

Disability Data in National Surveys

Final Report

August 22, 2011

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Contract Number: HHSP23320095642WC/
HHSP23337019T

Mathematica Reference Number:
06862.400

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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.

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ACRONYMS

ACS	American Community Survey
ADD	Attention Deficit Disorder
Add Health	National Longitudinal Study of Adolescent Health
ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activities of Daily Living
AHEAD	Aging and Health Dynamics Cohort
AHS	American Housing Survey
ASPE	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
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
COD	Children of the Depression Cohort
CPS	Current Population Survey
DOL	U.S. Department of Labor
EB	Early Boomers
ECLS	Early Childhood Longitudinal Survey
HHANES	Hispanic Health and Nutrition Examination Survey
HRS	Health and Retirement Study
HSLS	High School Longitudinal Study of 2009
HOS	Medicare Health Outcome Survey
HUD	U.S. Department of Housing and Urban Development
IADL	Instrumental Activities of Daily Living
IEP	Individualized Education Plan
IES	Institute of Education Sciences, U.S. Department of Education,
IRS	Internal Revenue Service

IUF	Internal Use File
LDS	Limited Data Sets
LSOA	Longitudinal Study of Aging
MAO	Medicare Advantage Organization
MB	Mid-Boomers
MCBS	Medicare Current Beneficiary Survey
MEPS	Medical Expenditure Panel Survey
MSA	Metropolitan Statistical Area
NBS	National Beneficiary Survey
NCHS	National Center for Health Statistics
NCS	National Comorbidity Survey
NCVS	National Crime and Victimization Survey
NDI	National Death Index
NELS	National Education Longitudinal Study
NHANES	National Health and Nutrition Examination Survey
NHATS	National Health and Aging Trends Study
NHES	National Household Education Survey
NIA	National Institute on Aging
NHIS	National Health Interview Survey
NHIS-D	National Health Interview Survey on Disability
NLSY79	National Longitudinal Survey of Youth 1979
NLSY97	National Longitudinal Survey of Youth 1997
NLTCS	National Long Term Care Survey
NLTS2	National Longitudinal Transition Study-2
NNHS	National Nursing Home Survey
NPSAS	National Postsecondary Student Aid Study
NS-CSHCN	National Survey of Children with Special Health Care Needs
NSCH	National Survey of Children's Health
NSDUH	National Survey on Drug Use and Health
NSCF	National Survey of SSI Children and Families
NSFH	National Survey of Families and Households
NSV	National Survey of Veterans

PSID	Panel Study of Income Dynamics
PUF	Public Use File
RIF	Research Identifiable Files
RSA	Rehabilitation Services Administration
SCF	Survey of Consumer Finances
SEER	Surveillance Epidemiology and End Results
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
SOA	Supplement on Aging
SPD	Survey of Program Dynamics
SSA	Social Security Administration
SSB	SIPP Synthetic Beta
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
SSN	Social Security Number
TTW	Ticket to Work
UI	Unemployment Insurance
VA	U.S. Department of Veterans Affairs
WB	War Baby Cohort

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I. INTRODUCTION

A. Purpose of the Report

Federal agencies, policymakers, 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 U.S. 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 to 17 to 37.4 percent among adults age 65 and over (U.S. 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 policymakers 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 policymakers. 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 U.S. 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

National Household Surveys	
1. American Community Survey	10. National Health and Nutrition Examination Survey
2. American Housing Survey	11. National Health Interview Survey
3. American Time Use Survey	12. National Household Education Survey
4. Behavioral Risk Factor Surveillance System	13. National Survey of Drug Use and Health
5. Census	14. National Survey of Families and Households
6. Consumer Expenditure Survey	15. Panel Study of Income Dynamics
7. Current Population Survey	16. Survey of Consumer Finances
8. Medical Expenditure Panel Survey	17. Survey of Income and Program Participation
9. National Crime Victimization Survey	
Surveys on Health, Disability, Aging, and Long-Term Care	
1. Health and Retirement Study	7. National Health Interview Survey on Disability
2. Longitudinal Study of Aging	8. National Long Term Care Survey
3. Medicare Current Beneficiary Survey	9. National Nursing Home Survey
4. Medicare Health Outcomes Survey	10. National Survey of Children with Special Health Care Needs
5. National Beneficiary Survey	11. National Survey of SSI Children and Families
6. National Comorbidity Survey	
Surveys on Youth, Education, and Transition	
1. Baccalaureate and Beyond Longitudinal Study	6. National Longitudinal Study of Adolescent Health
2. Beginning Postsecondary Students Longitudinal Study	7. National Longitudinal Survey of Youth
3. Early Childhood Longitudinal Survey	8. National Longitudinal Transition Study 2
4. High School Longitudinal Study of 2009	9. National Survey of Children's Health
5. National Education Longitudinal Study	
Other Surveys	
1. National Survey of Veterans	3. Survey of Inmates in State and Federal Correctional Facilities
2. Survey of Inmates in Local Jails	

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 U.S. government sponsors a number of national surveys that are representative of all or most of the U.S. 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 U.S. population. We reviewed 17 general population surveys, including 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 and 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 U.S. 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 four to eight 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 Studies 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 (NLTC), 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 U.S. 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 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 (NLSY97), National Longitudinal Transition Study 2 (NLTS2), and National Survey of Children's Health (NSCH).

1. Coverage of U.S. 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 ninth 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 ninth grade, the NELs on those enrolled in eighth 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 to 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 through 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 U.S. Households

The NSV is focused on collecting information for developing and evaluating 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 U.S. 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. 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 followup.
- 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

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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 multi-dimensional 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.

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Table A.1. Ongoing National Surveys

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

Table A.1 (continued)

Survey Features	Census	CE	CPS	MEPS
Population				
Household Population	X	X	X	X
Noninstitutional Group Quarters Population	X	X ⁸	X	X
Institutional Population	X			1996 only
Special Population Subgroup				
Age Groups				
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
Regional	X	X	X ⁹	X ¹⁰
State	X		X ¹¹	X ¹²
Timing				
Latest Year Available	2010	2010	2011	2008
Time Series	1790-2010	1980-present	1940-present	1996-present
Longitudinal				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	X
ADL Limitations			2008-present	X
IADL Limitations			2008-present	X
Limitations in Work/Usual Activities		X ⁴	X	X
Learning Disability				
Mental/Emotional Disorders or Symptoms			2008-present	X
Cognitive Impairment or Developmental Disorders			2008-present	X
Social Participation/Interpersonal Interactions				
Substance Use/Abuse/Dependence		X ¹³		
Specific Chronic Conditions/Medical Conditions				X
Use of/Need for Assistive Equipment		X ¹³		X
Use of or Need for Personal Assistance		X ¹³		X
Bed Days/Lost Productivity Days				X
Disability Benefit Receipt/Program Participation		X ¹⁴		X
Self/Others Identify as Disabled				
Topic Domains				
Education		X	X	X
Employment		X	X	X
Health		X		X
Health/Disability-Related Service Use		X ¹³		X
Health Insurance		X ¹³	X ¹⁵	
Household Expenditures		X		
Housing		X		
Income/Economic Well-Being		X	X ¹⁵	X
Public Program Participation		X ¹³		
Transportation		X ¹⁶		

Table A.1 (continued)

Survey Features	NCVS	NHANES	NHES	NHIS
Population				
Household Population	X	X	X	X
Noninstitutional Group Quarters Population	X ⁸	X		X
Institutional Population				
Special Population Subgroup		X ¹⁷		
Age Groups				
Children (under 18)	Age 12 and older	X	X	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
Regional	1979-2004 ¹⁸		X	X
State				X
Timing				
Latest Year Available	2008	2009-2010	2007	2010
Time Series	1972-2008	1999-present	1991-2007 ¹⁹	1997-present
Longitudinal		X ²⁰		
Health/Disability Indicators				
General Health Status		X		X
Body Mass (weight, height, obesity)		X	X	X
Sensory/Communication Limitations	X ²¹	X	X	X
Physical Limitations/Functional Limitations	X ²¹	X ²²	X	X
ADL Limitations	X ²¹	X ²³		X
IADL Limitations	X ²¹	X		X
Limitations in Work/Usual Activities	X ⁴	X		X
Learning Disability			X	X
Mental/Emotional Disorders or Symptoms		X	X	X
Cognitive Impairment or Developmental Disorders	X ²¹	X	X	X
Social Participation/Interpersonal Interactions		X		
Substance Use/Abuse/Dependence		X		
Specific Chronic Conditions/Medical Conditions	X ²¹	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		X
Disability Benefit Receipt/Program Participation		X	X	X
Self/Others Identify as Disabled	X ²¹	X	X	
Topic Domains				
Education	X	X	X	X
Employment	X	X	X	X
Health		X	X	X
Health/Disability-Related Service Use		X	X	X
Health Insurance	X ²¹	X	X	X
Household Expenditures		X		
Housing	X	X		
Income/Economic Well-Being	X	X	X	X
Public Program Participation	X		X	X
Transportation	X ²¹	X		

Table A.1 (continued)

Survey Features	NSDUH	NSFH	PSID	SCF	SIPP
Population					
Household Population	X	X	X	X	X
Noninstitutional Group Quarters Population	X	X ²⁴	X ¹		X
Institutional Population			X ¹		
Special Population Subgroup			X ²⁵		
Age Groups					
Children (under 18)	Age 12 and older	X	X		X
Working-Age Adults (18-64)	X	X	X	X	X
Seniors (65+)	X	X	X	X	X
Geographic Level of Estimates					
National	X	X	X	X	X
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		X	X	1983-1989	X
Health/Disability Indicators					
General Health Status		X	X	X	X
Body Mass (weight, height, obesity)	X		X		
Sensory/Communication Limitations					X
Physical Limitations/Functional Limitations		X	X		X
ADL Limitations		X	X		X
IADL Limitations		X	X		X
Limitations in Work/Usual Activities	X	X	X	X	X
Learning Disability			X		
Mental/Emotional Disorders or Symptoms	X	X	X		X
Cognitive Impairment or Developmental Disorders		X	X		X
Social Participation/Interpersonal Interactions	X				
Substance Use/Abuse/Dependence	X	X	X		
Specific Chronic Conditions/Medical Conditions	X	X	X		X
Use of/Need for Assistive Equipment			X		X
Use of or Need for Personal Assistance		X	X		X
Bed Days/Lost Productivity Days	X		X		
Disability Benefit Receipt/Program Participation	X	X	X	X	X
Self/Others Identify as Disabled					
Topic Domains					
Education	X	X	X	X	x
Employment	X		X	X	X
Health	X	X	X		x
Health/Disability-Related Service Use	X	X	X		X
Health Insurance	X	X	X	X	X
Household Expenditures			X	X	X
Housing		X	x	X	x
Income/Economic Well-Being	X	X	X	X	X
Public Program Participation	X	X	X	X	X
Transportation			X		

Table A.2. Surveys on Health, Disability, Aging, and Long-Term Care

Survey Features	HOS	HRS	LSOA	MCBS
Population				
Household Population		X	X	X
Noninstitutional Group Quarters Population		X ¹		X
Institutional Population		X ¹		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	X	X		
Timing				
Latest Year Available	2009	2010	2000	2005; 2004 ²⁶
Time Series	1998-present	1992-present		1991-present
Longitudinal	X	1992-present	1984-1990; 1994-2000	
Health/Disability Indicators				
General Health Status	X	X	X ²⁷	X
Body Mass (weight, height, obesity)	X	X	X ²⁸	X
Sensory/Communication Limitations	X	X	X	X
Physical Limitations/Functional Limitations	X	X	X	X
ADL Limitations	X	X	X	X
IADL Limitations		X	X	X
Limitations in Work/Usual Activities	X	X		
Learning Disability				
Mental/Emotional Disorders or Symptoms	X	X		X
Cognitive Impairment or Developmental Disorders		X	X ²⁹	X
Social Participation/Interpersonal Interactions	X	X	X	X
Substance Use/Abuse/Dependence		X		
Specific Chronic Conditions/Medical Conditions	X	X	X	X
Use of/Need for Assistive Equipment		X	X ³⁰	X
Use of or Need for Personal Assistance		X	X	X
Bed Days/Lost Productivity Days		X		
Disability Benefit Receipt/Program Participation		X	X	
Self/Others Identify as Disabled				
Topic Domains				
Education	X	X		X
Employment		X	X	X
Health	X	X	X	X
Health/Disability-Related Service Use				
Health Insurance		X	X	X
Household Expenditures			X ³¹	
Housing	X	X	X	X
Income/Economic Well-Being	X	X	X	X
Public Program Participation		X		X
Transportation		X	X	X ³²

Table A.2 (continued)

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

Table A.2 (continued)

Survey Features	NNHS	NSCF	NS-CSHCN
Population			
Household Population		X	X
Noninstitutional Group Quarters Population		? ⁴²	
Institutional Population	X		
Special Population Subgroup	X		
Age Groups			
Children (under 18)	X	X	X
Working-Age Adults (18-64)	X	X	
Seniors (65+)	X	X	
Geographic Level of Estimates			
National	X	X	X
Regional	X		
State		2004 and later	X
Timing			
Latest Year Available	2004	2008 panel	2006
Time Series	1973-2004	1984-present	
Longitudinal		X	
Health/Disability Indicators			
General Health Status		X	X
Body Mass (weight, height, obesity)			
Sensory/Communication Limitations		X	X
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	X	X	X
Cognitive Impairment or Developmental Disorders	X	X	X
Social Participation/Interpersonal Interactions			X
Substance Use/Abuse/Dependence			X
Specific Chronic Conditions/Medical Conditions	X	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		X	X
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	X
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 Population	X			X
Institutional Population				X
Special Population Subgroup	X ⁴³	X ⁴⁴	X ⁴⁵	
Age Groups				
Children (under 18)	X		X	X
Working-Age Adults (18-64)	X	X	X	
Seniors (65+)				
Geographic Level of Estimates				
National	X	X	X	X
Regional	X			
State				
Timing				
Latest Year Available	2008	2008-2009	2009	2007
Time Series		1993-present	1990-2009	
Longitudinal	X	1993-2003; 2000-2001; 2008-present	1990-1994; 1996-2001; 2004-2009	X
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	X	X
ADL Limitations	X			
IADL Limitations	X			
Limitations in Work/Usual Activities	X	X ⁴⁶		X
Learning Disability		X	X	X
Mental/Emotional Disorders or Symptoms	X	X	X	X
Cognitive Impairment or Developmental Disorders	X		X	X
Social Participation/Interpersonal Interactions	X			
Substance Use/Abuse/Dependence	X			
Specific Chronic Conditions/Medical Conditions	X			X
Use of/Need for Assistive Equipment	X		X	X
Use of or Need for Personal Assistance			X	
Bed Days/Lost Productivity Days	X			
Disability Benefit Receipt/Program Participation		X	X	X
Self/Others Identify as Disabled		X	X	
Topic Domains				
Education	X	X	X	X
Employment	X	X	X	X ⁴⁷
Health	X			X
Health/Disability-Related Service Use			X ⁴⁸	X
Health Insurance	X			X
Household Expenditures				
Housing	X		X	
Income/Economic Well-Being	X	X	X	X
Public Program Participation	X	X	X	X
Transportation			X ⁴⁹	

Table A.3 (continued)

Survey Features	HLSL	NELS	NLSY97	NLTS2	NSCH
Population					
Household Population	X	X	X	X	X
Noninstitutional Group Quarters Population	X	X	X ⁵⁰	X	
Institutional Population			X ⁵⁰		
Special Population Subgroup	X ⁵¹	X		X	
Age Groups					
Children (under 18)	X	Age 14-26	X	X	X
Working-Age Adults (18-64)		Age 14-26	X ¹	X ¹	
Seniors (65+)					
Geographic Level of Estimates					
National	X	X	X	X	X
Regional					
State	X				X
Timing					
Latest Year Available	2009	2000	2008	2008-9	2008
Time Series					2003-present
Longitudinal	X	1988-2000	1997-present	2000-01-2008-09	
Health/Disability Indicators					
General Health Status			X	X	X
Body Mass (weight, height, obesity)			X		X
Sensory/Communication Limitations	X	X	X	X	X
Physical Limitations/Functional Limitations	X	X	X	X	X
ADL Limitations					
IADL Limitations				X	
Limitations in Work/Usual Activities			X	X	X
Learning Disability	X	X		X	X
Mental/Emotional Disorders or Symptoms	X	X	X	X	X
Cognitive Impairment or Developmental Disorders	X	X	X	X	X
Social Participation/Interpersonal Interactions				X	X
Substance Use/Abuse/Dependence			X		
Specific Chronic Conditions/Medical Conditions				X	X
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		X	X	X
Self/Others Identify as Disabled		X		X	
Topic Domains					
Education	X	X	X	X	
Employment	X	X	X	X	X
Health			X	X	X
Health/Disability-Related Service Use				X	X
Health Insurance		X	X	X	X
Household Expenditures					
Housing		X	X		X
Income/Economic Well-Being	X	X	X	X	X
Public Program Participation		X	X	X	
Transportation				X	

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 ⁵²
Longitudinal			
Health/Disability Indicators			
General Health Status	X		
Body Mass (weight, height, obesity)		X	X
Sensory/Communication Limitations	X	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	X	X	X
Cognitive Impairment or Developmental Disorders			
Social Participation/Interpersonal Interactions			
Substance Use/Abuse/Dependence	X	X	X
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	X	X	X
Self/Others Identify as Disabled		X	X
Topic Domains			
Education		X	X
Employment		X	X
Health	X	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			

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 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 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 NHANES I Epidemiologic Follow-up Study, was jointly initiated by NCHS 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 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 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 NCS (1990 – 1992) includes a supplemental sample of students living in campus group housing.
- ³⁴ NCS (1990 – 1992) surveyed persons age 15 to 54; NCS-A (2001 – 2002) surveyed persons age 13 to 17.
- ³⁵ Only selected Ticket to Work participant samples were followed longitudinally.
- ³⁶ Information appears in core NHIS, not in the 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 7-12 graders in schools including an 11th 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 post-secondary 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 ninth-graders in high school were selected to be in the sample.

⁵² The SISCF covers 1974-2004, the SIFCF covers 1991-2004.

APPENDIX B
DETAILED SURVEY SUMMARIES

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AMERICAN COMMUNITY SURVEY (ACS)

General Purpose

The purpose of the ACS is to collect detailed information on the demographic, social, economic, and housing characteristics of the U.S. population in order to inform federal and local decision making. It has replaced the Census long form, which previously collected similar data.

Sponsoring Agencies

The ACS is sponsored by the U.S. Census Bureau.

Sampling Universe

The ACS uses a sample drawn from all valid residential housing unit addresses in all counties and county equivalents in the 50 states, as well as the District of Columbia, and group quarters that appeared in the previous census. Examples of group quarters include correctional facilities, homeless shelters, group homes, and college dormitories. Domestic violence shelters, soup kitchens, regularly scheduled mobile food vans, targeted non-sheltered outdoor locations, commercial maritime vessels, natural disaster shelters, and dangerous encampments are never sampled. While households and small group quarters are eligible to be sampled once every five years, large group quarters are eligible for sampling each year.

Detailed data are gathered from up to 5 residents of a given household, including the person in whose name the dwelling is rented or owned, or another adult if that person is not available. Ten to 15 individuals are surveyed in group quarters, depending on the size of the population residing there. Households in reporting areas with small populations are oversampled.

Sample Size

The ACS is sent via mail to three million households each year, and approximately two million respond. Data are pooled across three- and five-year periods to create estimates based on a larger sample.

Regional and State-Level Estimates

ACS estimates are available at regional and state levels as well as for smaller areas, including school districts, congressional districts, Alaska Native Regional Areas, counties, and Census tracts. Statistics for areas with fewer than 65,000 residents are available only as three- and five-year estimates, while statistics for areas with fewer than 20,000 residents are available only as five-year estimates.

Longitudinal Data

The ACS does not follow households or individuals over time.

Frequency of Data Collection and Year(s) Fielded

The ACS is mailed to 250,000 households each month, and data are aggregated for each year. In remote locations in Alaska, the survey takes the form of in-person interviews, which are scheduled for months in which the locations are most accessible.

The ACS has been fully fielded each year since 2005, following a large-scale demonstration from 2000-2004 and a smaller test from 1996-1999. Some data are available from years before 2005, but they are not necessarily complete or nationally representative. The latest data currently available are from 2009. Questions about disability changed slightly for the 2008 survey.¹ As a result, a consistent time series for disability prevalence or characteristics of individuals with disabilities is only available from 2005 through 2007 and from 2008 onwards.

Physical Health, Sensory, and Communication Disability Measures

The ACS includes information on whether the respondent is deaf or hard of hearing, is blind or low-vision, has difficulty walking or climbing stairs, has difficulty dressing or bathing, or has difficulty doing errands due to a physical, mental, or emotional condition.

Mental Health and Disability Measures

The ACS includes information on whether the respondent has difficulty concentrating, remembering, or making decisions and if they have difficulty doing errands due to a physical, mental, or emotional condition.

Cognitive and Intellectual Disability Measures

The ACS includes information on whether respondents have difficulty concentrating, remembering, or making decisions and if they have difficulty doing errands due to a physical, mental, or emotional condition.

Other Health and Disability Measures

The ACS includes information on whether respondents have a Veterans Administration service-connected disability rating and if so, what that rating is (new in 2010); health insurance coverage; Supplemental Security Income payments; Social Security or Railroad Retirement payments; other retirement, survivor, or disability pension payments; and whether they are working or looking for work.

Topic Areas

The ACS includes information on demographic characteristics such as age, sex, Hispanic or Latino origin, race, and relationships between household members; information on social characteristics including ancestry, citizenship status, disability status, educational attainment, fertility,

¹ For example, a question that asked whether the respondent has difficulty “learning, remembering, or concentrating” now asks if the respondent has difficulty “concentrating, remembering, and making decisions.”

field of degree, grandparents as caregivers, language, marital status and marital history, place of birth, school enrollment, migration, veteran status, and year of entry into the U.S.; economic characteristics including class of worker, employment status, health insurance coverage, income and earnings, industry, journey to work, occupation, poverty, and work status; and information on housing characteristics including Supplemental Nutrition Assistance Program participation, house-heating fuel, kitchen facilities, owner statistics, plumbing facilities, renter statistics, rooms and bedrooms, telephone service available, tenure, units in structure, value of home, vehicles available, year householder moved into unit, and the year the structure was built.

Links to Administrative Data

The ACS is not linked to administrative data.

Potential Uses for Disability-Related Research

The ACS provides cross-sectional data for very small areas. It can be used to determine the need for programs and funding, and the number of potential customers who could be served by a new mode of transportation or other service in a given location; to compare income and benefits received for those with different limitations, or of those who report limitations and those who do not; to estimate changes over time in the percent of the population reporting a limitation who are working, receiving benefits, living above or below a standard of living (for example, income at 133 percent of the poverty line), or are covered by a given source of health insurance. Because most questions have been administered consistently over time, the ACS can be used to assess changes in population characteristics.

Other Notable Features

The ACS is also administered in Puerto Rico, where it is called the Puerto Rico Community Survey. The six ACS disability questions are also used in the American Housing Survey (AHS) and the Current Population Survey (CPS).

Sources of Information About the Survey

<http://www.census.gov/history/pdf/ACSHistory.pdf>

http://www.census.gov/acs/www/about_the_survey/questions_and_why_we_ask/

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AMERICAN HOUSING SURVEY (AHS)

General Purpose

The AHS collects information about the quantity and characteristics of housing in America.

Sponsoring Agencies

The U.S. Census Bureau administers the AHS for the U.S. Department of Housing and Urban Development (HUD).

Sampling Universe

The AHS uses a sample of housing units selected randomly based on 1980 census data and periodically updated to reflect new housing units. The sample includes houses, apartments, manufactured/mobile homes, and special living facilities selected from the most recent census. The respondent provides information on demographic characteristics and characteristics of his or her housing unit and the surrounding neighborhood. If the housing unit is vacant, landlords, rental agents, or neighbors provide information about the housing unit and neighborhood. In 2015, the AHS will draw a new sample based on the 2010 Census.

Sample Size

The AHS uses a national sample of about 50,000 housing units, in addition to a cyclical supplemental survey of metropolitan areas. The national sample was drawn for the 1985 survey based on the 1980 census, and the U.S. Census bureau continues to update this sample with newly constructed housing units by sampling building permits. The 2007 AHS selected about 60,000 units for interview; however, 5,000 units were excluded from the sample due to budgetary constraints. An additional 2,150 either no longer existed or did not meet the AHS definition for inclusion, resulting in an eligible sample size of approximately 53,000 housing units.

In addition to the national sample, the AHS surveys a supplemental sample of housing units in metropolitan areas. In 2007, approximately 19,000 housing units were selected for interview in the seven metropolitan areas covered by the survey. The metropolitan survey cycles through a set of 21 areas, surveying each one approximately every six years. The 2007 AHS supplemental metropolitan surveys were conducted in Baltimore, Boston, Houston, Miami, Minneapolis, Tampa, and Washington, DC.

Regional and State-Level Estimates

The AHS produces both national and metropolitan area estimates.

Longitudinal Data

Since 1985, the AHS has surveyed a fixed sample of about 50,000 housing units. The national sample is surveyed in odd-numbered years. Metropolitan areas are revisited about once every six years.

Frequency of Data Collection and Year(s) Fielded

The AHS was first fielded in 1973 as the Annual Housing Survey. Since 1981, the national survey has been conducted in odd numbered years. The survey was redesigned in 1985 and renamed the American Housing Survey. Since then, AHS has used a fixed sample of about 50,000 homes.

Since 2007, the metropolitan survey has been conducted in odd-numbered years along with the national survey. Prior to this, the metropolitan survey was fielded in even numbered years.

The 1995 and 1978 versions of the AHS include supplemental questions about housing and disability. The 1995 AHS collected information about limitations, in addition to housing accessibility and the use of assistive devices. The 1978 AHS contained items on limitations, medical conditions, and availability of household accessibility features.

Physical Health, Sensory, and Communication Disability Measures

The AHS collects information about whether the members of the household are deaf or have serious difficulty hearing; are blind or have serious difficulty seeing, even when wearing glasses; have difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition; have serious difficulty concentrating, remembering, or making decisions due to a physical, mental, or emotional condition; have serious difficulty walking or climbing stairs; or have serious difficulty dressing or bathing. These questions were introduced for the first time in the 2009 AHS and are permanent additions to the survey.

Mental Health and Disability Measures

The AHS collects information about whether the members of the household have serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition, or whether they have difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition. These questions were introduced for the first time in the 2009 AHS and are permanent additions to the survey.

Cognitive and Intellectual Disability Measures

The AHS collects information about whether the members of the household have serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition, or whether they have difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition. These questions were introduced for the first time in the 2009 AHS and are permanent additions to the survey.

Other Health and Disability Measures

The AHS collects information about disability payments, such as Social Security Disability Insurance, worker's compensation, or veteran's disability.² The survey includes a separate question about receipt of Supplemental Security Income.

Housing accessibility is covered in the survey. The AHS collects information about whether it is possible to enter the household from the outside without climbing up or down steps or stairs. The survey also provides information about whether assistive or personal care services are provided to households in multifamily structures.

Topic Areas

Topics covered in the survey include characteristics of household occupants, information on recent moves, neighborhood and housing quality, housing unit structural features, size of unit and land, plumbing, appliances, heating and cooling equipment, fuels, housing costs (mortgage, rent, taxes), remodeling and renovations, and use of housing assistance programs.

Links to Administrative Data

HUD produces the Income Limits File, linking the AHS public use file with HUD administrative data. The Income Limits File is publically available.

Potential Uses for Disability-Related Research

With the addition of disability questions in 2009, the AHS data can be used to evaluate the current living conditions and housing needs of people with self reported limitations and those receiving disability benefits.

Other Notable Features

The 1995 and 1978 versions of the AHS include supplemental questions about housing and disability. As of 2009, the AHS has permanently added questions about six types of physical, cognitive, and mental limitations.

Internal Use Files (IUFs) are also available through the Census Bureau. The IUFs include detailed level of geography, as well as disaggregated data not included in the public use files for confidentiality reasons.

Sources of Information About the Survey

http://www.huduser.org/portal/datasets/ahs/AHS_Codebook.pdf

<http://www.census.gov/prod/2004pubs/ahsr04-1.pdf>

² The AHS is not able to distinguish between types of disability payments. The 2009 question reads "Did you receive any disability payments such as SSDI, worker's compensation, veteran's disability or other disability payments during the past 12 months?"

