37.0	(0.64)	62.4	(0.79)	
	1 of 8, somewhat difficult, very difficult, or can't do at all	10.7	(0.30)	26.8	(0.58)	51.4	(0.82)	
	1 of 8, very difficult or can't do at all	5.6	(0.21)	17.7	(0.47)	39.0	(0.81)	
MCBS <sup>3</sup> (2002)	1 of 5, a little difficulty, some difficulty, a lot of difficulty, or not able to do it	-	-	-	-	77.4	(0.58)	
	1 of 5, some difficulty, a lot of difficulty, or not able to do it	-	-	-	-	56.3	(0.68)	
	1 of 5, a lot of difficulty, or not able to do it	-	-	-	-	39.7	(0.62)	
	1 of 5, not able to do it	-	-	-	-	23.1	(0.51)	

Survey	Concept	Ages 18-44		Ages 45-64		Age 65+	
		Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>
ACS (2010)	Serious difficulty walking or climbing stairs.	2.1	±0.02	9.3	±0.05	23.8	±0.11

**Note:** Mobility activity limitations correspond to ICF Activities and participation Chapter 4, Mobility.

<sup>1</sup> The family-style questions ask about anyone in the family having difficulties walking, climbing stairs, grasping objects, reaching overhead, lifting, bending or stooping, or standing for long periods of time. The 8 items are: lifting 10 pounds, walking up 10 steps, walking about 3 city blocks or ¼ mile, walking a mile, standing for 20 minutes, bending or stooping, reaching up overhead, or using fingers to grasp or handle something.

<sup>2</sup> The 9 items are: walk a quarter of a mile, walk up 10 steps, stand for 2 hours, sit for 2 hours, stoop/bend/kneel, reach up over your head, grasp objectives, lift/carry 10 pounds, push large object without special equipment. The 8 activities excluded “push large object without special equipment.” The “do not do” category was included with “missing” since we do not know if this was because of a health problem.

<sup>3</sup> The 5 items are: stooping/crouching/kneeling, lifting/carrying, extending arm above shoulder, writing/handling, and walking ¼ mile.

- Data are not presented. For our analysis, data are restricted to age 65 and over.

<sup>†</sup> The margin of error (MOE) at the 90 percent confidence level are provided for the ACS.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey; CDC National Center for Health Statistics, National Health Interview Survey; Center for Medicare & Medicaid Services, Medicare Current Beneficiary Survey; U.S. Census Bureau, American Community Survey.

The NHIS estimates for persons age 65 and over with difficulty with any of the 8 items (omitting the push or pull large objects item) ranged from 62.4 percent for only a little difficult, somewhat difficult, very difficult, or can’t do at all, to 39.0 percent for very difficult or can’t do at all. The MCBS estimates with difficulties in any of 5 items ranged from 77.4 percent for a little difficulty, some difficulty, a lot of difficulty, or not able to do it, to 23.1 percent for not able to do it.

As mentioned above, NHIS and MCBS report wider ranges because of their response categories of “only a little difficult” and “a little difficulty”, respectively, seem to encourage reporting more minor difficulties. The ACS estimate for serious difficulty walking or climbing stairs for persons age 65 and over for 2010 was 23.8 percent, toward the lower end of the severity ranges for each survey.

The most similar conceptualizations and estimates for the three surveys are: for MEPS, a positive response to the screener question, along with reporting of some difficulty, a lot of difficulty, or completely unable to do for at least 1 of 8 items; for NHIS, reporting of very difficult or can’t do at

all for at least 1 of the 8 items (where the push or pull heavy equipment item is excluded); and, for MCBS, the reporting of a lot of difficulty, or is not able to do it for at least 1 of 5 items.

#### **2.4. Self-care activity limitations**

All three surveys (MEPS, NHIS, and MCBS) contain self-care activity limitations or ADL (activities of daily living) questions as indicated in Appendix A Table A.4. As discussed more in Appendix A, we consider the ICF Activities and participation component Chapter 5, Self-care, to more closely address the concept of ADLs than the other chapters.

MEPS asks about difficulties due to an impairment or physical or mental health problem.

Within MEPS, there first is a family-style question asked of the respondent about whether anyone in the family receives help or supervision with personal care, such as bathing, dressing, or getting around the house. For persons identified as receiving help or supervision with personal care, an additional question is asked about whether the care is expected to last for at least three more months.

NHIS starts with a family-style screener question asked of the respondent about whether any family members, because of a physical, mental, or emotional problem, need the help of other persons with personal care needs such as eating, bathing, dressing, or getting around inside this home. Persons identified as needing the help of other persons with personal care needs are then asked 6 additional questions about whether they need the help of other persons with 6 activities.

MCBS asks about whether the person, because of a health or physical problem, has any difficulty doing any of 6 activities, with response categories of yes, no, or doesn't do. For those identified as doesn't do an activity, a follow-up question is asked about whether this is because of a health or physical problem. Those with difficulty or doesn't do a particular activity

because of health or physical problems are asked whether they receive help from another person with that activity. Persons identified with difficulty or doesn't do because of health or physical problems and receive help from another person are then asked whether they will still need help three months from now.

**Table 4. Self-care activity limitations—concepts and estimates**

Survey	Concept	Ages 18-44		Ages 45-64		Age 65+	
		Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>
MEPS <sup>1</sup> (2003)	ADL family-style question Receives help/supervision with personal care etc.	0.5	(0.07)	1.5	(0.16)	7.3	(0.54)
	ADL family-style question Family style and expect will need help/supervision for at least three more months	0.4	(0.06)	1.2	(0.14)	6.8	(0.53)
NHIS <sup>2</sup> (2003)	ADL family-style question: needs help of other persons with personal care needs etc.	0.6	(0.08)	1.6	(0.14)	6.7	(0.38)
	Family-style and 1 of 6 activities	0.5	(0.08)	1.5	(0.13)	5.9	(0.36)
MCBS <sup>3</sup> (2002)	Difficulty with or doesn't do 1 of 5 items (excludes walking)	-	-	-	-	18.2	(0.55)
	Receives help with 1 of 5 activities(excludes walking)	-	-	-	-	7.8	(0.27)
	Receives help and expected will still need help 3 months from now (1 of 5 activities)	-	-	-	-	7.4	(0.27)
ACS (2010)	Difficulty dressing or bathing.	1.0	±0.02	2.9	±0.03	8.8	±0.07

**Note:** Self-care activity limitations correspond to ICF Activities and participation Chapter 5, Self-care.

<sup>1</sup> Asks about anyone in the family receiving help or supervision with personal care, such as bathing, dressing, or getting around the house.

<sup>2</sup> Asks about anyone in the family needing help of other persons with PERSONAL CARE NEEDS, such as eating, bathing, dressing, or getting around inside this home. The 6 items asked about separately are: Bathing or showering; Dressing; Eating; Getting in or out of bed or chairs; Using the toilet, including getting to the toilet; and Getting around inside the house.

<sup>3</sup> MCBS has 7 separate questions for each of 6 items: bathing or showering; dressing; eating; getting in or out of bed or chairs; walking; and using the toilet.

- Data are not presented. For our analysis, data are restricted to age 65 and over.

<sup>†</sup> The margin of error (MOE) at the 90 percent confidence level are provided for the ACS.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey; CDC National Center for Health Statistics, National Health Interview Survey; Center for Medicare & Medicaid Services, Medicare Current Beneficiary Survey; U.S. Census Bureau, American Community Survey.

Estimates for self-care activity limitations are provided in Table 4 for MEPS, NHIS, and MCBS. The MEPS estimates for persons age 65 and over range from 7.3 percent receiving help/supervision with personal care to 6.8 percent for those expecting to need the help/supervision for at least three more months. The NHIS estimates for persons age 65 and over range from 6.7 percent for persons needing help of other persons in personal care to 5.9 percent for persons who additionally report needing help of other persons for at least 1 of 6 items asked about after the screener question. MCBS estimates are provided for persons reported to have difficulty with or “doesn’t do” at least 1 of 5 items because of health reasons. The walking item was excluded from the list of 6 items because none of the other surveys ask about walking with their ADL question. The MCBS estimates were 18.2 percent for those with difficulty or “doesn’t do” at least 1 of 5 items for health reasons; 7.8 percent for those receiving help with at least 1 of 5 items; and 7.4 percent for those receiving help with at least 1 of 5 items and expected to still need help 3 months from now.

