

U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy



# DISABILITY DATA IN NATIONAL SURVEYS

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This report was prepared under contract #HHSP23320095642WC between HHS's ASPE/DALTCP and Mathematica Policy Research. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/\_/office\_specific/daltcp.cfm or contact the ASPE Project Officer, Hakan Aykan, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. His e-mail address is: Hakan.Aykan@hhs.gov.

# **DISABILITY DATA IN NATIONAL SURVEY**

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August 25, 2011

Prepared for
Office of Disability, Aging and Long-Term Care Policy
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Contract #HHSP23320095642WC

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

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# **ACKNOWLEDGMENTS**

We appreciate the thoughtful guidance and input of Hakan Aykan, our project officer at the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE). We also thank David Wittenburg at Mathematica, who provided useful comments on an early draft.

The opinions, conclusions, and any errors in this report are the sole responsibility of the authors and do not reflect the official views of ASPE or Mathematica.

## **ACRONYMS**

ACS American Community Survey

Add Health National Longitudinal Study of Adolescent Health

ADL Activities of Daily Living
AHS American Housing Survey

ASPE Office of the Assistant Secretary for Planning and Evaluation,

U.S. Department of Health and Human Services

ATUS American Time Use Survey

B&B Baccalaureate and Beyond Longitudinal Study

BLS Bureau of Labor Statistics, U.S. Department of Labor
BPS Beginning Postsecondary Students Longitudinal Study

BRFSS Behavioral Risk Factor Surveillance System

CDC Centers for Disease Control and Prevention, U.S. Department of

Health and Human Services

CE Consumer Expenditure Survey

CMS Centers for Medicare and Medicaid Services, U.S. Department of

Health and Human Services

CPS Current Population Survey

DOL U.S. Department of Labor

ECLS Early Childhood Longitudinal Survey
EPA U.S. Environmental Protection Agency

FAEP Federal Advisory Expert Panel

HHANES Hispanic Health and Nutrition Examination Survey
HHS U.S. Department of Health and Human Services

HOS Medicare Health Outcome Survey
HRS Health and Retirement Study

HSLS High School Longitudinal Study

HUD U.S. Department of Housing and Urban Development

IADL Instrumental Activities of Daily Living

ICDR Interagency Committee on Disability Research

ICF International Classification of Functioning, Disability, and Health IES Institute of Education Sciences, U.S. Department of Education Internal Revenue Service, U.S. Department of the Treasury

LSOA Longitudinal Study of Aging

MCBS Medicare Current Beneficiary Survey
MEPS Medical Expenditure Panel Survey

NBS National Beneficiary Survey

NCHS National Center for Health Statistics, U.S. Department of Health

and Human Services

NCS National Comorbidity Survey

NCVS National Crime Victimization Survey
NELS National Education Longitudinal Study

NHANES National Health and Nutrition Examination Survey

NHATS National Health and Aging Trends Study
NHES National Household Education Survey

NHIS National Health Interview Survey

NHIS-D National Health Interview Survey on Disability

NIA National Institute on Aging, U.S. Department of Health and Human

Services

NLSY97 National Longitudinal Survey of Youth 1997

NLTCS National Long Term Care Survey

NLTS National Longitudinal Transition Survey

NLTS 2012 National Longitudinal Transition Survey 2012 NLTS2 National Longitudinal Transition Study 2

NNHS National Nursing Home Survey

NS-CSHCN National Survey of Children with Special Health Care Needs

NSCF National Survey of SSI Children and Families

NSCH National Survey of Children's Health

NSDUH National Survey on Drug Use and Health
NSFH National Survey of Families and Households

NSV National Survey of Veterans

ONC Office of the National Coordinator for Health Information

Technology

PALS Participation and Activity Limitation Survey

PSID Panel Study of Income Dynamics

RSA Rehabilitation Services Administration

SAMHSA Substance Abuse and Mental Health Services Administration,

U.S. Department of Health and Human Services

SCF Survey of Consumer Finances
SILJ Survey of Inmates in Local Jails

SIPP Survey of Income and Program Participation

SISCF/SIFCF Survey of Inmates in State and Federal Correctional Facilities

SSA U.S. Social Security Administration
SSDI Social Security Disability Insurance
SSI Supplemental Security Income

SSN Social Security Number

TAG Technical Advisory Group

UI Unemployment Insurance

VA U.S. Department of Veterans Affairs

WIA Workforce Investment Act

#### I. INTRODUCTION

# A. Purpose of the Report

Federal agencies, policy makers, and researchers use information from national surveys for a variety of purposes, including monitoring the health and well-being of the population, designing new public programs and policies, and understanding the circumstances of vulnerable populations in order to assess the effectiveness of programs. One such vulnerable population is people with disabilities. A large and growing share of the United States population is affected by disability, and disability prevalence increases considerably as people age. Statistics from the 2009 American Community Survey (ACS) indicate that about 36 million (12 percent) of individuals age 5 and over residing in the community have disabilities. Disability prevalence ranges from 5.2 percent among children ages 5-17 to 37.4 percent among adults age 65 and over (Census Bureau 2011). With medical improvements that extend life expectancy and the aging of the baby boom generation, the prevalence of disability is increasing and will continue to rise for the foreseeable future.

Because disability can greatly affect a person's productivity, economic well-being, and reliance on publicly funded programs and supports, a large amount of public expenditures is devoted to this population. Recent estimates indicate that in fiscal year 2008 the Federal Government spent approximately \$357 billion on a wide range of programs that provide services to working-age adults with disabilities (Livermore et al. 2011). In light of this, it is especially important for policy makers to have access to a wide variety of high-quality data on people with disabilities in order to better understand the needs of this population, assess how existing programs and policies are performing, and plan for the future.

The Federal Government collects extensive survey and administrative data pertaining to disability that is used by federal agencies for a variety of purposes. However, existing national disability-related survey and administrative data are limited in their ability to meet the needs of federal programs and policy makers. Such limitations include inadequate and inconsistent measures of disability, small sample sizes or no data on particular subpopulations of interest, lack of information on specific topics, very limited longitudinal information, poor-quality survey data on program participation and service use, and lack of access to and linkages with administrative data (Livermore and She 2007). One potential response to the shortcomings of existing disability data is the fielding of a national disability survey or similar large-scale disability data collection effort. The National Health Interview Survey on Disability (NHIS-D), fielded from 1994 to 1997, represents one such effort; it is the only large-scale national disability survey data collection effort ever conducted for the United States general population.

This report was prepared as part of a project sponsored by the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE), to assess the need for developing and fielding another national

disability survey data collection effort. It presents the findings from one of the project's major activities designed to review the disability-related information that is available in existing national surveys.

#### B. Methods and Sources of Information

To develop an understanding of the scope and limitations of existing disability data, we conducted a review of 40 national surveys that cover a range of topics likely to be of importance to the policies, programs, and issues that affect the lives of people with disabilities. An important goal of this review was to provide written summaries documenting the key features of each survey that could act as a quick-reference guide for ASPE and other federal agency staff in their discussions and planning around disability data collection activities.

In selecting the surveys to be reviewed, we were guided by the following criteria:

- The survey was federally-sponsored and national in scope.
- The survey was fielded in 2000 or later.
- If not fielded since 2000, the survey contains significant disability-related content or other information of particular relevance to individuals with disabilities.