<http://www.census.gov/hhes/www/housing/ahs/ahs01/appendixb.pdf>
<http://www.census.gov/hhes/www/housing/ahs/ahs01/appendixc.pdf>
<http://www2.census.gov/prod2/ahsscan/codebook1990.pdf>
<http://www.census.gov/prod/2008pubs/h150-07.pdf>
http://www.huduser.org/portal/datasets/ahs/AHS_%20FAQ_9-9-08.pdf
<http://www.huduser.org/forums/index.php?q=node/39>

AMERICAN TIME USE SURVEY (ATUS)

General Purpose

The ATUS collects information about the activities that comprise daily life in the U.S.

Sponsoring Agencies

The U.S. Census Bureau administers the ATUS on behalf of the Bureau of Labor Statistics, U.S. Department of Labor.

Sampling Universe

The ATUS uses the same sample as the Current Population Survey (CPS), representing the noninstitutional, civilian household population. Each household that completes the CPS sequence of interviews becomes eligible to be selected for the ATUS survey. The ATUS is designed to be representative for all residents of U.S. households, age 15 and older.

Sample Size

Since 2004, approximately 26,000 housing units are selected for the ATUS annually.

Regional and State-Level Estimates

The ATUS provides national level estimates only.

Longitudinal Data

The ATUS is not a longitudinal survey.

Frequency of Data Collection and Year(s) Fielded

The ATUS was first fielded in 2003 and is conducted annually. The survey is administered at regular intervals throughout the year. Respondents answer a set of questions and also complete a time use diary. The respondent completes the time use diary once, reporting all activities of the previous day.³ The final section of the survey includes rotating modules. The U.S. Department of Agriculture sponsored the Eating and Health module from 2006 to 2008, with questions focusing on diet and nutrition.

Physical Health, Sensory, and Communication Disability Measures

The ATUS asks about temporary absences for work, and respondents may select that these missed days are due to illness, injury, or medical problems. The survey also queries whether a member of the household took a trip for medical reasons.

³ The respondent is asked to record all activities and duration from 4:00am on the day prior to the interview to 4:00am on the day of the interview.

The Eating and Health Module, fielded from 2006 to 2008, provides information about height and weight.

Mental Health and Disability Measures

The ATUS asks about temporary absences for work, and respondents may select that these missed days are due to illness, injury, or medical problems. The survey also queries whether a member of the household took a trip for medical reasons.

Cognitive and Intellectual Disability Measures

The ATUS asks about temporary absences for work, and respondents may select that these missed days are due to illness, injury, or medical problems. The survey also queries whether a member of the household took a trip for medical reasons.

Other Health and Disability Measures

The ATUS provides information about whether the respondent was unable to work due to a disability. The respondent is asked if he or she worked at any point in the past seven days, and may select disabled as a response option. Respondents who report not working due to disability are asked about looking for work and if the reported condition prevents working for the next 6 months.

ATUS respondents rate their general physical health on a five point scale from excellent to poor.

Because the ATUS sample is derived from the CPS, later years can be linked to the six disability questions recently added to the CPS.

Topic Areas

Topics covered in the ATUS include employment during the previous week, trips away from home, labor force status, income, and school enrollment. The time use diary includes the following activities: sleeping, grooming (self), watching TV, working at main job, working at other job, preparing meals or snacks, eating and drinking, cleaning the kitchen, laundry, grocery shopping, attending religious service, and paying household bills. Respondents provide information about how long each activity took, who was with them, and where the activity took place. Follow-up questions to the time use diary focus on secondary childcare, volunteer work, and work and income-generating activities.

The Eating and Health Module covers food preparation and identifies which member of the household is the primary grocery shopper and food preparer. The survey also provides information on whether children consume food that was prepared outside the home, school, or child care programs. A section of the module expands on the time diary and gives details about time spent eating (either as the primary activity or concurrently with another activity) and time spent drinking beverages (excluding water).

Links to Administrative Data

The ATUS is not linked to administrative data.

Potential Uses for Disability-Related Research

The ATUS can be used to evaluate how people who are not working due to disability spend their time compared to people without disabilities who are jobless. Using the Eating and Health Module, researchers can explore the correlation between BMI or nutritional habits and disability.

Other Notable Features

The ATUS is designed to include rotating modules, funded by other government agencies, as the final section of the survey. The U.S. Department of Agriculture sponsored the Eating and Health Module from 2006-2008.

The ATUS is linked to the CPS. Income questions are only asked on the ATUS for respondents who changed jobs or became employed since the final CPS interview. Income for all others is imputed from the CPS. The link to the CPS also permits use of the CPS disability questions to identify people with disabilities in later years of the ATUS.

Sources of Information About the Survey

<http://www.bls.gov/tus/atususersguide.pdf>

<http://www.bls.gov/tus/tuquestionnaire.pdf>

<http://www.ers.usda.gov/Publications/AP/AP047/AP047.pdf>

<http://www.bls.gov/tus/ehmquestionnaire.pdf>

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BACCALAUREATE AND BEYOND LONGITUDINAL STUDY (B&B)

General Purpose

B&B follows college graduates after they complete their bachelor's degree and collects information about post-baccalaureate education, work experience, and family life.

Sponsoring Agencies

B&B is sponsored by the Institute of Education Sciences, U.S. Department of Education.

Sampling Universe

B&B uses a nationally representative sample drawn from the National Postsecondary Student Aid Study (NPSAS). The NPSAS sample consists of students who are enrolled in postsecondary education at public, private, or for-profit institutions offering vocational, two-year or four-year degrees. All students who participated in the NPSAS and received, or expected to receive, an undergraduate degree during the NPSAS reporting period were eligible to participate in the B&B. B&B is administered to college graduates who completed their bachelor's degree in the year following the NPSAS.

Sample Size

The B&B sample size varies by cohort. The most recent B&B cohort will be followed from 2008 to 2012. The series of interviews administered to this cohort is referred to as B&B:08/12 and currently includes approximately 19,000 students. The B&B:00/01 included about 10,000 students, and the B&B:93/03 surveyed approximately 11,000 students.

Regional and State-Level Estimates

The B&B provides national level estimates only.

Longitudinal Data

B&B is a longitudinal study, with follow up varying by cohort. The first cohort was followed from 1993 to 2003, while the second cohort was followed only for one year from 2000 to 2001. Data collection is currently in progress for the third cohort. These students were initially interviewed in 2008 and 2009, with an additional follow-up survey planned for 2012.

Frequency of Data Collection and Year(s) Fielded

B&B has been conducted for three cohorts. The first cohort was initially surveyed as a part of the NPSAS:93, with follow up interviews in 1994, 1997, and 2003. The second cohort was interviewed for the NPSAS:00 and completed a follow-up interview in 2001. The third cohort was initially interviewed as a part of the NPSAS:08 and completed a first follow-up interview in 2009. A second follow-up survey is scheduled for 2012. Data, questionnaires, and codebooks are not yet available for the B&B:08/12.

Physical Health, Sensory, and Communication Disability Measures

Questions about disability in the B&B:93/03 vary by survey year. Disability questions in the B&B:93/94 were asked of those who reported a disability on the NPSAS:93, as well as those who did not, but who reported that their status had changed. The B&B:93/97 asked all respondents if they have any disabilities or limitations which interfere with their ability to work. The B&B:93/03 asked all respondents if they have a long lasting physical or mental condition that substantially limits one or more major life activities. If the respondent indicated a disability, limitation, or condition on the B&B:93/94, B&B:93/97, or B&B:93/03, the respondent was asked if he or she has a speech disability or limitation; vision impairment that cannot be corrected with glasses or is legally blind; hearing impairment; orthopedic or mobility limitation; or any other limitations, disabilities, or handicaps.

The B&B:00/01 only included a disability question at baseline (NPSAS:00). All respondents were asked if they have any long lasting conditions such as blindness, deafness, or a severe vision or hearing impairment; any conditions that substantially limit one or more basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying; or any other physical mental or emotional conditions that have lasted 6 months or more. If the respondent indicated an impairment, the survey collected information about any difficulties learning, remembering or concentrating; dressing, bathing or getting around the inside of the home or dormitory; getting to school to attend class; getting around campus; or working at a job. The survey also asked the respondent to indicate their main limitation and up to three other conditions.

Mental Health and Disability Measures

Questions about disability in the B&B:93/03 vary by survey year. Disability questions in the B&B:93/94 were asked of those who reported a disability on the NPSAS:93, as well as those who did not, but who reported that their status had changed. The B&B:93/97 asked all respondents if they have any disabilities or limitations which interfere with their ability to work. The B&B:93/03 asked all respondents if they have a long lasting physical or mental condition that substantially limits one or more major life activities. If the respondent indicated a disability, limitation, or condition on the B&B:93/94, B&B:93/97, or B&B:93/03, the respondent was asked if he or she has a mental illness or serious emotional disturbance; or any other limitations, disabilities, or handicaps.

The B&B:00/01 only includes a disability question at baseline (NPSAS:00). All respondents were asked if they have had any physical, mental, or emotional conditions that have lasted six months or more. If the respondent indicated an impairment, the survey collected information about any difficulties learning, remembering or concentrating; dressing, bathing or getting around the inside of the home or dormitory; getting to school to attend class; getting around campus; or working at a job. The survey also asked respondents to indicate their main limitation and up to three other conditions.

Cognitive and Intellectual Disability Measures

Questions about disability in the B&B:93/03 vary by survey year. Disability questions in the B&B:93/94 were asked of those who reported a disability on the NPSAS:93, as well as those who did not, but who report that their status had changed. The B&B:93/97 asked all respondents if they have any disabilities or limitations which interfere with their ability to work. The B&B:93/03 asked all respondents if they have a long lasting physical or mental condition that substantially limits one

or more major life activities. If the respondent indicated a disability, limitation, or condition on the B&B:93/94, B&B:93/97, or B&B:93/03, the respondent was asked if he or she has a specific learning disability; or any other limitations, disabilities, or handicaps.

The B&B:00/01 only includes a disability question at baseline (NPSAS:00). All respondents were asked if they have any physical mental or emotional conditions that have lasted 6 months or more. If the respondent indicated an impairment, the survey collected information about any difficulties learning, remembering or concentrating; dressing, bathing or getting around the inside of the home or dormitory; getting to school to attend class; getting around campus; or working at a job. The survey also asked respondents to indicate their main limitation and up to three other conditions.

Other Health and Disability Measures

All respondents were asked about their current employment. The respondent could answer that they are not working due to a disability. If respondents indicated a disability related to work, the survey queried respondents about when they last worked for pay, if they are currently looking for work, and if they have received unemployment. The survey also provides information about whether respondents consider themselves to have a disability.⁴

The B&B collects information about receipt of public assistance. The respondent is asked in separate questions about receipt of public assistance from Social Security, Temporary Aid to Needy Families, Supplemental Nutrition Assistance Program, child support, disability payments, or other untaxed income such as welfare benefits or workers compensation. The B&B:00/01 includes an additional question about receipt of either Supplemental Security Income or Supplemental Security Disability Insurance.

If the respondent indicated a disability on the NPSAS:00, the survey asked if they received or requested any disability-related services or accommodations to assist in school, including alternative exam formats or additional time; tutors to assist with ongoing homework; readers, classroom note takers, or scribes; registration assistance or priority class registration; sign language or oral interpreters; adaptive equipment and technology; course substitution or waiver; or vocational rehabilitation services.

Data, questionnaire, and codebook are not yet available for the B&B 08/12.

Topic Areas

Topics on the B&B include undergraduate enrollment history, student loans and debt, income, demographics, family background, graduate school and professional school enrollment, employment, career development, marital status, family, civic involvement, and disability status. A final section specifically for teachers includes questions on professional licensure, job satisfaction, certification, and job-related training.

⁴ This question is asked of all respondents on the B&B:00/01. Only respondents that indicated a condition are asked this question on the B&B:93/03.

Links to Administrative Data

B&B can be linked to financial aid application data from the Central Processing System and federal student loan amounts from National Student Loan Data System.

Potential Uses for Disability-Related Research

B&B can be used to investigate educational outcomes for students with physical, emotional, or learning disabilities. Researchers can compare employment rates, occupations, and starting salaries for people with and without disabilities. The survey data can also be used to explore predictors for pursuing graduate or professional degrees.

Sources of Information About the Survey

<http://nces.ed.gov/surveys/b%26b/>

BEGINNING POSTSECONDARY STUDENTS LONGITUDINAL STUDY (BPS)

General Purpose

The BPS follows first-time college students. The survey provides information about postsecondary educational outcomes, employment, and marriage and family formation.

Sponsoring Agencies

The BPS is sponsored by the Institute of Education Sciences, U.S. Department of Education.

Sampling Universe

The BPS is administered to a nationally representative sample of undergraduates drawn from the National Postsecondary Student Aid Study (NPSAS). The NPSAS sample consists of students who are enrolled in postsecondary education at public, private, or for-profit institutions offering vocational, two-year or four-year degrees. All students who participated in the NPSAS and were identified as beginning their postsecondary education during the NPSAS reporting period were eligible to participate in the BPS.

Sample Size

The BPS sample size varies by cohort. The most recent BPS cohort was followed from 2004 to 2009. This cohort participated in an initial baseline interview (NPS 2004) and two follow-up interviews. The series of interviews administered to this cohort is referred to as BPS:04/09 and includes approximately 16,700 students. The BPS:90/94 cohort included about 8,000 students, and the BPS:96/01 cohort included around 12,000 students.

Regional and State-Level Estimates

The BPS provides national level estimates only.

Longitudinal Data

The BPS follows each cohort for six years.

Frequency of Data Collection and Year(s) Fielded

The BPS has been conducted for three cohorts. The BPS:04/09 cohort was initially surveyed during the 2003-04 school year as a part of the NPSAS, with follow up interviews in 2005-06 and 2008-09. The BPS:90/94 cohort was initially surveyed as part of the NPSAS:90, with follow-up interviews in 1992 and 1994. The BPS:96/01 cohort was initially surveyed as a part of the NPSAS:96 and completed follow-up interviews in 1998 and 2001.

Physical Health, Sensory, and Communication Disability Measures

All respondents on the BPS:04/09 and BPS:96/01 were asked if they have a sensory impairment such as blindness, deafness, or a severe vision or hearing impairment that has lasted for six months or more; a mobility impairment that have substantially limited one or more basic physical

activities, such as walking, climbing stairs, reaching, lifting, or carrying, for six months or more; or any other physical, mental, emotional, or learning condition that has lasted six months or more, and limits their ability to learn, remember, or concentrate; dress; bathe; get around the house; or get to school, campus, or work. If respondents indicated an impairment, the survey asked if their main condition was a hearing impairment, blindness or visual impairment that cannot be corrected by wearing glasses; a speech or language impairment; an orthopedic or mobility impairment; a health impairment or problem; or a brain injury (BPS:04/09 only).

The BPS:90/94 asked all respondents if they have any functional limitation, disabilities, or handicaps. If respondents indicated any functional limitations, disabilities, or handicaps, they were asked if they have a hearing impairment; a speech disability or limitation; an orthopedic or mobility limitation; a vision impairment that cannot be corrected with glasses or legal blindness; or other health-related disability.

Mental Health and Disability Measures

All respondents to the BPS:04/09 and BPS:96/01 were asked if they have any physical, mental, emotional, or learning condition that has lasted six months or more and limits their ability to learn, remember, or concentrate; dress; bathe; get around the house; or get to school, campus, or work. If respondents indicated an impairment, they were asked if their main condition is a mental, emotional, or psychiatric condition; or depression (BPS:04/09 only).

The BPS:90/94 asked all respondents if they have any functional limitation, disabilities, or handicaps. If respondents indicated any functional limitations, disabilities, or handicaps, they were asked to specify the type.

Cognitive and Intellectual Disability Measures

All respondents to the BPS:04/09 and BPS:96/01 were asked if they have any physical mental, emotional, or learning condition that has lasted six months or more and limits their ability to learn, remember, or concentrate; dress; bathe; get around the house; or get to school, campus, or work. If respondents indicated an impairment, they were asked if their main condition is a specific learning disability or dyslexia; attention deficit disorder (ADD, BPS:04/09 only); or developmental disability (BPS:04/09 only)

The BPS:90/94 asked all respondents if they have any functional limitation, disabilities, or handicaps. If respondents indicated any functional limitations, disabilities, or handicaps, they were asked if they have a specific learning disability.

Other Health and Disability Measures

If respondents were not currently enrolled in school and did not have plans to go back to school, the survey asked about current employment. Respondents could answer, among other options, that they were not working due to a disability. The BPS:96/01 also provides information about whether respondents consider themselves to have a disability.

The BPS includes information about receipt of public assistance. Respondents were asked in separate questions about receipt of public assistance including disability payments, worker's compensation, Supplemental Security Income (BPS:04/09, BPS:96/01 only), Supplemental Security

Disability Insurance (BPS:04/09, BPS:96/01 only), and vocational rehabilitation services (BPS:04/09, BPS:96/01 only).

The BPS:04/09 and BPS:96/01 also include information about accommodations related to disabilities. If respondents indicated a disability, they were asked if they have received or requested any disability-related services or accommodations to assist in school. If respondents had received or requested services, they were asked to specify up to three types, including alternative exam formats or additional time; tutors to assist with ongoing homework; readers, classroom note takers, or scribes; registration assistance or priority class registration (BPS:96/01 only); sign language or oral interpreters; adaptive equipment and technology; course substitutions or waivers; special locations (BPS:96/01 only); and handicapped parking or special transportation (BPS:96/01 only).

Topic Areas

Topics on the BPS include enrollment history, characteristics of enrollment, degree goal of current program, classes, major, residence, work, financial support from parents, financial aid, employment, income, student loans and debt, civic participation, disabilities, volunteerism, marital status and family composition, and personal goals.

Links to Administrative Data

The BPS can be linked to financial aid application data from the Central Processing System, federal student loan amounts from National Student Loan Data System, and annual tuition and student budgets the Integrated Post Secondary Education Data System.

Potential Uses for Disability-Related Research

The BPS can be used to investigate educational outcomes for students with physical, emotional, or learning disabilities. Researchers can compare employment, postsecondary education, and family life for students with and without disabilities. The data can be used to evaluate the impact of a disability on completing undergraduate or graduate education.

Sources of Information About the Survey

<http://nces.ed.gov/pubs2008/2008184.pdf>

<http://nces.ed.gov/pubs99/1999187.pdf>

<http://nces.ed.gov/pubs2009/200901.pdf>

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BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS)

General Purpose

The BRFSS collects information about health risk behaviors, preventive health practices, specific diagnoses, and health care access. It is administered at the state level in order to allow states to ask the questions they believe to be most useful and to produce state-level estimates that are necessary for guiding the creation and implementation of public health policy.

Sponsoring Agencies

The BRFSS is primarily sponsored by the Centers for Disease Control and Prevention (CDC). The CDC prepares core questions, which are asked in every state, and optional question modules on specific topics, from which the states select which, if any, to use. States may also add their own questions, which are supported by state funds.

Sampling Universe

The BRFSS samples adults living in households with a telephone. Each state decides how to select its sample, though all samples must support estimates of this population. A disproportionate stratified sample or simple random sample of phone numbers is selected, and one adult (age 18 or older) is interviewed from each household. Most questions address only the sampled adult, though some optional modules request information on a randomly selected child in the household. Most states oversample phone numbers that are believed to belong to households based on the proportion of similar numbers that are known to be households, and many oversample some substate regions, including areas in which a new program has been launched, areas of particular concern, or areas with small populations. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam.

Sample Size

The BRFSS sample size has increased over time, with large growth experienced in the early years of the survey when the number of states participating was growing. The sample size was 12,258 in 1984, 124,085 in 1996, and 432,607 in 2009.

Regional and State-Level Estimates

The BRFSS is expressly designed to produce state-level estimates. Some states design their samples to also provide estimates for smaller regions.

Longitudinal Data

The BRFSS does not follow households or individuals over time.

Frequency of Data Collection and Year(s) Fielded

The BRFSS has been fielded each year since 1984. Originally surveying 15 states, it has covered all 50 states and the District of Columbia since 1996. The BRFSS is fielded throughout the year, and data are aggregated to produce yearly estimates.

Physical Health, Sensory, and Communication Disability Measures

The BRFSS collects information about whether respondents have any health problem that requires them to use special equipment such as a wheelchair or special phone. Optional modules collect information on diabetes; oral health; cardiovascular disease; asthma; falls; cancer; arthritis; and whether the respondent is blind or low-vision.

Mental Health and Disability Measures

The BRFSS includes information about the number of days on which the respondent's mental health was not good. An optional module on anxiety and depression collects information on the number of days respondents had little interest or pleasure in doing things; felt down, depressed, or hopeless; had trouble falling asleep or staying asleep, or slept too much; felt tired or had little energy; had a poor appetite or ate too much; felt bad about themselves, that they were a failure, or had let their family down; had trouble concentrating on things; moved and spoken noticeably slowly, or been restless and fidgety; and whether respondents had been told they have an anxiety or depressive disorder.

Cognitive and Intellectual Disability Measures

The BRFSS includes information about cognitive impairment in an optional module. Questions address whether respondents or another member of the household has experienced confusion or memory loss that is getting worse or happening more often; those individuals' ages; whether they have given up household activities or chores as a result; whether they require the most assistance with safety (for example, remembering to turn off the stove), transportation, household activities, or personal care; whether their confusion or memory loss has interfered with their ability to work, volunteer, or engage in social activities; how often a family member or friend has provided assistance; whether the confusion or memory loss has been discussed with a doctor; if it is being treated; and if a doctor has said that they have Alzheimer's or another form of dementia.

Other Health and Disability Measures

The BRFSS includes information on general health; healthy days; days on which health prevented respondents from normal activities; health insurance and use and source of health care; and veterans' health (optional module).

Topic Areas

The BRFSS questionnaire is comprised of core questions and optional modules. All states are required to administer the core questions. The optional modules are standardized questions that are supported by the CDC that cover additional health topics or are more detailed questions on a health topic that is included in the core. Each year, states must choose which optional modules, if any, they will use based on their data needs. States can also add their own content. The specific topics covered by the survey change somewhat from year to year, but address issues of health and behavioral risk factors.

In 2010, core questions addressed health status; healthy days and health-related quality of life; health care access; sleep; exercise; diabetes; oral health; cardiovascular disease; asthma; disability; tobacco use; demographic characteristics; alcohol consumption; immunization; falls; seatbelt use;

drinking and driving; women's health; prostate cancer screening; colorectal cancer screening; HIV/AIDS; and emotional support and life satisfaction.

Optional modules in the 2010 survey addressed pre-diabetes; diabetes; healthy days and the symptoms suffered on other days; visual impairment and access to eye care; excess sun exposure; inadequate sleep; family planning; adult asthma history; arthritis; whether the respondent is a health care worker; shingles vaccines; tetanus and diphtheria vaccines; human papilloma virus; cancer survivorship; caregivers; reactions to race; anxiety and depression; cognitive impairment; social context; general preparedness; veterans' health; adverse childhood experiences; basic demographic information on a randomly selected child in the household; childhood asthma; and childhood immunization.

Links to Administrative Data

The BRFSS is not linked to administrative data.

Potential Uses for Disability-Related Research

BRFSS data can be used to evaluate the effectiveness of public health policies and programs, or to identify the need for new or expanded programs and services.

Other Notable Features

Core questions are composed of fixed, rotating, and emerging questions. Fixed core questions are asked every year. Rotating core questions are asked in alternating years, and supported as optional questions in years they are not asked. Emerging questions generally address issues that have recently become of interest. They are included for one year, and then evaluated to determine whether to add them to the fixed or rotating core in future years.

Sources of Information About the Survey

<http://www.cdc.gov/brfss/questionnaires/pdf-ques/2010brfss.pdf>

http://www.cdc.gov/brfss/technical_infodata/surveydata/2009.htm

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CENSUS

General Purpose

The purpose of the U.S. Census is to generate statistics on the U.S. population that are used to determine political representation and government funding.

Sponsoring Agencies

The Census is sponsored by the U.S. Census Bureau.

Sampling Universe

The Census collects data on the entire U.S. population, including those who are not legally allowed to reside in the country and some U.S. citizens residing abroad. Full data are collected on up to six members of a household, including the person in whose name the dwelling is owned or rented, or another adult if they are not available. Basic information (gender and date of birth) is collected on up to six additional members of the household.

From 1940 to 2000, a randomly selected subset of the population (about 17 percent in 2000) received a “long form” Census questionnaire, which requested additional information.

Sample Size

The sample size for the Census has increased with the U.S. population, which was estimated to be 308,745,538 in 2010.

Regional and State-Level Estimates

Census data are available at regional, state, and local levels.

Longitudinal Data

The Census does not produce longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The Census has been administered every 10 years since 1790. From 1940 to 2000, a proportion of respondents received the long form Census, which requested additional information. The long form was not used in 2010 because it was replaced by the American Community Survey (ACS).

Physical Health, Sensory, and Communication Disability Measures

The Census no longer includes information on disability. In 2000, the long form Census included information on whether any individual was deaf, blind, or had a vision or hearing impairment; had a condition that limited basic physical activities such as climbing stairs or carrying; or, due to a physical, mental or emotional condition lasting more than six months, had difficulty bathing, dressing, or getting around the home; had difficulty going outside the home to shop or visit a doctor’s office; or had difficulty working.

Mental Health and Disability Measures

The Census no longer includes information on disability. In 2000, the long form Census included information on whether, due to a physical, mental, or emotional condition lasting more than six months, any individual had difficulty learning, remembering or concentrating; difficulty bathing, dressing, or getting around the home; difficulty going outside the home to shop or visit a doctor's office; or difficulty working.

Cognitive and Intellectual Disability Measures

The Census no longer includes information on disability. In 2000, the long form Census included information on whether, due to a physical, mental, or emotional condition lasting more than six months, any individual had difficulty learning, remembering or concentrating; difficulty bathing, dressing, or getting around the home; difficulty going outside the home to shop or visit a doctor's office; or difficulty working.

Other Health and Disability Measures

The Census no longer includes information on disability. In 2000, the long form Census included information on whether any individual received Social Security or Railroad Retirement benefits, Supplemental Security Income, other retirement payments, or survivor disability payments, as well as short-term illnesses that prevented work.

Topic Areas

In 2010, the Census covered gender, age, race, ethnicity, and relationship to the person who owns or rents the home. In previous years, the Census also collected information from a sample of the population on additional demographic characteristics (for example, marital history), social characteristics (for example, disability, education, veteran status, and occupation), and economic characteristics (for example, income and hours worked).

Links to Administrative Data

The Census is not linked to administrative data.

Potential Uses for Disability-Related Research

The Census can be used to describe the prevalence of disability dating back to 1830, or to track changes in disability patterns in small geographic areas, using the ACS for data after 2000.

Other Notable Features

Beginning in 2005, the ACS has fielded questions similar to those in the long form version of the 2000 Census. A long form was not used in the 2010 Census, because it has been replaced by the ACS.

Sources of Information About the Survey

<http://www.census.gov/prod/2002pubs/pol02marv-pt4.pdf>

CONSUMER EXPENDITURE SURVEY (CE)

General Purpose

The CE collects information about household income and expenditures through two components: the quarterly Interview Survey and the weekly Diary Survey.

Sponsoring Agencies

The U.S. Census Bureau administers the CE for the Bureau of Labor Statistics, U.S. Department of Labor.

Sampling Universe

The CE uses a sample of addresses from the most recent Census and periodically updates this list to reflect new construction permits and newly identified housing units. The CE surveys consumer units,⁵ which includes all related and non-related members of households, and may be answered by any member age 16 or older. The CE is designed to represent the total civilian non-institutional population.

Sample Size

Approximately 12,000 housing units are selected for the Diary Survey sample. Each household completes the survey over a two-week period, with field interviewing spread evenly throughout the year.

The Interview Survey uses a national sample of approximately 14,000 housing units each quarter. Households are interviewed once a quarter for five quarters, or 15 months. The sample is continuously updated as new households are selected for interview to replace those that have completed the interview cycle. Twenty percent of the sample is interviewed for the first time each quarter.

Regional and State-Level Estimates

The CE produces regional estimates for Northeast, Midwest, South, and West. Metropolitan level estimates are also available for the largest Metropolitan Statistical Areas (MSAs) within each region.⁶ The CE does not produce state level estimates.