The categories most similar across the three surveys are: for MEPS, the ADL screener question about receiving help/supervision with personal care (7.3 percent); for NHIS, the ADL screener about needing help of other persons with personal care needs (6.7 percent); and for MCBS, those receiving help with at least 1 of 5 items (where walking is excluded from the 6 items) (7.8 percent). The ACS estimate for difficulty dressing or bathing for persons age 65 and over for 2010 was 8.8 percent, slightly higher (statistically significant) than the most comparable MEPS, NHIS, and MCBS estimates of receiving or needing help.

## **2.5. Domestic life activity limitations**

All three surveys (MEPS, NHIS, and MCBS) contain IADL (instrumental activities of daily living) questions (Table A.5, Appendix A). They capture concepts most closely aligned to Chapter 6, Domestic life, of the ICF Activities and participation component (Appendix A).

Within MEPS, there is a family-style question asking whether anyone in the family receives help or supervision using the telephone, paying bills, taking medications, preparing light meals, doing laundry, or going shopping. Persons identified as receiving help or supervision are asked whether they expect to need help for at least three more months.

NHIS also has a family-style question asking whether anyone in the family needs the help of other persons in handling ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes.

MCBS asks whether the person, because of a health or physical problem, has any difficulty doing any of 6 activities; response categories consist of yes, no, or doesn't do. MCBS estimates are provided for any of the 6 activities and also for any of the 5 activities where heavy housework is excluded since the other surveys do not have this item. Within MCBS, for those who don't do an activity, a follow-up question is asked whether this is because of a health or physical problem. Those with difficulty or doesn't do a particular activity because of a health or physical problem are asked whether they receive help from another person with that activity.

**Table 5. Domestic life activity limitations—concepts and estimates**

Survey	Concept	Ages 18-44		Ages 45-64		Age 65+	
		Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>
MEPS <sup>1</sup> (2003)	IADL family-style question: Receives help/supervision using the telephone etc.	1.2	0.12	2.9	0.27	13.3	0.71
	IADL family-style question and expect will need help/supervision for at least three more months	1.1	0.11	2.6	0.25	12.4	0.68
NHIS <sup>2</sup> (2003)	IADL family-style question: Needs help of other persons in handling routine needs etc.	1.1	0.11	3.8	0.22	12.9	0.53
MCBS <sup>3</sup> (2002)	IADL difficulty with or doesn't do because of a health or physical problem 1 of 6 activities	-	-	-	-	36.4	0.63
	Receives help 1 of 6 activities	-	-	-	-	28.9	0.59
	IADL difficulty with or doesn't do because of a health or physical problem 1 of 5 activities (excludes heavy housework)	-	-	-	-	22.0	0.50
	Receives help 1 of 5 activities	-	-	-	-	18.2	0.46
ACS <sup>4</sup> (2010)	Difficulty doing errands alone	2.2	±0.03	5.2	±0.04	16.2	±0.09

**Note:** Domestic life activity limitations correspond to ICF Activities and participation Chapter 6, Domestic life.

<sup>1</sup> The family-style question asks about anyone in the family receiving help or supervision using the telephone, paying bills, taking medications, preparing light meals, doing laundry, or going shopping.

<sup>2</sup> The family-style question asks about anyone in the family needing the help of other persons in handling ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes.

<sup>3</sup> MCBS has three separate questions for each of 6 items: using the telephone, doing light housework (like washing dishes, straightening up, or light cleaning), doing heavy housework (like scrubbing floors or washing windows), preparing own meals, shopping for personal items (such as toilet items or medicines), managing money (like keeping track of expenses or paying bills). The 1 of 5 activities excludes heavy housework.

<sup>4</sup> Because of a physical, mental, or emotional condition, has difficulty doing errands alone such as visiting a doctor's office or shopping.

- Data are not presented. For our analysis, data are restricted to age 65 and over.

<sup>†</sup> The margin of error (MOE) at the 90 percent confidence level are provided for the ACS.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey; CDC National Center for Health Statistics, National Health Interview Survey; Center for Medicare & Medicaid Services, Medicare Current Beneficiary Survey; U.S. Census Bureau, American Community Survey.

The MEPS estimates (Table 5) for persons age 65 and over range from 13.3 percent for persons receiving help or supervision according to the family-style screener question to 12.4 percent for those whose care is expected to last for at least three more months. According to NHIS, an estimated 12.9 percent of persons age 65 and over need the help of other persons in handling routine needs.

The MCBS estimates for persons ages 65 and over range from 22.0 percent for persons with difficulty or “doesn’t do” because of health problems at least 1 of five activities (heavy housework is excluded); and 18.2 percent for persons who receive help with at least 1 of five activities (heavy housework is excluded).

The categories most similar across the three surveys (MEPS, NHIS, and MCBS) and estimates for age 65 and over are: the MEPS IADL family-style question about receiving help/supervision with these activities (13.3 percent); the NHIS IADL family-style question about needing help of other persons (12.9 percent); and the MCBS questions for those who receive help with at least 1 of 5 activities (18.2 percent). One reason the MCBS estimate (18.2 percent) is statistically larger than the estimates for MEPS (13.3 percent) and NHIS (12.9 percent) is that there are 5 (or 6) different MCBS questions that give a person 5 (or 6) different chances to be included; MEPS and NHIS have only a single question. Furthermore, the MEPS and NHIS single questions are family-style questions, which generally provide lower estimates (Hess, et al., 2001). The ACS estimate for difficulty doing errands alone for persons age 65 and over for 2010 was 16.2 percent, statistically higher than the MEPS (13.3 percent) and NHIS (12.9 percent) estimates from the family-style questions and slightly lower than the MCBS (18.2 percent) estimate for receiving help with 1 of 5 activities.



## 2.6. Major life areas activity limitations

We restricted our estimates of activity limitations in major life areas to those ages 18-44 and 45-64 since these are the main age groups involved with working. MEPS and NHIS both have estimates for this domain. MCBS has no estimates for this domain because MCBS estimates are analyzed only for age 65 and over.<sup>vii</sup> Also, ACS does not have a question for this domain.

Both MEPS and NHIS have family-style screener questions asked of the respondent about everyone in the family (Table A.6, Appendix A). The MEPS question asks whether anyone in the family is limited in any way in the ability to work at a job, do housework, or go to school because of an impairment or a physical or mental health problem. A follow-up question is asked to identify the activities in which they are limited. For those activities in which a person is limited, a final question is asked about whether they are unable to do those activities.

The NHIS screener question asks whether a physical, mental, or emotional problem NOW keeps anyone from working at a job or business. A second question is asked whether there are other persons who are limited in the kind OR amount of work they can do because of a physical, mental, or emotional problem.

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<sup>vii</sup> For our purposes, MCBS data are restricted to those age 65 and over living in the community to ensure comparisons across surveys are using similar population groups.

**Table 6. Major life areas activity limitations—concepts and estimates**

Survey	Concept	Ages 18-44		Ages 45-64		Age 65+	
		Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>
MEPS <sup>1</sup> (2003)	Family-style question Limited in any way work, housework, or school limitation	3.7	0.20	11.3	0.57	-	-
	Work limitation or school limitation	3.6	0.20	10.8	0.56	-	-
	Work limitation	3.6	0.20	10.8	0.56	-	-
	School limitation	1.5	0.13	3.3	0.31	-	-
NHIS <sup>2</sup> (2003)	Family-style question Now keep from working at a job or business	5.3	0.21	15.4	0.41	-	-
MCBS (2002)	-	-	-	-	-	-	-
ACS (2010)	-	-	-	-	-	-	-

**Note:** Major life areas activity limitations correspond to ICF Activities and participation Chapter 8, Major life areas.

<sup>1</sup> The family-style question asks if anyone in the family is limited in any way in the ability to work at a job, do housework, or go to school because of an impairment or a physical or mental health problem.

<sup>2</sup> Two questions: Does a physical, mental, or emotional problem NOW keep anyone in the family from working at a job or business? Who is this? Other than the persons mentioned, are any of these family members limited in the kind OR amount of work they can do because of a physical mental, or emotional problem?

- Data are not presented. For our analysis, data are restricted to age 65 and over.

<sup>†</sup> The margin of error (MOE) at the 90 percent confidence level are provided for the ACS.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey; CDC National Center for Health Statistics, National Health Interview Survey; Center for Medicare & Medicaid Services, Medicare Current Beneficiary Survey; U.S. Census Bureau, American Community Survey.