Due to resource constraints, not all possible surveys meeting the above criteria were reviewed. In the discussion of the surveys presented in Chapter II, we note instances of surveys that meet the above criteria that were not included in our initial review. A tabular, quick-reference summary of the features of the 40 surveys is provided in Appendix A; more detailed text summaries of each survey are provided in Appendix B.

# II. OVERVIEW OF EXISTING DISABILITY-RELATED SURVEY DATA

Many existing national surveys collect disability-related information, and some do so in great detail. There is substantial variation across surveys in terms of target populations, the disability measures used, topics covered, frequency, and design. Here, we provide an overview of the 40 national, federally-sponsored surveys we reviewed for this study, focusing on the disability-related content. A list of the surveys reviewed is shown in Table II.1. A tabular summary of the features of the 40 surveys is presented in Appendix A and more detailed information on each survey is provided in Appendix B.

	TABLE II.1. Surveys Reviewed						
Nat	tional Household Surveys						
	American Community Survey (ACS) American Housing Survey (AHS) American Time Use Survey (ATUS) Behavioral Risk Factor Surveillance System (BRFSS) Census Consumer Expenditure Survey (CE) Current Population Survey (CPS) Medical Expenditure Panel Survey (MEPS) National Crime Victimization Survey (NCVS) National Health and Nutrition Examination Survey (NHANES)	12. 13. 14. 15. 16. 17.	National Health Interview Survey (NHIS) National Household Education Survey (NHES) National Survey of Families and Households (NSFH) National Survey on Drug Use and Health (NSDUH) Panel Study of Income Dynamics (PSID) Survey of Consumer Finances (SCF) Survey of Income and Program Participation (SIPP)				
Sui	rveys on Health, Disability, Aging, and Long-To	erm (	Care				
1. 2. 3. 4. 5. 6. 7.	Health and Retirement Study (HRS) Longitudinal Study of Aging (LSOA) Medicare Current Beneficiary Survey (MCBS) Medicare Health Outcomes Survey (HOS) National Beneficiary Survey (NBS) National Comorbidity Survey (NCS) National Health Interview Survey on Disability (NHIS-D)		National Long Term Care Survey (NLTCS) National Nursing Home Survey (NNHS) National Survey of Children with Special Health Care Needs (NS-CSHCN) National Survey of SSI Children and Families (NSCF)				
Sui	rveys on Youth, Education, and Transition						
1. 2. 3. 4.	Baccalaureate and Beyond Longitudinal Study (B&B) Beginning Postsecondary Students Longitudinal Study (BPS) Early Childhood Longitudinal Survey (ECLS) High School Longitudinal Study of 2009 (HSLS) National Education Longitudinal Study (NELS)	<ul><li>6.</li><li>7.</li><li>8.</li><li>9.</li></ul>	National Longitudinal Study of Adolescent Health (Add Health) National Longitudinal Survey of Youth 1997 (NLSY97) National Longitudinal Transition Study 2 (NLTS2) National Survey of Children's Health (NSCH)				
	ner Surveys						
1. 2.	National Survey of Veterans (NSV) Survey of Inmates in Local Jails (SILJ)	3.	Survey of Inmates in State and Federal Correctional Facilities (SISCF/SIFCF)				

We identified several additional surveys that we did not review but which met the criteria for inclusion in our review. These excluded surveys include the Consumer Assessment of Healthcare Providers and Systems, Healthcare Cost and Utilization Project, Integrated Postsecondary Education Data System, National Home and Hospice Care Survey, National Hospital Discharge Survey, National Postsecondary Student Aid Study, National Survey of America's Families, National Survey on Family Growth,

Postsecondary Education Quick Information System, Special Education Elementary Longitudinal Study, Surveillance, Epidemiology and End Results Program, Survey of Veteran Enrollees' Health and Reliance upon VA, and the Youth Risk Behavior Surveillance System.

In the sections that follow, we provide an overview of the 40 surveys reviewed for this study. The discussion is divided into four sections: ongoing national general population surveys; surveys of health, disability, aging, and long-term care subpopulations; surveys of youth, education, and transition subpopulations; and other surveys. The final two sections describe several new survey efforts and provide some general observations about the nature and content of the 40 surveys, respectively.

## A. Ongoing National General Population Surveys

The United States government sponsors a number of national surveys that are representative of all or most of the United States population. These surveys are conducted on a regular basis and represent the core of the government's national data collection efforts to monitor the characteristics, health, and well-being of the United States population We reviewed 17 general population surveys, including ACS, American Housing Survey (AHS), American Time Use Survey (ATUS), Behavioral Risk Factor Surveillance System (BRFSS), Census, Consumer Expenditure Survey (CE), Current Population Survey (CPS), Medical Expenditure Panel Survey (MEPS), National Crime Victimization Survey (NCVS), National Health and Nutrition Examination Survey (NHANES), National Household Education Survey (NHES), National Health Interview Survey (NHIS), National Survey on Drug Use and Health (NSDUH), National Survey of Families and Households (NSFH), Panel Study of Income Dynamics (PSID), Survey of Consumer Finances (SCF), and Survey of Income and Program Participation (SIPP).

#### 1. Coverage of United States Households

Generally, the ongoing national surveys cover the household population or noninstitutional population, however, the ACS (since 2006), AHS, Census, and the 1996 MEPS also cover certain nonhousehold or group quarters populations. Most ongoing national surveys include individuals of all ages in their samples, but in many cases a single household member provides information on all other family members, and in several instances children under a particular age are excluded. Surveys in this category are fielded regularly, some annually and others less frequently (for example, every 4-8 years). Most have data available from 2007 or later. Seven of the 17 surveys in this category produce longitudinal data, and all but one (the PSID) can generate time-series data. About half of these support estimates at regional or state levels.

#### 2. Disability-Related Content

In some cases, surveys that are not explicitly concerned with health include disability indicators. The ACS, AHS, and CPS use a common set of six questions to

identify hearing impairments, vision impairments, physical disabilities, mental disabilities, self-care disabilities, and independent living limitations. These questions were added to the AHS and CPS very recently. As a result, the surveys can be used to compare the population with disabilities with the rest of the population, or those with one category of disability against those with another. However, they do not allow for descriptions of disabilities or limitations, or for certain distinctions, such as whether a limitation in decision making is due to cognitive impairment, a developmental disability, or mental health.

Some surveys contain very little disability information. The CE and SCF collect disability information only in the context of income and expenditures. In both cases, respondents are asked about disability income (for example, Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), workers' compensation, and Veterans compensation). In the CE, respondents are also asked about medical expenditures; in both surveys, respondents can indicate disability as a reason for not working (if they indicate they are not working), but in neither survey are all respondents directly queried about their disability status. While these surveys can be used to identify the population with a disability that prevents work or with expenditures on given services or devices associated with certain limitations or conditions, their utility for disability research is limited due to their lack of disability indicators. The ATUS has a similar issue; however, its sample is derived from the CPS and so it is possible to match responses to the new CPS disability questions to the ATUS sample. As of 2010, the Census no longer collects information on disability; the ACS is intended to provide the information to replace disability and other questions previously included on the Census long form.