⁵ According to the CE, a consumer unit is defined as (1) all members of a particular housing unit who are related by blood, marriage, adoption, or some other legal arrangement, such as foster children; (2) a person living alone or sharing a household with others, or living as a roomer in a private home, lodging house, or in permanent living quarters in a hotel or motel, but who is financially independent; or (3) two or more unrelated persons living together who pool their income to make joint expenditure decisions. Students living in university sponsored housing are also included in the sample as separate consumer units.

⁶ The most recent CE produced regional-level estimates for MSAs in the Midwest (Chicago, Detroit, Minneapolis-St. Paul, Cleveland), Northeast (New York, Philadelphia, Boston), South (Washington, D.C., Baltimore, Atlanta, Miami, Dallas-Fort Worth, Houston), and West (Los Angeles, San Francisco, San Diego, Seattle, Phoenix).

Longitudinal Data

The CE Interview Survey is administered to respondents once per quarter for five quarters.

Frequency of Data Collection and Year(s) Fielded

The CE was first fielded in the late 1800's as a decennial survey. Since 1980, the survey has been conducted annually. The CE surveys each household selected for the Interview Survey once every three months over five quarters. The CE surveys each household selected for the Diary Survey for two consecutive one-week periods.

Physical Health, Sensory, and Communication Disability Measures

The Interview Survey collects information about expenditures on medical services, including eye care, dental care, inpatient care, services by physicians and other medical professionals, and lab tests or x-rays. The survey also collects information about expenditures on medicine and medical supplies, including hearing aids, prescription drugs, medical or surgical equipment for general use, and supportive or convalescent equipment (canes, crutches, walkers, wheelchairs). It also provides information on expenditures on care for individuals inside the home, in a convalescent or nursing home, or at an adult daycare center.

Mental Health and Disability Measures

The Interview Survey collects information about expenditures on inpatient care, which includes psychiatric hospitals and substance abuse hospitals. The survey also collects information on expenditures on services by mental health professionals, including substance abuse professionals and psychologists. It also provides information on expenditures on care for individuals inside the home, in a convalescent or nursing home, or at an adult daycare center.

Cognitive and Intellectual Disability Measures

The Interview survey provides information on expenditures on care for individuals either inside the home, in a convalescent or nursing home, or at an adult daycare center.⁷

Other Health and Disability Measures

The Interview Survey collects information about Medicaid, Medicare, and private health insurance enrollment.

Topic Areas

Topics covered in the Interview Survey include general housing characteristics; major household appliances; rented and owned living quarters and real estate; utilities and fuels; construction, repairs, alterations, and maintenance of property; household item repairs and service

⁷ Respondents could be using these services due to a cognitive or intellectual condition. However, there is no way to identify respondents with cognitive/intellectual disabilities in the CE.

contracts; home furnishings and related household items; clothing and sewing materials; rented and leased vehicles; owned vehicles; vehicle operating expenses; insurance other than health; hospitalization and health insurance; medical and health expenditures; educational expenses; subscriptions, memberships, books and entertainment expenses; trips and vacations; food and beverage expenses; credit liability; and work experience and income.

The Diary Survey records all expenses incurred within one week. Respondents include expenses in the following categories: food and drinks away from home; food and drinks for home consumption; clothing, shoes, jewelry, and accessories; all other products, services, and expenses.

Links to Administrative Data

The CE is not linked to administrative data.

Potential Uses for Disability-Related Research

The CE can be used to evaluate spending on healthcare expenses.

Other Notable Features

The CE is currently undergoing a redesign. This redesign effort is referred to as the Gemini Project. The primary purpose of the Gemini Project is to improve the quality of CE data by reducing measurement error, particularly the error caused by underreporting. Further information about the Gemini Project is available at <http://www.bls.gov/cex/geminimaterials.htm>.

Sources of Information About the Survey

http://www.bls.gov/cex/current/i_infobook.pdf
http://www.bls.gov/cex/current/d_infobook.pdf
<http://www.bls.gov/opub/hom/pdf/homch16.pdf>
<http://www.bls.gov/cex/ceturnsthirty.htm>
<http://www.bls.gov/cex/csxgeography.htm>

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CURRENT POPULATION SURVEY (CPS)

General Purpose

The CPS provides monthly data at national, state, and local levels on the size of the labor force, employment, unemployment, persons not in the labor force, hours of work, earnings, and other demographic and labor force characteristics. Supplements produce data on a variety of other topics, including income, voting, and volunteering.

Sponsoring Agencies

The CPS is sponsored by the Census Bureau and the Bureau of Labor Statistics, U.S. Department of Labor. Other agencies or organizations can add supplemental content, which is funded by the agency or organization.

Sampling Universe

The CPS uses a two- or three-stage probability sample of the noninstitutionalized civilian population aged 15 and older, including those living in group quarters. One person generally provides data for all eligible members of the household or group quarters unit (for example, bed or room). If a respondent is unable to respond for all members of the household or group quarters unit, attempts are made to contact those people directly.

Sample Size

Since 2001, the CPS has used a sample of about 60,000 occupied households each month. The sample size has changed periodically, ranging from 50,000 to 60,000 since 1967.

Regional and State-Level Estimates

The CPS is designed to produce estimates at state and local levels.

Longitudinal Data

The CPS does not produce longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The CPS has been conducted monthly since 1940. Because the survey underwent significant changes in 1994, data before and after that date are not comparable.

Households are sampled for four consecutive months, then during the same four months one year later. While earlier surveys identify work limitations, six questions on disability were added to

the CPS in June 2008.⁸ These are asked of households during their first month in the sample and the same month one year later.

Physical Health, Sensory, and Communication Disability Measures

The CPS includes information on whether any household member is deaf or has serious difficulty hearing; is blind or has serious difficulty seeing even when wearing glasses; serious difficulty walking or climbing stairs; or difficulty dressing or bathing; and whether because of a physical, mental, or emotional condition any individual has serious difficulty concentrating, remembering or making decisions; or difficulty doing errands alone such as visiting a doctor's office or shopping.

Mental Health and Disability Measures

The CPS includes information on whether because of a physical, mental or emotional condition any individual has serious difficulty concentrating, remembering or making decisions or difficulty doing errands alone such as visiting a doctor's office or shopping.

Cognitive and Intellectual Disability Measures

The CPS includes information on whether because of a physical, mental or emotional condition any individual has serious difficulty concentrating, remembering or making decisions or difficulty doing errands alone such as visiting a doctor's office or shopping.

Other Health and Disability Measures

The CPS includes information on those who are not participating in the labor force due to a disability or temporary health condition. This is the only measure of disability status that was regularly collected before 2008. Information on the presence of veterans' service-connected disabilities has been collected approximately every two years.

Topic Areas

The core section of the CPS collects data on demographic characteristics, annual work activity and income, veteran status, school enrollment, contingent employment, worker displacement, and job tenure. Supplements have addressed home vacancies; health insurance and pension enrollment; awareness of lead paint hazards; contingent workers; food security; race and ethnicity; marital history; fertility; educational attainment; veterans; school enrollment; tobacco use; displaced workers; worker mobility and job tenure; child support; voting and registration; work schedule; computer and internet use; participation in the arts; volunteering; and cellular phone use. The Annual Social and Economic Supplement provides information on family characteristics, household composition, marital status, education attainment, health insurance coverage, foreign born population, previous year's income from all sources, work experience, receipt of noncash benefit, poverty, program participation, and geographic mobility.

⁸ Disability data was collected in a different manner from June-September 2008 than was used starting in October 2008, so estimates based on those questions cannot be directly compared before and after the change.

Links to Administrative Data

The CPS is not routinely linked to administrative data. It has been linked to Social Security Administration (SSA) data for specific and restricted use by SSA staff.

Potential Uses for Disability-Related Research

With the additional of the six disability questions, the CPS can now provide information on the labor force participation and employment of people with disabilities over time which may be disaggregated by age, sex, race, marital status, industry, and occupation. It can be used to track employment statistics of people with disabilities over time, to compare the unemployment rates of people with and without disabilities, or to identify occupations with particularly high or low numbers of people with disabilities. The work limitation measure of disability can be used to track work disability over a longer period.

Other Notable Features

Disability data are not available at state or local levels, due to small sample sizes.

Sources of Information About the Survey

<http://www.census.gov/prod/2006pubs/tp-66.pdf>

http://stats.bls.gov/cps/cpsdisability_faq.htm

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EARLY CHILDHOOD LONGITUDINAL SURVEY (ECLS)

General Purpose

The ECLS is composed of three longitudinal studies that examine child development, school readiness, and early school experiences. The original ECLS-K focused on children's early school experiences beginning with kindergarten and following children through middle school. The ECLS-B focused on early childhood experiences, and followed children from nine months of age through kindergarten entry. The 2010-2011 ECLS-K is much like the original ECLS-K, but follows children only through fifth grade.

Sponsoring Agencies

The ECLS is sponsored by the National Center for Education Statistics of the Institute of Education Sciences, in the U.S. Department of Education in partnership with various other components within the U.S. Department of Education and agencies of the U.S. Department of Health and Human Services and the U.S. Department of Agriculture.

Sampling Universe

The ECLS-K used a multistage probability sample design to select a representative sample of children attending kindergarten in 1998-1999. A sample of students who were enrolled in first grade in 1999-2000, but had not attended kindergarten the previous year were added beginning in spring 2000. At each interview, only a subsample of those who had moved schools was followed.

The sample for ECLS-B was selected from listings of registered births in the National Center for Health Statistics vital statistics system. Asian and Pacific Islander children, American Indian and Alaska Native children, Chinese children, twins, and low and very low birth weight children were oversampled. Sampled children who died or were adopted were excluded from the sample, as were those whose birth mothers were younger than 15 years at the time of the child's birth.

Survey data are collected from parents, childcare providers, and teachers. Children provide some survey data in the 5th and 8th grade interviews of the ECLS-K.

Sample Size

The ECLS-B used a sample of 14,000 children. The original ECLS-K started with a sample of 21,387 in 1998 and had a sample size of 12,129 in spring 2007.

Regional and State-Level Estimates

The ECLS surveys do not support regional or state-level estimates.

Longitudinal Data

The ECLS surveys follow children for various periods of time, depending on the sample (see next section).

Frequency of Data Collection and Year(s) Fielded

The ECLS is composed of three surveys. The ECLS-B collected information on children born in 2001 when the children were nine months old (2001-2), two years old (2003-4), four years old (2005-6), and in fall 2006. Interviews were conducted in fall 2007 for those who were not yet in kindergarten in 2006, or were repeating it in 2007.

The ECLS-K collected information on students who were in kindergarten in 1998-1999. Surveys were administered in the fall and spring of kindergarten (1998-1999), the fall and spring of first grade (1999-2000), the spring of third grade (2002), the spring of fifth grade (2004), and the spring of eighth grade (2007).

The ECLS-K:2011 will follow students in kindergarten in 2010-2011 through fifth grade. Data was collected in the fall and spring of kindergarten (2010-2011), and will be collected in the fall and spring of first grade (2011-2012), the spring of second grade (2013), the spring of third grade (2014), the spring of fourth grade (2015), and the spring of fifth grade (2016).

Physical Health, Sensory, and Communication Disability Measures

The ECLS-K asks how children compare to others of the same age in their coordination using limbs, and their ability to pronounce words and communicate with and understand others. The ECLS-K asks if children have a hearing problem, and if so how severe it is; if they use a hearing aid or have cochlear implants; and to what extent that improves their ability to hear and understand conversations. The survey asks whether children have problems seeing letters on paper or objects in the distance; and if so if it is correctable with glasses, and what they can see.

The ECLS-B asks if children have been evaluated by a professional in response to their use of limbs; ability to communicate; hearing; or vision, and in each case if this resulted in a diagnosis. If a child has been diagnosed with a hearing problem the ECLS-B collects information on whether the child is deaf in one or both ears. If children have an eyesight problem the survey asks if their eyesight is correctable with glasses, and if they wear glasses. The survey also asks if children use a hearing aid, have an impairment or health problem that requires the use of special equipment; and if they have a problem with stuttering and if so when it began and ended.

Both the ECLS-B and ECLS-K ask if children received speech or language therapy; occupational therapy; physical therapy; vision services; hearing or audio logical services; social work services; psychological services; home visits; parent support or training; special classes; private tutoring; instruction in brail (if a child has a sight problem); or in lip reading or American Sign Language, (if a child has a hearing problem); and in all how many hours of services and where services are received.

Mental Health and Disability Measures

The ECLS-K asks students in the eighth-grade if they feel good about themselves; have enough control over the direction their life is taking; feel good luck is more important than hard work; feel they are a person of worth, the equal of other people; feel useless at times; are satisfied with themselves on the whole; or feel they do not have much to be proud of, and who they go to when they need to be cheered up.

The ECLS-K asks parents if they have ever had concerns about how their children behave and relate with others; their emotional behavior; or their weight or an eating disorder; and in each case if they have been evaluated by a professional for the problem, if they were diagnosed, and if so what the diagnosis was and when the diagnosis occurred.

Cognitive and Intellectual Disability Measures

The ECLS-K asks how children compare with others of the same age in being independent and taking care of themselves; paying attention; thinking, learning and solving problems; and if they lag in any of these whether they have been evaluated, if they were diagnosed, and what the primary diagnosis was (learning disability, Attention Deficit Disorder, developmental delay, dyslexia, mental retardation) and when the condition was diagnosed. Respondents are asked how a child's overall activity level compares to that of other children of the same age, if they have concerns about it, if the child has been evaluated, if they were diagnosed, what the diagnosis was (learning disability, Attention Deficit Disorder, developmental delay, dyslexia, mental retardation), and when the child was diagnosed.

The ECLS-B asks if children have been evaluated by a professional in response to their ability to pay attention or learn; or overall activity level, and in each case if this resulted in a diagnosis.

Other Health and Disability Measures

The ECLS-K asks parents about the general quality of their children's health. It also asks if their children have been to the emergency room; admitted overnight to the hospital; received therapy services and if so from whom and for what reason; and if their children are covered by insurance and the source.

The ECLS-K asks special education teachers about students' primary disabling conditions; for what conditions they received special education services; when they began receiving services; what services were provided to students at school (audiology, counseling service, occupational therapy, physical therapy, psychological services, school health services, social work services, special transportation, and speech or language therapy) and if students received adaptive physical education, classroom aides, instruction in Braille, an interpreter if deaf or hard of hearing, instruction in American Sign Language, instruction in Manual English, or instruction in Cued Speech. The survey also asks the teacher whether students used assistive technology, and if so, what type.

The ECLS-B collects information on the general quality of the child's health. It asks if the child has been to a doctor for well-child visits; been to a dentist; is taking prescription medicine and if so why; has been admitted overnight to the hospital; has been to the emergency room; and if the child is covered by health insurance and what kind. If children are repeating kindergarten the survey asks for the reason they are repeating. The survey also asks if the child receives special education services related to an individualized education program or individualized family service plan, and if so where and for how much time each week. Respondents are asked if they have been told that the child has a problem with mobility; another development delay; epilepsy or seizures; a heart defect; mental retardation; autism or pervasive developmental disorder; Oppositional defiant disorder; attention deficit hyperactivity disorder; diabetes; anemia; a blood disease; allergies; a skin condition; or another chronic medical problem.

Both the ECLS-K and the ECLS-B ask if the child was born three or more weeks early, born with low birth weight, or was part of a multiple birth.

Topic Areas

The ECLS-K and ECLS-B collect information on family structure; school experiences; child development, literacy, and school readiness; home environment; parenting behavior and attitudes; child care arrangements; child health; family health; marriages and partner relationships; spouse and partner information, welfare and other public assistance; household income and assets; neighborhood quality and safety; and household food sufficiency.

Links to Administrative Data

ECLS data are linked to information from the child's school.

Potential Uses for Disability-Related Research

The ECLS surveys can be used to track the special education services used by children with disabilities; to estimate differences in academic achievement of children with certain disabilities versus that of children with other disabilities or without disabilities; and to compare the health concerns, diagnoses, and services used between the original ECLS-K cohort and the 2010-2011 ECLS-K cohort.

Other Notable Features

In addition to surveys, the ECLS administers age-appropriate tests to children in order to measure their cognitive development.

Sources of Information About the Survey

http://nces.ed.gov/ecls/data/ECLSK_K8_Manual_part1.pdf

<http://aspe.hhs.gov/hsp/06/catalog-ai-an-na/ECLS-B.htm>

HEALTH AND RETIREMENT SURVEY (HRS)

General Purpose

The HRS is a large-scale longitudinal project that studies the labor force participation and health transitions that individuals undergo toward the end of their work lives and in the years that follow. Since its launch in 1992, the study has collected information about income, work, assets, pension plans, health insurance, disability, physical health and functioning, cognitive functioning, and health care expenditures. Through its interviews with a nationally representative sample of adults over age 50, the HRS provides a wide range of data intended to help researchers address the challenges and opportunities of aging.

Sponsoring Agencies

The HRS is sponsored by the National Institute on Aging and the Social Security Administration, and administered by the University of Michigan.

Sampling Universe

The HRS is comprised of six samples: the original Health and Retirement Survey cohort (HRS, born 1931-1941), the Aging and Health Dynamics cohort (AHEAD, born before 1923), the Children of the Depression cohort (COD, born 1923-1930), the War Baby cohort (WB, born 1942-1947), the Early Boomers (EB, born 1948-1953), and the Mid Boomers cohort (MB, born 1954-1959).

The original HRS, WB, EB, and MB groups are multistage probability samples of the target birth cohort residing in households. Those living in institutional settings or other group quarters were not sampled, but sample members who moved into those settings were followed. African Americans, Hispanics, and Floridians were oversampled to allow for subgroup analyses. The COD group was drawn from Medicare enrollment data. The AHEAD sample was drawn from both the household and Medicare data.

In all cases, one eligible sample member was selected as the primary respondent from each sampled household. Their spouse, as well as any spouse they may have in the future, is interviewed. As samples were added to the original HRS sample, individuals who were age-ineligible spouses of a member of an earlier sample, and thus already part of the study, continued to complete interviews, but were now considered eligible members of their own birth cohort, rather than ineligible members of another.

Sample Size

The HRS uses a sample of slightly more than 22,000 individuals across all cohorts. In 2004, 9,759 interviews were conducted for the original HRS sample, 4,438 for the AHEAD sample, 1,970 for the COD sample, 2,324 for the WB sample, and 3,340 for the EB sample.

Regional and State-Level Estimates

The HRS supports estimates at the state level.

Longitudinal Data

The HRS follows respondents and their spouses over time until they die or are lost to follow-up.

Frequency of Data Collection and Year(s) Fielded

The HRS was first fielded in 1992 using the original HRS cohort, and has been administered every two years. The AHEAD cohort began as part of a different study in 1993, was fielded again in 1995, and joined the HRS in 1998. The COD and WB cohorts were added in 1998, the EB cohort in 2004, and the MB cohort in 2010. These additional cohorts have been interviewed every two years, at the same time as the original HRS cohort.

Physical Health, Sensory, and Communication Disability Measures

The HRS collects information on whether, before age 16, respondents had difficulty seeing even with glasses or prescription lenses; a speech impairment; were disabled for six months or more (unable to do the usual activities of classmates or other children of the same age), and if so the cause of that disability; or if they had problems in learning the usual lessons in school. If so, respondents are asked when the problem was diagnosed and how long it lasted. Respondents also are asked whether they use a hearing aid.

The HRS collects information on whether respondents experience difficulty with the following activities due to a health condition that is expected to last three months or longer: walking one or a few blocks; running or jogging a mile; sitting for two hours; getting up from a chair after sitting; climbing one or several flights of stairs without resting; kneeling, stooping, or crouching; extending arms above shoulder level; pushing or pulling large objects; carrying weights over 10 pounds; and picking up a dime from a table. Respondents also are asked whether, because of a health or memory problem, they experience difficulty dressing; walking across a room, and if so if they use assistive equipment; bathing; eating; getting in and out of bed, and if so if they use assistive equipment; using the toilet; preparing hot meals; shopping for groceries; making phone calls; taking medications; managing money; and in each case if so if they ever receive help. If respondents receive help in any of these activities they are asked who helps, if they are paid, how much they are paid, and by whom. Respondents also are asked for their height and weight.

Mental Health and Disability Measures

The HRS collects information on whether, before age 16, respondents had depression; drug or alcohol problems; other emotional or psychological problems; were disabled for six months or more (unable to do the usual activities of classmates or other children of the same age), and if so the cause of that disability; or if they had problems in learning the usual lessons in school. If so, respondents are asked when the problem was diagnosed and how long it lasted.

The HRS collects information on whether there has been a period in the past 12 months during which respondents felt sad, blue, or depressed, or lost interest in most things for two weeks or more, and if so how long each day the feeling lasted, whether they felt low in energy; lost their appetite; had their appetite increase; had trouble falling asleep; had more difficulty concentrating than usual; felt down on their self, no good, or worthless; or thought a lot about death.

The HRS asks whether respondents take prescription medicine for anxiety or depression.

Respondents are asked whether much of the time in the past week they felt depressed; felt that everything they did was an effort; were happy; felt lonely; enjoyed life; felt sad; could not get going; had a lot of energy; and whether their sleep was restless.

Cognitive and Intellectual Disability Measures

The HRS collects information on whether, before age 16, the respondent was disabled for six months or more (unable to do the usual activities of classmates or other children of the same age), and if so the cause of that disability; or if they had problems in learning the usual lessons in school. If so, the respondent is asked when the problem was diagnosed and how long it lasted.

Respondents also are asked whether, because of a health or memory problem, they experience difficulty dressing; walking across a room, and if so if they use assistive equipment; bathing; eating; getting in and out of bed, and if so if they use assistive equipment; using the toilet; preparing hot meals; shopping for groceries; making phone calls; taking medications; managing money; and in each case if so if they ever receive help. If respondents receive help in any of these activities they are asked who helps, if they are paid, how much they are paid, and by whom. The HRS also asks whether due to a health or memory problem respondents have difficulty using a map to figure out how to get around in a strange place.

The HRS administers tests of word recall, arithmetic, basic facts, and word definitions to gauge a respondent's cognitive health. A proxy is asked about the general quality and changes in specific elements of the sample member's memory, including remembering birthdays, where things are usually kept, conversations that happened several days before, and the date, as well as handling financial matters, learning new things, and reasoning through questions or problems. The proxy also is asked whether the sample member ever gets lost in a familiar environment; ever wanders off and does not return on his or her own; can be left alone; or sees or hears things that are not there.

Other Health and Disability Measures

The HRS collects information on the respondent's health before age 6; general health; information on specific conditions (high blood pressure, diabetes, cancer, chronic lung disease, heart disease, stroke, emotional, nervous, or psychiatric problems, memory problems, arthritis, shingles, falls and injuries, cataracts and glaucoma), including when the condition was diagnosed, symptoms experienced, how it is treated, and whether it restricts the respondent's activities in any way; physical activity; days on which the respondent stayed in bed half the day or more due to illness or injury; health insurance coverage; health insurance premiums and co-payments; and what services are covered by health insurance.

The HRS asks whether respondents who have served in the military have a disability related to their service.

Respondents are asked whether they have an impairment or health problem that limits the kind or amount of paid work they can do, and if so what causes it; if it is a temporary condition; and if they have had the condition before. They also are asked if any impairment or health problem limits the kind or amount of work they can do around the house, if not they are asked if they are limited in any way in activities because of an impairment or health problem, and if so, when the problem first

bothered them. Respondents are asked if they are able to work full-time or part-time; regularly or occasionally; if they are able to do the same kind of work as before the limitation began; when the problem began to limit work if that has occurred; when it prevented them from working entirely if that has occurred; if the condition is expected to improve or get worse; if it is the result of an accident or injury, and if so where it occurred; if it is related to their work; if respondents were employed when it began to limit their ability to work; and whether the impairment began to affect their ability to work before or after they started to work regularly. If respondents were employed or had been employed since, they are asked if each employer provided accommodations (got someone to help, shortened the work day, more breaks and rests, arranged for special transportation, changed the job, helped them learn new job skills, received special equipment, or assisted in receiving rehabilitative services from an outside provider). Respondents also are asked how their work has changed, and if they have used any savings since their health began to limit their ability to work.

The survey also asks about receipt of an application for Social Security Disability Insurance, Supplemental Security Income, veterans' benefits, and workers' compensation.

Topic Areas

The HRS collects information on demographic characteristics; health status; health care utilization; health care costs; functional limitations, activities of daily living, instrumental activities of daily living, and helpers; cognition; expectations; family structure; transfers; housing; assets and debts; income; capital gains; employment, retirement, and pensions; retirement plans; disability; health and life insurance; widowhood; divorce; internet use; and physical measures and biomarkers.

Questionnaires on other topics are administered to members of the HRS sample in odd years. These have included human capital and educational expenses in 2001; individual activities and household expenses in 2001, 2003, 2005, 2007 and 2009; diabetes in 2003; prescription drug use in 2005 and 2007 to track changes around the implementation of Medicare Part D; and questions that asked respondents to classify the limitations faced by people presented in several vignettes.

Links to Administrative Data

The HRS is linked periodically with mortality information from the National Death Index, and also has been linked to Social Security benefit records and Medicare records.

Potential Uses for Disability-Related Research

The HRS can be used to compare the financial well-being of those who experience disability onset with those who do not; to track changes in activities as respondents age and generally experience more limitations; and to estimate the prevalence of limitations among the population over age 50.

Sources of Information About the Survey

<http://hrsonline.isr.umich.edu/>

<http://hrsonline.isr.umich.edu/sitedocs/surveydesign.pdf>

<http://hrsonline.isr.umich.edu/sitedocs/userg/HRSSAMP.pdf>

HIGH SCHOOL LONGITUDINAL STUDY OF 2009 (HSLS)

General Purpose

The purpose of the HSLS is to understand students' trajectories from the beginning of high school into postsecondary education, the workforce, and beyond; what students decide to pursue when, why, and how, especially in regards to science, technology, engineering, and math courses, majors, and careers; and students' algebraic skills, reasoning, and problem solving.

Sponsoring Agencies

The HSLS is sponsored by the Institute of Education Sciences, U.S. Department of Education.

Sampling Universe

The HSLS uses a sample of about 25 to 30 ninth-graders randomly selected from each of 844 nationally representative high schools, including both public and private schools. Separate surveys are administered to students' parents, math and science teachers, school administrators, and lead school counselors.

Sample Size

The HSLS uses a sample of about 21,000 individuals.

Regional and State-Level Estimates

The HSLS is representative of individuals at the state level in California, Georgia, Florida, Michigan, North Carolina, Ohio, Pennsylvania, Tennessee, Texas, and Washington.

Longitudinal Data

The HSLS follows individuals for twelve years, from 9th grade to approximately age 26.

Frequency of Data Collection and Year(s) Fielded

The HSLS has been fielded since 2009, when the first wave of data collection began. The next wave will begin in the spring of 2012. A wave of data collection is planned for the spring of 2013 to record students' postsecondary options and plans. Subsequent data collections are planned for 2017 to learn about students' postsecondary experiences, and in 2021 to learn about participants' choices, decisions, attainment, and experiences in adulthood.

Physical Health, Sensory, and Communication Disability Measures

Parents are asked if they have ever been told by a doctor, health care provider, teacher, or school official that their ninth graders have hearing problems or vision problems that cannot be corrected with glasses or contact lenses; or bone, joint, or muscle problems.

Questions ask parents how much difficulty their ninth graders experience with speaking, communicating, or being understood compared with other ninth graders.

Mental Health and Disability Measures

The HSLS asks parents how much difficulty their ninth graders experience with feeling anxious or depressed; behavior problems; or making and keeping friends compared with other ninth graders.

Questions ask parents how many times during the last school year they or another family member were contacted by the school because of problem behavior of their ninth graders.

Cognitive and Intellectual Disability Measures

The HSLS asks if parents have ever been told by a doctor, health care provider, teacher, or school official that their ninth graders have a specific learning disability; any developmental delay that affects the ability to learn; autism, Asperger's disorder, pervasive developmental disorder, or another autism spectrum disorder; an intellectual disability or mental retardation; attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD); and if they are taking medication for ADD or ADHD.

Questions ask parents how much difficulty their ninth graders experience learning, understanding, or paying attention compared with other ninth graders.

Other Health and Disability Measures

The HSLS asks parents if their ninth graders currently receive special educational services.