For ages 45-64, the MEPS estimates identify 11.3 percent with limitation in work, housework, or school activities according to the family-style screener question, 10.8 percent report work or school limitations, 10.8 percent report work limitations, and 3.3 percent report school limitation. The NHIS estimate of those kept from working at a job or business or limited in the kind or amount of work they can do is 15.4 percent for those ages 45-64.

The categories selected as most similar are: for MEPS, the family-style screener question about being limited in any way in the ability to work at a job, do housework, or go to school (11.3 percent); for NHIS, the combination of the two questions of being kept from working at a job or business or limited in the kind or amount of work they can do (15.4 percent).

One reason the MEPS estimate for being limited in the ability to work at a job, do housework, or go to school was selected as most comparable to the NHIS estimate is that NHIS asks about everyone being kept from working or limited in the kind or amount of work they can do regardless of whether they self-identify as students or homemakers. For the MEPS question, some people may self-identify as homemakers or students (although not the intent of the MEPS question) and give only information about limitations in doing housework or going to school and not give information about whether they are limited in the amount or kind of work they can do.

### **2.7 Community, social and civic life activity limitations**

The community, social and civic life activity limitations questions for MEPS, NHIS, and MCBS (provided in Table A.7, Appendix A) are very different. MEPS has a family-style question asking whether anyone in the family is limited in participating in social, recreational, or family activities because of an impairment or a physical or mental health problem.

NHIS asks three questions of the sample adult about how difficult it is to: 1.) go out to things like shopping, movies, or sporting events; 2.) participate in social activities such as visiting friends, attending clubs and meetings, going to parties; and 3.) do things to relax at home or for leisure. The six NHIS response options are: not at all difficult; only a little difficult; somewhat difficult; very difficult; can't do at all; do not do this activity.

MCBS has one question that asks about how much of the time during the past month the person's health has limited the person's social activities, like visiting with friends or close relatives. The MCBS response options are: none of the time; some of the time; most of the time; or all of the time.

**Table 7. Community, social and civic life activity limitations—concepts and estimates**

Survey	Concept	Ages 18-44		Ages 45-64		Age 65+	
		Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>	Estimate (%)	Standard Error <sup>†</sup>
MEPS <sup>1</sup> (2003)	Family-style question Limited in participating in social, recreational or family activities	2.4	0.16	6.9	0.4	14.1	0.75
NHIS <sup>2</sup> (2003)	<b>Sample adult</b>						
	<b>Limitations in going out to things, participating in social activities, and in doing things to relax or for leisure</b>						
	Only a little difficult, Somewhat difficult, Very difficult, can't do at all	4.7	0.22	11.7	0.38	24.7	0.74
	Somewhat difficult, Very difficult, can't do at all	3.3	0.18	8.6	0.34	18.1	0.62
	Very difficult, can't do at all	1.5	0.12	4.5	0.25	11.5	0.51
	<b>Limitations in participating in social activities</b>						
	Only a little difficult, Somewhat difficult, Very difficult, can't do at all	3.2	0.17	8.3	0.32	17.2	0.65
	Somewhat difficult, Very difficult, can't do at all	2.3	0.14	5.9	0.27	12.6	0.54
Very difficult, can't do at all	1.0	0.10	2.9	0.19	8.2	0.43	
MCBS <sup>3</sup> (2002)	<b>Amount of time during past month limited in social activities</b>						
	Some of the time, Most of the time, All of the time	-	-	-	-	31.5	0.61
	Most of the time, All of the time	-	-	-	-	12.9	0.37
	All of the time	-	-	-	-	4.9	0.24
ACS (2010)	-	-	-	-	-	-	

**Note:** Community, social and civic life activity limitations correspond to ICF Activities and participation Chapter 9, Community, social and civic life.

<sup>1</sup> The family-style question asks if anyone in the family is limited in participating in social, recreational or family activities because of an impairment or a physical or mental health problem.

<sup>2</sup> Three questions: The first asks by yourself, and without using any special equipment, how difficult it is to go out to things like shopping, movies, or sporting events. The second is about participating in social activities such as visiting friends, attending clubs and meetings, going to parties. The third asks about doing things to relax at home or for leisure (reading, watching TV, sewing, listening to music).

<sup>3</sup> Asks about how much of the time during the past month has health limited social activities, like visiting with friends or close relatives.

- Data are not presented. For our analysis, data are restricted to age 65 and over.

† The margin of error (MOE) at the 90 percent confidence level are provided for the ACS.

Source: Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey; CDC National Center for Health Statistics, National Health Interview Survey; Center for Medicare & Medicaid Services, Medicare Current Beneficiary Survey; U.S. Census Bureau, American Community Survey.

Estimates for community, social and civic life activity limitations are provided in Table 7 for MEPS, NHIS and the MCBS. According to MEPS, 14.1 percent of persons age 65 and over are limited in participating in social, recreational, or family activities. When the NHIS estimates are limited to difficulty with social activities (the second of the three NHIS questions), the estimates range from: 17.2 percent for persons reporting only a little difficult, somewhat difficult, very difficult, or can't do at all; to 12.6 percent for persons reporting somewhat difficult, very difficult, or can't do at all; and 8.2 percent for persons reporting very difficult or can't do at all. The MCBS estimates for persons ages 65 and over in terms of how much of the time during the past month a person was limited in social activities range from: 31.5 percent for some of the time, most of the time, or all of the time; to 12.9 percent for most of the time, or all of the time; to 4.9 percent for all of the time.

Because of the different approaches to determining community, social and civic life limitations (MEPS asks about being limited in participation, the NHIS asks about how difficult it is to participate in social activities, and the MCBS asks for how much of the time during the past month their health limited social activities), the estimates based on severity level vary quite a bit within and across the three surveys. In addition, the surveys ask about different time periods: the timeframe for MEPS and NHIS is now; the timeframe for MCBS is during the past

month. Also, NHIS has the “Do not do this activity” category complication which was excluded from both the numerator and denominator for NHIS estimates.

The conceptualization most similar across the three surveys and shown for persons age 65 and over are: The MEPS social limitation family-style question about being limited in social, recreational or family activities (14.1 percent); the NHIS estimates limited to difficulty with social activities at the somewhat difficult, very difficult, or can’t do at all levels (12.6 percent); and the MCBS estimate for being limited in social activities most of the time or all of the time during the past month (12.9 percent).

### **3. Discussion**

As is often seen in survey research, similar concepts might be measured in different ways across surveys. To make some sense of a cross-walk among survey measures of disability, it was necessary to examine the conceptual elements operationalized, the language used in the questions and the answer categories, and to locate those elements within a bigger scheme, in this case the ICF. For each question in each survey, a determination was made about: who gets asked the question, the question lead-in wording, the question wording, response options, reference period, use of a family-style approach vs asking each individual, and use of a screener question before more detailed questions.

This approach, while tedious, provided good results. For the most part, questions associated with the domains of disability map to a single chapter of the Activities and participation component of the ICF and allowed the DWG to find a tool to provide common ground among the diverse surveys. For example, the mobility questions map to the ICF Activities and participation component Chapter 4, Mobility; and the community, social and civic life activity

limitations questions map to Chapter 9, Community, social and civic life. An exception is with the traditional ADL and IADL questions.<sup>viii</sup>

In comparing survey questions and estimates across the domains of disability of the ICF Activities and participation component, the DWG found that even when surveys have questions in the same domain, there is no guarantee that the concepts, questions, and estimates will be similar or that they capture the same people. For example, the seeing and hearing activity limitations questions contained in the ICF Activities and participation component Chapter 1, Learning and applying knowledge, have been asked since the earliest censuses of the 19th century (U.S. Census, 2002; Chevarley, et al., 2009). But the current seeing and hearing activity limitation questions/concepts in MEPS, NHIS, and MCBS are quite different. The three surveys ask about different concepts ranging from difficulty seeing as measured by specific activities (MEPS), to any trouble seeing (NHIS), to level of trouble seeing (MCBS). The only similar concept across the three surveys was whether a person was blind. For the hearing questions, MEPS and MCBS ask about limitations with a hearing aid and the NHIS questions are without a hearing aid. Again, MEPS measures hearing difficulties in terms of specific activities, while NHIS and MCBS measure level of trouble hearing. The only similar concept for the three surveys was being deaf.