The BRFSS, MEPS, NHANES, NHIS, PSID, and SIPP contain a substantial amount of information on health and disability, but even among these surveys the level of detail varies considerably. Some, like the BRFSS, collect relatively simple information on issues relevant to disability, such as functional limitations, use of special equipment, and need for assistance or care. At the other end of the spectrum, the SIPP and the NHIS contain numerous measures of health status and disability.

Other surveys in this group collect information on a particular category of disability or disability information only from some respondents. The NHES collects information about disabilities that might affect respondents' education. Questions address whether they have a disability that affects their ability to learn, or have ever needed or used specialized services. The NSDUH solicits information on issues of mental health, particularly substance abuse, but does not address any other types of disabilities. The NSFH focuses on relationship dynamics among family members, so questions on disability address needs for care and assistance, care provided by family members, symptoms of depression, and drug and alcohol abuse. The NCVS asks detailed questions about disability, but only if the respondent has been the target of a crime during the reference period.

Information on program participation, education, and employment appears in nearly all of the ongoing national surveys. Relatively few, however, provide detailed information on learning disability, social participation, transportation, and whether the respondents are considered by themselves or others to have a disability.

#### B. Surveys on Health, Disability, Aging, and Long-Term Care

A number of national surveys focus on health, disability, aging, and long-term care topics, but are conducted less frequently than the ongoing surveys described above and/or focus only on specific subpopulations. We reviewed 11 such surveys, including Health and Retirement Study (HRS), Longitudinal Study of Aging (LSOA), Medicare Current Beneficiary Survey (MCBS), Medicare Health Outcomes Survey (HOS), National Beneficiary Survey (NBS), National Comorbidity Survey (NCS), NHIS-D, National Long Term Care Survey (NLTCS), National Nursing Home Survey (NNHS), National Survey of SSI Children and Families (NSCF), and National Survey of Children with Special Health Care Needs (NS-CSHCN). With the exception of the NCS, all of these studies use samples restricted to particular subpopulations: older age groups, those receiving specific types of benefits or care, and those screened-in based on their reported health status and needs.

#### 1. Coverage of United States Households

The surveys in this group are generally conducted less frequently than the ongoing national surveys described above. However, with the exception of the NHIS-D, which was only conducted in 1994-1996, and the LSOA, which was last conducted in 2000, data are available from 2004 or later. Seven of the 11 surveys produce time-series data, and six produce longitudinal data. Six of the 11 surveys support regional or state-level estimates.

The HRS, LSOA, and NLTCS are longitudinal studies that examine changes as individuals age. The HRS targets people over age 50 and follows them based on their birth cohort. Two LSOA studies followed individuals age 55 or older from the 1984 and 1994 NHIS samples until 1990 and 2000, respectively. The NLTCS used a sample of individuals ages 65 and older drawn from Medicare eligibility files in 1982 and followed them until 2004.

In addition to the NLTCS, several other surveys derive their samples from program participation populations. The MCBS draws its sample from Medicare beneficiaries, the HOS from Medicare Advantage enrollees, the NBS from SSI and SSDI beneficiaries, and the NSCF from children receiving SSI benefits. Though not specifically a program participant sample, the NNHS derives its sample from nursing home residents, many of whom are Medicaid and Medicare beneficiaries.

The NHIS-D and NS-CSHCN screened respondents based on their own or their child's health and disability status. The first Phase of the NHIS-D was a supplement to

the NHIS, administered to all respondents in 1994 and 1995. If individuals were identified as having or potentially having a disability, they were screened into Phase II, which collected more detailed information related to disability. The NS-CSHCN similarly asked questions of a nationally representative sample of children in households. Another general population survey that screened for particular health conditions is the NCS. The NCS screened respondents for a variety of mental health disorders based on a lengthy questionnaire.

#### 2. Disability-Related Content

Because they are intended to provide information related to disability and health, these surveys include more extensive information on disability than most national household surveys. All include information on physical and functional limitations, limitations in activities of daily living (ADLs), cognitive impairment or developmental disorders, specific conditions, health, and health insurance. Less common topics include substance use, abuse, and dependence (three surveys); bed days (three surveys); learning disabilities (two surveys); and whether the respondents are considered by themselves or others to have a disability (one survey).

A variety of disability-related topic areas are covered in surveys focused on aging. In the HRS, details are collected on disabilities and limitations experienced before age 16, those present at the time of interview, and the impact of disability and aging on work activity. The LSOA focused on physical and cognitive impairments and how respondents cope with challenges as they age. The NLTCS focused on the factors that cause individuals to move from community settings into long-term care facilities, including health, functional status, medical expenditures, and sources of care from family members and others in the community.

The MCBS, HOS, NBS, NSCF, and NNHS include detailed questions about disability, targeted to the populations surveyed, and most have links to administrative records from the relevant program. For example, the NBS includes questions about barriers to work and use of U.S. Social Security Administration (SSA) work incentives and is linked to SSA records, and the NSCF focuses on the services needed and used by children who qualify for SSI. Information from the NNHS provides a picture of the needs and characteristics of nursing home residents.

For those screened to participate, the NHIS-D, NS-CSHCN, and NCS collected detailed information on participants. Phase II of the NHIS-D asked participants to report on particular limitations, their severity, and their effects. The NS-CSHCN collected additional information on those who have more or different medical needs than most children their age for those screened-in to the sample. The NCS asks a detailed battery of questions related to mental illness as well as questions on physical disabilities.

#### C. Surveys on Youth and Education

We reviewed nine surveys on youth and education topics and subpopulations, including Baccalaureate and Beyond Longitudinal Study (B&B), Beginning Postsecondary Students Longitudinal Study (BPS), Early Childhood Longitudinal Survey (ECLS), High School Longitudinal Study (HSLS), National Education Longitudinal Study (NELS), National Longitudinal Study of Adolescent Health (Add Health), National Longitudinal Survey of Youth 1997 (NLSY97), National Longitudinal Transition Study 2 (NLTS2), and National Survey of Children's Health (NSCH).

#### 1. Coverage of United States Households

All of these surveys restrict their samples to particular age groups, and many focus on even more specific target populations. For example, the B&B and BPS sampled those graduating from and beginning postsecondary education, and the HSLS sampled only students enrolled in the 9<sup>th</sup> grade. Nearly all have been fielded relatively recently; with the exception of NELS, which was last fielded in 2000, data are available from 2007 or later. Only three of the nine surveys in this category can produce estimates at the state or regional level.

Most of the surveys in this category are sponsored by the Institute of Education Sciences (IES) in the U.S. Department of Education and are longitudinal in nature, to track how children and young adults develop over time and to relate experiences to outcomes. The major differences across the IES surveys are the age groups and populations of interest. B&B focuses on college graduates, BPS on college freshmen, HSLS on those enrolled in 9<sup>th</sup> grade, the NELS on those enrolled in 8<sup>th</sup> grade, and ECLS on young children, sampled at nine months or at kindergarten enrollment. Somewhat different from the other IES studies, the NLTS2 followed secondary students who were receiving special education services as they moved into adult roles. Though not sponsored by IES, NLSY97 used a similar sample--youth ages 12-16--and followed similar outcomes.

Add Health and the NSCH are focused on issues of health and health care. Add Health sampled adolescents enrolled in grades 7-12 and collected information on how social and behavioral factors influence health over time. The NSCH sampled children under age 18.