Topic Areas

Questions solicit information from students about their ethnic background and age; previous educational experiences; educational experiences at home and school; plans for postsecondary education; and plans after high school. The parent component asks about students' family structure; family origin and language; parents' education and occupation; students' previous educational experiences; parents' involvement; and parents' opinions of their children's future plans. The math and science teacher component collects information about teachers' backgrounds; science and math instruction; and teachers' beliefs about teaching and their current schools. School administrators are asked about school characteristics including student population; teachers; courses offered; and administrators' background and goals. The lead school counselor component asks about school staffing and practices; school programs and policies; math and science placement; and counselors' opinions of schools' counseling programs

Links to Administrative Data

The HSLS is not linked to administrative data.

Potential Uses for Disability-Related Research

The HSLS is useful for determining how disability affects students' educational achievement and realization of future plans. It also can provide information about how schools might better accommodate students with disabilities. By including student, parent, teacher, counselor, and administrator components, the HSLS allows consideration of various perspectives on school improvement.

Other Notable Features

Disability-related questions were asked in the previous educational experiences section of the survey. Information about future questionnaires and disability questions is not yet available.

The HSLs continues to follow students who do not continue high school after selection for the sample. Student's parents, teachers, school counselors, and administrators are not required to complete surveys, so these components may not be available for each student.

Sources of Information About the Survey

<http://nces.ed.gov/surveys/hsls09/index.asp>

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LONGITUDINAL STUDY OF AGING (LSOA)

General Purpose

The LSOA assesses physical health, health care usage, and living arrangements of seniors. The survey followed two cohorts of older Americans and can be used to evaluate the effects of aging over time.

Sponsoring Agencies

The LSOA is sponsored by the National Center for Health Statistics and the National Institute on Aging.

Sampling Universe

The LSOA is a nationally representative household survey of noninstitutionalized civilians based on the National Health Interview Survey (NHIS) sample. If a respondent is unable to complete the survey due to incapacitation or death, the survey collects information from family members or proxy respondents.

All respondents age 55 and older living in a household selected for the 1984 or 1994 NHIS were eligible to complete the Supplement on Aging (SOA). The SOA acts as the baseline component for the LSOA. The LSOA selected a subsample of SOA participants age 70 and older and oversampled the oldest, minorities, and their family members.

Sample Size

The LSOA has been fielded twice, once starting in 1984, and again in 1994, with sample sizes of 7,527 and 9,447, respectively.

Regional and State-Level Estimates

The LSOA provides national level estimates.

Longitudinal Data

Each round of the LSOA followed participants for six years.

Frequency of Data Collection and Year(s) Fielded

The LSOA has been fielded twice; the earlier data are referred to as the LSOA and the more recent collection as the LSOA II. The baseline fielding occurred in 1984 as a component of the NHIS. Three subsequent follow-ups occurred in 1986, 1988, and 1990. The second wave baseline fielding occurred in 1994 as a component of the NHIS with two subsequent follow-ups in 1997 to 1998 and 1999 to 2000.

Physical Health, Sensory, and Communication Disability Measures

The survey collects information on weight, height, physical exercise, smoking, and alcohol consumption.⁹ All respondent are asked to provide information about any medical conditions and diagnoses at baseline on the SOA and SOA II.

The LSOA collects more detailed health and disability measures than is covered in the SOA. The LSOA queries respondents about difficulties bathing or showering, dressing, eating, getting in and out of bed or chairs, walking, getting outside, using the toilet, preparing meals, shopping for personal items, managing money, using the telephone, doing heavy housework, doing light housework, driving,¹⁰ or using public transportation¹¹ due to a health or physical problem. If respondents indicate one or more limitations, the survey queries about the degree of difficulty, any changes in difficulties since the previous interview, use of special equipment, and any help received from either family members or non-relatives. In addition, the LSOA II contains a detailed section on usage of personal assistive devices and technologies, including catheters, hearing aids, crutches canes, wheelchairs, and glucose monitors.

The LSOA contains detailed questions about where respondents spend most of the day (in a bed or in a chair); vision; and physical ability, including difficulties walking long or short distances, stooping, kneeling, reaching, and lifting. If respondents indicate a limitation, the survey queries the specific medical conditions that cause any limitations.

Mental Health and Disability Measures

The survey does not collect data on mental health and disability measures.

Cognitive and Intellectual Disability Measures

The SOA provides information about any instances of memory loss or confusion and any changes experienced in these functions over the past year. The LSOA II contains sections on cognitive functioning. The survey asks respondents to rate memory from excellent to poor and to recall basic facts, including the current date, counting backwards from 20 and basic factual questions.¹² Respondents also are asked to complete a word recall section. If a proxy responds to the interview on behalf of a respondent, the proxy is asked to rate the respondent's memory, report any changes in memory, and answer questions about instances of wondering off, getting lost, or seeing or hearing things that are not there.

Other Health and Disability Measures

Respondents are asked to rate their general physical health status and how it compares to the previous year and the health of peers. The LSOA queries the respondent in separate questions about

⁹ Questions about smoking and alcohol consumption are included on the LSOA II only.

¹⁰ SOA II only.

¹¹ SOA II only.

¹² Examples include: What is used to cut paper?; Name a desert plant.; and Name the current president.

income from disability payments, Supplemental Security Income, public assistance or welfare, and food stamps.

Service usage during the past year, including hospitalizations, nursing home use, use of prescriptions, doctor visits, and paid or unpaid help with activities of daily living are included in the survey. Respondents also specify if care was paid for by oneself or family, Medicare, Medicaid, or private insurance. The LSOA economic supplement asks about services provided in retirement communities including group meals, maid or cleaning services, laundry, transportation, recreation, nursing or help with medication. The SOA includes information about use of community services, including senior centers, special transportation, meal delivery services (such as Meals on Wheels), visiting nurse service, home health aides, or adult day care.

LSOA contains information on the current living arrangement of the respondent (house apartment, hospital, nursing home, institution, retirement community). If a change from the previous interview is indicated, the respondent can detail when the move occurred and if the move was due to among other reasons health status, financial status, change in the people or availability of people who help, downsizing, or home accessibility. The survey also includes questions about household accessibility, including if one or more steps must be used to access the house from the outside; the number of floors; if the bathroom, bedroom, and kitchen are all on the same floor; and if the housing unit has a walk-in shower. The SOA II contains information about special features or assistive devices for the home, including elevators, chair lifts, or widened doorways.

Topic Areas

Topics in the LSOA include changes in living arrangements, instances of institutionalization, occupation, physical limitations, activities of daily living, difficulties with physical movements, nursing home stays, hospitalizations, and health care utilization. The last interview in the series includes a supplemental section with detailed questions on economic status, income, and expenses. The LSOA II includes additional sections on family structure, relationships, social activity, health opinions, behaviors and nutrition, cognitive function, income, and childhood health and family longevity.

Baseline data from the SOA cover family structure, relationships, support, and living arrangements; community and social support; occupation and retirement; conditions and impairments; activities of daily living; nursing home stays, help with care, and hospice; health opinions; and conditions. The SOA II also includes sections on transportation and assistive devices and technologies.

Links to Administrative Data

LSOA is linked to Medicare, Social Security Administration, and National Death Index data.

Potential Uses for Disability-Related Research

The survey can be used to evaluate how physical limitations progress over time, to model future medical service usage as Americans age, and to assess the housing needs of older Americans. Researchers can use the economic supplement section to explore the financial situation of older Americans, and how it changes as they age.

Sources of Information About the Survey

<http://www.cdc.gov/nchs/lsoa.htm>

http://www.cdc.gov/nchs/data/series/sr_01/sr01_028.pdf

MEDICAL EXPENDITURE PANEL SURVEY (MEPS)

General Purpose

The purpose of the MEPS is to provide information on health care use and spending, insurance coverage, and accessibility of health care in the U.S. The MEPS collects data on the specific health services that Americans use including frequency of use, cost, and payment, as well as data on the cost, scope, and breadth of health insurance held by and available to those living in the U.S. through employers.

Sponsoring Agencies

The MEPS is sponsored by the Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services.

Sampling Universe

The MEPS has three major components: a household component; an insurance component; and a medical provider component. The MEPS household component is a nationally representative survey of the U.S. civilian noninstitutionalized population age 90 years and younger, including those living in group quarters. The sampling frame is drawn from respondents to the National Health Interview Survey (NHIS). The insurance component collects data from an independent sample of private and public sector employers on the health insurance plans they offer their employees. The medical provider component covers a sample of hospitals, physicians, home health care providers, and pharmacies drawn from those identified by MEPS household component respondents who gave permission for their providers to be contacted. In 1996 only, MEPS included a nursing home component that collected information from a sample of nursing homes and residents.

Sample Size

The household component of the MEPS uses a sample of about 30,000 individuals each year; the insurance component uses a sample of about 40,000 private sector employers and 3,000 government employers each year; and the medical provider component uses a sample of about 25,000 to 40,000 providers each year.

Regional and State-Level Estimates

The household and medical provider components of the MEPS are not representative at the state or regional levels. Data are available by individual states and regions for the insurance component of the MEPS.

Longitudinal Data

The household component of the MEPS follows individuals for two-year periods.

Frequency of Data Collection and Year(s) Fielded

The MEPS has been fielded since 1996. The MEPS household component uses an overlapping panel design. A new panel of sample households is selected each year, and data for each panel are collected for two calendar years in five rounds of interviews.

The insurance component selects a sample of employers each year independently of the household component sample and does not follow employers longitudinally.

The medical provider component sample for each year is fielded in two or more waves. The first wave begins while household interviewing for the data year is still in progress. A first wave of the medical provider component sample is drawn from the first two rounds of household data collection for the calendar year. The final wave of the medical provider component sample is fielded after the household rounds that close out the calendar year data collection are completed.

Physical Health, Sensory, and Communication Disability Measures

The MEPS household component includes information about disability days taken as a result of a physical illness or injury, or a mental or emotional problem. Questions specify how many days of work or school were missed, for what health condition they were missed, and how many days were missed because of someone else's illness, injury, or health care needs. It also identifies the specific physical health conditions, accidents, or injuries affecting each person that caused them to take disability days.

The MEPS solicits additional information about each physical health condition that caused medical events or disability days, including if it was due to an accident or injury and whether it is on a priority list of conditions. If either is the case the survey asks whether a medical provider has been consulted about the condition, when the condition was first noticed, the severity of the condition, the current status of the condition, and any treatments received.

The MEPS includes information on whether anyone in a household receives personal assistance or supervision or uses aids for personal care, including bathing, dressing, or getting around the house, or daily activities, including using the telephone, paying bills, taking medications, preparing light meals, doing laundry, or going shopping; has difficulties with walking, climbing stairs, grasping objects, reaching overhead, lifting, bending or stooping, or standing for long periods of time, which of these activities they have difficulty performing, and how much difficulty the individual has (no difficulty, some difficulty, a lot of difficulty, or completely unable to do it); is limited in any way in the ability to work at a job, do housework, or go to school; or is limited in participating in social, recreational, or family activities. If respondents answer that they have one of these difficulties or limitations they are asked if this is due to a physical or mental health problem, but are not asked to specify if the problem is mental or physical.

The MEPS solicits information about the use of glasses or contacts; if an individual has difficulty seeing with the use of glasses or contacts; and if anyone in a household is blind. It includes information on whether anyone in a family wears a hearing aid; if an individual has difficulty hearing with the use of a hearing aid; if the person is deaf; and whether the individual can hear some or most of the things people say with the use of the hearing aid. The MEPS also solicits information about expenditures on assistive equipment generally, and on vision and hearing aids specifically.

The MEPS includes information about height and weight.

Mental Health and Disability Measures

The MEPS contains information about disability days taken as a result of physical illness, injury, or mental illness or emotional problems including how many days of work or school were missed; how many days were missed because of someone else's illness, injury, or health care needs; and the specific mental health conditions, accidents, or injuries affecting each person that caused them to take disability days.

The MEPS solicits additional information about each mental health condition identified through medical events or disability days, including whether it was due to an accident or injury, on a priority list of conditions, and if so whether a medical person has been consulted about the condition, when the condition was first noticed, the condition's severity, the current status of the condition, and any treatments received.

The MEPS includes information about whether anyone in a household receives personal assistance or uses aids for personal care or daily activities; is limited in any way in the ability to work at a job, do housework, or go to school; or is limited in participating in social, recreational, or family activities. If respondents answer that they have one of these difficulties or limitations they are asked if this is due to a physical or mental health problem, but are not asked to specify if the problem is mental or physical.

Cognitive and Intellectual Disability Measures

The MEPS asks if anyone in a household experiences confusion or memory loss that interferes with daily activities or has problems making decisions to the point that it interferes with daily activities.

Other Health and Disability Measures

The MEPS solicits information about specific health conditions that caused the respondent to spend the day in bed for those reporting having spent more than a half day in bed.

The MEPS provider component includes information about services or drugs provided during visits to hospitals or by office-based providers, home care health care providers, home care non-health care providers, institutional facilities, pharmacies, and separately billing doctors; the costs of the services; who paid for the services; and how much each party paid for the services.

Starting with the 2000 panel, respondents are asked about priority conditions including diabetes, asthma, hypertension, coronary heart disease, angina, heart attacks, other heart disorders, strokes, emphysema, joint pain, and arthritis.

Topic Areas

Questions solicit information about access to health care; children's health; children's insurance coverage; disability; services provided by doctors; elderly health care; employment status; health care disparities; health insurance; health status; home health care; injuries; jobs; medical conditions; Medicare, Medicaid, and children's health insurance program coverage; men's health; mental health; minority health; obesity; pharmacies; prescription drugs; preventive care; arthritis; asthma; diabetes;

emphysema and bronchitis; general priority conditions; heart conditions; high blood pressure; high cholesterol; strokes; state and metro area estimates; quality of health care; the uninsured; usual source of care; and vision impairment.

Links to Administrative Data

In May 2011, MEPS data from 1996 through 2009 will be linked to person records on NHIS files. Because the NHIS is linked with Social Security Administration, Medicare, and National Death Index data, and soon will be linked to Medicaid data, the MEPS also will be linked with these sources.

MEPS data from some panels are linked at the county level with information obtained from the Area Resource File on health facilities, health professions, and measures of resource scarcity, health status, economic activity, health training programs, and socioeconomic and environmental characteristics.

Potential Uses for Disability-Related Research

The MEPS allows national and regional estimates of the impact of changes in financing, coverage, and reimbursement policy as well as estimates of who benefits and who bears the cost of a change in policy. It provides a foundation for estimating the impact of changes on different economic groups or special populations of interest, such as the poor, the elderly, the uninsured, and veterans.

Other Notable Features

The survey instrument is updated each calendar year, and data released on full-year files are based on the questions being asked during that year regardless of panel. Examples of changes include the addition of body mass index information beginning with the 2002 survey; the inclusion of nursing home residents in 1996; the addition of information about diseases, like asthma, heart disease, and diabetes beginning with the 2000 panel; and the discontinuation of selected questions about the use of assistive equipment beginning with the 1999 survey.

From 1996 to 2001, the MEPS insurance component sampled employers that were identified in the household component by respondents as their main employer or secondary employer that was the source of their health insurance.

Sources of Information About the Survey

<http://www.meps.ahrq.gov/mepsweb/>

http://www.meps.ahrq.gov/mepsweb/survey_comp/hc_data_collection.jsp

http://www.acponline.org/clinical_information/journals_publications/ecp/mayjun02/cohen.htm

MEDICARE CURRENT BENEFICIARY SURVEY (MCBS)

General Purpose

The MCBS collects information about health status, service use, and health care expenditures for persons covered by Medicare.

Sponsoring Agencies

The MCBS is sponsored by Office of Strategic Planning of the Centers for Medicare and Medicaid Services.

Sampling Universe

The MCBS uses a nationally representative sample of Medicare beneficiaries. The MCBS selects respondents from the Medicare enrollment file and is updated annually to include newly enrolled persons and exclude those who leave the program. If a beneficiary selected for the survey is unable to participate in the interview, a proxy respondent may be designated.

The survey oversamples people with disabilities under age 64 and people age 80 and older. The MCBS is representative for both the Medicare population in general, as well as for Medicare beneficiaries in the following age groups: under 45, 45 to 64, 65 to 69, 70 to 74, 75 to 79, 80 to 84, and 85 and over.

Sample Size

The MCBS surveys approximately 16,000 beneficiaries annually residing in households or group facilities.

Regional and State-Level Estimates

The MCBS provides national level estimates only.

Longitudinal Data

Each respondent remains in the sample for a series of 12 interviews conducted over four years.

Frequency of Data Collection and Year(s) Fielded

The MCBS has been fielded annually since 1991. The MCBS consists of three interviews per year over a four-year period, and uses a rotating panel design. One panel consisting of approximately 4,000 beneficiaries is replaced annually.

Physical Health, Sensory, and Communication Disability Measures

The survey collects information on weight, height, and smoking. All respondents are asked to specify active conditions and diagnoses as they relate to activity limitations, cognition, behavior, medical treatments, or risk of death. If conditions are specified, the survey asks if any of these

conditions were the original cause of Medicare eligibility. The MCBS also collects information about the use of any medical devices, supplies or equipment associated with any conditions or limitations.

The MCBS queries the respondent about any difficulties transferring in and out of bed or chairs, walking, dressing, eating, using the toilet, or bathing. If respondents indicate one or more limitations, the survey collects information about the degree of difficulty, how long they have had the limitation, if they expect to have the limitation three months from now, use of special equipment, and any help the respondent receives from others.

The survey collects information about any difficulties stooping, crouching or kneeling; lifting or carrying objects as heavy as 10 pounds; reaching or extending arms above shoulder level; writing or handling and grasping small objects; walking a quarter of a mile; using the telephone, light or heavy house work; preparing meals; shopping for personal items; or managing money. If respondents indicate one or more limitations, the survey collects information about the degree of difficulty and whether they are able to perform the activity without assistance.

In addition, the survey collects information on hearing ability, vision ability, continence, ability to eat solid foods, and ability to be understood by others.

Mental Health and Disability Measures

All respondents are asked to specify active conditions and diagnoses as they relate to activity limitations, cognition, behavior, medical treatments, or risk of death. If conditions are specified, the survey asks if any of these conditions were the original cause of Medicare eligibility. The MCBS also collects information about the use of any medical devices, supplies or equipment associated with any conditions or limitations.

The MCBS collects information from facilities about any diagnoses of mental illness. If a respondent resides in a facility, the facility respondent is asked to rate the sample person's short-term and long-term memory, ability to make daily decisions, and any occurrence (and if so the frequency) of delusions, hallucinations, wandering, verbally abusive behavior, physically abusive behavior, socially inappropriate or disruptive behavior, or resistance to care. The survey also includes questions about psychological and social well being, including ability to interact with others, participation in structured activities, self-initiated activities, and participation in facility activities.

Respondents are asked about instances of sadness, depression, or lost interest or pleasure in things that they usually cared about or enjoyed during the past year.

Cognitive and Intellectual Disability Measures

All respondents are asked to specify active conditions and diagnoses as they relate to activity limitations, cognition, behavior, medical treatments, or risk of death. If conditions are specified, the survey asks if any of these conditions were the original cause of Medicare eligibility. The MCBS also collects information about the use of any medical devices, supplies or equipment associated with any conditions or limitations.

The MCBS collects information from facilities about any diagnoses of mental retardation or developmental disability problems. If a respondent resides in a facility, the facility respondent is also asked to rate the sample person's short-term and long-term memory, ability to make daily decisions,

and any occurrence (and if so the frequency) of delusions, hallucinations, wandering, verbally abusive behavior, physically abusive behavior, socially inappropriate or disruptive behavior, or resistance to care. The survey also includes questions about psychological and social well being, including ability to interact with others, participation in structured activities, self-initiated activities, and participation in facility activities.

The survey asks respondents to specify if they have experienced any cognitive difficulties that disrupt daily life, including memory loss, inability to concentrate, or inability to make decisions.

Other Health and Disability Measures

Respondents are asked to rate their general physical health status and how it compares to the previous year and the health of peers. The MCBS collects information about income from Supplemental Security Income and Social Security Disability Insurance (single question), other disability payments, or any other public assistance such as Temporary Aid to Needy Families or Supplemental Nutrition Assistance Program. If respondents have a disability related to military service, they are asked to specify their VA disability rating.

The MCBS collects information about enrollment in discount membership plans; Medicare Prescription Drug Benefit; private health insurance to supplement Medicare; private prescription drug plans; or publically provided health care coverage including Medicaid, Medicare, Medicare advantage plan, TRICARE or CHAMPVA, or another public assistance health insurance program. If a respondent indicates enrollment in any health plan, the survey asks about coverage of services and medical expenses.

If a respondent lives a housing unit, the survey asks questions about household accessibility, including the number of floors; if the bathroom, bedroom, and kitchen are all on the same floor; if a bathroom is on each level; if one or more steps must be used to access the house from the outside; and if the housing unit has a walk-in shower. The MCBS collects information about special features or assistive devices for the home, including elevators, entrance ramps, bathroom modifications (grab bars or shower seats), and railings.

The MCBS asks about admission to nursing homes, rehabilitation centers, residential care facilities, retirement homes, private homes, long-term care facilities, and hospitals. If a respondent received care from any of these facilities, the survey asks about length of stay and frequency of visits with a facility doctor or outside doctor. The survey also collects information about prescribed medicines, including name, form, strength, and dosage. The survey ask about services provided in group communities, including prepared meals, maid or cleaning services, laundry, help with medications, transportation, and recreational services.

The survey collects information about where the respondent usually goes for medical care, such as an emergency room, hospital clinic, outpatient facility, or doctor's office. The survey also queries about how respondents travel to this location; approximate travel time; if someone accompanies them to provide physical assistance; the reason care was needed; waiting time for appointment; waiting time for care once arrived; and any difficulties obtaining care due to Medicare.

The MCBS includes a detailed section on expenditures and sources of payment. The survey data are supplemented by Medicare claims data, which include utilization and expenditure information on

prescribed medicines, outpatient hospital visits, physician services, institutional facilities, inpatient hospital care, home health, emergency room, dental services, and other medical expenses.

The survey collects information about satisfaction with quality of care, access to care, coverage, and out-of-pocket costs. If respondents indicate that they did not seek care or did not fill a prescription, the survey prompts them for reasons, which include cost, trouble getting to a doctor or obtaining medicine, or that they did not think it was necessary.

Topic Areas

Topics on the MCBS include demographic characteristics and income, housing characteristics and household composition, discount membership, usual source of care, satisfaction with care, health status, health insurance, and access to care. The survey also provides utilization information on prescribed medicines, outpatient hospital visits, physician services, institutional facilities, inpatient hospital care, home health, emergency room, dental services, and other medical expenses.

Topics on the MCBS facilities survey include prescribed medicines; beneficiary health status; residence history; health insurance; use of health care services; expenditures; facility type, size, and ownership; and demographics.

Links to Administrative Data

The MCBS can be linked to both Medicare claims data.

Potential Uses for Disability-Related Research

The MCBS can be used to evaluate health care service usage and expenditures for people with and without disabilities. Researchers can evaluate to what extent current Medicare beneficiaries are covered, both in terms of out-of-pocket costs and service coverage. The information in the survey can be used to model the impact of changes in Medicare policy on coverage for people with disabilities.

Other Notable Features

The MCBS includes supplement sections. In 2008, supplemental sections on income and assets, drug coverage, and knowledge about Medicare were included.

The MCBS produces two public use data files: Access to Care and Cost and Use. The Access to Care file includes information from Medicare claims and contains information about on health status, satisfaction with care, income information, and demographics. The Cost and Use file links respondent reported health care usage with the Medicare claims to produce data on service usage and expenditures.

Sources of Information About the Survey

http://www.resdac.org/MCBS/data_available.asp
<http://www.cms.gov/mcbs/downloads/HHC2003appendixA.pdf>
<http://www.icpsr.umich.edu/icpsrweb/ICPSR/series/34#summary>
http://www.cms.gov/MCBS/01_Overview.asp#TopOfPage

MEDICARE HEALTH OUTCOMES SURVEYS (HOS)

General Purpose

The HOS provides information about the health status and quality of life of people enrolled in Medicare Advantage Organizations (MAOs).

Sponsoring Agencies

The HOS is administered by the Centers for Medicare and Medicaid Services.

Sampling Universe

The HOS uses a sample of eligible Medicare beneficiaries selected from MAOs. A beneficiary is identified as eligible if they do not have end stage renal disease. Prior to 2009, eligibility for participation in the HOS was contingent on six months of enrollment in the MAO prior to sample selection; however, this requirement is no longer in effect.

The sampling methodology varies by the size of the MAO. MAOs with fewer than 500 members do not participate in the HOS. All eligible beneficiaries from MAOs consisting of 500 to 1,200 members are selected to participate. A random sample of eligible beneficiaries is selected from large MAOs (more than 1,200 members). Baseline respondents from the previous year are excluded from MAOs with more than 3,000 members. For MAOs with fewer than 3,000 members, eligible beneficiaries are included in multiple cohorts.

Sample Size

Sample sizes vary by cohort. The 2009 baseline sample size consisted of 487,861 respondents, selected from a sample of 1,200 MAOs. Prior to 2007, the HOS selected beneficiaries from 1,000 MAOs, yielding a smaller sample size.

Regional and State-Level Estimates

The HOS provides national, state, and MAO-level estimates.

Longitudinal Data

Each cohort is surveyed at baseline and then contacted again two years later to complete a follow up interview. Both the baseline and follow up interviews use the same questionnaire.

Frequency of Data Collection and Year(s) Fielded

The HOS is fielded annually in the spring. Each year, a new cohort is selected and completes a baseline interview. A follow up interview is conducted annually and administered to respondents who completed the baseline interview for the first time two years earlier. For example, in 2010, Cohort 13 was interviewed for the first time and Cohort 11 received a follow up interview.

Physical Health, Sensory, and Communication Disability Measures

The HOS collects information about height and weight. Respondents are asked if they have accomplished less than they would like, were limited in work or other activities, or experienced any interference with social activities as a result of their physical health. The survey also provides information about the number of days during the past month that respondents' physical health was not good and the number of days that their physical or mental health kept them from doing usual activities.

The survey queries respondents about specific symptoms experienced during the previous four weeks, including chest pain or pressure, shortness of breath, arthritis pain, or numbness in feet. Respondents are asked to indicate any specific medical conditions, including hypertension, coronary artery disease, congestive heart failure, stroke, emphysema, Crohn's disease, arthritis, osteoporosis, cancer, and diabetes. Respondents are asked to indicate any vision or hearing limitations.

Respondents are asked about the occurrence of doctor's visits to discuss their level of physical activity, falling, or balance problems. The survey also collects information about any instances of problems with urinary incontinence or balance during the past six months. If a respondent indicates a problem, the survey asks about the extent of the problem and about any medical care received.

Mental Health and Disability Measures

The HOS asks respondents if they have accomplished less than they would like, did not do work or do other activities as carefully as usual, or if their social activities were limited as a result of their emotional health. Respondents are asked how often they had a lot of energy; felt downhearted and blue; or felt calm and peaceful during the past four weeks. The survey provides information about and instances of long term (two years or more) or short term (two weeks or more) sadness, depression or lost pleasure.

The survey asks respondents to rate their current emotional problems in comparison to last year. The HOS collects information about the number of days during the past month that respondents' mental health was not good and the number of days that their physical or mental health kept them from doing usual activities.

Cognitive and Intellectual Disability Measures

The HOS does not include cognitive and intellectual disability measures.

Other Health and Disability Measures

The HOS asks respondents to rate their current general health status, how it compares to the previous year, and how it compares to other people the same age. The HOS asks all respondents if their health limits moderate activities or climbing several flights of stairs.

All respondents are asked about any difficulties with activities of daily living without special equipment or help from another person, including bathing, dressing, eating, getting in or out of chairs, walking, or using the toilet.

Topic Areas

Topics on the HOS include physical and mental health status, chronic medical conditions, limitations in activities of daily living, depression, smoking, physical health symptoms, weight and height, urinary incontinence, osteoporosis testing, and fall risk management. The survey also includes demographic questions, including race, sex, education, family income, and homeownership.

Links to Administrative Data

The HOS can be linked to the Surveillance Epidemiology and End Results (SEER) data from the National Cancer Institute. The linked SEER – MHOS dataset for 1998 to 2003 is publically available. The HOS can also be linked to Medicare Part D data.

Potential Uses for Disability-Related Research

The survey can be used to evaluate how physical and mental health evolves over time and to explore the medical service needs of Medicare beneficiaries enrolled in MAOs. Researchers can use HOS data to evaluate the quality of care received by beneficiaries at MAOs. The information provided in the survey can also be used to model the impact of changes in Medicare policy.