Other domains in which the three surveys have different concepts are the Major life areas domain and the Community, social and civic life domain. For the Major life areas domain, both MEPS and NHIS ask family-style questions. MEPS asks whether anyone in the family is

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<sup>viii</sup> Although the ICF Activities and Participation component Self-care chapter (Chapter 5) more closely gets at the concept of the ADL questions than any other chapter, and the Domestic life chapter (Chapter 6) is more closely aligned than any other chapter with the IADL questions, perhaps future versions of the ICF and ADL and IADL questions will align more closely (Further discussion in Appendix A.2).

limited in their ability to work at a job, do housework, or go to school. NHIS asks whether a physical, mental, or emotional problem now keeps anyone in the family from working at a job or whether any others in the family are limited in the kind or amount of work they can do. Estimates are somewhat similar when the “work, housework, or school” limitation for MEPS and the “work” limitation for NHIS are used.

Although all three surveys have questions in the Community, social, and civic life domain, their concepts differ. MEPS has a family-style question asking about being limited in participating in social, recreational, or family activities. NHIS asks the sample adult about level of difficulty for three activities, (going out to things, participating in social activities, relaxing or for leisure) with a broad range of six response options (not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, do not do this activity.) MCBS asks about how much of the time during the past month the person’s health has limited social activities, with a narrower set of four response options (none of the time, some of the time, most of the time, or all of the time). The concept and estimates are most similar when the MEPS social limitation family-style question is compared with the NHIS estimate limited to difficulty with social activities at the somewhat difficult, very difficult, or can’t do at all level and compared with the MCBS estimate of being limited in social activities most of the time or all of the time during the past month.

Even when concepts and questions are similar as in the Mobility, Self-care, and Domestic life domains, how the questions are asked (family style or not, screener question before more detailed questions vs. just detailed questions) and different response options produce different estimates. For the Mobility domain, MEPS has a family-style screener question asking about difficulties for a long list of activities before asking about 8 items separately for four levels of



difficulty (no difficulty, some difficulty, a lot of difficulty, or completely unable to do it). NHIS asks about level of difficulty separately for nine tasks, and MCBS asks about level of difficulty separately for five tasks. NHIS asks about each task using six levels of difficulty (not at all difficult, only a little difficult, somewhat difficult, very difficult, can't do at all, do not do this activity). MCBS asks about each task using five levels of difficulty (no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, not able to do it). The family-style MEPS question generally produce lower estimates than asking questions individually of everyone in the family (Hess, et al., 2001). Having a screener question with a list of items before asking separately about a list of activities also tends to produce lower estimates since not everyone gets asked the separate questions. Having a broader range of response options reflecting only minor difficulties as in NHIS and MCBS (“only a little difficult” in NHIS and “a little difficulty” in MCBS) increases the reporting of minor limitations, leading to higher estimates. The NHIS and MCBS wider range of response options may also increase the reporting of more minor difficulties for the more moderate categories, but work is needed to confirm whether this is so.

For the Self-care and Domestic life domains, the concept of receiving help/needing help for the is similar in all three surveys. MCBS includes more extensive questions that also get at the concept of difficulty with or doesn't do in addition to the receives help concept for each of these two domains.

An alternative approach to the NHDR/QR crosswalk reported here is seen in the movement toward standard disability questions in national surveys. The work to develop ACS disability measures and the subsequent use of the ACS disability question set in other surveys may improve consistency. ACS also required an interagency workgroup to develop its 6-item

disability question set (Brault, 2009; Brault, et al., 2006). Agency representatives to the ACS interagency workgroup identified their statutory needs for measurement of disability, worked together on question concepts and wording, and reviewed the results of cognitive testing and analyses from a variety of national data sources. The final ACS six disability questions (contained in Appendix B, along with estimates) identify a substantial proportion of the population with disabilities. Unfortunately, for reasons of space within the overall ACS, the 6-item question set is not sufficient to identify the full population of individuals with disabilities.

#### **4. Conclusion**

In comparing survey questions and estimates across the domains of disability identified in the ICF, the DWG found that even when surveys have questions in the same domain, there is no guarantee that the questions and estimates will be similar or that they necessarily capture the same people. The DWG also found question structure and response options are as important as question wording. Some questions have one response option and others offer some type of continuum. In addition, the differences in the broadness of the continuum of response options affect the estimates. As noted in the mobility domain, the inclusion of response categories reflecting only minor difficulties increased the estimates dramatically.

In summary, all three national surveys—MEPS, NHIS, and MCBS—include questions within each major domain. The concepts and questions are very different for some domains (Seeing, Hearing, Major life area, and Community, social and civic life) and are more similar in other domains (Mobility, Self-care, and Domestic life). Despite the differences in concepts, question type (family style or not, screener question or not), question wording, and response categories, the group was able to select for each of the three surveys concepts with somewhat similar estimates for each domain. The similar estimates for each domain were used to create the

agreed on paired measures of disability: Limitations in basic activities; and Limitations in complex activities. As discussed (See Section 1.3), the Seeing, Hearing, Mobility, Self-care and Domestic life domains make up Limitations in basic activities; the Major life area and Community, social and civic life domains make up Limitations in complex activities.

These comparable disability measures have been used for adults in the NHDR/QR starting with the 2007 NHDR/QR with MEPS data and the 2008 NHDR/QR with NHIS data. Analyses were included as charts and text in NHDR Chapter 4, Priority Populations. In addition, the NHDR/QR appendix tables include these measures as a stub variable for all MEPS and NHIS tables.<sup>ix</sup> Based on an IOM recommendation to integrate the disability text within chapters of the reports, disability analysis for the 2010 NHDR/QR was included in the Patient Centeredness chapter of both the NHQR

(<https://archive.ahrq.gov/research/findings/nhqrdr/nhqr10/index.html>) and NHDR

(<https://archive.ahrq.gov/research/findings/nhqrdr/nhdr10/index.html>) using the composite

poor communication measure. Also, the 2010 NHDR was the first in which the Priority

Populations chapter summarized disparities for adults with disability across all the different

measures in the report. To augment the composite poor communication measure used in the

2010 NHDR/QR, the MEPS Statistical Brief “Patient-Provider Communication by

Race/Ethnicity and Disability Status: United States, 2007” (Chevarley, 2011) provides analysis

for the components of the poor communication composite measure by disability status. The

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<sup>ix</sup> There are around 50 MEPS tables and around 30 NHIS tables in the NHDR/QR appendix tables in which the disability measures are stub variables. Each of these tables deals with a separate indicator or outcome variable and each has actually up to four tables—dealing with race, ethnicity, income, and education. Thus, there are approximately 200 MEPS tables ( $50 \times 4 = 200$ ) and approximately 120 NHIS tables ( $30 \times 4 = 120$ ) with activity limitations as a stub variable.

2013 NHDR/QR was the latest published report using these measures (at the time of this analyses) and is available at <http://www.ahrq.gov/research/findings/nhqrdr/nhqr13/index.html>.

Although successful in finding comparable disability measures across MEPS, NHIS and MCBS to use in the NHDR/QR, this process was very time consuming. Widely different concepts and estimates for some domains suggest the usefulness of having common concepts and questions in each survey. Having the same concepts and common questions would increase the ability to benchmark and compare estimates across surveys.

Someone wanting a simple set of disability measures should give consideration to the 6-item disability set of ACS questions since 2008 (see Appendix B.) These are currently included or will soon be included in several national surveys, such as the American Housing Survey, CPS, National Crime Victimization Survey, MEPS, NHIS, National Survey of Family Growth, and SIPP. Here, too, question format varies by survey (e.g., individual versus family-style questions, placement within a survey). In addition, in all surveys the ACS questions continue the focus on the individual without consideration of environmental factors that interact with functional limitations. Still, the underlying concepts and wording are identical across surveys.

Another promising approach to the measurement of disability with a short set of questions for international data collection on disability is found in the work of the Washington Group on Disability Statistics (WGDS) (see Appendix B). The WGDS questions use concepts similar to those found in the ACS. However, for response categories the WGDS questions offer a four-item continuum of answer categories (No - no difficulty, Yes - some difficulty, Yes - a lot of difficulty, cannot do at all) rather than a dichotomous “Yes-No” choice for response options. The continuum of answer choices in the WGDS questions versus the dichotomous “Yes-No” choices in the ACS questions might better allow policymakers and others to estimate severity

of disability, which is key to identifying populations most likely to be eligible for a variety of benefits and services. Because of the importance of specific wording, the number of categories, and the broadness of response categories for estimates on a continuum, the WGDS response categories may need further study as to how they are interpreted and the estimates they would produce if they were to become standard.