#### 2. Disability-Related Content

Information on physical and functional limitations, mental and emotional disorders or symptoms, and employment appear in all of the surveys on youth and education. Seven of the nine surveys cover learning disability, which is relatively uncommon in surveys of other populations. None of these surveys covers household expenditures and only two cover issues related to substance use, abuse, and dependence, or transportation.

Disability content in B&B, BPS, HSLS, NELS, and ECLS focuses on the services children and youth need and receive in school and on the effect of childhood disability on adult outcomes. The disability content in NLTS2 is much more extensive than in the other education-focused surveys and includes information on limitations as well as on services and accommodations provided by school, work, and other sources.

Add Health and NSCH include content related to physical limitations, symptoms of depression and anxiety, and diagnoses. The NSCH provides a general description of children's health. It includes extensive disability content, including limitations, diagnoses, medications prescribed, and services used, as well as more general questions on health and health care.

#### D. Other Surveys

In addition to the surveys described above, we reviewed three surveys of specific subpopulations: National Survey of Veterans (NSV), Survey of Inmates in Local Jails (SILJ), and Survey of Inmates in State and Federal Correctional Facilities (SISCF/SIFCF). These surveys address specific agency needs and are useful primarily for research about their specific target populations, which are generally not addressed in other surveys. They are conducted relatively infrequently and do not support state or regional estimates.

#### 1. Coverage of United States Households

The NSV is focused on collecting information for developing and evaluating U.S. Department of Veterans Affairs programs. It uses a sample of veterans and, starting in 2009, active members of the military as well as their families. The SILJ and SISCF/SIFCF are nearly identical surveys that collect information on inmates in local jails and prisons, respectively, in order to evaluate the needs of the incarcerated population and remedy deficiencies in correctional institutions.

#### 2. Disability-Related Content

Information collected by the NSV includes ADL limitations and instrumental activities of daily living (IADL) limitations, as well as Veterans Administration (VA) disability ratings, sources of health insurance, and medical services used. The SILJ and SISCF/SIFCF include detailed sections on drug and alcohol abuse and dependence and on other mental health issues. Some information on physical health and physical limitations is also collected.

All three surveys include information on sensory and communication limitations, physical and/or functional limitations, mental and emotional disorders or symptoms, specific conditions, disability benefit receipt or program participation, health, use of services related to health and disability, and participation in public programs. None addresses cognitive impairment or developmental disorders, social participation or

interpersonal interaction, use of or need for personal assistance, bed days, household expenses, or transportation.

#### E. New Survey Efforts

While many of the surveys listed above continue to collect data, some are undergoing significant changes. Three surveys are adding disability supplements and two are changing the way the survey collects data. In addition, a new survey targeting Medicare beneficiaries over age 65 is in progress. We describe these new efforts below.

#### 1. Modifications to Existing Surveys

In addition to short supplements on disability, which have appeared in various forms since 2008, the 2011 NHIS includes a longer supplement on functioning and disability. The supplement contains questions on the severity of difficulty with particular activities, use of assistive devices (for example, a hearing aide or a cane), activity limitations, anxiety and depression, and pain. The same questions are being fielded as part of national health surveys in several other countries so that comparisons can be made across cultures.

The U.S. Department of Labor (DOL) is in the process of developing a new disability supplement to the 2012 CPS. The focus of the supplement is to provide new, detailed information on the employment-related issues of people with disabilities. Potential topics include the nature of the disability, work history, living arrangements, social environment, family background, income, employment counseling and training, assistive technology and employer accommodations, telecommuting and transportation, and use of government programs. The survey instrument is currently under development and its final contents will reflect input from researchers and disability advocates.

The SIPP, conducted by the Census Bureau, is currently undergoing major changes. The product of these changes, referred to as the Re-Engineered SIPP, will have a new survey design with annual interviews replacing interviews three times a year, and a new survey instrument. SSA is sponsoring a disability supplement to the Re-Engineered SIPP. Detailed information about the contents of the disability supplement is not yet available, as SSA is scheduled to deliver the contents and questions for the survey to the Census Bureau in summer 2011.

#### 2. New Data Collection Efforts

The U.S. Department of Education is sponsoring, a new round of data collection called the National Longitudinal Transition Survey 2012 (NLTS 2012). The NLTS 2012 will build off the questions included in the NLTS2, but has a more ambitious sample design. The NLTS 2012 sample will contain not only youth identified as needing special education services, but also two other groups: those with a condition that qualifies them

for accommodations under Section 504 of the Vocational Rehabilitation Act of 1973 and other students with no identified disability. This will allow the study to gauge how the characteristics, experiences, and outcomes of special education students differ from those of the other two groups of youth. The data collected in the NLTS 2012 will permit comparisons to data in the NLTS2 and NLTS, to examine changes in the characteristics, school experiences, and postsecondary outcomes of special education students.

With funding from the National Institute on Aging (NIA) within the National Institutes of Health, Johns Hopkins Bloomberg School of Public Health and Westat are conducting the National Health and Aging Trends Study (NHATS). The NHATS is a longitudinal survey of Medicare beneficiaries over age 65. The goal of the survey is to monitor changes in daily life and activities throughout the aging process. Participants will be interviewed once a year on topics including living arrangements, economic status and well-being, work status and participation in valued activities, quality of life, daily activities and help provided with such activities, mobility and use of assistive devices, cognitive functioning, health, and health care. During the interview, participants will also be asked to conduct activities including standing, getting up from a chair, walking, breathing, and memory exercises. In addition, the interviewer will record the respondent's height, weight, and waist circumference.

#### F. Commentary on Existing Disability-Related Survey Data

Some general observations based on our review of the 40 surveys include the following:

- The specific measures of disability and wording of questions designed to elicit information about a particular type of disability (for example, visual impairment), differ markedly across surveys. Nearly all of the national surveys reviewed have questions that can be used to identify people with disabilities, but a few do not.
- A concerted effort is being made to use a uniform set of disability indicators across surveys. The six-question series included in the ACS, CPS, AHS, and NHIS supplement is part of this effort. A new supplement in the 2011 NHIS, which will include a battery of questions related to disability, represents an effort to make more uniform, descriptive information on disability available across countries.
- Few surveys contain measures to specifically identify individuals with cognitive or intellectual disabilities. Measures to identify specific health conditions underlying disability also are uncommon.
- There are numerous surveys of specific subpopulations (for example, students, inmates, nursing home residents, and beneficiaries of specific programs) on a variety of disability-related topics. This likely reflects the specific data and

information needs of particular agencies and the fact that the general population surveys do not contain large enough samples of individuals in these specific target populations.

- Many national surveys have longitudinal components, though most cover a specific subgroup rather than a general population. The PSID and HRS represent the most extensive efforts in that they regularly interview individuals from the time of sampling until death or loss to follow-up.
- New disability supplements to the SIPP and CPS will increase the information available on employment, economic well-being, and program participation. Two new longitudinal surveys will provide information about the school-to-work transitions of youth and health status changes of Medicare beneficiaries age 65 and over.
- Consumption, expenditures, job accommodations, transportation and means for getting around outside of the home, environmental barriers, and community supports are the general topic areas least commonly addressed for people with disabilities in the surveys we reviewed.