Other Notable Features

Limited Data Sets (LDSs) and Research Identifiable Files (RIFs) are available for researchers on a restricted-access basis. The Public Use Files (PUFs) are constructed so that individuals and MAOs cannot be identified. The LDSs contain all items included in the PUFs, in addition to plan identifiers and beneficiary-level health information to allow identification of MAOs. The RIFs include personally identifiable information, such as respondent name and health insurance claim number, not included in the LDSs, and can be used in linkages to administrative data.

Questions on the HOS are used by the National Committee on Quality Assurance to calculate Healthcare Effectiveness Data and Information Set measures on effectiveness of care.

A modified version of the HOS, called the HOS-M, collects information from elderly Medicare beneficiaries and uses a random sample of participants from Program of All-Inclusive Care for the Elderly organizations. The HOS-M survey instrument includes questions on physical and mental health status, activities of daily living, and memory loss. Unlike the HOS, the HOS-M does not re-interview participants.

Sources of Information About the Survey

<http://www.hosonline.org/Default.aspx>

http://www.hosonline.org/surveys/hos/download/HOS_DUG_QIO_C12B.pdf

<http://www.hosonline.org/surveys/hos/hosresults.aspx>

<http://outcomes.cancer.gov/surveys/seer-mhos/overview/>

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NATIONAL BENEFICIARY SURVEY (NBS)

General Purpose

The NBS was developed and implemented as part of an evaluation of the Social Security Administration's Ticket to Work (TTW) program, which began in 2002. The survey collects cross-sectional data from a national sample of Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries, and a sample of Ticket to Work program (TTW) participants. In addition, cohorts of TTW participants were followed longitudinally. In all, four rounds of interviews were conducted from 2004 to 2010. The primary purposes of the survey are to: provide information on the work-related activities of SSI and SSDI beneficiaries, particularly as they relate to the implementation of TTW; describe the characteristics and program experiences of beneficiaries who participate in TTW; gather information about beneficiaries who do not use their Tickets and the reasons they do not; evaluate the employment outcomes of TTW participants and other SSI and SSDI beneficiaries; and collect data on service utilization, barriers to work, and perceptions about TTW and other SSA programs designed to help SSI and SSDI beneficiaries find and keep jobs.

Sponsoring Agencies

The NBS is sponsored by the Social Security Administration.

Sampling Universe

The NBS uses a nationally representative sample of SSI and SSDI beneficiaries age 18 to full retirement age. Interviews were attempted with all sample members or their proxies, regardless of whether the sample member resided in the community, group quarters, or an institution. Four rounds of the NBS were conducted in 2004, 2005, 2006, and 2010. The samples for each round are representative of SSI and SSDI beneficiaries on the SSI and SSDI rolls as of June of the calendar year preceding each survey year. Because the survey focus is employment, the sample design includes an oversample of younger beneficiaries.

Each of the first three NBS rounds also contains cross-sectional and longitudinal samples of SSI and SSDI beneficiaries participating in TTW. The 2004 NBS TTW participant sample is representative of SSI and SSDI beneficiaries residing in the Phase 1 states where TTW was first implemented who were participating in TTW at some time during the first half of 2003.¹³ The 2005 NBS TTW sample is representative of SSI and SSDI beneficiaries residing in Phase 1 and Phase 2 states who were participating in TTW at some time during the first half of 2004. The 2006 NBS TTW sample is representative of SSI and SSDI beneficiaries residing in Phase 3 states.¹⁴ In addition, the sample of Phase 1 TTW participants interviewed in the first round of the NBS (2004) were

¹³ TTW was rolled out in three phases. Phase 1, occurring from February to June 2002, included 13 states. Phase 2, occurring from November 2002 to September 2003, included an additional 20 states. Phase 3, occurring from November 2003 to September 2004, included the remaining 17 states and U.S. territories.

¹⁴ The sample also contains all Phase 1 and Phase 2 TTW participants in the longitudinal sample, however, these are not necessarily representative of Phase 1 and Phase 2 TTW participants as the sample was not refreshed at Round 3.

interviewed in the next two rounds, comprising a three-year longitudinal sample of early TTW participants. The sample of Phase 2 TTW participants interviewed in the second round of the NBS (2005) were interviewed in Round 3, comprising a two-year longitudinal sample of early TTW participants.

The 2010 NBS includes only a cross-sectional sample of TTW participants. This sample is representative of SSI and SSDI beneficiaries who assigned their Tickets to TTW providers any time after August 1, 2008. That time frame was selected to focus on beneficiaries who began participating in TTW after implementation of new regulations that substantially changed the program's provider payment systems.

Sample Size

The sample sizes for the cross-sectional samples of the four NBS rounds are shown in the table below. The Phase 1 Longitudinal TTW sample size for those who answered all three survey rounds is 767.

	National Cross-Sectional Samples	Cross-Sectional TTW Participant Samples
2004 NBS	6,520	1,083 (Phase 1 only)
2005 NBS	4,864	3,091 (Phase 1 and 2 only)
2006 NBS	2,508	1,053 (Phase 3 only)
2010 NBS	3,683	4,355

Regional and State-Level Estimates

The NBS was not designed to produce regional or state-level estimates. The Phase-specific TTW participant samples of the first three NBS rounds are representative of TTW participants residing in the subset of states in the Phase 1, Phase 2, and Phase 3 rollout groups, as applicable to each particular round of the survey.

Longitudinal Data

Only members of the 2004 and 2005 TTW participant samples were followed longitudinally. The Phase 1 TTW participants in the 2004 sample were followed in the 2005 and 2006 NBS rounds. The Phase 2 TTW participants in the 2005 sample were followed in the 2006 NBS round.

Frequency of Data Collection and Year(s) Fielded

The NBS was administered in 2004, 2005, 2006, and 2010.

Physical Health, Sensory, and Communication Disability Measures

The NBS includes information on the self-reported main physical, sensory, or communication condition(s) causing activity limitations, when onset occurred, and if the individual was employed at disability onset; whether any prescription medications are taken for physical health conditions; questions needed to construct the physical component summary measure of the SF-8 (an index measure of physical health status); limitations associated with seeing, hearing, speaking, walking,

climbing steps, lifting and carrying, using hands and fingers, reaching overhead, standing, stooping, crouching, and kneeling, getting around inside and outside the home, getting into and out of bed, bathing and dressing, shopping, preparing meals, and eating; use of mobility, vision, hearing, or speaking aids and devices.

Mental Health and Disability Measures

The NBS includes information on the self-reported main mental health condition(s) causing activity limitations, when onset occurred; if the individual was employed at disability onset; whether any prescription medications are taken for mental or emotional conditions; whether the respondent received any treatment or counseling for a mental or emotional condition, or for alcohol or drug use during the past year; questions needed to construct the mental component summary measure of the SF-8 (an index measure of mental health status); difficulty associated with concentrating and coping with stress; the four CAGE screening questions for alcohol abuse; and questions related to drug use (any use, tolerance, emotional or physical problems, being told to stop by a doctor).

Cognitive and Intellectual Disability Measures

The NBS includes information on the self-reported main cognitive or intellectual health condition(s) causing activity limitations, when onset occurred, and if the individual was employed at disability onset. Some of the activity limitations noted above might be applicable to cognitive and intellectual disabilities.

Other Health and Disability Measures

The NBS includes information on general health status; health insurance coverage; need for and use of accommodations at work; use of special equipment and personal assistance services at work and sources of payment; and receipt of disability benefits (SSI, SSDI, workers' compensation, private disability, and veterans' benefits).

Topic Areas

The NBS collects information on disability and current work status; current employment; jobs during the previous calendar year; awareness of SSA work incentives and TTW; reasons for non-participation in TTW; employment-related services and supports used in the previous calendar year; experiences and satisfaction with TTW; health and functional status; health insurance; income and other assistance; and sociodemographic characteristics.

Links to Administrative Data

All NBS rounds have been matched with SSA administrative data, however, only a limited set of administrative variables (related to program participation and benefits) is available on the public use files. Other administrative data linked to the NBS may be available from SSA on a restricted-access basis.

Potential Uses for Disability-Related Research

The NBS is useful for analyzing the characteristics, employment service use, use of SSA work incentives, job characteristics, and employment-related experiences of SSI and SSDI beneficiaries,

including TTW participants and for producing national-level estimates on these topics. Data from the three NBS rounds could potentially be combined to increase sample sizes for purposes of studying small subpopulations of beneficiaries (for example, defined by disabling health condition).

Other Notable Features

Only data from the national cross-sectional samples of the three completed NBS rounds are available as public use files. Data from the TTW samples are available from SSA on a restricted-access basis. Data from the fourth NBS round (2010) will be made available as a public use file in mid-2011.

Sources of Information About the Survey

<http://www.mathematica-mpr.com/publications/PDFs/TTWyear2.pdf>

http://www.mathematica-mpr.com/publications/PDFs/disability/TTW_2006_NBS.pdf

http://www.mathematica-mpr.com/publications/PDFs/TTW_crossroadsappen.pdf

http://www.mathematica-mpr.com/publications/PDFs/disability/NBS_rnd1_codebk.pdf

http://www.mathematica-mpr.com/publications/PDFs/disability/NBS_rnd2_codebk.pdf

http://www.mathematica-mpr.com/publications/PDFs/disability/NBS_rnd3_codebk.pdf

NATIONAL COMORBIDITY SURVEY (NCS)

General Purpose

The NCS was designed to evaluate the mental health of respondents based on the recognized mental disorders and diseases in the Diagnostic and Statistical Manual of Mental Disorders. Three follow-up surveys have been conducted: the NCS-2, the longitudinal component to the NCS; the NCS Replication (NCS-R), which repeats the NCS questions to a new group of respondents; and the NCS for adolescents (NCS-A).

Sponsoring Agencies

The NCS was sponsored by the National Institute of Mental Health and the National Institute on Drug Abuse, and administered by the Institute for Social Research Survey Research Center at the University of Michigan.

Sampling Universe

The NCS, NCS-2, and NCS-R use nationally representative household samples of the non-institutionalized civilian population living in the contiguous United States. The NCS includes respondents age 15 to 48, while the NCS-R sample includes respondents age 18 and older. Both the NCS and NCS-R include students housed in group quarters. The NCS-2 re-interviewed the original NCS respondents. The NCS-A samples adolescents ages 13 to 17. Data, questionnaire and codebook for the NCS-A are not available at this time.

Sample Size

Both the NCS and NCS-R consist of a diagnostic interview and a risk factor interview. A total of 8,098 respondents completed the NCS diagnostic interview. Of the initial sample, 5,877 were re-interviewed complete the NCS risk factor interview. The NCS risk factor interview subsample contained all respondents age 15 to 24, all respondents age 24 to 54 who indicated symptoms during the diagnostic interview, and a random sample of additional diagnostic interview participants. In addition, approximately half of the sample was selected to complete the Tobacco Use supplemental section of the NCS. Information for the NCS-2 is not available at this time.

A total of 9,282 respondents completed the NCS-R diagnostic interview, and 5,692 of the initial sample completed the NCS-R risk factor interview. Sample selection for the NCS-R was similar to that of the NCS. The NCS-R risk factor interview subsample contained all respondents who met criteria for at least one of the mental disorders assessed on the risk factor interview, received treatment for a mental disorder, or attempted suicide. A probability sample of respondents who met other risk factor criteria were also included, and a random sample of additional diagnostic interview participants.

Regional and State-Level Estimates

The NCS surveys produce only national-level estimates.

Longitudinal Data

The NCS-2 re-interviewed the NCS baseline sample after 10 years. Data from the NCS-2 are not yet available.

Frequency of Data Collection and Year(s) Fielded

The NCS was first conducted from 1990 to 1992. Three additional administrations of the core survey questions occurred from 2001 to 2002. The NCS-2 re-interviewed the original NCS respondents. The NCS-R administered the NCS questions to a new, nationally representative sample. The NCS-A surveyed a new sample of adolescents age 13 to 17.

Physical Health, Sensory, and Communication Disability Measures

The NCS risk factor interview includes an expanded section on physical health. Respondents are asked to specify any diseases or major health problems that have affected them in the last 12 months, and the associated pain, impact on daily life, and date of onset of the condition. Respondents to the NCS-R are also asked for their height and weight.

The NCS-2 and NCS-R contain additional questions about physical limitations and disabilities. If respondents indicate a limitation in being able to do things that most people their age do, both surveys prompt them to specify the specific learning disability, physical handicap, physical illness, mental illness or emotional or mental disability. For each specific condition listed, the surveys collect information about age of onset, severity of symptoms, and impact on quality of life (ability to work, have relationships, perform basic functions, or need for supervision or help).

The NCS-R includes a set of specific disability questions not included in the NCS or NCS-2. These questions provide information about whether respondents are blind, deaf, or have a serious speech problem; a hearing problem that prevents hearing a normal conversation even with a hearing aid; a vision problem that prevents reading a newspaper even when wearing glasses or contacts; a learning disability of any kind; any other physical handicap or disability; any other condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying; or any emotional or mental disability.

The NCS-R also collects information on activity limitations, querying the respondent about any difficulties learning, remembering or concentrating; getting along with people; dressing, bathing, or getting around inside the home; going outside alone to shop or visit a doctor's office; working at a job or business; or participating fully in school, housework, or other daily activities due to a physical, mental, or emotional condition lasting three months or longer. The survey provides information about the use of assistive devices or persons to help with personal care needs.

Mental Health and Disability Measures

The NCS, NCS-R and NCS-2 diagnostic interview asks respondents to rate their overall mental health status on a five-point scale from excellent to poor. The NCS risk factor interview asks about the number of days in the last month that the respondent was unable to work or carry out normal activities, and whether this was due to emotions, nerves, mental health or drugs/alcohol.

The NCS baseline diagnostic interview asks about any “unreasonably strong” fears or phobias; periods of long term (lasting 2 years or longer) or short term (lasting two weeks or more) sadness or depression; manic behavior (for a period of 2 days or more); any instances of paranoid behavior (being spied or followed, secretly plotted against, reading mind, hearing thoughts, etc.).¹⁵ If the respondent experiences any one of these symptoms, the NCS collects information on the date of first occurrence,¹⁶ frequency, severity, any physical effects (changes in weight, sleep, energy level, sexual desire, or attention level), avoidance of situations or interruption of everyday life, and any inability to take care of basic needs. If the respondent indicates any symptoms, the survey also provides information about hospitalization or seeking help from doctors, mental health professional, spiritual leaders, counselors, or self-help groups. Respondents are asked to provide specific diagnoses and prescriptions obtained from health care professionals.

Both the NCS-2 and NCS-R contain a similar screening section. If a respondent indicates a limitation in being able to do things that most people their age do, the survey prompts the respondent to specify the specific learning disability, physical handicap, physical illness, mental illness or emotional or mental disability and collects information about the onset and severity of the limitations. Based on the responses provided in the screening portion of the interview, the respondent skips to specific sections on depression, mania, irritable depression, panic, specific phobia, social phobia, agoraphobia, generalized anxiety disorder, intermittent explosive disorder, suicidality, personality, post-traumatic stress disorder, chronic conditions, neurasthenia, 30-day functions, 30-day symptoms, tobacco usage, premenstrual syndrome, attention deficit disorder, oppositional defiant disorder, conduct disorder, separation anxiety, terror, and dementia. In addition to the sections contained in the NCS-2, the NCS-R includes sections on eating disorders, obsessive compulsive disorder, psychosis, gambling, worries and unhappiness, family burden, and perceptions of the past. These sections consist of specific questions focused on evaluating aspects of recognized mental disorders and diseases.

The NCS, NCS-2 and NCS-R contain information on alcohol consumption, non-medical use of prescription drugs, and usage of illegal drugs or controlled substances. The diagnostic portion of the interview also provides information about seeking help for substance abuse problems from doctors, mental health professional, spiritual leaders, counselors, or self-help groups and any prescriptions obtained from these practitioners.

Cognitive and Intellectual Disability Measures

If respondents indicate a limitation in being able to do things that most people their age do, the NCS-2 and NCS-R prompt them to specify the specific learning disability, physical handicap, physical illness, mental illness or emotional or mental disability that causes the limitation. The surveys also contain information about how long a respondent has experienced a limitation and the severity of the limitation.

¹⁵ Paranoid behavior questions are asked on the risk factor interview.

¹⁶ If the respondent indicates that the first occurrence of symptoms occurred over 1 year ago, the survey prompts the respondent to specify how old they were when they first experienced symptoms.

Other Health and Disability Measures

The NCS risk factor interview asks about health insurance coverage. Separate questions are asked about private health care coverage and publically provided health insurance, such as Medicaid. If a respondent is covered by either public or private insurance, the survey asks how much of the costs the plan covers. NCS-2 and NCS-R sections on chronic conditions ask about coverage by military health insurance, private health insurance, Medicare, or Medicaid. The survey provides information about co-payments and costs associated with health care visits or prescriptions.

The NCS provides information about disabilities that prevent work for both the respondent and spouse. The respondent is asked about current job status, and can select “permanently disabled” as the response.

NCS-2 and NCS-R employment sections ask respondents to identify the main reasons they were not working. Response options include physical injury or illness, mental or emotional problems, and alcohol or substance abuse. Both surveys also query about disabilities that impede the ability to work. The survey provides information on absences from work, disability leave, or any instances of not working due to a disability. If respondents indicate a disability, the survey probes about the type (physical, emotional, combination, or other), how many days it will keep them out of work, if they are looking for work, and if it will prevent work during the next six months.

General health information on sleeping habits, exercise, how current health compares to health in the previous year, frequency of physical activity, smoking, general mood, frequency of eating well balanced meals are also included. In addition, the NCS-R asks respondents if they consider themselves to have a disability, if people who know them consider them to have a disability, or if strangers would consider them to have a disability.

The data, questionnaire and codebook for the NCS-A are not yet available.

Topic Areas

Topics on the NCS diagnostic interview include activities of daily life; relationships with relatives, spouse, and friends; lifetime moods and health behaviors; ongoing sadness; mania; alcohol use; non-medical use of prescription drugs; illegal drugs or controlled substance usage; and problem behaviors (lying, cheating, stealing, fighting, illegal activities, other violent behavior). The risk factor interview, administered to a subset of the original NCS sample, includes sections on beliefs and experiences, personality, marriage, employment, home and work, children, self-description of traits, health, finances, life event history and recent life events, family history, and religion. A supplement on tobacco was included in the baseline NCS and administered to a subsample of the NCS population.

The NCS-2 includes a screening section followed by detailed sections on depression, mania, irritable depression, panic, specific phobia, social phobia, agoraphobia, generalized anxiety disorder, intermittent explosive disorder, suicidality, substances, services, pharmacoepidemiology, personality, post-traumatic stress disorder, chronic conditions, neurasthenia, 30-day functions, 30-day symptoms, tobacco usage, premenstrual syndrome, attention deficit disorder, oppositional defiant disorder, conduct disorder, separation anxiety, terrors, and dementia. Other general topics include employment, finance, marriage, children, social networks, life events, adult demographics, childhood demographics, childhood and schooling.

The NCS-R contains all of the sections contained in the NCS-2, in addition to eating disorders, obsessive compulsive disorder, psychosis, gambling, worries and unhappiness, family burden, and perceptions of the past.

Links to Administrative Data

The NCS and NCS-R are not linked to administrative data.

Potential Uses for Disability-Related Research

The NCS surveys can be used to evaluate the prevalence of mental illnesses and to compare the mental health status of people with and without disabilities. It can be used to model service use and to explore the reasons why people with mental illnesses or disabilities do not seek, or stop seeking, medical care. Researchers can also look into the physical effects and limitations caused by mental illnesses, as well as the impact of mental health and disabilities on various aspects of life, such as finances or personal relationships.

Sources of Information About the Survey

<http://www.hcp.med.harvard.edu/ncs/index.php>

http://www.hcp.med.harvard.edu/wmh/publishedpaper_kessler_design.pdf

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NATIONAL CRIME VICTIMIZATION SURVEY (NCVS)

General Purpose

The NCVS collects information on the characteristics and impact of household and personal crimes in the U.S., as reported by victims.

Sponsoring Agencies

The U.S. Census Bureau administers the NCVS on behalf of the Bureau of Justice Statistics, U.S. Department of Justice.

Sampling Universe

The NCVS samples civilian households from the most recent census, updating the sample periodically to include newly constructed housing units. Each member of the household age 12 and older is interviewed.¹⁷

Sample Size

Approximately 40,000 households and 75,000 people participate in the NCVS annually. The survey is conducted as an overlapping panel in which households are followed for three years. New households are added to the sample as others complete the NCVS interview series.

Regional and State-Level Estimates

The NCVS provides national-level estimates. MSA-level estimates are available from 1979 to 2004 for counties sampled in the 40 largest metropolitan statistical areas (MSAs). MSA-level estimates are comprised of counties selected for the NCVS sample and do not include data from all counties within the MSA.

Longitudinal Data

Each selected household is a part of the sample for a set of seven interviews, conducted semiannually over the course of three years.

Frequency of Data Collection and Year(s) Fielded

The NCVS, originally named the National Crime Survey, has been fielded annually since 1972. The survey questionnaire was redesigned in 1992 to capture additional types of personal and household crimes and renamed the NCVS.

¹⁷ A proxy respondent may be used for children ages 12 – 13 who do not have permission to be interviewed directly, incapacitated persons, and household members away from the housing unit during time period covered by the interview.

Physical Health, Sensory, and Communication Disability Measures

The NCVS Crime Incident Report, administered if a respondent indicates being victimized by one or more crimes in the basic questionnaire, collects information about whether a respondent is deaf or has serious difficulty hearing, or is blind or has serious difficulty seeing even when wearing glasses. The Crime Incident Report also provides information on difficulties concentrating, remembering or making decisions; walking or climbing stairs; dressing or bathing; or doing errands alone because of a physical, mental, or emotional condition. It also collects information about whether respondents believe they were victimized due to a disability, and if so, which specific limitation, disability, or medical condition.

The NCVS also provides information about injuries, physical problems, and medical care related to any reported crimes.

Mental Health and Disability Measures

The NCVS Crime Incident Report, administered if a respondent indicates being victimized by one or more crimes in the basic questionnaire, provides information on difficulties concentrating, remembering or making decisions; dressing or bathing; or doing errands alone because of a physical, mental, or emotional condition. The Crime Incident Report collects information about whether respondents believe they were victimized due to a disability, and if so, which specific limitation, disability, or medical condition.

Cognitive and Intellectual Disability Measures

The NCVS Crime Incident Report, administered if a respondent indicates being victimized by one or more crimes in the basic questionnaire, provides information on difficulties concentrating, remembering or making decisions; dressing or bathing; or doing errands alone because of a physical, mental, or emotional condition. The Crime Incident Report collects information about respondents believe they were victimized due to a disability, and if so, which specific limitation, disability, or medical condition.

Other Health and Disability Measures

The Crime Incident Report asks about limitations in work or usual activities as they relate to reported incidents. The report collects information about lost days from work. If a respondent did not have a job at the time of the incident, the respondent is queried about major activities the week of the incident. The respondent can select unable to work among other response options.

If a respondent reports an incident on the survey, the NCVS collects information about medical insurance coverage. The question does not distinguish between private medical insurance or public benefits, such as Medicaid, veterans' benefits, or other public programs.

Topic Areas

The NCVS collects information about employment; type of living quarters; and attempted or committed criminal victimization including personal or household property thefts, break-ins, vandalism, vehicle theft, personal attacks, threats, and sexual harassment or abuse. If the respondent reports one or more crimes, the NCVS Crime Incident Report provides additional details, including

frequency, characteristics of the crime and the offender(s), whether the crime was reported to the police or reasons for not reporting the crime, and repercussions for the victim.

Recent supplemental sections focus on identity theft and school-related crime.

Links to Administrative Data

The NCVS is not linked to administrative data.

Potential Uses for Disability-Related Research

The NCVS can be used to assess the incidence and nature of victimization of persons with disabilities. More specifically, the data can be used to determine if people with disabilities are targeted based on their limitations, and if victimization varies by condition. It can be used to model the probability of victimization by disability status. Researchers can also compare reported crimes to those not reported to the police by victim characteristics. The data in the NCVS can be used to estimate the prevalence of unreported crimes, in comparison to police records or other official statistics for people with and without disabilities.

Other Notable Features

The NCVS includes supplemental survey sections. The school-related crime supplement has been included periodically since 1989. A stalking victimization section was included in 2006, and the 2008 NCVS includes a new supplement focused on identity theft.

Sources of Information About the Survey

http://bjs.ojp.usdoj.gov/content/pub/pdf/ncvs_methodology.pdf

<http://www.icpsr.umich.edu/NACJD/NCVS/>

<http://www.icpsr.umich.edu/cocoon/NACJD/STUDY/04576.xml>

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NATIONAL EDUCATION LONGITUDINAL STUDY (NELS)

General Purpose

The NELS is a longitudinal survey that followed eighth-grade students for 12 years. The survey collected information from students, parents, teachers, and school principals and provides information about high school completion, school environment, postsecondary education, job preparation and placement, and marriage and family formation.

Sponsoring Agencies

NELS was sponsored by the Institute of Education Sciences, U.S. Department of Education.

Sampling Universe

NELS used a nationally representative sample of eighth grade students in both public and private schools. The survey utilized stratified sampling to select schools proportional to the size of the eighth grade class. A total of 1,057 schools from around the country participated in the NELS and a random sample of eighth grade students was selected from participating schools. Teachers, parents, and school principals corresponding to each student were also selected for interview.

Sample Size

A total of 24,599 eighth graders participated in the 1988 fielding of the NELS. Respondents were added at the first two follow up interviews to maintain a representative sample throughout the longitudinal study.

Regional and State-Level Estimates

The NELS provides national level estimates.

Longitudinal Data

The original sample was re-interviewed four times in 1990, 1992, 1994, and 2000.

Frequency of Data Collection and Year(s) Fielded

The NELS was first fielded in 1988. The original sample of eighth grade students was re-interviewed four times in 1990, 1992, 1994, and 2000. The survey consists of four components: a student interview, teacher interview, parent interview, and school principal interview. School principals were interviewed in 1988, 1990, and 1992 about the school. Two teachers of each student were interviewed in 1988, 1990, and 1992 regarding the student, themselves, and the school environment. A parent was also interviewed in 1988 and 1992 about family characteristics and student activities.

Physical Health, Sensory, and Communication Disability Measures

The survey asked the parent to describe any impairments experienced by their children and if their children received any special services for a visual handicap not correctable by glasses; hearing

problem; deafness; speech problem; orthopedic problem; physical disability; or another health problem. The survey queried the parent about their children's enrollment in special programs or services, including special services for orthopedically handicapped students.

The NELS teacher questionnaire asked the teacher to indicate if the student had ever fallen behind due to a health problem, or currently had a learning disability or physical/emotional handicap that was affecting the student's school work.

Mental Health and Disability Measures

The survey asked the parent to describe any problems and if their children received any special services for an emotional problem or another health problem. The survey queried the parent about their children's enrollment in any special programs or services.

The survey asked questions about student health behavior including frequency of smoking, using illegal drugs, drinking any amount of alcohol, and binge drinking.

The NELS teacher questionnaire asked the teacher to indicate if the student had ever fallen behind due to a health problem, or currently had a learning disability or physical/emotional handicap that was affecting the student's school work.

Cognitive and Intellectual Disability Measures

The survey asked the parent to describe any problems and if their children received any special services for a specific learning problem (for example, dyslexia, or other reading, spelling, writing, or math difficulties); mental retardation; or another health problem. The survey queried the parent about their children's enrollment in any special programs or services, including special education services for students with learning disabilities.

The NELS teacher questionnaire asked the teacher to indicate if the student had ever fallen behind due to a health problem, or currently had a learning disability or physical/emotional handicap that was affecting the student's school work.

Other Health and Disability Measures

The NELS collected information about the number of days absent from school due to illness and whether the student became seriously ill or disabled during the response period. The NELS also collected information about the sample member's employment status following high school and asked all students if they were limited in the kind of job or work they could do because of any impairment or health problem. If respondents had dropped out of high school, they could specify that this was for a health related reason.

Students were asked whether their parents were currently working and could select that they were not because they were disabled. Parents were asked if they had worked in the past week, and if not could respond that they were disabled and not looking for work. The NELS also collected information about whether a family member became seriously ill or disabled during the reporting period.