In conclusion, the harmonization of questions from MEPS, NHIS, and MCBS developed by experts in the NHDR/QR DWG and discussed in this paper has been an effective way to identify comparable populations at risk of poor health outcomes. This approach can be used in lieu of or in addition to a standard set of questions such as those used in the ACS. Although many surveys now include the ACS standard set of questions, there might be financial or other barriers to universal adoption of such measures in Federal surveys. Until MEPS, NHIS, and MCBS all adopt a standard set of disability questions, someone wanting to report disability information from these surveys may want to consider the measures discussed here.

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<sup>x</sup> The NHDR and QR have since been combined into the *National Healthcare Quality and Disparities Report*.

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## Appendix A. Survey questions, Relationship to the ICF, and How severity levels within domains were created

### Appendix A.1. Survey questions

**Table A.1. Seeing activity limitations—Questions**

MEPS (2003)	<p>Family-style question (all ages):</p> <ul style="list-style-type: none"> <li>● Does anyone in the family wear eyeglasses or contact lenses? Who is that?</li> <li>● Does anyone in the family have any difficulty seeing {with glasses or contacts, if they use them}? Who is that?</li> <li>● For persons identified as having difficulty seeing: <ul style="list-style-type: none"> <li>○ Can (PERSON) not see anything at all, that is, (are/is) (PERSON) blind?</li> <li>○ {With glasses or contacts, can/Can}(PERSON) see well enough to read ordinary newspaper print, even if (PERSON) cannot read?</li> <li>○ {With glasses or contacts, can/Can}(PERSON) see well enough to recognize familiar people if they are two or three feet away?</li> </ul> </li> </ul>
NHIS (2003)	<p>Sample Adult (age 18 and over) and Sample Child (SC) (ages 2-17):</p> <ul style="list-style-type: none"> <li>● Do (you/SC) have any trouble seeing, even when wearing glasses or contact lenses?</li> <li>● For persons with trouble seeing continue with: <ul style="list-style-type: none"> <li>○ Are (you/SC) blind or unable to see at all?</li> </ul> </li> </ul>
MCBS (2002)	<p>Medicare beneficiaries:</p> <ul style="list-style-type: none"> <li>● Main Questions <ul style="list-style-type: none"> <li>○ (Do you/Does SP) wear eyeglasses or contact lenses? Yes or No</li> <li>○ Which statement best describes (your/SP's) vision (while wearing glasses or contact lenses) – no trouble seeing, a little trouble, a lot of trouble, or no usable vision?</li> </ul> </li> </ul>
ACS (2010)	<p>All ages:</p> <ul style="list-style-type: none"> <li>● Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?</li> </ul>

**Table A.2. Hearing activity limitations—Questions**

MEPS (2003)	<p>Family-style question (all ages):</p> <ul style="list-style-type: none"> <li>● Does anyone in the family have a hearing aid? Who is that?</li> <li>● Does anyone in the family have any difficulty hearing {with a hearing aid if they use one}? Who is that?</li> <li>● For persons identified as having difficulty hearing {with a hearing aid, if they use one}: <ul style="list-style-type: none"> <li>○ Can (PERSON) not hear any speech at all, that is, (are/is) (PERSON) deaf?</li> <li>○ {With a hearing aid, can/Can} (PERSON) hear <b>most</b> of the things people say?</li> <li>○ {With a hearing aid can/Can} (PERSON) hear <b>some</b> of the things people say?</li> </ul> </li> </ul>
NHIS (2003)	<p>Sample Adult (age 18 and over):</p> <ul style="list-style-type: none"> <li>● Have you ever worn a hearing aid? <ul style="list-style-type: none"> <li>○ Sample Adult (ages 18 and over) and Sample Child (ages 0-17): Which statement best describes (your/SC's) hearing without a hearing aid: Good, a little trouble, a lot of trouble, or deaf?</li> </ul> </li> </ul>

<p>MCBS (2002)</p>	<p>Medicare beneficiaries:</p> <ul style="list-style-type: none"> <li>• Main Questions <ul style="list-style-type: none"> <li>○ (Do you/Does SP) use a hearing aid? Yes or No</li> <li>○ Which statement best describes (your/SP's) hearing (with a hearing aid) – no trouble hearing, a little trouble, a lot of trouble, or deaf?</li> </ul> </li> </ul>
<p>ACS (2010)</p>	<p>All ages</p> <ul style="list-style-type: none"> <li>• Is this person deaf or does he/she have serious difficulty hearing?</li> </ul>

**Table A.3. Mobility activity limitations—Questions**

<p>MEPS (2003)</p>	<p>Family-style screener question (all ages):</p> <ul style="list-style-type: none"> <li>● Does anyone in the family have difficulties walking, climbing stairs, grasping objects reaching overhead, lifting, bending or stooping, or standing for long periods of time? Who is that?</li> <li>● For persons identified as having difficulties (ages 13+): <ul style="list-style-type: none"> <li>○ Please look at this card and tell me how much difficulty (do/does) (PERSON) have lifting something as heavy as 10 pounds, such as a full bag of groceries? Would you say no difficulty, some difficulty, a lot of difficulty, or completely unable to do it?</li> <li>○ How much difficulty (do/does) (PERSON) have walking up 10 steps without resting? Would you say no difficulty, some difficulty, a lot of difficulty, or completely unable to do it?</li> <li>○ How much difficulty (do/does) (PERSON) have walking about 3 city blocks or about a quarter of a mile? Would you say no difficulty, some difficulty, a lot of difficulty, or completely unable to do it?</li> <li>○ How much difficulty (do/does) (PERSON) have walking a mile? Would you say no difficulty, some difficulty, a lot of difficulty, or completely unable to do it?</li> <li>○ How much difficulty (do/does) (PERSON) have standing for about 20 minutes? Would you say no difficulty, some difficulty, a lot of difficulty, or completely unable to do it?</li> <li>○ How much difficulty (do/does) (PERSON) have bending down or stooping from a standing position to pick up an object from the floor or tie a shoe? Would you say no difficulty, some difficulty, a lot of difficulty, or completely unable to do it?</li> <li>○ How much difficulty (do/does) (PERSON) have reaching up overhead, for example to remove something from a shelf? (no difficulty, some difficulty, a lot of difficulty, or completely unable to do it)</li> <li>○ How much difficulty (do/does) (PERSON) have using fingers to grasp or handle something such as picking up a glass from a table or using a pencil to write? Would you say no difficulty, some difficulty, a lot of difficulty, or completely unable to do it?</li> </ul> </li> <li>● For persons identified as having difficulty with any of the above: <ul style="list-style-type: none"> <li>○ Is PERSON expected to have difficulty with any of these activities for at least three months?</li> </ul> </li> </ul>
<p>NHIS (2003)</p>	<p>Sample Adult (age 18 and over):</p> <ul style="list-style-type: none"> <li>● The next questions ask about difficulties you may have doing activities because of a <b>HEALTH PROBLEM</b>. By “Health problem” we mean any physical, mental, or emotional problem or illness (not including pregnancy).</li> <li>● By yourself and without any special equipment, how difficult is it for you to... <ul style="list-style-type: none"> <li>○ ...Walk a quarter of a mile - about 3 city blocks? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, do not do this activity)</li> <li>○ ...Walk up 10 steps without resting? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, do not do this activity)</li> <li>○ ...Stand or be on your feet for about 2 hours? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, do not do this activity)</li> <li>○ ...Sit for about 2 hours? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, do not do this activity)</li> <li>○ ...Stoop, bend, or kneel? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, do not do this activity)</li> <li>○ ...Reach up over your head? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, do not do this activity)</li> </ul> </li> <li>● By yourself and without any special equipment, how difficult is it for you to... <ul style="list-style-type: none"> <li>○ ...Use your fingers to grasp or handle small objects? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can’t do at all, do not do this activity)</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ ...Lift or carry something as heavy as 10 pounds such as a full bag of groceries? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can't do at all, do not do this activity)</li> <li>○ ...Push or pull large objects like a living room chair? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can't do at all, do not do this activity)</li> </ul>
MCBS (2002)	<p>Now I'm going to ask about how difficult it is, on the average, for (you/SP) to do certain kinds of activities. Please tell me for each activity whether (you have/SP has) no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, or (are/is) not able to do it.</p> <ul style="list-style-type: none"> <li>● How much difficulty, if any, (do you/does SP) have stooping, crouching, or kneeling? Would you say (you have/SP has) no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, or (are/is) not able to do it?</li> <li>● How much difficulty, if any, (do you/does SP) have lifting or carrying objects as heavy as 10 pounds, like a sack of potatoes? Would you say (you have/SP has) no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, or (are/is) not able to do it?</li> <li>● What about reaching or extending arms above shoulder level? (no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, or (are/is) not able to do it)</li> <li>● How much difficulty if any, (do you/does SP) have either writing or handling and grasping small objects? Would you say (you have/SP has) no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, or (are/is) not able to do it?</li> <li>● What about walking a quarter of a mile – that is about 2-3 blocks? (no difficulty at all, a little difficulty, some difficulty, a lot of difficulty, or(are/is) not able to do it)</li> </ul>
ACS (2010)	Does this person have serious difficulty walking or climbing stairs?