A final important observation is that a considerable amount of survey data is already being collected on disability issues and populations. Finding ways to improve, augment, and coordinate these existing mechanisms is an important means for addressing the limitations of survey data on disability-related issues and populations.

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# APPENDIX A. QUICK-REFERENCE SUMMARY OF SURVEYS

#### Note to Readers About Appendix A

The summary tables provided in this appendix are not intended to present a detailed level of information about each of the 40 national surveys reviewed for this report. Rather, they are intended to portray the large and multidimensional variation across the 40 surveys in terms of their frequency of administration, nature of their samples, topic areas, and how health and disability concepts are measured. For more information about each survey, the reader is referred to the detailed survey summaries that are provided in Appendix B of this report.

		g National Surve		
Survey Features	ACS	AHS	ATUS	BRFSS
Population				
Household Population	X	X	X	X
Noninstitutional Group Quarters	2006 and later	X	X <sup>1</sup>	
Population				
nstitutional Population	2006 and later	X		
Special Population Subgroup				
Age Groups		1		
Children (under 18)	X	X	Age 15 and older	
Norking-Age Adults (18-64)	Χ	X	X	X
Seniors (65+)	X	X	X	X
Geographic Level of Estimates				
National	X	X	Χ	X
Regional	Х	X <sup>2</sup>		Χ
State	Χ			X
Гiming				
_atest Year Available	2010	2009	2009	2010
Time-Series	2006-2010 <sup>3</sup>	1973-2009	2003-present	1984-present
_ongitudinal		1985-2009	·	· · · · · · · · · · · · · · · · · · ·
Health/Disability Indicators				
General Health Status			2006-2008	Х
Body Mass (weight, height, obesity)			2006-2008	X
Sensory/Communication Limitations	Х	1978; 1995; 2009	2000 2000	X
Physical Limitations/Functional Limitations	X	1978; 1995; 2009		X
ADL Limitations		1978; 1995; 2009		
ADL Limitations		1978; 1995; 2009		
imitations in Work/Usual Activities	Х	1978; 1995; 2009	X <sup>4</sup>	Х
Learning Disability		1978; 2009 <sup>5</sup>	Λ	
Mental/Emotional Disorders or Symptoms	X <sup>6</sup>			Х
	X6	1978; 2009 <sup>5</sup>		
Cognitive Impairment or Developmental	Χ <sub>e</sub>	1978; 2009 <sup>5</sup>		X
Disorders	V			
Social Participation/Interpersonal	Х			
Interactions				
Substance Use/Abuse/Dependence		4070		V
Specific Chronic Conditions/Medical		1978		X
Conditions		4070, 4005		V
Use of/Need for Assistive Equipment		1978; 1995		X
Use of or Need for Personal Assistance		1978; 1995; 2009		
Bed Days/Lost Productivity Days	V	V		X
Disability Benefit Receipt/Program	X	X		
Participation		4070	4	
Self/Others Identify as Disabled		1978	X <sup>4</sup>	
Topic Domains		1		
Education	X	X	X	X
Employment	X	X	X	X
-lealth	Х		2006-2008	X
Health/Disability-Related Service Use				
Health Insurance	Х			Х
Household Expenditures	Х	X		
Housing	Х	X		
ncome/Economic Well-Being	Χ	X	$X^7$	X
Public Program Participation	X	X	2006-2008	
Transportation	Х	Х		

TABLE A.1. (continued)							
Survey Features	Census	CE	CPS	MEPS			
Population							
Household Population	X	X	X	X			
Noninstitutional Group Quarters	Х	X <sup>8</sup>	Х	X			
Population							
nstitutional Population	X			1996 only			
Special Population Subgroup							
Age Groups		T					
Children (under 18)	X	Age 16 and older	Age 15 and older	X			
Working-Age Adults (18-64)	X	X	X	X			
Seniors (65+)	X	X	X	X			
Geographic Level of Estimates							
National	X	X	X	X 10			
Regional	Χ	X	X <sup>9</sup>	X X <sup>10</sup>			
State	X		X <sup>11</sup>	X <sup>12</sup>			
Timing							
_atest Year Available	2010	2010	2011	2008			
Time-Series	1790-2010	1980-present	1940-present	1996-present			
_ongitudinal				X			
Health/Disability Indicators							
General Health Status				X			
Body Mass (weight, height, obesity)				2002-present			
Sensory/Communication Limitations			2008-present	X			
Physical Limitations/Functional Limitations			2008-present	Χ			
ADL Limitations			2008-present	Χ			
ADL Limitations			2008-present	Χ			
imitations in Work/Usual Activities		X <sup>4</sup>	X	Χ			
Learning Disability							
Mental/Emotional Disorders or Symptoms			2008-present	Х			
Cognitive Impairment or Developmental			2008-present	Х			
Disorders							
Social Participation/Interpersonal							
Interactions		40					
Substance Use/Abuse/Dependence		X <sup>13</sup>					
Specific Chronic Conditions/Medical				Χ			
Conditions							
Jse of/Need for Assistive Equipment		X <sup>13</sup>		X			
Use of or Need for Personal Assistance		X <sup>13</sup>		Χ			
Bed Days/Lost Productivity Days				Х			
Disability Benefit Receipt/Program		X <sup>14</sup>		X			
Participation							
Self/Others Identify as Disabled							
Topic Domains							
Education		X	X	Х			
Employment		X	X	X			
-lealth		X		X			
Health/Disability-Related Service Use		X <sup>13</sup>		Х			
Health Insurance		X <sup>13</sup>	X <sup>15</sup>				
Household Expenditures		X					
Housing		X					
		<u> </u>	15				
		X	χ.,	X			
ncome/Economic Well-Being Public Program Participation		X X <sup>13</sup>	X <sup>15</sup>	X			

TABLE A.1. (continued)							
Survey Features	NCVS	NHANES	NHES	NHIS			
Population							
Household Population	X	X	X	X			
Noninstitutional Group Quarters	X X <sup>8</sup>	X		X			
Population							
Institutional Population							
Special Population Subgroup		X <sup>17</sup>					
Age Groups							
Children (under 18)	Age 12 and older	Χ	X	X			
Working-Age Adults (18-64)	Χ	Χ	X	X			
Seniors (65+)	X	Χ	X	X			
Geographic Level of Estimates							
National	X	X	X	X			
Regional	1979-2004 <sup>18</sup>		X	X			
State				Х			
Timing							
Latest Year Available	2008	2009-2010	2007	2010			
Time-Series	1972-2008	1999-present	1991-2007 <sup>19</sup>	1997-present			
Longitudinal		$\chi^{20}$					
Health/Disability Indicators				L			
General Health Status		X		Х			
Body Mass (weight, height, obesity)		X	Х	X			
Sensory/Communication Limitations	X <sup>21</sup>	X	X	X			
Physical Limitations/Functional Limitations	X <sup>21</sup>	X <sup>22</sup>	X	X			
ADL Limitations	<b>√</b> 21	X <sup>23</sup>		X			
IADL Limitations	X <sup>21</sup>	X		X			
Limitations in Work/Usual Activities	X X <sup>4</sup>	X		X			
	X	۸	.,				
Learning Disability			X	X			
Mental/Emotional Disorders or Symptoms	21	X	X	X			
Cognitive Impairment or Developmental	X <sup>21</sup>	Х	X	X			
Disorders Social Participation/Interpersonal		X					
Interactions		^					
Substance Use/Abuse/Dependence		X					
Specific Chronic Conditions/Medical	X <sup>21</sup>	X		Х			
Conditions	^	X		^			
Use of/Need for Assistive Equipment		X		Х			
Use of or Need for Personal Assistance		X		X			
Bed Days/Lost Productivity Days		X		X			
Disability Benefit Receipt/Program		X	Х	X			
Participation							
Self/Others Identify as Disabled	X <sup>21</sup>	Х	Х				
Topic Domains							
Education	Х	X	X	X			
Employment	X	X	X	X			
Health		X	X	X			
Health/Disability-Related Service Use		Х	X	Х			
Health Insurance	X <sup>21</sup>	Χ	X	X			
Household Expenditures		Х					
Housing	Х	X					
Income/Economic Well-Being	X	X	X	X			
Public Program Participation	Х	<u> </u>	X	X			
Transportation	X <sup>21</sup>	X		-			
	^	- • •	I	1			