The NELS collected information about health insurance coverage. Respondents could select that they had health insurance coverage through Medicaid, a private health plan, or a plan provided

by an employer. The survey also collected information about receipt of public assistance, including separate responses for Temporary Assistance for Needy Families, Supplemental Nutrition Assistance Program, housing assistance or public housing, and Medicaid or other public programs for medical expenses.

Topic Areas

Topics on the student questionnaire include language use; family; opinions about oneself and attitudes; plans for the future; jobs and chores; school life; schoolwork; school experiences and activities; religion; money and work; and friendships. If students had dropped out of school, they were asked to complete an interview focused on reasons why they left school and plans for the future.

The third and fourth follow up interviews for students contain sections on current activities; employment; job related training; high school completion; postsecondary education; adult education; family formation; income; voting behavior; health insurance; health behaviors; race and ethnicity; and residence.

Topics on the school principal questionnaire include school characteristics and composition including the percentage of students receiving special education services; availability of special education services; student characteristics; school climate; teaching staff characteristics; school programs; school admission policies and practices; and grading and testing structure. Teachers were asked to provide information on the student; class information; teacher background and activities; and school climate.

The parent questionnaire includes questions on family background; child's school life; child's family life; child's opinions about school; child's future; financial information and educational costs.

Links to Administrative Data

The NELS can be linked to student records in a restricted use dataset. Public use files are available with limited student record information, but use of restricted data is limited to researchers with a National Center for Education Statistics restricted data license.

Potential Uses for Disability-Related Research

The NELS can be used to investigate educational outcomes for students with physical, emotional, or learning disabilities. Researchers can compare employment, postsecondary education, and family life for students with and without disabilities. The data about schools and teachers can be used to explore the impact of school resources or teacher education on students with disabilities. The NELS can also be used to investigate the characteristics of high school dropouts.

Sources of Information About the Survey

<http://nces.ed.gov/pubs2002/2002323.pdf>
<http://nces.ed.gov/surveys/nels88/index.asp>

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NATIONAL HEALTH AND NUTRITION EXAMINATION SURVEY (NHANES)

General Purpose

The purpose of NHANES is to assess the health and nutritional status of adults and children in the U.S. by means of interviews and physical examinations. This information is collected to determine the prevalence of major diseases and identify risk factors for diseases; to provide the basis for national standards for measurements, such as height, weight, and blood pressure; and to guide further health studies and research that will develop health policies and programs and expand the nation's health knowledge.

Sponsoring Agencies

The NHANES is sponsored by the National Center for Health Statistics, Centers for Disease Control and Prevention.

Sampling Universe

Starting with the 1999 survey, the NHANES uses a multistage-stratified sample of the U.S. civilian, noninstitutionalized population of all ages. The sample includes the noninstitutionalized group quarters population. It oversamples adolescents aged 12 to 19 years, persons 60 and older, African Americans, Mexican Americans, and, starting in 2000, low income Caucasians.

Sample Size

The NHANES uses a sample of about 5,000 individuals each year.

Regional and State-Level Estimates

The NHANES is designed to be a nationally representative sample of individuals, and is not representative at regional or state levels.

Longitudinal Data

Starting with the 1976 survey, the NHANES does not follow individuals longitudinally.¹⁸

Frequency of Data Collection and Year(s) Fielded

NHANES was first fielded in 1971. Previously, a similar survey, called the National Health Examination Survey, was conducted from 1960 to 1970. In 1971, the survey's name was changed and a large nutrition component was added. In addition, data collection was broadened to include a representative sample of the entire U.S. population age 1 to 74 years. NHANES I was administered

¹⁸ The NHANES I Epidemiologic Follow-up Study was a national longitudinal study that was jointly initiated by the National Center for Health Statistics and the National Institute on Aging in collaboration with other agencies of the Public Health Service. This survey followed NHANES I sample members through 1992.

between 1971 and 1975, NHANES II between 1976 and 1980, and NHANES III between 1988 and 1994. NHANES I sampled individuals aged 1 to 74 years. NHANES II was similar in content to NHANES I but sampled individuals age six months to 74 years. NHANES III included more disability measures (for example, questions about functional limitations, need for assistance with activities of daily living and instrumental activities of daily living, the use of assistive devices, and Social Security benefits due to disability) than NHANES I and II and sampled individuals age two months and over.

A special study of Hispanic populations (HHANES) was conducted in 1982-84, focusing on the health issues common among Mexican-, Cuban-, and Puerto-Rican Americans.

Continuous NHANES was fielded in 1999 and has been administered as an annual nationally representative survey, rather than as a series of surveys focusing on different populations and topics, as it was previously. Continuous NHANES selects a new sample every year, and the sample is interviewed and examined once. Survey data are released every two years in order to obtain a sufficient sample size, and the survey instrument is updated every two years.

Physical Health, Sensory, and Communication Disability Measures

The NHANES includes information obtained from a physical exam on the ability to perform timed walks; spinal mobility; body measurements; and vision and hearing impairments.

A question about vision impairments asks if individuals have trouble seeing, even when they are wearing glasses or contact lenses.

Questions about hearing ask individuals how good their hearing is and if they are deaf. Respondents at least 70 years of age are asked if they have ever worn a hearing aid; if they have worn a hearing aid at least five hours a week in the past 12 months; if they have ever used assistive listening devices, such as FM systems, closed-captioned television, or amplified telephone; if they have been bothered by ringing, roaring, or buzzing in their ears or head that lasts five minutes or more, how long this has bothered them, if this only bothers them after listening to loud sounds or music, if it bothers them when they go to sleep, and how big of a problem it is; if they have ever used firearms; if they have ever had a job where they were exposed to loud noise for five or more hours a week; if they have ever been exposed to loud noise for five or more hours a week outside of a job; and how often they wear hearing protection devices when exposed to loud noises or sounds.

Questions about physical functioning ask individuals under age 20 if they have an impairment or health problem that limits their ability to walk, run, or play;¹⁹ if the impairment or health problem has lasted or is expected to last 12 months or longer; and if they receive special education or early intervention services. Questions about physical functioning ask respondents of all ages if a physical, mental, or emotional problem now keeps them from working at a job or business; if they are limited in the kind or amount of work they can do because of a physical, mental, or emotional problem; if they have difficulty walking without using any special equipment because of a health problem; and if they are limited in any way because of a physical, mental, or emotional problem. If the answer to any

¹⁹ “Play” is only included if the individual is age 5 to 15.

of these questions is yes or respondents are at least age 59, they are asked how much difficulty they have doing the following activities without using any special equipment: managing money; walking short distances or a quarter mile; walking 10 steps without resting; stooping, crouching, or kneeling; lifting or carrying something as heavy as 10 pounds; doing chores around the house; preparing meals; standing up from an armless straight chair; getting in and out of bed; eating dressing; standing for about two hours; sitting up for about two hours; reaching over their heads; using fingers to grasp or handle small objects; going out, for example, shopping, to the movies, or to sporting events; participating in social activities; doing things to relax at home or for leisure; and pushing or pulling large objects. If respondents had any difficulty they were asked what condition or health problem causes them to have difficulty with or need help with the activities. All individuals are asked if they now have any health problem that requires them to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone.

Questions specific to physical health problems ask individuals at least age 12 for how many days in the past 30 days their physical health was not good and how many days the problem kept them from doing usual activities, such as self-care, work, school, or recreation.

Mental Health and Disability Measures

Questions ask individuals under age 20 if they receive special education or early intervention services. Questions ask respondents of all ages if a physical, mental, or emotional problem now keeps them from working at a job or business, limits the kind or amount of work they can do, or limits them in any way. If the answer to any of these questions is yes or individuals are at least age 59, they are asked how much difficulty they have doing the following activities without using any special equipment: managing money; doing chores around the house; preparing meals; going out to things like shopping, movies, or sporting events; participating in social activities; and doing things to relax at home or for leisure. If respondents had any difficulty they are asked what condition or health problem causes them to have difficulty with or need help with the activities. Individuals at least age 12 are asked for how many days in the past 30 days their mental health was not good and how many days the problem kept them from doing usual activities, such as self-care, work, school, or recreation; and how many days they felt worried, tense or anxious.

Questions about depression asked of individuals at least age 12 include information about how often over the last two weeks they were bothered by having little interest or pleasure in doing things; felt down, depressed, or hopeless; had trouble falling or staying asleep, or slept too much; felt tired or had little energy; poor appetite or over ate; felt bad about themselves, felt that they are failures, or felt they let themselves or their families down; had trouble concentrating on things like reading the newspaper or watching TV; moved or spoke so slowly that other people could have noticed, or were so fidgety or restless that they moved around a lot more than usual; and had thoughts that they would be better off dead or of hurting themselves. If the answer is yes, respondents are asked how difficult these problems make it for them to do their work, take care of things at home, or get along with people.

Individuals age 12 to 69 are asked if they have ever used marijuana; their age at time of first use; if they have ever used marijuana at least once a month for more than one year, and if so at what age they started; how long it has been since they last used marijuana once a month for one year; how often they usually used marijuana each month; how many joints or pipes they usually smoked in a day; how long it has been since they last used marijuana; and how many days in the last 30 days they used marijuana. Other questions solicit information about cocaine, heroin, and methamphetamine

use. Individuals are asked if they have ever used each drug; how old they were at time of first use; how long it has been since they last used it; how many times they have used it during their lives (not asked for heroin); and how many times they used it during the past 30 days. Additional questions ask if individuals have ever used a needle to inject a drug not prescribed by a doctor; which drug they have injected; how old they were the first time they did this; how long it has been since they last did this; how many times they have done this during their lives; how often they injected when they did it most often; and if they have ever been in a drug rehabilitation program.

Individuals age 12 to 19 are asked if they have ever tried cigarette smoking; how old they were when they smoked a cigarette for the first time; how many days they smoked cigarettes in the past 30 days; how many cigarettes they smoked per day on days they smoked; how soon they smoke after waking up; what brand of cigarettes they usually smoked in the past 30 days; if they smoked menthol or non-menthol cigarettes; if the cigarettes of the brand they reported smoking were regular, lights, or ultralights; if they had stopped smoking for one day or longer in the past 12 months because they were trying to quit; if they used any product containing nicotine in the past five days; which nicotine product they used; and for each product (cigarettes, pipes, cigars, chewing tobacco, snuff) how many days they used it in the past five days; how many they used each day on the days they used the product in the past five days; when they last used it; how many days in the last five days they used any nicotine product to help them stop smoking; and when they last used a product containing nicotine.

Individuals at least age 20 are asked if they have smoked at least 100 cigarettes in their entire lives; how old they were when they started to smoke cigarettes fairly regularly; how often they now smoke cigarettes; and how long it has been since they quit smoking cigarettes. If it had been one year or longer since they quit smoking cigarettes they were asked how old they were when they last smoked cigarettes; how many cigarettes they typically smoked per day; how soon after waking up they smoke; how many days they smoked cigarettes in the past 30 days; how many cigarettes they smoked on days they smoked in the past 30 days; if they could show the interviewer the pack of cigarettes they usually smoke in order to identify the brand; for the universal product code from the cigarette pack; if the cigarette product is filtered or non-filtered; if the product is mentholated or non-mentholated; what the cigarette product size is; and what other name brand qualifiers for the product are.

Individuals age 12 to 19 are asked how old they were when they had their first drink of alcohol; on how many days during their lives they had at least one drink of alcohol; on how many days in the past 30 days they had at least one drink; and on how many days in the past 30 days they had five or more drinks in a row within a couple of hours.

Individuals at least age 20 are asked if they have ever had at least 12 drinks in any one year; if they have had at least 12 drinks in their entire lives; how often they drank any alcoholic beverage in the past 12 months; how many drinks they had on days they drank in the past 12 months; on how many days they had five or more drinks in the past 12 months; and if there was ever a time when they drank five or more drinks almost every day.

Cognitive and Intellectual Disability Measures

Questions ask if individuals are limited in any way because of difficulty remembering or because they experience periods of confusion. Questions ask individuals under age 20 if they receive special education or early intervention services. Questions ask respondents of all ages if a physical, mental,

or emotional problem now keeps them from working at a job or business, limits the kind or amount of work they can do, or limits them in any way. If the answer to any of these questions is yes or respondents are age 59 or older they are asked how much difficulty they have doing the following activities: managing money; doing chores around the house; preparing meals; eating; dressing; going out, for example, shopping, to the movies, or to sporting events; and doing things to relax at home or for leisure. If respondents have any difficulty they are asked what condition or health problem causes them to have difficulty with or need help with the activities.

Other Health and Disability Measures

The NHANES includes information on receipt of Social Security benefits due to disability; dietary habits; body measurements; laboratory test results; dental health; risk factors for disease (for example, smoking, alcohol consumption); and reproductive health.

Topic Areas

Core questions and examination procedures, which are repeated in each two-year cycle of the survey, gather information about anemia; cardiovascular disease; diabetes; environmental exposure; eye diseases; hearing loss; infectious diseases; kidney diseases; nutrition, obesity; oral health; osteoporosis; physical fitness and physical functioning; reproductive history and sexual behavior; respiratory disease; sexually transmitted diseases; and vision.

The early surveys collected information on the prevalence of certain medically defined illnesses; information on the distribution of a variety of physical, physiological, and psychological measurements; and demographic and socioeconomic data. Continuous NHANES incorporated additional core components, such as medical examination components, laboratory tests, and an environmental health component.

Links to Administrative Data

Continuous NHANES has been linked to the National Death Index (NDI) and Medicare data. Continuous NHANES is in the process of being linked to air quality data and traffic indicators data. The NHANES III has been linked to Social Security Administration data, the NDI; Medicare data; and air quality data. NHANES II has been linked to the NDI.

Potential Uses for Disability-Related Research

The NHANES provides data on demographic and socioeconomic information, blood work, physical functioning, and general health status obtained from a questionnaire, laboratory tests, and a physical examination. It can be used to study the relationship between disability and disease, diet, environmental risk factors, blood components, and physical anomalies. NHANES collects genetic information from a portion of participants' blood samples and thus, has the potential to provide new information for understanding the relationship between genetics and disabilities. Since NHANES also collects information on environmental risks, (for example, exposure to pesticides and dietary habits), NHANES can be used to study the extent to which disabilities result from genetic predispositions versus environmental factors.

Other Notable Features

The NHANES has oversampled different subgroups depending on the survey year. For example, in 2007, NHANES oversampled the entire Hispanic population, rather than just the Mexican-American population. More participants age 40 and over were included in the sample and fewer age 12 to 19 were included than in previous years. Oversampling of those age 12 to 19 was discontinued to allow for oversampling of the Hispanic population.

Sources of Information About the Survey

http://www.cdc.gov/nchs/nhanes/about_nhanes.htm

<http://www.faqs.org/nutrition/Met-Obe/National-Health-and-Nutrition-Examination-Survey-NHANES.html>

<http://cfpub.epa.gov/ncea/cfm/recordisplay.cfm?deid=59053>

<http://aspe.hhs.gov/daltcp/reports/resagdd.htm>

<http://www.answers.com/topic/panel-study>

<http://www.cdc.gov/nchs/data/nhanes/guidelines1.pdf>

http://www.cdc.gov/nchs/tutorials/nhanes/SurveyDesign/Weighting/intro_1.htm

<http://www.cdc.gov/nchs/tutorials/nhanes/SurveyOrientation/SurveyOverview/Info1.htm>

<http://www.cdc.gov/physicalactivity/professionals/data/explanation.html>

<http://www.cdc.gov/nchs/nhanes/nhefs/nhefs.htm>

NATIONAL HEALTH INTERVIEW SURVEY (NHIS)

General Purpose

The NHIS is the principal source of information on the health of the civilian noninstitutionalized population of the United States. It produces timely statistical information on the prevalence, distribution, and effects of illness and disability in the U.S. and the services rendered for or because of such conditions. Survey results have been instrumental in providing data to track health status, health care access, and progress toward achieving national health objectives.

Sponsoring Agencies

The NHIS is sponsored by the National Center for Health Statistics, Centers for Disease Control and Prevention. Some supplements are added by other organizations, which provide funding for those sections. The U.S. Census Bureau administers the NHIS.

Sampling Universe

The NHIS uses a cross sectional sample of the civilian noninstitutionalized population of the 50 states and the District of Columbia. Households and noninstitutional group quarters are sampled based on information from the previous Census, as well as new building permits. Black, Hispanic, and Asian households have been oversampled since 2006, by pre-screening based on race or via selection of sampling areas based on racial and ethnic composition. Some information is collected for each member of the household, including detailed demographic characteristics and information on health status and limitations, injuries, healthcare access and utilization, health insurance, and income and assets. Additional information on health status, health care services, and health behavior is collected from one adult and one child randomly selected from each family.

Sample Size

The NHIS sample size is approximately 35,000 households containing about 87,500 individuals each month. Budget cuts have resulted in smaller samples for some years.

Regional and State-Level Estimates

The NHIS can support regional and state-level estimates. Data with geographic information is available on a restricted-access basis..

Longitudinal Data

The NHIS does not provide longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The NHIS has been conducted since 1957, though it has been substantially revised about once every ten years. The most recent revision occurred in 1997. A new sample is selected for interview each week throughout the year and interviewed once. In some years, one week per month has been dropped as a cost-saving measure.

Physical Health, Sensory, and Communication Disability Measures

The NHIS includes information on whether respondents face limitations in play or work activities (depending on age); whether children use or have used special education or early intervention services; specific conditions, including vision or hearing problems and arthritis; whether those conditions cause limitations in activities; whether a health problem requires the use of assistive equipment; and activity limitations. Questions also address whether and to what degree, as the result of a health problem, the respondent has difficulty doing the following without assistive equipment or the help of others: walking a short distance or up stairs; standing; sitting; stooping, bending or kneeling; reaching over their head; grasping small objects; lifting or carrying; pushing or pulling large objects; going out, for example, shopping, to the movies, or to sporting events; participating in social events; or doing things at home for leisure; as well as what condition causes these difficulties and how long that condition has persisted. Respondents are asked for their height and weight.

Mental Health and Disability Measures

The NHIS includes information on whether respondents face limitations in play or work activities; whether children use or have used special education or early interventions services; whether children have visited a doctor due to emotional or behavioral problems; specific activity limitations; limitations caused by difficulty remembering, or periods of confusion; specific conditions (for example, depression and anxiety); and time of limitation onset. Respondents are asked how often in the past 30 days they have felt nervous; restless or fidgety; hopeless; that everything was an effort; or worthless; and how much these interfered with normal activities. Questions also address whether and to what degree, as the result of a health problem, the respondent has difficulty doing the following without assistive equipment or the help of others: going out, for example, shopping, to the movies, or to sporting events; participating in social events; doing things at home for leisure; as well as what condition causes these difficulties and how long that condition has persisted.

Cognitive and Intellectual Disability Measures

The NHIS includes information on whether respondents face limitations in play or work activities; whether children use or have used special education or early intervention services; limitations caused by difficulty remembering, or periods of confusion; specific activity limitations; specific conditions (for example, mental retardation); and time of limitation onset. Questions also address whether and to what degree, as the result of a health problem, the respondent has difficulty doing the following without assistive equipment or the help of others; going out, for example, shopping, to the movies, or to sporting events; participating in social events; or doing things at home for leisure; as well as what condition causes these difficulties and how long that condition has persisted.

Other Health and Disability Measures

The NHIS includes information on general health status; details on injuries and poisonings including, health care received in response and days of work or school missed as a result; health care use; details on health insurance coverage, including the type of plan (for example, Medicaid, Medicare, private), deductibles, and reasons for not having coverage; medical expenditures; household members who are not working due to a disability; disability benefits received; applications

for Social Security Disability Insurance benefits; risks experienced at the worksite; and workers' compensation claims.

Topic Areas

The NHIS is comprised of core sections and supplements. The core addresses demographic characteristics, health status and limitations, injuries, healthcare access and utilization, health insurance, and income and assets. Supplemental sections can be fielded on a regular basis or only once. Past supplements have addressed cancer screening, complementary and alternative medicine, children's mental health, and healthcare utilization

Links to Administrative Data

The NHIS has been linked to Environmental Protection Agency data on air quality, the National Death Index, Medicare enrollment and claims data, and Social Security Administration data. In the future NHIS files will be linked with information on Medicare Part D and Medicaid enrollment and claims data, and information on end stage renal disease from the National Institute of Diabetes and Digestive and Kidney Diseases. Analytical files will also be released with linked NHIS and Medicare data, including the beneficiary's reason for Medicare entitlement, total number of months of Medicare entitlement, Group Health Plan enrollment, and summarized Medicare service charges and reimbursement amounts.

Potential Uses for Disability-Related Research

The NHIS provides detailed information on issues related to health and health care. It can be used to estimate the number of individuals in a region experiencing a specific limitation; to determine the number at a particular level of income (for example, between the state Medicaid threshold and 133 percent of the federal poverty level) who are forgoing medical care because of cost; or to track the share of individuals experiencing specific conditions, or exposed to certain risks, over time. Because it is linked with Social Security administrative data, it can be used to study health-related issues of those receiving Social Security disability benefits, or who received them in the past.

Other Notable Features

Since 2008, the NHIS has included disability questions as part of an effort to develop and implement a standardized set of questions across multiple surveys in multiple countries. The questions in the 2010 survey focus on limitations in activities such as seeing, walking, and making decisions, and are similar to those used in the Current Population Survey.

Sources of Information About the Survey

http://www.cdc.gov/nchs/nhis/about_nhis.htm

http://www.cdc.gov/nchs/nhis/quest_data_related_1997_forward.htm

ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2009/srvydesc.pdf

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NATIONAL HEALTH INTERVIEW SURVEY ON DISABILITY (NHIS-D)

General Purpose

The goal of the NHIS-D was to develop a series of questionnaires that would provide a useful set of disability measures while maintaining a balance between the social, administrative, and medical considerations involved in disability measurement. The NHIS-D is not limited to one definition of disability; therefore, it allows analysts from varying programs to combine data items in different ways to meet specific agency or program needs. It is designed to collect data that can be used to understand disability, to develop public health policy, to produce simple prevalence estimates of selected health conditions, and to provide descriptive baseline statistics on the effects of disabilities.

Sponsoring Agencies

The NHIS-D was a collaborative effort sponsored by several components in the U.S. Department of Health and Human Services, the U.S. Department of Education, the U.S. Department of Transportation, the Social Security Administration, the National Center for Medical Rehabilitation Research, and the Robert Wood Johnson Foundation.

Sampling Universe

The Phase I Disability questionnaire was administered to a cross sectional sample of the civilian noninstitutionalized population of the 50 states and the District of Columbia which had been selected to participate in the core portion of the NHIS in 1994 or 1995. The 1995 NHIS oversampled Black and Hispanic persons. The Phase I Disability questionnaire collected information about all members of the NHIS households from an adult who was knowledgeable about the health of household members, and was used as a screening device to determine eligibility for the second phase of the survey. Individuals were screened into Phase II if they were identified as children with disabilities; people with a history of polio; people with mental retardation or developmental disabilities; people with sensory impairments; assistive device users; people with mental illness; people with cognitive impairments; people with functional limitations or limitations in Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL); Supplemental Security Income (SSI) recipients; SSI applicants; Social Security Disability (SSDI) recipients; SSDI applicants; belonging to a residual category which included persons who received certain disability pensions or had an artificial limb; or healthy elderly, including people over age 69 not selected as disabled by any of the other policy groups. Information in Phase II was collected by the individual with the disability when possible.

Sample Size

The NHIS-D used a sample of approximately 202,560 individuals for Phase I and 32,788 for Phase II.

Regional and State-Level Estimates

The NHIS-D can support state and regional estimates, but detailed geographic data are not available on public use files.

Longitudinal Data

The NHIS-D does not provide longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The NHIS-D was fielded from 1994 to 1995. All households who participated in the NHIS in 1994 or 1995 completed Phase I of the survey, and individuals were screened into Phase II based on their responses to Phase I and the core NHIS.

Physical Health, Sensory, and Communication Disability Measures

Phase I of the NHIS-D collects information on whether any household member has serious difficulty seeing, even when using glasses or contacts, and if so what condition causes the difficulty, whether the person is legally blind, and whether the difficulty is expected to continue for at least 12 months; whether anyone uses a hearing aid, whether anyone has serious difficulty hearing (even when wearing a hearing aid), what problem or condition causes the difficulty, whether they are able to hear loud noises, whether the problem is expected to continue for at least 12 months, and whether they use an assistive device.

Questions in Phase I also address whether anyone has serious difficulty communicating; lifting 10 pounds; walking up 10 steps; walking a quarter mile; standing for 10 minutes; bending; reaching over their head; using fingers to grasp or handle; holding a pen or pencil; and if so how much difficulty is experienced, when the difficulty first occurred, and whether it is expected to last 12 months or longer. Questions also ask whether because of a physical, mental, or emotional problem anyone gets assistance, needs to be reminded about, has difficulty, or uses special equipment for bathing; dressing; eating; getting in and out of bed and chairs; toileting; or getting around inside the home, and if they have difficulty how much. The survey also addresses whether because of a physical, mental, or emotional problem anyone gets help or supervision with, or has difficulty preparing meals; using the telephone; doing heavy work around the house; doing light work around the house; shopping for personal items; managing money and if they have difficulty how much.

Phase I also asks whether the respondent thinks any household member under age 18 has significant problems or delays in physical development and if so if a doctor has discussed or mentioned it; if anyone uses assistive equipment to get around; and if anyone has an artificial arm, leg, hand, or foot.

Phase II collects information on whether the person screened into the disability section experiences any difficulty doing the following without help: walking for a quarter mile; walking up 10 steps; standing for 2 hours; sitting for 2 hours; stooping, crouching, or kneeling; reaching up over their head; reaching out; using fingers to grasp or handle; lifting or carrying 10 or 25 pounds, and if so how much difficulty and how long they have had difficulty.

Phase II also asks whether, due to a health or physical problem, the respondent experiences any difficulty bathing; dressing; eating; getting in and out of bed and chairs; walking; getting outside; toileting; preparing meals; using the telephone; doing heavy housework; doing light housework; managing medication; shopping for groceries and personal items; managing money; or getting to places outside of walking distance; and when they do these activities by themselves without any

special equipment how much difficulty they experience and whether it is tiring, takes a long time, or is painful. Respondents are asked if they use special equipment for these activities, and if so whether when they do not it is tiring, takes a long time, or is painful. Respondents are asked if they receive help, and if so if it is tiring, takes a long time, or is painful. Respondents are also asked if they have someone who supervises or stays nearby during these activities.

Mental Health and Disability Measures

Phase I of the NHIS-D gathers information on whether any household member has a lot of trouble making or keeping friendships; getting along with other people in social or recreational settings; concentrating long enough to complete everyday tasks; coping with day-to-day stresses; is frequently confused, disoriented, or forgetful; has phobias or unreasonably strong fears; or has specific mental health conditions. If an individual is reported to have any mental health conditions the survey asks whether as a result they are unable to work or limited in the kind or amount of work they can do, and if they have trouble finding or keeping a job, or doing job tasks.

Questions also ask whether because of a physical, mental, or emotional problem anyone gets assistance or needs to be reminded about bathing; dressing; eating; getting in and out of bed and chairs; toileting; or getting around inside the home. The survey also asks if, because of a physical, mental, or emotional problem, anyone gets help or supervision with, or has difficulty preparing meals; using the telephone; doing heavy work around the house; doing light work around the house; shopping for personal items; or managing money and if they experience difficulty how much.

Phase II of the NHIS-D asks if, because of a health or physical problem, the respondent has any difficulty preparing meals; using the telephone; doing heavy housework; doing light housework; managing medication; shopping for groceries and personal items; managing money; or getting to places outside of walking distance, and if they do the activity by themselves and without any special equipment how much difficulty they experience and whether it is tiring, takes a long time, or is painful. Respondents are asked if they use special equipment for these activities, and if so when they do not whether it is tiring, takes a long time, or is painful. Respondents are asked if they receive help, and if so if it is tiring, takes a long time, or is painful. Respondents are also asked if they have someone who supervises or stays nearby during these activities.

Cognitive and Intellectual Disability Measures

Phase I of the NHIS-D gathers information on whether any household member has a lot of trouble making or keeping friendships; getting along with other people in social or recreational settings; concentrating long enough to complete everyday tasks; coping with day to-day stresses; are frequently confused, disoriented, or forgetful; have phobias or unreasonably strong fears; or have specific cognitive health conditions. If an individual is reported to have any cognitive health conditions the survey asks whether as a result they are unable to work or limited in the kind or amount of work they can do, and if they have trouble finding or keeping a job, or doing job tasks.