**Table A.4. Self-care activity limitations (ADLs)—Questions**

<p>MEPS (2003)</p>	<p>The next few questions are about difficulties people may have with everyday activities such as getting around, bathing, or taking medications. We are interested in difficulties due to an impairment or a physical or mental health problem. (This is really in front of the IADL questions, which are asked right before the ADL questions.)</p> <p>Family-style question (all ages):</p> <ul style="list-style-type: none"> <li>• Does anyone in the family receive help or supervision with personal care such as bathing, dressing, or getting around the house? Who is that?</li> <li>• For persons identified as receiving help or supervision with personal care:             <ul style="list-style-type: none"> <li>○ Do you expect that {PERSON} will need help or supervision with personal care for at least three more months?</li> </ul> </li> </ul>
<p>NHIS (2003)</p>	<p>Family-style screener question (age 3 and over):</p> <ul style="list-style-type: none"> <li>• Because of a physical, mental, or emotional problem, {do/does} {you/anyone in the family} need the help of other persons with PERSONAL CARE NEEDS, such as eating, bathing, dressing, or getting around inside this home?</li> <li>• For persons identified as needing help of other persons with PERSONAL CARE NEEDS:             <ul style="list-style-type: none"> <li>○ {Do/Does} {you/subject's name} need the help of other persons with...?                 <ul style="list-style-type: none"> <li>▪ Bathing or showering?</li> <li>▪ Dressing?</li> <li>▪ Eating?</li> <li>▪ Getting in or out of bed or chairs?</li> <li>▪ Using the toilet, including getting to the toilet?</li> <li>▪ Getting around inside the home?</li> </ul> </li> </ul> </li> </ul>
<p>MCBS (2002)</p>	<p>Medicare beneficiaries:</p> <p>Now I'll ask about some other everyday activities. I'd like to know whether (you have/SP has) any difficulty doing each one <u>by (yourself/himself/herself)</u> and without special equipment.</p> <ul style="list-style-type: none"> <li>• Because of a health or physical problem, (do you/does SP) have <u>any</u> difficulty with the following? (yes, no, doesn't do)             <ol style="list-style-type: none"> <li>a. bathing or showering?</li> <li>b. dressing?</li> <li>c. eating?</li> <li>d. getting in or out of bed or chairs?</li> <li>e. walking?</li> <li>f. using the toilet?</li> </ol> </li> <li>• For ADLs person doesn't do:             <ul style="list-style-type: none"> <li>○ [You said that (ADL) is something that (you don't/SP doesn't) do.] Is this because of a <u>health</u> or <u>physical</u> problem?</li> </ul> </li> <li>• For those with difficulty or doesn't do ADL because of health or physical problems:             <ul style="list-style-type: none"> <li>○ [You said/ (your/SP's) heath makes (ADL) difficult.]/[You said that (ADL) is something (you don't/SP doesn't) do.] (Do you/does SP) receive help from another person with (ADL)?</li> </ul> </li> <li>• For those with difficulty or don't/doesn't do because of health or physical problems AND receive help from another person with (ADL):             <ul style="list-style-type: none"> <li>○ Do you expect (you/SP) will still need help with (ADL) three months from now?</li> </ul> </li> </ul>

ACS (2010)	Age 5 and over: Does this person have difficulty dressing or bathing?
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**Table A.5. Domestic life activity limitations (IADLs)—Questions**

<p>MEPS (2003)</p>	<p>Family-style question (all ages): The next questions are about difficulties people may have with everyday activities such as getting around, bathing, or taking medications. We are interested in difficulties due to an impairment or a physical or mental health problem.</p> <ul style="list-style-type: none"> <li>• Does anyone in the family receive help or supervision using the telephone, paying bills, taking medications, preparing light meals, doing laundry, or going shopping?</li> <li>• Who is that?</li> <li>• For those receiving help or supervision with these activities: <ul style="list-style-type: none"> <li>○ Do you expect that {PERSON} will need help or supervision with these activities for at least three more months?</li> </ul> </li> </ul>
<p>NHIS (2003)</p>	<p>Family-style question (age 18 and over): Because of a physical, mental, or emotional problem, {do/does} {you/anyone in the family} need the help of other persons in handling ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?</p>
<p>MCBS (2002)</p>	<p>Medicare beneficiaries: Now I'm going to ask about some everyday activities and whether (you have/SP has) any difficulty <u>doing them by (yourself/himself/herself)</u>.</p> <ul style="list-style-type: none"> <li>• Because of a health or physical problem, (do you/does SP) have <u>any</u> difficulty with the following? (yes, no, doesn't do) <ol style="list-style-type: none"> <li>a. using the telephone?</li> <li>b. doing light housework (like washing dishes, straightening up, or light cleaning)?</li> <li>c. doing heavy housework (like scrubbing floors or washing windows)?</li> <li>d. preparing (your/his/her) own meals?</li> <li>e. shopping for personal items (such as toilet items or medications)?</li> <li>f. managing money (like keeping track of expenses or paying bills)?</li> </ol> </li> <li>• For IADLs person doesn't do: <ul style="list-style-type: none"> <li>○ [You said that (IADL) is something that (you don't/SP doesn't) do.] Is this because of a <u>health</u> or <u>physical</u> problem?</li> </ul> </li> <li>• For those with difficulty or doesn't do IADL because of health or physical problems: <ul style="list-style-type: none"> <li>○ [You said/ (your/SP's) heath makes (IADL) difficult.]/[You said that (IADL) is something (you don't/SP doesn't) do.] (Do you/does SP) receive help from another person with (IADL)?</li> </ul> </li> </ul>
<p>ACS (2010)</p>	<p>Age 15 and over: Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?</p>



**Table A.6. Major life area activity limitations—Questions**

MEPS (2003)	<p>Family-style screener question (all ages):</p> <ul style="list-style-type: none"> <li>• Is anyone in the family limited in any way in the ability to work at a job, do housework, or go to school <b>because of an impairment or a physical or mental health problem?</b> Who is that?</li> <li>• For persons identified as being limited (age 5 and over): <ul style="list-style-type: none"> <li>○ Which activities is (PERSON) limited in doing because of an impairment or a physical or mental health problem – working at a job, doing housework, or going to school?</li> <li>○ For persons identified as being limited in specific activities: <ul style="list-style-type: none"> <li>▪ (Are/Is)(PERSON) completely unable to {work at a job}{,/and}{do housework}{and}{go to school}?</li> </ul> </li> </ul> </li> </ul>
NHIS (2003)	<p>Family-style question (age 18 and over):</p> <ul style="list-style-type: none"> <li>• Does a physical, mental, or emotional problem NOW keep {you/anyone in the family/any of these family members}(READ NAMES) from working at a job or business?</li> <li>• {Are/(Other than the persons mentioned), are any of these family members}{you/READ ADULT NAMES} limited in the kind OR amount of work {you/they} can do because of a physical, mental or emotional problem?</li> </ul>
MCBS (2002)	NA
ACS (2010)	NA

**Table A.7. Community, social, and civic life activity limitations—Questions**

MEPS (2003)	<p>Family-style question (all ages), right after the major life areas questions:</p> <p>Besides the limitations we just talked about, is anyone in the family limited in participating in social, recreational or family activities <b>because of an impairment or a physical or mental health problem?</b> Who is that?</p>
NHIS (2003)	<p>Sample adult (age 18 and over):</p> <p>By yourself, and without using any special equipment, how difficult is it for you to...</p> <ul style="list-style-type: none"> <li>• ...Go out to things like shopping, movies, or sporting events? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can't do at all, do not do this activity)</li> <li>• ...Participate in social activities such as visiting friends, attending clubs and meetings, going to parties? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can't do at all, do not do this activity)</li> <li>• ...Do things to relax at home or for leisure (reading, watching TV, sewing, listening to music)? (not at all difficult, only a little difficult, somewhat difficult, very difficult, can't do at all, do not do this activity)</li> </ul>
MCBS (2002)	<p>Medicare beneficiaries:</p> <ul style="list-style-type: none"> <li>• How much of the time during the <u>past month</u> has (your/SP's) health limited (your/SP's) social activities, like visiting friends or close relatives? Would you say...none of the time, some of the time, most of the time, or all of the time?</li> </ul>
ACS (2010)	NA

## Appendix A.2. Relationship to the ICF

The International Classification of Functioning, Disability and Health (ICF) organizes information in two *parts*, each with two components: Part 1. Functioning and Disability has the Body component (includes the classification for body functions and the classification for body structures), and the Activities and Participation component; and, Part 2. Contextual Factors has the Environmental Factors component and the Personal Factors component (WHO, 2001).