TABLE A.1. (continued)								
Survey Features	NSDUH	NSFH	PSID	SCF	SIPP			
Population				•				
Household Population	X	Х	Х	X	X			
Noninstitutional Group Quarters Population	Х	X <sup>24</sup>	X <sup>1</sup>		Χ			
Institutional Population			X <sup>1</sup>					
Special Population Subgroup			X <sup>25</sup>					
Age Groups			^					
Children (under 18)	Ago 10 and	Х	Х		X			
,	Age 12 and older							
Working-Age Adults (18-64)	Χ	Χ	X	X	X			
Seniors (65+)	X	Χ	X	X	X			
Geographic Level of Estimates								
National	X	Χ	Χ	X	Χ			
Regional	X							
State	X				2004 and later			
Timing								
Latest Year Available	2009	2001-2003	2009	2007	2008 panel			
Time-Series	1972-present	1987-1988, 1992-1994, 2001-2003		1983-present	1984-present			
Longitudinal		Х	Х	1983-1989	Х			
Health/Disability Indicators								
General Health Status		Х	Χ	X	X			
Body Mass (weight, height, obesity)	Х		X					
Sensory/Communication Limitations					X			
Physical Limitations/Functional Limitations		Х	X		Х			
ADL Limitations		Х	X		Х			
IADL Limitations		Х	Х		Х			
Limitations in Work/Usual Activities	Х	X	X	Х	X			
Learning Disability			X					
Mental/Emotional Disorders or Symptoms	Х	Х	X		Х			
Cognitive Impairment or Developmental Disorders	,	X	X		X			
Social Participation/Interpersonal Interactions	Х							
Substance Use/Abuse/Dependence	X	Х	Х					
Specific Chronic Conditions/Medical	X	Х	X		Х			
Conditions								
Use of/Need for Assistive Equipment			Χ		Χ			
Use of or Need for Personal Assistance		Х	Х		X			
Bed Days/Lost Productivity Days	X		X					
Disability Benefit Receipt/Program Participation	Х	Х	Х	Х	Х			
Self/Others Identify as Disabled								
Topic Domains								
Education	X	Х	Х	X	х			
Employment	X	Λ.	X	X	X			
Health	X	Х	X	^	X			
Health/Disability-Related Service Use	X	X	X	+	X			
Health Insurance	X	X	X	X	X			
Household Expenditures	^	^	X	X	X			
Housing		Х		X				
Income/Economic Well-Being	V	X	X	X	X X			
Public Program Participation	X	X	X	X	X			
	^	^	X	^	^			
Transportation			Å					

TABLE A.2. Surveys				
Survey Features	HOS	HRS	LSOA	MCBS
Population				
Household Population		X	X	X
Noninstitutional Group Quarters		X <sup>1</sup>		Х
Population		1		
Institutional Population		X <sup>1</sup>		X
Special Population Subgroup	X			X
Age Groups				
Children (under 18)				X
Working-Age Adults (18-64)		X		X
Seniors (65+)		X	X	X
Geographic Level of Estimates				
National	X	X	X	X
Regional		X		
State	Χ	X		
Timing				
Latest Year Available	2009	2010	2000	2005; 2004 <sup>26</sup>
Time-Series	1998-present	1992-present		1991-present
Longitudinal	X	1992-present	1984-1990;	
•			1994-2000	
Health/Disability Indicators				
General Health Status	Х	X	X <sup>27</sup>	X
Body Mass (weight, height, obesity)	Χ	Х	X <sup>28</sup>	Х
Sensory/Communication Limitations	Х	Х	X	Х
Physical Limitations/Functional Limitations	X	X	X	X
ADL Limitations	X	X	X	X
IADL Limitations		X	X	X
Limitations in Work/Usual Activities	Х	X		^
Learning Disability		,		
Mental/Emotional Disorders or Symptoms	X	X		Х
Cognitive Impairment or Developmental	Λ	X	X <sup>29</sup>	X
Disorders		Λ	^	^
Social Participation/Interpersonal	Х	Х	Х	Х
Interactions	**		,,	,
Substance Use/Abuse/Dependence		Х		
Specific Chronic Conditions/Medical	Х	X	X	X
Conditions				
Use of/Need for Assistive Equipment		Х	X <sup>30</sup>	X
Use of or Need for Personal Assistance		Х	X	Х
Bed Days/Lost Productivity Days		X		,
Disability Benefit Receipt/Program		X	X	
Participation			,,	
Self/Others Identify as Disabled				
Topic Domains				
Education	X	Х		X
Employment	- •	X	Х	X
Health	Х	X	X	X
Health/Disability-Related Service Use		^		<u> </u>
Health Insurance		X	X	X
Household Expenditures		^	X X <sup>31</sup>	<del>                                     </del>
Housing	X	X	X	X
Income/Economic Well-Being	X	X	X	X
	^	X	^	X
Public Program Participation				