Questions also ask whether because of a physical, mental, or emotional problem anyone gets assistance, or needs to be reminded about bathing; dressing; eating; getting in and out of bed and chairs; toileting; or getting around inside the home. The survey also asks if, because of a physical, mental, or emotional problem, anyone gets help or supervision with, or has difficulty preparing meals; using the telephone; doing heavy work around the house; doing light work around the house; shopping for personal items; or managing money and if they experience difficulty how much.

Phase II of the NHIS-D asks if, because of a health or physical problem, the respondent has any difficulty preparing meals; using the telephone; doing heavy housework; doing light housework; managing medication; shopping for groceries and personal items; managing money; or getting to places outside of walking distance, and if they do the activity by themselves and without any special equipment how much difficulty they experience and whether it is tiring, takes a long time, or is painful. Respondents are asked if they use special equipment for these activities, and if so when they do not whether it is tiring, takes a long time, or is painful. Respondents are asked if they receive help, and if so if it is tiring, takes a long time, or is painful. Respondents are also asked if they have someone who supervises or stays nearby during these activities.

Other Health and Disability Measures

Phase II of the NHIS-D asks whether an ongoing health problem, impairment or disability prevents the respondent completely from working or limits the kind or amount of work they can do.

Topic Areas

Topics covered in Phase I include: sensory, communication, and mobility; vision, hearing, and mobility aids; communication, understanding, and learning (age 5 and older); dizziness, balance, ringing in ears, and sense of smell and taste (age 18 and older); developmental disability conditions (including polio); disability; ADL limitations (age 5 and older); IADL limitations (age 18 and older); functional limitation (age 18 and older); mental health (age 18 and older); services and benefits (age 18 and older); special health needs of children (primarily age 17 and under); early child development (age 5 and under); education (age 17 and under); relationship to respondent (age 17 and under); and perceived disability (all ages).

For children identified in Phase I, additional information was collected on utilization and need for services, functional assessment, emotional and behavioral development, and the impact of the child's disability on the family.

For adults identified in Phase I or age 69 or older, the Phase II questionnaire obtained more extensive information about the persons with disabilities on issues such as employment, use of services and benefits, transportation and personal assistance needs, housing characteristics, environmental barriers, and participation in social activities.

The Polio Questionnaire collected additional information about the symptoms and impact of the illness at the time of initial diagnosis of polio and at various times after the diagnosis.

Links to Administrative Data

The NHIS-D can be linked with the core NHIS from 1994 and 1995, which is linked or linkable to several administrative datasets. The NHIS-D is linkable by block group and county with air quality data from the Environmental Protection Agency. It is also linkable at the person level with mortality data from the National Death Index; Social Security Administration data, and Medicare enrollment and claims data. In the future NHIS-D files will be linkable with information on Medicare Part D and Medicaid enrollment and claims, and information on end stage renal disease from the National Institute of Diabetes and Digestive and Kidney Diseases. Analytical files will also be released with linked NHIS and Medicare data, including the beneficiary's reason for Medicare

entitlement, total number of months of Medicare entitlement, Group Health Plan enrollment, and summarized Medicare service charges and reimbursement amounts.

Potential Uses for Disability-Related Research

The NHIS-D can be used to compare the effect of different definitions of disability on program eligibility; to identify unmet needs for transportation or other services in geographic areas; and to describe limitations faced, services used, and benefits received by those with different diagnoses.

Other Notable Features

Many of the questions which are asked in the core section of the NHIS or Phase I of the NHIS-D are repeated in Phase II. This is intentionally done because responses often differ based on whether they are given by the person who is identified as disabled or another person in the household.

Sources of Information About the Survey

<http://dsc.ucsf.edu/main.php?name=nhis-d>

Maag, Elaine. (2006, April). *A Guide to Disability Statistics from National Health Interview Survey – Disability Supplement*. Rehabilitation Research and Training Center on Disability Demographics and Statistics, Cornell University, Ithaca, NY. Available at [http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1206&context=edicollect]

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NATIONAL HOUSEHOLD EDUCATION SURVEY (NHES)

General Purpose

The NHES provides descriptive data on the educational activities of the U.S. population.

Sponsoring Agencies

The NHES is sponsored by the Institute for Education Sciences, U.S. Department of Education.

Sampling Universe

The NHES samples households who own telephones. A random sample of phone numbers is selected from number blocks with one or more known residential number(s), based on listings in the white pages. Number blocks with high proportions of minorities are oversampled. Sampled households are screened to determine their eligibility for the collection of modules comprising the survey, which vary by year. For example, modules might require having a preschool-aged child or a child in K-12 education, or might oversample adults participating in adult education. The survey module sample is then selected from those who are eligible, with households selected for one module less likely to be chosen for another.

Sample Size

In 2007 about 62,000 households were screened for eligibility to participate in the survey. The school readiness module had a final sample size of 2,633, the parent and family involvement in education module a sample size of 10,681, and the adult education module a sample size of 7,710.

Regional and State-Level Estimates

The NHES can produce estimates for large regions (e.g. East, Midwest, North, South, and West) but not for states or smaller regions.

Longitudinal Data

The NHES does not produce longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The NHES has been fielded in 1991, 1993, 1995, 1996, 1999, 2001, 2003, 2005, and 2007. The survey is composed of several modules, which vary across survey years. Information on adult education was collected in 1991, 1995, 1999, 2001, 2003, 2005, and 2007; information on before- and after-school programs in 1999, 2001, and 2005; information on early childhood program participation in 1991, 1995, 1999, 2001, and 2005; information on civic involvement in 1996 and 1999; information on household library use in 1996; information on school readiness in 1993, 1999, and 2007; information on school safety and discipline in 1993; and information on parent and family involvement in education in 1996, 2003, and 2007.

The survey is fielded in the spring, and respondents are interviewed once.

Physical Health, Sensory, and Communication Disability Measures

Disability content in the NHES varies by year, based on which modules are fielded, and as modules are updated over time. In 2007 the modules on school readiness and parent and family involvement in education collected information on whether the child had a speech or language delay; deafness or another hearing impairment; blindness or another visual impairment; an orthopedic impairment; or another health impairment lasting 6 months or more; and if so if they were receiving services for their disability; where services were received; if the child had an individualized education plan (IEP); if they were currently receiving special education services; how satisfied the respondent was with the IEP and special education services; and if the child's disability affected their ability to learn. Questions also address whether the child has ever been served by an early intervention program or had an individual family service plan. These sections also ask whether a doctor has expressed concern with the child's weight, and if so if the concern is that they are overweight or underweight.

The adult education module contains information on whether the respondent has a vision or hearing disability that affects learning; or any other long-term physical, mental, or emotional problem that limits them in any way.

Mental Health and Disability Measures

Disability content in the NHES varies by year, based on which modules are fielded, and as modules are updated over time. In 2007 the school readiness and parent and family involvement in education modules collected information on whether the child had a serious emotional disturbance; or another health impairment lasting 6 months or more; and if so if they were receiving services for their disability; where services were received; if the child had an IEP; if they were currently receiving special education services; how satisfied the respondent was with the IEP and special education services; and if the child's disability affected their ability to learn. Questions also address whether the child has ever been served by an early intervention program or had an individual family service plan.

The adult education module contains information on whether the respondent has a long-term physical, mental, or emotional problem that limits them in any way.

Cognitive and Intellectual Disability Measures

Disability content in the NHES varies by year, based on which modules are fielded, and as modules are updated over time. In 2007 the school readiness and parent and family involvement in education modules collected information on whether the child had a specific learning disability; mental retardation; autism; attention deficit disorder (attention deficit or attention deficit hyperactivity disorder); pervasive developmental disorder; or another health impairment lasting 6 months or more; and if so if they were receiving services for their disability; where services were received; if the child had an IEP; if they were currently receiving special education services; how satisfied the respondent was with the IEP and special education services; and if the child's disability affected their ability to learn. Questions also address whether the child has ever been served by an early intervention program or had an individual family service plan.

The adult education module contains information on whether the respondent has a learning disability, such as dyslexia; attention deficit disorder, or attention deficit hyperactivity disorder; or any other long-term physical, mental, or emotional problem that limits them in any way.

Other Health and Disability Measures

Since 2003 respondents to all modules have been able to answer that they were not working because they were disabled or otherwise unable to work. In 2007 modules on school readiness and parent and family involvement in education also addressed health insurance coverage and the general health status of the child.

Topic Areas

The NHES covers children's participation in formal and informal non parental care and education programs; characteristics of care arrangements; children's home literacy activities with family members; school adjustment; early school experiences; participation in adult education; parent and family involvement in children's education; before- and after-school programs and activities; school choice; homeschooling; parent satisfaction with children's schools; school-age children with disabilities; household library use; school safety and discipline; and detailed background and demographic information.

Links to Administrative Data

The NHES is not linked to administrative data.

Potential Uses for Disability-Related Research

The NHES can be used to compare parent and family participation in education between students with certain disabilities and those without; to track adult education among adults with disabilities; and to estimate participation in early childhood education among children with disabilities.

Sources of Information About the Survey

http://nces.ed.gov/pubs2009/2009047_1.pdf

<http://nces.ed.gov/nhes/questionnaires.asp>

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NATIONAL LONG-TERM CARE SURVEY (NLTC)

General Purpose

The NLTC is a longitudinal survey designed to study changes in the health and functional status of Americans age 65 or older. It also tracks health expenditures, Medicare service use, and the availability of personal, family, and community resources for caregiving.

Sponsoring Agencies

The NLTC was sponsored by the National Institute on Aging and Duke University.

Sampling Universe

The NLTC used a nationally representative sample of individuals age 65 or older, drawn from Medicare eligibility files. Sampled individuals were screened in order to classify them as disabled or non-disabled and to determine whether they reside in institutional or community settings. Those living in the community who were classified as disabled and about 10 percent of those who were not composed the community sample. Those who were living in institutional settings composed the institutional sample, and answered fewer questions. More information is provided in the “Other Notable Features” section.

Sample Size

The NLTC began in 1982 with a sample of 35,789 individuals. At each wave approximately 5,000 sample members had died since the previous wave, and were replaced by a sample of 5,000 people who had become age 65 since the last wave. Due to budget constraints, not all non-disabled sample members were continued into the next wave. Since the first follow-up survey, approximately 20,000 sample members were interviewed in each wave.

Regional and State-Level Estimates

The NLTC does not support regional or state-level estimates.

Longitudinal Data

The NLTC followed disabled and some nondisabled respondents over time.

Frequency of Data Collection and Year(s) Fielded

The NLTC was first fielded in 1982, with follow-up surveys in 1984, 1989, 1994, 1999, and 2004. At each wave some respondents who were categorized as non-disabled were eliminated from the sample, and approximately 5,000 individuals who had reached age 65 since the last wave were added to the sample.

Physical Health, Sensory, and Communication Disability Measures

Those screened in to the community sample were asked if they had specific medical conditions (rheumatism or arthritis, paralysis, other permanent stiffness or numbness, multiple sclerosis,

cerebral palsy, epilepsy, Parkinson's disease, glaucoma, diabetes, cancer, frequent constipation, frequent trouble sleeping, frequent severe headaches, obesity, or atherosclerosis) and whether in the last 12 months they had had a heart attack; other heart problem; hypertension; a stroke; circulation trouble in the arms or legs; pneumonia; bronchitis; flu; emphysema; asthma; a broken hip; or other broken bones.

Both those living in the community and those living in institutional settings were asked if in the past week they had needed help to eat; get out of bed; get around inside; dress; bathe; or get to and use the toilet. For each activity the survey asked if they used special equipment; if someone usually stayed nearby in case they needed help, if someone did the activity for them, and if any of these were the case how often they were helped, how long they had needed help, and how long they had not done the activity.

The survey includes information on whether respondents living in the community usually do heavy work around the house; do light work around the house; do laundry; prepare meals; shop for groceries; manage money; take medicine; make telephone calls; go outside the home; or go beyond walking distance; and in each case whether they could do it if necessary and if not if this is because of a disability or health problem. Respondents were asked if someone had helped them in the past week due to their disability or health problem, and if so how long they had helped, who they were, if and how much they were paid, and by whom.

Respondents living in the community were asked if they were missing any body parts, and if so which one(s); how difficult it was for them to climb a flight of stairs; lift 10 pounds; reach above their head, comb or brush their hair; bend to put on socks or stockings; wash their hair, use their fingers to grasp or handle small objects; whether they could see well enough to read ordinary newsprint; if most people could understand their speech; if they could usually hear and understand what is said; how their general health was in comparison to others of the same age, and how often they avoided doing things because they did not have enough energy.

Mental Health and Disability Measures

The NLTCs collected information on whether respondents who were screened into the community sample were taking prescription medicines to calm them or relieve depression.

These respondents were also asked if they ever felt they need the help of a doctor or counselor for a mental or emotional problem; if they had been hospitalized for a mental or emotional problem ever or in the past 5 years; if they had been advised by a doctor to get help for a mental or emotional problem ever or in the past 5 years; if they ever lost their temper and threw, kicked, slammed, or destroyed things; how happy they were; and how satisfied they were with their life as a whole.

The survey includes information on whether screened-in respondents living in the community usually do heavy work around the house; do light work around the house; do laundry; prepare meals; shop for groceries; manage money; manage their medicine; or make telephone calls; and in each case whether they could do it if necessary and if not if this is because of a disability or health problem. Respondents were asked if someone had helped them in the past week due to their disability or health problem, and if so how long they had helped, who they were, if and how much they were paid, and by whom.

Cognitive and Intellectual Disability Measures

Those screened in to the community sample were asked if they have mental retardation, or senility. They were also asked if in the past month they had lost their way and not found the way back; took money or something else that did not belong to them without realizing it; or forgot to do important things.

The survey includes information on whether those screened in to the community sample usually do heavy work around the house; do light work around the house; do laundry; prepare meals; shop for groceries; manage money; manage their medicine; or make telephone calls; and in each case whether they could do it if necessary and if not if this is because of a disability or health problem. Respondents were asked if someone had helped them in the past week due to their disability or health problem, and if so how long they had helped, who they were, if and how much they were paid, and by whom.

The NLTCS administered a set of questions of basic facts to evaluate memory and cognitive health. These were asked both of respondents living in community and institutional settings.

Other Health and Disability Measures

The screening portion of the NLTCS includes information on whether respondents living in community settings have any problem eating without the help of another person or special equipment, getting in or out of bed without help; getting in or out of chairs without help; walking around inside without help; going outside without the help of another person or special equipment; dressing without help; bathing without help; getting to the bathroom or using the toilet; or any accidents or problems controlling bowel movements or urination. If so, respondents were asked if the problem had persisted or was expected to persist three month or longer. The survey also includes information on whether, without help, respondents are able to prepare meals; do laundry; do light housework; shop for groceries; manage money; take medicine; or make telephone calls, and if they are unable to do any of these if it because of a disability or health problem. All of those identified by these questions as disabled, as well as about 10 percent of those who are not, were screened into the community sample and answered the remainder of the survey.

The NLTCS asked members of the community sample if they had a disability related to service in the armed services and if so what their disability rating was. It also asked about receipt of income from Social Security, veterans' compensation or pension, workers' compensation, and Supplemental Security Income.

Members of the community sample were asked if they were covered by Medicaid, military health insurance, or private insurance. They were asked if they had ever been a patient in a nursing home, convalescent or rest home; or a hospital; and in each case if so how many times, when, and for how long. The survey also asked if in the past month they had seen a physical therapist; occupational therapist; hearing therapist; mental health professional; dentist; podiatrist; optometrist; chiropractor; or other doctor, and in each case how many times; whether in their home or elsewhere; how much was paid; and who paid.

Topic Areas

The NLTCS includes information on active life expectancy, activities of daily living, aging, assistive devices, caregiver income, cognitive functioning, disability trends, disease, family support,

institutionalization, instrumental activities of daily living, insurance, medical providers, Medicare and Medicaid, military service, mortality, paid caregivers, unpaid caregivers, and demographics.

Supplemental surveys include a caregiver survey, which acquired data on informal caregivers themselves (done in 1982, 1989, 1999, and 2004) and next-of-kin surveys administered to the survivors of sample persons who had died between 1982 and 1984 and again between 1994 and 1999. In 1999, physical specimens were drawn from a sample of respondents.

Links to Administrative Data

The NLTCS can be linked to complete Medicare billing records for each person in the sample through an anonymous linking identifier. In addition, 1991-2004 Medicare Standard Analytic File records for the 49,242 people who entered the survey from 1982-2004, 1984-1990 Medicare records for the 30,308 people who entered the survey from 1982-1989, and 1982-1983 Medicare records for the 25,398 people who entered the survey in 1982 and 1984 also are available.

Potential Uses for Disability-Related Research

The NLTCS can be used to estimate the prevalence of disability in the population of those age 65 and older, and to trace how this changes over time for specific age cohorts or across different generations. It can also be used to estimate the need for and use of assistance by those experiencing limitations, and to compare the financial well-being and social participation of those with and without limitations.

Other Notable Features

The NLTCS used a complex screening pattern. All sample members were screened to determine whether they experienced one or more limitations in activities of daily living and instrumental activities of daily living. All respondents who did, and about 10 percent of those who did not, moved on to the next level of screening. Information on household composition, demographics, and military service was collected. Those who were identified as disabled and living in community settings answered all further questions. Those who were not identified as disabled but screened in anyway answered all further questions, except for those on activity limitations. Those living in institutional settings answered a limited number of questions, as noted above. Additional information was also collected on the facility in which these respondents lived, including the number of beds and what proportion of beds were certified by Medicaid or Medicare.

Sources of Information About the Survey

<http://www.nltcs.aas.duke.edu/>

<http://www.nltcs.aas.duke.edu/questionnaires.htm>

NATIONAL LONGITUDINAL STUDY OF ADOLESCENT HEALTH (ADD HEALTH)

General Purpose

Add Health collects information about respondents' social, economic, psychological and physical well-being; and families, neighborhoods, communities, schools, friendships, peer groups, and romantic relationships. Its purpose is to provide information on how social and behavioral factors influence adolescent health over time.

Sponsoring Agencies

Add Health is a collaborative effort of numerous foundations and federal agencies, including the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Robert Wood Johnson Foundation, the MacArthur Foundation, the National Cancer Institute, the National Center for Health Statistics, the National Institute of Mental Health, the National Institute on Aging, and other agencies in the U.S. Department of Health and Human Services.

Sampling Universe

Add Health uses a sample of adolescents in grades 7-12 drawn from a stratified, random sample of high schools in the U.S.. A school was eligible for the sample if it included an 11th grade and had a minimum enrollment of 30 students. In some years, separate surveys were also administered to individuals' school administrators, parents, and romantic partners.

Sample Size

Add Health used a sample of 90,118 adolescents and 144 of their school administrators in 1994; 20,745 adolescents from the original sample and 17,670 of their parents in 1995; 14,738 adolescents from the original sample and 128 of the original 144 school administrators in 1996; 15,197 former adolescents from the original sample and 1,507 of their romantic partners in 2001-2002; and 15,701 former adolescents from the original sample in 2007-2008.

Regional and State-Level Estimates

Add Health produces estimates at the national and regional levels (Northeast, Midwest, South, and West).

Longitudinal Data

Add Health has followed some individuals from the original sample for 14 years, from junior high or high school to age 24 to 32. 20,745 individuals from the original sample were targeted for inclusion in the longitudinal sample. African-American adolescents with a parent with a college degree; Chinese adolescents; Cuban and Puerto Rican adolescents; and siblings who live together were oversampled.

Frequency of Data Collection and Year(s) Fielded

Add Health has been fielded since 1994 when the first wave of data collection began. Data has been collected in four waves: Wave I from 1994 to 1995; Wave II in 1996; Wave III from 2001 to 2002; and Wave IV from 2007 to 2008.

Physical Health, Sensory, and Communication Disability Measures

Add Health includes information about how much respondents' health limits their ability to do moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf; and to climb several flights of stairs; if each limitation is caused by a condition that has lasted more than a year or developed recently; if respondents use a brace, cane, wheelchair or other device because of a physical condition; if they have suffered any serious injuries in the past 12 months that interfered with their ability to perform daily tasks; if they have total blindness in one or both eyes; use of eyeglasses, contact lenses, or both; ability to see with corrective lenses; if respondents have ever worn a hearing aid; hearing without a hearing aid or other assistive devices; if respondents stutter or stammer; how they would describe their stuttering or stammering currently; if they have been bothered by ringing in the ears that lasts for 5 minutes or more; how long it has bothered them; how often it bothers them; if they have had any problem with their voices; how often their voices have been hoarse, raspy, or breathy; how often they have had difficulty being heard; and how often their voices have affected their personal, social, or professional life in the past 12 months.

Add Health also includes information about height, weight, waist measurements, and respondents' perceptions of their weight.

Mental Health and Disability Measures

Add Health asks if respondents have ever been told by a health care provider they have or had depression, post-traumatic stress disorder, or anxiety or panic disorder; and at what age they were told.

Add Health includes information on how often in the past 30 days respondents felt isolated from other people; felt unable to control the important things in their lives; were confident in their ability to handle their personal problems; felt things were going their way; or were unable to overcome their difficulties. It also includes information on how often in the past 7 days they were bothered by things that do not usually bother them; were unable to shake off the blues; felt they were just as good as other people; had trouble concentrating; were depressed; were too tired to do things; felt happy; were enjoying life; felt sad; or felt that people disliked them; and what the main reason was for these experiences. Questions ask about respondents' perceptions of their intelligence and attractiveness.

Questions ask if during the past 12 months respondents have seriously considered suicide; attempted suicide; and if family or friends have attempted suicide.

Cognitive and Intellectual Disability Measures

Add Health asks if respondents have ever been told by a health care provider they have or had attention problem, such as attention deficit disorder; and at what age they were told.

Other Health and Disability Measures

Add Health solicits information about general health; how many times a day of school or work was missed in the past 30 days due to a health problem; date of last menstrual period; date of first menstrual period; times in the past seven days respondents had fast food, sweetened drinks, or diet drinks; the time they last ate or drank anything other than water; and if a caffeinated beverage was consumed in the past 24 hours and at what time.

Questions ask about current health insurance; reason for not having health insurance; time of last routine check-up; where respondents go when sick; how many months respondents had health insurance; the number of times respondents thought they should get medical care but did not; whether they had a health problem that got worse because they did not get care when needed; if they had a dental examination; and if they received psychological or emotional counseling in the past 12 months.

Questions ask if respondents have ever been told by a health care provider that they have or had cancer, high blood cholesterol, high blood pressure, high blood sugar or diabetes, heart disease, asthma or emphysema, migraine headaches, epilepsy or another seizure disorder, HIV/AIDS, or Hepatitis C; and at what age they were told; if they have had gum disease or tooth loss due to cavities, an active infection, an injury, an acute illness, surgery, or active seasonal allergies in the past 4 weeks; if they have had cold or flu-like symptoms, a fever, night sweats, nausea or vomiting or diarrhea, blood in stool or urine, frequent urination, or a skin rash or abscess in the past 2 weeks; and if they have taken Aspirin-containing medications or other anti-inflammatory medications in the past 24 hours.

Saliva and blood specimens are obtained from consenting respondents, and blood pressure and pulse are measured.

Topic Areas

Core questions, which are repeated in each wave, solicit information about demographics; relationships with parents; romantic relationships; general health; physical limitations; access to health services; households; education; employment; income; religion; feelings and mental health; sexually transmitted diseases; criminal offenses; and daily activities.

Topics that appear in select waves include relationships with siblings; general diet; illnesses and medications; sleep patterns; military history; suicide; sexual experiences; pregnancy; live births; children and parenting; mistreatment by adults; personality; biological specimens; a knowledge quiz; motivations for birth control; physical development; parents' attitudes; neighborhood; sun exposure; self-efficacy; the Bem Sex Role Inventory; and civic participation.

Links to Administrative Data

Add Health is linked to spatial data obtained from respondents' addresses allowing the calculation of distances between friends in a school community; climate data from the nearest climate station to respondents' addresses; population density data from the U.S. Census; and weather data from the nearest weather station for each Wave I respondent.

Potential Uses for Disability-Related Research

Add Health provides opportunities to study how social environments and behaviors in adolescence are linked to health and achievement outcomes in young adulthood. Additional biological data collected in later waves allows researchers to understand the social, behavioral, and biological linkages in health trajectories as adolescents become adults.

Other Notable Features

The survey instrument has been updated for each wave. Waves I and II focus on environmental factors that may influence adolescents' health and risk behaviors, including personal traits, families, friendships, romantic relationships, peer groups, schools, neighborhoods, and communities. Wave III focuses on how adolescent experiences and behaviors are related to decisions, lifestyle, achievement, and health outcomes in the transition to adulthood. Wave IV questions ask about pregnancy, marriage, children, and parenting.

Sources of Information About the Survey

<http://www.cpc.unc.edu/projects/addhealth>

NATIONAL LONGITUDINAL SURVEY OF YOUTH (NLSY97)

General Purpose

The NLSY97 uses a nationally representative sample of approximately 9,000 youths who were 12 to 16 years old as of December 31, 1996. The NLSY97 is designed to document the transition from school to work and into adulthood. It collects extensive information about youths' labor market behavior and educational experiences over time.

Sponsoring Agencies

The NLSY97 is sponsored by the Bureau of Labor Statistics, U.S. Department of Labor.

Sampling Universe

The NLSY97 sampled of U.S. residents in 1997. Black and Hispanic households were oversampled. All members of sampled households who had been born between 1980 and 1984 were selected. Youth who usually resided in a sampled household but were away at school or college, as well as those in a hospital, correctional facility, or other type of institution were included in the sample. Both parents and youths in the appropriate age group were interviewed in 1997. In subsequent years, only the youth sample members were interviewed.

Sample Size

The NLSY97 began with a sample of 8,984 respondents in 6,819 unique households. A total of 7,756 individuals were included in the 2003-2004 interviews.

Regional and State-Level Estimates

The NLSY97 does not support estimates at the regional or state level.

Longitudinal Data

The NLSY97 follows youth from age 12-16 into adulthood.

Frequency of Data Collection and Year(s) Fielded

The NLSY97 was first fielded in 1997-1998, and has been administered each year.

A similar survey, the National Longitudinal Survey of Youth (1979) (NLSY79) was first administered in 1979 to youth who were 14-22 years old at the time. They were interviewed annually through 1994, and are now interviewed every two years.

Physical Health, Sensory, and Communication Disability Measures

The NLSY97 asked parents if the youth regularly took any medicines; had trouble seeing, hearing, or speaking; had part of their body that was or had been deformed or missing; or had another chronic or life-threatening disease (asthma, heart condition, anemia, diabetes, cancer, epilepsy).

Mental Health and Disability Measures

In the first round of the survey a parent was asked how often the youth had trouble sleeping; was unhappy, sad, or depressed; couldn't concentrate or pay attention for long; or didn't get along with other kids. In all surveys the youth is asked this set of questions, as well as to whom they would turn if they had an emotional or personal relationship problem. They are also asked if they usually expect things to turn out for the best; rarely count on good things happening; are always optimistic about their future; or hardly ever expect things to go their way.

The NLSY97 asked parents if the youth currently had or had previously had any physical, emotional, or mental condition that limited their ability to attend school regularly, do regular school work, or work at a job for pay; if the youth regularly took any medicines; and if they had or had previously had a learning or emotional problem that limited the kind or amount of schoolwork or other daily activities they could perform.

Cognitive and Intellectual Disability Measures

The NLSY97 asked parents if the youth currently had or had previously had a learning or emotional problem that limited the kind or amount of schoolwork or other daily activities they could perform.

Other Health and Disability Measures

In the first round of the NLSY97 parents were asked about the youth's general health; if the youth currently had or had previously had any physical, emotional, or mental condition that limited their ability to attend school regularly, do regular school work, or work at a job for pay; and if the youth was covered by health insurance and what kind. Youth report on their own general health in all rounds, as well as their height and weight. In the first round youth living independently of their parents were asked about their own health insurance coverage; in subsequent rounds all youth report on their health insurance coverage.

If not working, youth can answer that they are disabled and unable to work. They are then asked if the disability prevents them from doing any kind of work for the next 6 months, and in subsequent years are asked if they are still unable to work because of a disability.

The NLSY97 asks if respondents have attended training, including vocational rehabilitation, and if so how much they paid; if they received a training allowance for attending; whether they completed the program; whether they received any certification or license; and activities in the program.