The NHDR/QR Disability Working Group focused their work on the following domains of disability in the Activities and Participation component:

- Seeing activity limitations (Watching, d110) and Hearing activity limitations (Listening, d115) under Purposeful sensory experiences (d110-d129) in Chapter 1, Learning and applying knowledge (d110-d199);
- Mobility activity limitations in Chapter 4, Mobility (d410-d499);
- Self-care activity limitations in Chapter, 5 Self-care (d510-d599);
- Domestic life activity limitations in Chapter 6, Domestic life (d610-d699);
- Major life areas activity limitations in Chapter 8, Major life areas (d810-d899); and
- Community, social and civic life activity limitations in Chapter 9, Community, social and civic life (d910-d999).

1 and 2. Seeing and Hearing activity limitations—ICF Chapter 1, Learning and applying knowledge

The actual impairments associated with sensory functions (e.g., seeing and hearing) are found in the Body component of Part 1 Functioning and disability (Body Functions Chapter 2, Sensory functions and pain, and Body Structures Chapter 2, The eye, ear and related

structures). However, the disabling effects of the sensory impairments, seeing activity limitations (Watching, d110) and hearing activity limitations (Listening, d115), are categorized under Purposeful sensory experiences (d110-d129) within Chapter 1, Learning and applying knowledge of the Activities and Participation component of Part 1 Functioning and Disability.

### 3. Mobility activity limitations—ICF Chapter 4, Mobility

The mobility domain reflected in the questions used in the surveys are captured in the ICF Activities and Participation component Chapter 4 Mobility (d410-d499).

### 4. Self-care activity limitations—ICF Chapter 5, Self-care

Traditionally, surveys ask about activities of daily living (ADL) to capture self-care activity limitations. Unfortunately, not all of the ADLs are coded to a single chapter of the current version of the ICF Activities and Participation component. For example, the ADL items of bathing and dressing are coded to the Activities and Participation component Chapter 5, Self-care, but the ADL item of getting around inside the house is coded to Chapter 4, Mobility.

For our purposes, we consider the ICF Activities and Participation component Self-care chapter to more closely get at the concept of the ADLs than any other chapter. Perhaps a future version of the ICF will have the ADLs and the ICF Activities and Participation Self-care chapter more closely aligned.

### 5. Domestic life activity limitations—ICF Chapter 6, Domestic life

Surveys have traditionally asked about instrumental activities of daily living (IADL), and they capture concepts most closely aligned to the ICF Activities and Participation Component Chapter 6, Domestic life. Unfortunately, not all of the common IADL items are mapped or

coded to the Domestic life chapter of the Activities and Participation component of the current version of the ICF.

Although the IADL items of preparing meals and shopping are included in Chapter 6, Domestic life, the IADL items of using the telephone (included in the Communication chapter), paying bills (included in the Major life areas chapter), and taking medications (included in the Self-care chapter) are not. For our purposes, we consider the ICF Activities and Participation component Domestic life chapter to more closely align with the concept of the IADLs. Perhaps the IADL questions and ICF Activities and Participation component will be aligned more closely in the future.

#### 6. Major life activity limitations—ICF Chapter 8, Major life areas

The major life activity limitations are included in the ICF Activities and Participation component Chapter 8, Major life areas (d810-d899).

#### 7. Community, social and civic life activity limitations—ICF Activities and Participation component Chapter 9, Community, social and civic life

The community, social and civic life activity limitations questions are captured in the ICF Activities and Participation component Chapter 9, Community, social and civic life (d910-d999).

## **Appendix A.3. Severity Levels by Survey within Domains for Tables 1-7**

### **1. Seeing activity limitations**

For MEPS five mutually exclusive hierarchical categories for persons (with glasses or contacts, if they use them) were constructed based on severity: (1) no difficulty; (2) some difficulty but can read newsprint; (3) cannot read newsprint but can recognize people; (4) cannot read newsprint and cannot recognize people (but not blind); and (5) blind. MEPS estimates shown in Table 1 are for the following four groups defined from the categories above: Any difficulty seeing—categories 2-5; Cannot read newsprint—categories 3-5; Cannot read newsprint and cannot recognize people—categories 4-5; and Blind—category 5.

NHIS has two levels of severity: Any trouble seeing; and Blind or unable to see at all.

MCBS asks which of the four categories best describes their vision: (1) no trouble seeing, (2) a little trouble, (3) a lot of trouble, or (4) no usable vision. Three levels of severity were created for MCBS defined from the categories above: A little trouble, a lot of trouble, or no usable vision—categories 2-4; A lot of trouble or no usable vision—categories 3-4; and No usable vision—category 4 by itself.

### **2. Hearing activity limitations**

For MEPS, the following five mutually exclusive hierarchical categories for persons (with a hearing aid if they use one) were created based on severity: (1) no difficulty; (2) some difficulty but can hear most of the things people say; (3) cannot hear most but can hear some of the things people say; (4) cannot hear some of the things people say but not deaf; and (5) cannot hear any speech at all, that is, deaf.

MEPS estimates (with a hearing aid) shown in Table 2 were created from the categories above in the following way: Any difficulty hearing—categories 2-5; Cannot hear most of the things

people say—categories 3-5; Cannot hear some of the things people say—categories 4-5; and Cannot hear any speech at all, that is, deaf—category 5.

NHIS asks which of four categories describes their hearing without a hearing aid: (1) good; (2) a little trouble; (3) a lot of trouble; and (4) deaf. Three levels of severity were created for NHIS defined from the categories above (without a hearing aid): A little trouble, a lot of trouble, or deaf—categories 2-4; A lot of trouble, or deaf—categories 3-4; and Deaf—category 4.

MCBS has four categories for best describing their hearing (with a hearing aid if they wear one): (1) no trouble hearing; (2) a little trouble; (3) a lot of trouble; and (4) deaf. Three levels of severity were created from the categories above (with a hearing aid): A little trouble, a lot of trouble, or deaf—categories 2-4; A lot of trouble, or deaf—categories 3-4; and Deaf—category 4.

### **3. Mobility activity limitations**

Four MEPS estimates by severity are provided in Table 3: (1) persons in the family identified as having difficulties by the screener question; (2) persons identified by the screener question where the difficulty is expected for at least three months duration; (3) persons identified by the screener question who additionally have at least some difficulty with at least 1 of the 8 activities; and (4) persons identified by the screener question and additionally with at least some difficulty with at least 1 of the 8 activities where the difficulty is expected for at least three months duration.

NHIS estimates are provided for any of 9 activities and for the reduction to any of 8 activities where the NHIS push or pull large objects item was not included since it is not included in other surveys. NHIS has six categories describing level of difficulty for each of the 9 activities: (1) not at all difficult; (2) only a little difficult; (3) somewhat difficult; (4) very difficult;

(5) can't do at all; and (6) do not do this activity. The "Do not do this activity" Category 6 was excluded from both the numerator and the denominator of all the NHIS estimates.

Three severity levels were created for NHIS when the 9 activities were considered: those reporting for at least 1 of 9 items only a little difficult, somewhat difficult, very difficult, or can't do at all—categories 2-5; those reporting for at least 1 of 9 activities somewhat difficult, very difficult, or can't do at all—categories 3-5; and those reporting for at least 1 of 9 activities very difficult or can't do at all—categories 4-5. Three severity levels were similarly created when the 8 activities (without push or pull large objects without special equipment) were considered.