	TABLE A.2. (continued)							
Survey Features	NBS	NCS	NHIS-D	NLTCS				
Population								
Household Population	Χ	Χ	X	X				
Noninstitutional Group Quarters	X	X <sup>33</sup>	Х	Х				
Population								
Institutional Population	Χ			X				
Special Population Subgroup	X			65 and older				
Age Groups		24						
Children (under 18)		X <sup>34</sup>	X					
Working-Age Adults (18-64)	X	X	X					
Seniors (65+)		X	X	X				
Geographic Level of Estimates								
National	Χ	X	X					
Regional			X					
State			X					
Timing				T				
Latest Year Available	2010	2002	1994-1995	2004				
Time-Series	2004-2006,			1982-2004				
1 P 1	2010 X <sup>35</sup>			1000 0001				
Longitudinal	X°°			1982-2004				
Health/Disability Indicators			36	T				
General Health Status	X	X	X <sup>36</sup>	Х				
Body Mass (weight, height, obesity)	X	X <sup>37</sup>	X <sup>26</sup>	Х				
Sensory/Communication Limitations	Х	X <sup>38</sup>	Х	Х				
Physical Limitations/Functional Limitations	Х	X <sup>38</sup>	X	X				
ADL Limitations	Χ	X	Х	Х				
IADL Limitations	Χ	Х	X	X				
Limitations in Work/Usual Activities	Χ	Х	Х	Х				
Learning Disability		X <sup>38</sup>	X <sup>39</sup>					
Mental/Emotional Disorders or Symptoms	Χ	Х	X	Х				
Cognitive Impairment or Developmental	X	X <sup>38</sup>	X	X				
Disorders		7.						
Social Participation/Interpersonal Interactions	Х	Х	X	Х				
Substance Use/Abuse/Dependence	X	Χ	X					
Specific Chronic Conditions/Medical	X	X	X	Х				
Conditions	Λ	Λ	^	^				
Use of/Need for Assistive Equipment	Х	X <sup>37</sup>	X	Х				
Use of or Need for Personal Assistance	X	X <sup>37</sup>	X	X				
Bed Days/Lost Productivity Days	Λ		X	^				
Disability Benefit Receipt/Program	X	X <sup>38</sup>	X	X				
Participation	^	Х	^	^				
Self/Others Identify as Disabled		X <sup>4</sup>	X <sup>40</sup>					
Topic Domains		^	^					
Education	Х	X	X	Х				
Employment	X	X	X <sup>41</sup>	X				
Health	X X	Х	X	X				
Health/Disability-Related Service Use		V	X ,41					
Health Insurance	Х	X	X <sup>41</sup>	Х				
Household Expenditures			X41	.,				
Housing			X <sup>41</sup>	X				
ncome/Economic Well-Being	Χ	X	X	X				
Public Program Participation	Χ	Χ	X	X				
Transportation			X <sup>41</sup>	X				

TABLE A.2. (continued)						
Survey Features	NNHS	NSCF	NS-CSHCN			
Population						
Household Population		X	Х			
Noninstitutional Group Quarters Population		? <sup>42</sup>				
Institutional Population	X					
Special Population Subgroup	X					
Age Groups						
Children (under 18)	Х	Х	Х			
Working-Age Adults (18-64)	X	X				
Seniors (65+)	X	X				
Geographic Level of Estimates						
National	Х	X	Х			
Regional	X					
State		2004 and later	Х			
Timing						
Latest Year Available	2004	2008 panel	2006			
Time-Series	1973-2004	1984-present				
Longitudinal	1010 = 001	X				
Health/Disability Indicators						
General Health Status		X	X			
Body Mass (weight, height, obesity)						
Sensory/Communication Limitations		Х	Х			
Physical Limitations/Functional Limitations	X	X	X			
ADL Limitations	X	X	X			
IADL Limitations		X	X			
Limitations in Work/Usual Activities		X	X			
Learning Disability			X			
Mental/Emotional Disorders or Symptoms	Х	Х	X			
Cognitive Impairment or Developmental Disorders	X	X	X			
Social Participation/Interpersonal Interactions		,	X			
Substance Use/Abuse/Dependence			X			
Specific Chronic Conditions/Medical Conditions	Х	X	X			
Use of/Need for Assistive Equipment		X	X			
Use of or Need for Personal Assistance		X	X			
Bed Days/Lost Productivity Days			X			
Disability Benefit Receipt/Program Participation		X	X			
Self/Others Identify as Disabled		,				
Topic Domains						
Education		Х	Х			
Employment		X	X			
Health	X	X	X			
Health/Disability-Related Service Use	,,	X	X			
Health Insurance	X	X	X			
Household Expenditures		X				
Housing	X	X	Х			
Income/Economic Well-Being		X	X			
Public Program Participation		X				
Transportation		^				

TABLE A.3. Surveys on Youth and Education							
Survey Features	Add Health	B&B	BPS	ECLS			
Population							
Household Population	X			X			
Noninstitutional Group Quarters	Х			Х			
Population							
Institutional Population	43	44	45	X			
Special Population Subgroup	X <sup>43</sup>	X <sup>44</sup>	X <sup>45</sup>				
Age Groups		T					
Children (under 18)	X	.,	X	X			
Working-Age Adults (18-64)	X	X	Х				
Seniors (65+)							
Geographic Level of Estimates	.,						
National	X	X	Х	X			
Regional	X						
State							
Timing	0000	1 0000 0000	2002				
Latest Year Available	2008	2008-2009	2009	2007			
Time-Series		1993-present	1990-2009	.,			
Longitudinal	X	1993-2003;	1990-1994;	Χ			
		2000-2001;	1996-2001;				
Health/Diaghiliter Indiagtage		2008-present	2004-2009				
Health/Disability Indicators							
General Health Status	X			X			
Body Mass (weight, height, obesity)	X						
Sensory/Communication Limitations	X	X	X	X			
Physical Limitations/Functional Limitations	X	X	Х	Х			
ADL Limitations	X						
IADL Limitations	X	46					
Limitations in Work/Usual Activities	X	X <sup>46</sup>		Х			
Learning Disability		X	Χ	X			
Mental/Emotional Disorders or Symptoms	X	X	Χ	Х			
Cognitive Impairment or Developmental	Χ		X	X			
Disorders							
Social Participation/Interpersonal	Χ						
Interactions							
Substance Use/Abuse/Dependence	X						
Specific Chronic Conditions/Medical	X			Х			
Conditions							
Use of/Need for Assistive Equipment	X		Χ	X			
Use of or Need for Personal Assistance			Χ				
Bed Days/Lost Productivity Days	X						
Disability Benefit Receipt/Program		X	X	Х			
Participation							
Self/Others Identify as Disabled		X	Χ				
Topic Domains							
Education	X	X	X	X			
Employment	Χ	X	X	X <sup>47</sup>			
Health	Χ			Х			
Health/Disability-Related Service Use			X <sup>48</sup>	X			
Health Insurance	Х		**	Х			
Household Expenditures							
Housing	X		Х				
Income/Economic Well-Being	X	X	X	Х			
Public Program Participation	X	X	X	X			
Transportation	^	^	X <sup>49</sup>	^			

TABLE A.3. (continued)							
Survey Features	HSLS	NELS	NLSY97	NLTS2	NSCH		
Population							
Household Population	Х	X	X	Х	X		
Noninstitutional Group Quarters Population	Х	Х	X <sup>50</sup>	Х			
Institutional Population			X <sup>50</sup>				
Special Population Subgroup	X <sup>51</sup>	X	,	Х			
Age Groups							
Children (under 18)	X	Age 14-26	X	Х	X		
Working-Age Adults (18-64)		Age 14-26	X <sup>1</sup>	X <sup>1</sup>			
Seniors (65+)		Agc 14 20	^	^			
Geographic Level of Estimates							
National	X	X	X	X	X		
Regional	^	^	^	^	^		
State	X				X		
Timing	^						
Latest Year Available	2009	2000	2008	2008-09	2008		
Time-Series	2009	2000	2006	2006-09	2003-present		
Longitudinal	X	1988-2000	1997-present	2000-01-	2003-present		
Longitudinal	^	1900-2000	1997-present	2008-09			
Health/Disability Indicators							
General Health Status			X	Χ	X		
Body Mass (weight, height, obesity)			Х		Х		
Sensory/Communication Limitations	X	X	X	X	X		
Physical Limitations/Functional Limitations	Х	X	X	Х	Х		
ADL Limitations							
IADL Limitations				Χ			
Limitations in Work/Usual Activities			X	Χ	X		
Learning Disability	Χ	Х		Χ	Х		
Mental/Emotional Disorders or Symptoms	Χ	X	X	Х	Х		
Cognitive Impairment or Developmental Disorders	Χ	Х	Х	Х	Х		
Social Participation/Interpersonal				X	X		
Interactions							
Substance Use/Abuse/Dependence			X				
Specific Chronic Conditions/Medical				Χ	X		
Conditions							
Use of/Need for Assistive Equipment				X			
Use of or Need for Personal Assistance				X			
Bed Days/Lost Productivity Days				X			
Disability Benefit Receipt/Program Participation	X		Х	Х	Х		
Self/Others Identify as Disabled		Х		Х			
Topic Domains							
Education	Х	Х	Х	Х			
Employment	Х	Х	X	Х	X		
Health			Х	Х	Х		
Health/Disability-Related Service Use				Х	Х		
Health Insurance		X	X	X	X		
Household Expenditures							
Housing		Х	Х		Х		
Income/Economic Well-Being	Х	X	X	Х	X		
Public Program Participation		Х	Х	Х			
Transportation				Х			