MCBS asks about difficulty for 5 activities using five categories: (1) no difficulty at all; (2) a little difficulty; (3) some difficulty; (4) a lot of difficulty; and (5) not able to do it. Four severity levels were created: those reporting for at least 1 of 5 activities a little difficulty, some difficulty, a lot of difficulty, or not able to do it—categories 2-5; those reporting for at least 1 of 5 activities some difficulty, a lot of difficulty, or not able to do it—categories 3-5; those reporting for at least 1 of 5 activities a lot of difficulty, or not able to do it—categories 4-5; and those reporting for at least 1 of 5 activities not able to do it—category 5.

#### **4. Self-care activity limitations**

MEPS estimates in Table 4 are provided for two severity levels: those identified by the family-style question who receive help/supervision with personal care; and for those identified by the family-style question and expected to need help or supervision for at least three more months.

NHIS estimates are provided for the NHIS family-style screener question identifying persons who need the help of other persons with personal care needs. Estimates are also provided for persons identified as needing the help of other persons with the screener question and

additionally needing the help of other persons for at least 1 of the 6 activities asked about after the screener question.

MCBS estimates are provided for persons identified as having difficulty with or doesn't do because of health reasons at least 1 of the 5 activities. The walking item was excluded from the 6 activities that are asked about because none of the other surveys ask about walking with their ADL questions. MCBS estimates are also provided for those who receive help with at least 1 of the 5 activities; and those who receive help with at least 1 of the 5 activities and expected will still receive help 3 months from now.

### **5. Domestic life activity limitations**

MEPS estimates in Table 5 are for the following two severity levels: anyone identified by the family-style question as receiving help or supervision with any of the listed activities; and those identified by the family-style question as receiving help or supervision and whose care is expected to last for at least three more months.

NHIS estimates are provided for persons identified by the family-style question.

Four different MCBS estimates by severity level are provided: (1) persons with difficulty or doesn't do because of health problems at least 1 of 6 activities; (2) persons who receive help from another person with at least 1 of 6 activities; (3) persons with difficulty or doesn't do because of health problems at least 1 of the 5 activities (heavy housework is the excluded activity); and (4) persons who receive help from another person with at least 1 of 5 activities (heavy housework is the excluded activity).

### **6. Major life area activity limitations**

MEPS asks a family-style screener question about anyone in the family being limited in any way in the ability to work at a job, do housework, or go to school. For persons identified by the



screening question as being limited, information is obtained about which of the activities they are limited in doing, and whether they are completely unable to do activities in which they are limited. Four estimates were provided in Table 6 for MEPS: (1) those with a work, housework, or school limitation; (2) those with a work or school limitation; (3) those with a work limitation; and (4) those with a school limitation.

NHIS asks whether a physical, mental, or emotional problem NOW keeps anyone from working at a job or business, and then whether there are others who are limited in the kind OR amount of work they can do. Information from these two questions is used for the one NHIS estimate on work limitation.

## **7. Community, social and civic life activity limitations**

For MEPS, one estimate is provided in Table 7 for those identified from a family-style question asking about being limited in participating in social, recreational, or family activities.

NHIS asks separately about level of difficulty for three activities: (1) go out to things like shopping, movies, or sporting events; (2) participate in social activities such as visiting friends; and attending clubs and meetings, going to parties; and (3) do things to relax at home or for leisure. There are six levels of difficulty for each of the three activities: (1) not at all difficult; (2) only a little difficult; (3) somewhat difficult; (4) very difficult; (5) can't do at all; and (6) do not do this activity. The "Do not do this activity" response option 6 was excluded from both the numerator and the denominator for all of the NHIS estimates.

Three severity levels were created for NHIS when the 3 activities were considered: those reporting for at least 1 of the 3 activities only a little difficult, somewhat difficult, very difficult, or can't do at all—levels of difficulty categories 2-5; those reporting for at least 1 of the 3 activities, somewhat difficult, very difficult, or can't do at all—levels of difficulty

categories 3-5; and those reporting for at least 1 of the 3 activities very difficult, or can't do at all—levels of difficulty categories 4-5. Three severity levels were similarly created when the second activity (participating in social activities...) was considered by itself.

MCBS asks which of four categories best describes how much of the time their health limited their social activities: (1) none of the time; (2) some of the time; (3) most of the time; or (4) all of the time. Three levels of severity were created for MCBS defined from the categories above: Some of the time, most of the time, or all of the time—categories 2-4; Most of the time, or all of the time—categories 3-4; and All of the time—category 4 by itself.

**Appendix B. Disability survey questions from the Washington Group on Disability Statistics and the American Community Survey and ACS Disability Estimates**

**B.1. Disability survey questions from the WGDS and ACS**

<b>Washington Group on Disability Statistics Questions<sup>1</sup></b>	<b>American Community Survey Questions<sup>2</sup></b>
Introductory phrase: The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.	
2. Do you have difficulty hearing, even if using a hearing aid? a. No - no difficulty b. Yes - some difficulty c. Yes - a lot of difficulty d. Cannot do at all	16a. Is this person deaf or does he/she have serious difficulty hearing? <input type="checkbox"/> Yes <input type="checkbox"/> No
1. Do you have difficulty seeing, even if wearing glasses? a. No - no difficulty b. Yes - some difficulty c. Yes - a lot of difficulty d. Cannot do at all	16b. Is this person blind or does he/she have serious difficulty seeing even when wearing glasses? <input type="checkbox"/> Yes <input type="checkbox"/> No
4. Do you have difficulty remembering or concentrating? a. No - no difficulty b. Yes - some difficulty c. Yes - a lot of difficulty d. Cannot do at all	17a. Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? <input type="checkbox"/> Yes <input type="checkbox"/> No
3. Do you have difficulty walking or climbing steps? a. No - no difficulty b. Yes - some difficulty c. Yes - a lot of difficulty d. Cannot do at all	17b. Does this person have serious difficulty walking or climbing stairs? <input type="checkbox"/> Yes <input type="checkbox"/> No
5. Do you have difficulty (with self-care such as) washing all over or dressing? a. No - no difficulty b. Yes - some difficulty c. Yes - a lot of difficulty d. Cannot do at all	17c. Does this person have difficulty dressing or bathing? <input type="checkbox"/> Yes <input type="checkbox"/> No
	18. Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? <input type="checkbox"/> Yes <input type="checkbox"/> No

Washington Group on Disability Statistics Questions <sup>1</sup>	American Community Survey Questions <sup>2</sup>
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood? <ul style="list-style-type: none"> <li>a. No - no difficulty</li> <li>b. Yes - some difficulty</li> <li>c. Yes - a lot of difficulty</li> <li>d. Cannot do at all</li> </ul>	

<sup>1</sup> Information about the Washington Group on Disability Statistics disability questions can be found at [http://www.cdc.gov/nchs/washington\\_group/wg\\_questions.htm](http://www.cdc.gov/nchs/washington_group/wg_questions.htm). Accessed March 25, 2019.

<sup>2</sup> Information about and the American Community Survey disability questions can be found at: <https://www.census.gov/library/working-papers/2009/demo/brault-01.html>. Accessed March 25, 2019.

## B.2. ACS disability estimates

### ACS Disability estimates for the 18-44, 45-64, and 65 and over age groups in the United States: 2010

Category	Ages 18-44		Ages 45-64		Ages 65 and over	
	Percent	Margin of Error <sup>†</sup>	Percent	Margin of Error <sup>†</sup>	Percent	Margin of Error <sup>†</sup>
Total	100.0	(X)	100.0	(X)	100.0	(X)
With a disability	6.1	0.04	15.2	0.07	36.7	0.12
Hearing difficulty	1.0	0.02	3.5	0.04	15.1	0.08
Vision difficulty	1.0	0.02	2.6	0.02	6.9	0.06
Cognitive difficulty	3.4	0.03	5.2	0.04	9.5	0.09
Ambulatory difficulty	2.1	0.02	9.3	0.05	23.8	0.11
Self-care difficulty	1.0	0.02	2.9	0.03	8.8	0.07
Independent living difficulty	2.2	0.03	5.2	0.04	16.2	0.09
No disability	93.9	0.04	84.8	0.07	63.3	0.12

<sup>†</sup> The margin of error (MOE) at the 90 percent confidence level are provided for the ACS.

**Source:** U.S. Census Bureau, 2010 American Community Survey.

**Note:** Subcategories add to more than the total because some people have multiple disabilities.