TABLE A.4. Surveys of Other Subpopulations			
Survey Features	NSV	SILJ	SISCF/SIFCF
Population		•	
Household Population			
Noninstitutional Group Quarters Population			
Institutional Population	X	X	X
Special Population Subgroup	X	X	X
Age Groups		•	
Children (under 18)		Age 12 and older	Age 12 and older
Working-Age Adults (18-64)		X	X
Seniors (65+)		X	X
Geographic Level of Estimates		•	
National	X	X	X
Regional			
State			
Timing		•	
Latest Year Available	2001	2002	2004
Time-Series	1978-2009		X <sup>52</sup>
Longitudinal			
Health/Disability Indicators			
General Health Status	Х		
Body Mass (weight, height, obesity)		X	X
Sensory/Communication Limitations	Х	X	X
Physical Limitations/Functional Limitations	X	X	X
ADL Limitations	X	^	
IADL Limitations	X		
Limitations in Work/Usual Activities		X	X
Learning Disability		X	X
Mental/Emotional Disorders or Symptoms	Х	X	X
Cognitive Impairment or Developmental Disorders			
Social Participation/Interpersonal Interactions			
Substance Use/Abuse/Dependence	Х	X	Х
Specific Chronic Conditions/Medical Conditions	X	X	X
Use of/Need for Assistive Equipment		X	X
Use of or Need for Personal Assistance			
Bed Days/Lost Productivity Days			
Disability Benefit Receipt/Program Participation	Х	X	X
Self/Others Identify as Disabled		X	X
Topic Domains			
Education		X	Х
Employment		X	X
Health	Х	X	X
Health/Disability-Related Service Use	X	X	X
Health Insurance	X		,
Household Expenditures			
Housing		X	X
Income/Economic Well-Being		X	X
Public Program Participation	X	X	X
Transportation		<u> </u>	^
Transportation			l

#### Table Notes:

- 1. Group not eligible for initial selection, existing sample members were followed if they entered the group.
- 2. As of 2007, the survey of metropolitan areas is conducted annually, cycling through a set of 21 areas about every six years.
- 3. Disability questions changed in 2008.
- 4. Respondents can answer that they are disabled in response to a question about their work status.
- 5. Question in 2009 AHS is not specific. The 1978 survey allows respondents to specify conditions.
- 6. Question is not specific.
- 7. Income questions are only asked of those who changed jobs or became employed since the final Current Population Survey (CPS) interview. Income for all others is imputed from the CPS.
- 8. Sample excludes military personnel living on base.
- 9. Disability information, except for work disability, is not available at state or regional levels, due to small sample sizes.
- 10. Only available for the insurance component of the survey.
- 11. Disability information, except for work disability, is not available at state or regional levels, due to small sample sizes.
- 12. Only available for the insurance component of the survey.
- 13. In the interview survey of the CE.
- 14. Disability payments are grouped with other types of income.
- 15. In supplements only.
- 16. In the diary survey of the CE.
- 17. A study of Hispanic populations (HHANES) was conducted in 1982-84.
- 18. Regional estimates are provided from 1979-2004 for counties selected for the National Crime Victimization Survey (NCVS) sample in the 40 largest metropolitan statistical areas.
- 19. Different modules are fielded in different years, so the time span covered varies by topic.
- 20. A national longitudinal study, the National Health and Nutrition Examination Survey (NHANES) I Epidemiologic Follow-up Study, was jointly initiated by National Center for Health Statistics and NIA in collaboration with other agencies from 1982-1992.
- 21. In the NCVS crime report, asked if the respondent reports a crime in the initial questionnaire.
- 22. Only in NHANES III and Continuous NHANES.
- 23. Only in Continuous NHANES.

- 24. Those who are described as away at school or away in the armed forces are eligible for sampling.
- 25. The Panel Study of Income Dynamics (PSID) uses two independent samples. One is a national sample of low-income families.
- 26. Access to care data are available from 1991 to 2008. The cost and use data are available from 1992 to 2006.
- 27. Supplement on Aging (SOA) I and II.
- 28. SOA II.
- 29. Questions included in the SOA I and II and the Longitudinal Study of Aging (LSOA) II. Baseline survey collects information on any instances of difficulty remembering or confusion. LSOA II includes a section with questions about cognitive abilities.
- 30. SOA II includes detailed questions on both home and personal assistive devices.
- 31. Detailed questions on household expenditures are included in the economic supplement.
- 32. Transportation to and from medical care.
- 33. The National Comorbidity Survey (NCS; 1990-1992) includes a supplemental sample of students living in campus group housing.
- 34. NCS (1990-1992) surveyed persons age 15-54; NCS-A (2001-2002) surveyed persons age 13-17.
- 35. Only selected Ticket to Work participant samples were followed longitudinally.
- 36. Information appears in core National Health Interview Survey (NHIS), not in the National Health Interview Survey on Disability (NHIS-D).
- 37. In NCS-R only.
- 38. In NCS-2 and NCS-R only.
- 39. Asked of respondents age 17 and younger.
- 40. Asked only about children with physical delays.
- 41. In Phase 2 of the NHIS-D only.
- 42. Unknown.
- 43. The sample only includes 7<sup>th</sup>-12<sup>th</sup> graders in schools including an 11<sup>th</sup> grade with a minimum enrollment of 30 students. Certain populations are oversampled.
- 44. People who complete an undergraduate degree.
- 45. First-time enrollees in a postsecondary education institution.
- 46. Asked on the B&B:93/03.
- 47. Employment of parents.

- 48. The BPS includes a question about Vocational Rehabilitation service usage. BPS:90/94 does not include this question.
- 49. The BPS:96/01. Includes a question about receiving or requesting services for handicapped parking or special transportation.
- 50. Youth were eligible if they were away at school or in a correctional institution or hospital if they were tied to a sampled household.
- 51. Only 9<sup>th</sup> graders in high school were selected to be in the sample.
- 52. The Survey of Inmates in State Correctional Facilities (SISCF) covers 1974-2004; the Survey of Inmates in Federal Correctional Facilities (SIFCF) covers 1991-2004.