Youth are asked if they have received payments from workers' compensation or Supplemental Security Income, and for each when the payments began; when the payments ended; who in their household qualified for the payments; and how much the payments were.

Topic Areas

The NLSY97 collects information on employment; schooling; training; income, assets, and program participation; family formation; family background; expectations; attitudes, behaviors, and time use; health; environmental variables; and the timing of major life events.

Links to Administrative Data

The NLSY97 is linked to the high school transcripts of sample members.

Potential Uses for Disability-Related Research

The NLSY97 can be used to track the educational and employment outcomes of those with and without disabilities over time; to describe the attitudes and expectations of youth with disabilities and their parents; and to compare profiles of youth with disabilities to similar youth in the NLSY79.

Other Notable Features

In the fall of 1996, all public and private schools that had a 12th grade and that were located in one of the NLSY97 primary sampling units received school survey questionnaires. Over the summer and fall of 1997 and the winter of 1998, NLSY97 respondents took the computer adaptive version of the Armed Services Vocational Aptitude Battery.

Sources of Information About the Survey

<http://www.bls.gov/nls/handbook/2005/nlshc2.pdf>

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NATIONAL LONGITUDINAL TRANSITION STUDY 2 (NLTS2)

General Purpose

The NLTS2 collected information on a national sample of students who were 13 to 16 years of age in 2000 as they moved from secondary school into adult roles. The study aimed to describe the characteristics of secondary school students receiving special education and their households; describe the secondary school experiences of students in special education; describe the experiences of students once they leave secondary school; measure the secondary school and post-school outcomes of students in the education, employment, social, and residential domains; and identify factors in students' secondary school and post-school experiences that contribute to positive outcomes.

Sponsoring Agencies

The NLTS2 was funded by the Institute of Education Sciences, U.S. Department of Education.

Sampling Universe

The NLTS2 randomly selected school districts on the basis of their geographic region, size, and socioeconomic status. These school districts were contacted and invited to participate in the study. For each district that agreed to participate, NLTS2 asked for the district's list of special education students along with each student's grade, date of birth, and disability classification. Approximately 12,000 students were randomly selected to participate in NLTS2 based on the student's age and disability classification.

Sample Size

The NLTS2 used a sample of approximately 12,000 youth.

Regional and State-Level Estimates

The NLTS2 does not produce regional or state-level estimates.

Longitudinal Data

The NLTS2 followed youth from 2000 to 2009.

Frequency of Data Collection and Year(s) Fielded

The NLTS2 administered parent interviews in 2000-2001 and both parent and youth interviews in 2002-2003, 2004-2005, 2006-2007, and 2008-2009. Direct assessment, a teacher survey, and a school program survey were collected in 2001-2002 and 2003-2004. A school characteristics survey was conducted in 2001-2002.

The NLTS2 was a follow-up to the original NLTS, which was conducted from 1985 through 1993.

Physical Health, Sensory, and Communication Disability Measures

The NLTS2 includes information on what physical, sensory, learning, or other disabilities or problems the youth has been diagnosed with; which is their main problem or disability; for what disability or disabilities they receive special help at school; at what age the youth had their first disability or condition; and whether it was a professional or family member who first noticed.

If the youth had a vision problem, the survey asked if the youth wore glasses or contacts and how well they saw with and without them; if the youth used Braille, a portable Braille note taker or writer; large print type; optical devices; mobility devices; assistive technology; or other devices to see or read. If the youth had a hearing problem the survey asked how well they heard without a hearing aid; if they used a hearing aid; and if so how they heard with it; if they had a cochlear implant; how well the youth communicated; and if the youth used sign language or manual communication; lip reading; cued speech; oral speech; a communication board or book; or anything else to help them communicate. If the youth used oral speech the survey asked how clearly they spoke and how well they carried on conversation. If the youth used sign language the survey asked which language was used and whether members of the household used manual sign language or manual communication. If the youth had a speech impairment the survey asked how well the youth communicates and whether they used words; sounds that are not words; gestures; sign language; a communication board or book; a computer; or any other method of communicating. The survey asked how well the youth used their arms and hands to handle things; how well they used their arms and hands for lifting, throwing, and carrying; how well they used their legs and feet; and if they used equipment to get around.

The survey asked how well youth could dress themselves; feed themselves; tell time on a clock with hands; read and understand common signs; count change; look up telephone numbers and use the telephone; and get to places outside the home. It collected information on how often in the past month a health or emotional problem had caused the youth to miss a social or recreational activity; how often they missed school due to a health or emotional problem; whether they were taking prescription medicine for a condition or problem related to their disability or special need; and if so which medicine.

The survey asked whether in the past 12 months youth had received speech or language therapy, or communication services; audiology services; physical therapy; occupational therapy or mobility services; medical services for diagnosis or evaluation related to their special needs; a personal assistant or in-the-home or in-the-classroom aide; a reader or interpreter; nursing care; assistive technology services or devices; respite care; or career counseling; and in each case if it was through the school or district.

Mental Health and Disability Measures

The NLTS2 collected information on what physical, sensory, learning, or other disabilities or problems the youth had been diagnosed with; if they had attention deficit disorder or attention deficit hyperactivity disorder; which was their main problem or disability; for what disability or disabilities they received special help at school; at what age the youth had their first disability or condition; and whether it was a professional or family member who first noticed. The NLTS2 asked whether youth were taking prescription medicine that controls attention or changes mood; and which medicine.

The survey asked youth how often in the past week they had enjoyed life; felt depressed; felt that people disliked them; were hopeful about the future; or felt lonely; how often they got together with friends outside of school and organized activities; how often they were invited by friends to social activities at their homes or parties; and how often youth were called on the phone by their friends. It asked parents how often youth joined group activities without being told to; made friends easily; ended disagreements with the respondent calmly; seemed confident in social situations; got into situations that were likely to result in trouble; started conversations rather than waiting for someone else to initiate conversation; received criticism well; behaved at home in a way that caused problems for the family; controlled their temper when arguing with peers; kept working at something until it was finished; and spoke in an appropriate tone at home.

The NLTS2 collected information on how often in the past month a health or emotional problem had caused the youth to miss a social or recreational activity; how often they had missed school due to a health or emotional problem; whether they were taking prescription medicine for a condition or problem related to their disability or special need; whether they were taking precipitation medicine that controls attention or changes mood; and if so which medicine.

The survey asked whether in the past 12 months youth had received psychological or mental health services or counseling; social work services; medical services for diagnosis or evaluation related to their special needs; respite care; or career counseling; and in each case if it was through the school or district.

Cognitive and Intellectual Disability Measures

The NLTS2 collected information on what physical, sensory, learning, or other disabilities or problems the youth had been diagnosed with; which was their main problem or disability; for what disability or disabilities they received special help at school; at what age the youth had their first disability or condition; and whether it was a professional or family member who first noticed.

The survey asked how well youth could dress themselves; feed themselves; tell time on a clock with hands; read and understand common signs; count change; look up telephone numbers and use the telephone; and get to places outside the home.

Other Health and Disability Measures

The NLTS2 asked at what age youth started getting special services; if the youth received early intervention services; if they had an individualized education program (IEP) or received special education services between the ages of 3 and 5; and what kind of school the youth attended. The survey asked about the youth's general health; if the youth used medical equipment such as an oxygen tank or catheter; and if so what.

The survey asked whether the youth was covered by private insurance; government assisted or public health insurance; or another source of insurance; if their coverage was with an HMO; whether their coverage was managed care; and whether their insurance covered dental care; vision care; medicines and prescriptions; or mental health care; if the respondent had needed to change plans or buy extra insurance for the youth because of their special needs; and whether they had ever tried to get insurance to pay for a service that was refused and if so what that service was.

The NLTS2 also asked how the youth usually got to their job if they had one. If youth were not working or looking for work respondents were asked why, and could respond that they would lose

benefits such as Supplemental Security Income. It asked if the household had received Supplemental Security Income for the youth in the past 2 years; if it still did, and if not why the benefits stopped.

Youth were asked whether they considered themselves to have a disability or special need; whether they thought they knew what services they needed; whether they got services; how often they told professionals what they thought about the services they received; how difficult it was for them to get where they wanted to go; their attitudes toward school; whether they had an IEP; whether they were involved in planning their IEP; and how they felt about their IEP and their part in making decisions in it.

The survey asked youth what services, accommodations, and supports they received at school; how useful these had been; and whether they had received enough to do their best. These questions were asked for high school, as well as any postsecondary vocational, business, or technical schools or 4-year colleges or universities attended. Respondents reported whether their employer was aware of their learning problem, disability, or special need; what accommodations, if any, they received; and how they usually got to work.

A survey completed by the school personnel gathered information on the settings in which youth learned; whether they took standardized assessments; if they used testing accommodations, and if so which. If the student had a visual impairment the survey asked how well they used different methods to find their way around. The school program also reported on the student's disabilities, and which one was primary; and services provided through the school system.

Topic Areas

The NLTS2 collected information on diagnoses and limitations; services used; parent and youth attitudes and expectations; school characteristics; family income; program participation; educational experience; work experience; health insurance; and demographics.

Links to Administrative Data

The NLTS2 is linked to the school transcripts from every year the youth was in high school.

Potential Uses for Disability-Related Research

The NLTS2 can be used to estimate the usage and need for services and supports among youth with disabilities; to track changes in expectations as youth with disabilities age into adulthood; and to compare educational and employment outcomes of youth in special education in 2000 to those 15 years earlier.

Sources of Information About the Survey

http://www.nlts2.org/studymeth/nlts2_sampling_plan2.pdf

<http://www.nlts2.org/studymeth/index.html>

NATIONAL NURSING HOME SURVEY (NNHS)

General Purpose

The NNHS is a continuing series of national sample surveys of nursing homes, their residents, and their staff. Although each of these surveys has emphasized different topics, they all provide some common basic information. The NNHS provides information on nursing homes from two perspectives - that of the provider of services and that of the recipient of care.

Sponsoring Agencies

The NNHS is sponsored by the Centers for Disease Prevention and Control. A supplemental survey of nursing assistants employed by nursing homes, the National Nursing Assistant Survey, was sponsored by the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

Sampling Universe

The NNHS sample represents U.S. nursing homes and their residents, and is drawn using a stratified two-stage probability design. Nursing homes are selected from the Centers for Medicare and Medicaid Services Provider of Services file of U.S. nursing homes and state licensing lists compiled by a private organization. The likelihood of a facility being selected is proportional to the number of beds. Up to 12 individuals are selected from the population of residents on the register of the sampled facility, including those who are physically absent from the facility due to overnight leave or a hospital visit but have a bed maintained for them at the facility. In all cases, information on individuals is provided by staff members familiar with the residents and their care, not by the nursing home residents.

Sample Size

In 2004 the NNHS used a sample of 1,174 nursing homes and 14,017 residents from the responding facilities.

Regional and State-Level Estimates

The NNHS supports estimates for geographical regions.

Longitudinal Data

The NNHS does not produce longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The NNHS was first conducted in 1973-1974 and has been repeated in 1977, 1985, 1995, 1997, 1999, and most recently in 2004. The 2004 version reflected a redesign of the survey and collected information on an expanded set of variables.

Physical Health, Sensory, and Communication Disability Measures

The NNHS collects information on how independent individuals are in bed mobility; transfer; walking in their room; walking in the corridor; locomotion on and off their unit; dressing; eating; using the toilet; doing personal hygiene; and bathing.

The NNHS also collects information on weight loss and gain; falls and fractures; pressure ulcers; current and most intense pain levels; how pain is managed; symptoms experienced (difficulty with coughing and secretions, shortness of breath, constipation, diarrhea, dry mouth, fecal impaction, nausea or vomiting, change in sleep patterns, restlessness, urinary retention, fever, impaired endurance, offensive odor, open lesions or infections of the mouth, and pruritis or itching), and treatments used.

Mental Health and Disability Measures

The NNHS asks if individuals have indicators of depressed, sad, or anxious mood that are not easily altered by attempts to ‘cheer up’, console, or reassure them; or display any behavioral symptoms such as wandering, verbally abusive language, physically abusive actions, socially inappropriate or disruptive behavior, or resisting care.

Cognitive and Intellectual Disability Measures

The NNHS asks how independently individuals make decisions regarding tasks of daily life; and if they display any behavioral symptoms such as wandering, verbally abusive language, physically abusive actions, socially inappropriate or disruptive behavior, or resisting care.

Other Health and Disability Measures

The NNHS collects information on the use of side rails or restraints. It also asks about participation in special programs for hospice, palliative, or end of life care; pain management; behavioral problems; skin problems or wounds; continence management; dementia; and restorative care. Information is collected on the individual’s primary diagnosis when admitted and at the time of interview, as well as current secondary diagnoses; visits to the emergency room and hospital admissions in the past 90 days; and vaccination status. The survey also acquires a list of medications used by the individual. Information is also collected on sources of payment, total charges, and the amount the individual’s family is expected to pay.

Topic Areas

The NNHS collects information on characteristics of the nursing home; demographics; length of stay; symptoms experienced; treatments received; diagnoses; sources of payment; medications used; and activities of daily living.

Links to Administrative Data

The NNHS is linked with mortality data from the National Death Index, Social Security Administration data, and Medicaid enrollment and claims data (2004 NNHS only). In the future, NNHS files from 2004 will be linked with information on Medicare Part D and information on end stage renal disease from the National Institute of Diabetes and Digestive and Kidney Diseases. Analytical files will also be released with linked NNHS and Medicare data, including the beneficiary’s

reason for Medicare entitlement, total number of months of Medicare entitlement, Group Health Plan enrollment, and summarized Medicare service charges and reimbursement amounts.

Potential Uses for Disability-Related Research

The NNHS can be used to examine trends in costs incurred by nursing home residents over time; to estimate differences in the needs of those who enter nursing homes with different diagnoses; and to understand the challenges of moving nursing home residents into community settings.

Other Notable Features

In 2004 the NNHS also collected information about the employees of sampled nursing homes.

Sources of Information About the Survey

http://www.cdc.gov/nchs/data/nhds/2004NNHS_DesignCollectionEstimates_072706tags.pdf

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NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS (NS-CSHCN)

General Purpose

The purpose of the NS-CSHCN is to provide information on children's special health care needs in the U.S. and children's and their families' access to and satisfaction with care.

Sponsoring Agencies

The NS-CSHCN is sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services.

Sampling Universe

The NS-CSHCN uses a sample representative of the U.S. population of children under 18 years of age living in households. The sample was randomly selected using the State and Local Area Integrated Telephone Survey mechanism. Interviews were conducted with parents or guardians of children selected into the sample.

Sample Size

The 2000 survey used a sample of 364,841 children, and the 2005 survey used a sample of 372,174 children.

Regional and State-Level Estimates

The NS-CSHCN supports estimates at the state level.

Longitudinal Data

The NS-CSHCN does not follow individuals longitudinally.

Frequency of Data Collection and Year(s) Fielded

The NS-CSHCN was first fielded from 2000 to 2002, and again from 2005 to 2006. Each respondent is interviewed once.

Physical Health, Sensory, and Communication Disability Measures

The NS-CSHCN includes information on whether children need or use medicine prescribed by a doctor; need or use medical care, mental health, or educational services more than is usual for most children of the same age; are limited or prevented in any way in their ability to do things most children of the same age can do; or need or get special therapy, such as physical, occupational, or speech; and in each case if it is because of a medical, behavioral, or other health condition; if the condition has lasted or is expected to last 12 months or longer; and if the need, use, or limitation has lasted or is expected to last 12 months or more. If respondents answer that children have any of these special needs or limitations and that the problem has lasted or is expected to last 12 months or more, children are classified as special needs and are asked more questions than children without

special needs. The survey includes information on how often during the past 12 months medical, behavioral, or other health conditions have affected the ability of children identified as having special needs to do things other children of the same age do; how much these conditions affect children's ability; and how often children's health care needs change.

The NS-CSHCN includes information on whether children experience difficulty with seeing; hearing; breathing; swallowing, digesting food, or metabolism; blood circulation; repeated or chronic physical pain; taking care of themselves; coordination or moving around; using their hands; and speaking, communicating, or being understood; and the severity of these difficulties. If the child does not experience these difficulties the survey includes information on whether that is because their health problems are being treated, and the specific reason their health problems do not currently cause them difficulty.

The survey includes information about whether there was a time any of the following were needed in the past 12 months (or since birth for children younger than 12 months): physical, occupational, or speech therapy; eyeglasses or vision care; hearing aids or hearing care; mobility aids or devices such as canes, crutches, wheelchairs, or scooters; or communication aids or devices. If so the respondent was asked if all of the needed type of care was received, and if not why the care needed was not received; and if any of each type of care was received.

The NS-CSHCN includes information on whether children have asthma; diabetes; insulin; heart problems; blood problems; Cystic Fibrosis; Cerebral Palsy; Muscular Dystrophy; epilepsy or another seizure disorder; migraine or frequent headaches; arthritis or other joint problems; allergies; or food allergies.

Mental Health and Disability Measures

The NS-CSHCN includes information on whether children need or use medicine prescribed by a doctor; need or use medical care, mental health, or educational services more than is usual for most children of the same age; are limited or prevented in any way in the ability to do things most children of the same age can do; or need or get special therapy, such as physical, occupational, or speech; and in each case if it is because of any medical, behavioral, or other health condition; if the condition has lasted or is expected to last 12 months or longer; and if the need, use, or limitation has lasted or is expected to last 12 months or more. If respondents answer that children have any of these special needs or limitations and that the problem has lasted or is expected to last 12 months or more, children are classified as special needs and are asked more questions than children without special needs. The survey includes information on how often during the past 12 months medical, behavioral, or other health conditions affected the ability of children identified as having special needs to do things other children of the same age do; how much these conditions affect children's ability; and how often children's health care needs change.

The NS-CSHCN includes information on whether children feel anxious or depressed; have behavior problems; or experience difficulty making and keeping friends; the severity of these difficulties; whether they do not experience any difficulties because their health problems are being treated; and the specific reason their health problems do not currently cause them difficulty.

The survey includes information on whether children have depression, anxiety, an eating disorder, or another emotional problem.

The survey includes information about whether there was any time mental health care or counseling or substance abuse treatment or counseling was needed in the past 12 months (or since birth for children younger than 12 months); if all of the needed type of care was received, and if not why the care needed was not received; and if any of each type of care was received.

Cognitive and Intellectual Disability Measures

The NS-CSHCN includes information on whether children need or use medicine prescribed by a doctor; need or use medical care, mental health, or educational services more than is usual for most children of the same age; are limited or prevented in any way in ability to do things most children of the same age can do; or need or get special therapy, such as physical, occupational, or speech; and in each case if it is because of any medical, behavioral, or other health condition; if the condition has lasted or is expected to last 12 months or longer; and if the need, use, or limitation has lasted or is expected to last 12 months or more. If respondents answer that children have any of these special needs or limitations and that the problem lasted or is expected to last 12 months or more, children are classified as special needs and are asked more questions than children without special needs. The survey includes information on how often during the past 12 months medical, behavioral, or other health conditions affected the ability of children identified as having special needs to do things other children of the same age do; how much these conditions affect children's ability; and how often children's health care needs change.

The survey includes information on whether children experience difficulty with taking care of themselves; coordination or moving around; using their hands; learning, understanding, or paying attention; and speaking, communicating, or being understood; the severity of these difficulties; whether they do not experience any difficulties because their health problems are being treated; and the specific reason their health problems do not currently cause them difficulty.

The NS-CSHCN includes information on whether children have attention deficit or hyperactivity disorder; autism or autism spectrum disorder; Down syndrome; or mental retardation or developmental delay.

Other Health and Disability Measures

The survey includes information about how many times during the past 12 months (or how many times since birth for children less than 12 months old) children missed school because of an illness or injury; visited a hospital emergency room; or visited a health care provider.

The NS-CSHCN includes information on whether there is a place children usually go when sick or in need of advice about health; what type of place this is; if there is a place children usually go for routine preventive care; if children go to the same place for preventive care as they go to when sick; if there is anyone respondents think of as children's personal doctor or nurse; and what type of health professional this person is. The survey includes information on whether there was a time during the past 12 months (or since birth for children younger than 12 months of age) when respondents delayed or went without needed health care for children and what the reason was for delaying or not seeking care. The survey includes information about whether there was any time in the past 12 months (or since birth for children younger than 12 months) that routine preventive care; care from a specialty doctor; preventive dental care; other dental care; prescription medications; home health care; medical supplies; or durable medical equipment) were needed; if all of the needed type of care was received; why the care needed was not received; and if any of each type of care was received.

The survey includes information about whether there was any time family members of children with special needs needed certain types of care (respite care; genetic counseling related to children's medical, behavioral, or other health conditions; and mental health care related to children's medical, behavioral, or other health conditions) in the past 12 months (or since birth for children younger than 12 months); if all of the needed type of care was received; why the care needed was not received; and if any of each type of care was received. Questions also address health-related medical, educational, and social services; satisfaction with health care providers; coordination of care; and the transition from pediatrics to a physician who treats adults.

Questions address whether children 36 months of age or younger receive services from Early Intervention Services and whether children of all ages receive services from Special Education Services.

The survey addresses whether children are currently covered by health insurance provided through an employer or union and whether the health insurance helps pay for both doctor visits and hospital stays; whether children are covered by any Medicaid plan; children's health insurance plan; military health care; or any other health insurance or health care plan; whether there was a time during the past 12 months or since children's birth when children were not covered by any health insurance, how many months children did not have health insurance coverage, and how long it has been since children had health insurance that paid for all types of care; what kind of health coverage children had and if it paid for both doctor visits and hospital stays.

The survey includes information about how often children's health insurance covers services that meet their needs; if the respondent perceives that the costs not covered by insurance are reasonable; and if health insurance allows children to see the health care providers they need.

Questions address how much families paid for children's medical care in the past 12 months or since children's birth; if families provide health care at home; how many hours family members spend providing this care; how many hours family members spend coordinating children's care; if children's health care causes financial problems for the family; if family members have stopped working or have worked less because of children's health; and if respondents need additional income to cover children's medical expenses.

The survey includes information on whether respondents or any other adults living in households have breathing problems; asthma; diabetes; a heart problem; blood problems; kidney problems; or a weakened immune system; work in a health care facility; have direct contact with patients as part of their routine work; received a flu vaccine in the past 12 months; and if all adults in households received a flu vaccine in the past 12 months.

Topic Areas

Questions solicit information about health and functional status; access to care; care coordination; family centered care; transition of health care from childhood to adulthood ease of service use; hurricane evacuees; health insurance; adequacy of health care coverage; the impact of children's special needs on families; family composition; influenza vaccination; income; and household information.

Links to Administrative Data

The NS-CSHCN data on insurance coverage has been linked to birth defect data and the National Immunization Survey data on immunization status.

Potential Uses for Disability-Related Research

The NS-CSHCN allows estimates of the prevalence of certain disabilities among children in the U.S. Its emphasis on health insurance coverage and access to and utilization of healthcare can help researchers determine how effectively health care meets the needs of children with disabilities and what improvements can be made.

Sources of Information About the Survey

<http://mchb.hrsa.gov/cshcn05/>

<http://mchb.hrsa.gov/chscn/pages/prevalence.htm>

<http://www.norc.uchicago.edu/projects/ByFocusArea/Health/National+Survey+of+Children+with+Special+Health+Care+Needs.htm>

<http://cshcndata.org/Content/CompareSurveys.aspx>

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NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

General Purpose

The purpose of the NSCH is to estimate national and state-level prevalence of a variety of physical, emotional, and behavioral child health indicators; generate information about children, their families, and neighborhoods to help guide policymakers, advocates, and researchers; provide baseline estimates for federal and state Title V Maternal and Child Health performance measures; and complement the 2005/2006 National Survey of Children with Special Health Care Needs by providing data on the health of the general child population.

Sponsoring Agencies

The NSCH is sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services.

Sampling Universe

The NSCH is representative of the U.S. population of children under 18 years of age living in households. Sample households were randomly selected using the State and Local Area Integrated Telephone Survey mechanism. Interviews were conducted with parents or guardians of one child randomly selected from each household.

Sample Size

The 2003 survey used a sample of 102,353 children, the 2007 survey used a sample of 91,642 children, and the 2011 survey is expected to use a sample of 91,800 children.

Regional and State-Level Estimates

The NSCH produces estimates at the state level.

Longitudinal Data

The NSCH does not follow individuals longitudinally.

Frequency of Data Collection and Year(s) Fielded

The NSCH was first fielded from 2003 to 2004, again from 2007 to 2008, and is expected to be fielded from 2011 to 2012.

Physical Health, Sensory, and Communication Disability Measures

The NSCH asks if children need or use medicine prescribed by a doctor; need or use medical care, mental health, or educational services more than is usual for most children of the same age; are limited or prevented in any way in their ability to do things most children of the same age can do; or need or get special therapy, such as physical, occupational, or speech; and in each case if it is because of any medical, behavioral, or other health condition; if the condition has lasted or is expected to last

12 months or longer; and whether each need, use, or limitation has lasted or is expected to last 12 months or more.

Questions ask if children have ever been diagnosed with hearing problems; vision problems that cannot be corrected with glasses or contact lenses; stuttering, stammering, or other speech problems; bone problems; joint problems; muscle problems; or a brain injury or concussion; and in each case if they currently have the problem; the severity of the problem; how many times in total they saw a health care provider in the past 12 months because of their condition(s); and the reason for not seeing a health care provider if they did not.

Questions address whether respondents have concerns about their children's ability to talk and make speech sounds; understanding of what is said; ability to use hands and fingers to do things; or ability to use their arms and legs.

The survey collects information on whether children have ever been diagnosed with asthma; diabetes; or epilepsy or a seizure disorder; and in each case if they currently have the problem; the severity of the problem; how many times in total they have seen a health care provider in the past 12 months because of their condition(s); and the reason for not seeing a health care provider if the respondents answered that they did not. Questions asked about children at least 12 months of age solicit information about whether respondents have been told by a doctor during the past 12 months that the child had hay fever or any kind of respiratory allergy; eczema or any kind of skin allergy; migraine headaches; or 3 or more ear infections; and in each case the severity of the condition; and whether the child had a toothache; decayed teeth or cavities; broken teeth; or bleeding gums within the past 6 months.

Questions provide information about whether during the past 12 months (for children at least 12 months old) or since birth (for children younger than 12 months) health care providers asked if respondents had concerns about their children's learning, development, or behavior or had respondents fill out a questionnaire on specific concerns about their children's development, communication, or social behaviors. The NSCH includes information about whether the questionnaire asked about respondents' concerns or observations about how their children talk or make speech sounds; and words and phrases their children use and understand.

The NSCH also solicits information about children's height, weight, and birth weight.

Mental Health and Disability Measures

The NSCH includes information about whether children need or use medicine prescribed by a doctor; need or use medical care, mental health, or educational services more than is usual for most children of the same age; are limited or prevented in any way in their ability to do things most children of the same age can do; or need or get special therapy, such as physical, occupational, or speech; and in each case if it is because of any medical, behavioral, or other health condition; whether the condition has lasted or is expected to last 12 months or longer; and whether each need, use, or limitation has lasted or is expected to last 12 months or more. Questions ask whether children have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling and whether this problem has lasted or is expected to last 12 months or longer.

The survey asks whether children have ever been diagnosed with depression; anxiety problems; or behavioral or conduct problems; and in each case whether they currently have the problem; the

severity of the problem; how many times in total they have seen a health care provider in the past 12 months because of their condition(s); and the reason for not seeing a health care provider if they did not. Questions ask whether, during the past 12 months, children at least 24 months of age have received treatment or counseling from a mental health professional or taken any medication because of difficulties with emotions, concentration, or behavior.

The survey asks how often children age 6 to 17 argue; bully or are cruel or mean to others; show respect for teachers and neighbors; get along well with other children; are disobedient; are stubborn, sullen, or irritable; try to understand other people's feelings; try to resolve conflicts with classmates, family, or friends; feel worthless or inferior; are unhappy, sad, or depressed; are withdrawn and do not get involved with others; care about doing well in school; and do all required homework.

Questions provide information about whether during the past 12 months (for children at least 12 months old) or since birth (for children younger than 12 months) health care providers asked if respondents had concerns about their children's learning, development, or behavior or had respondents fill out a questionnaire on specific concerns about their children's development, communication, or social behaviors.

The survey includes information on the status of respondents' mental and emotional health.

Cognitive and Intellectual Disability Measures

The NSCH collects information on whether children need or use medicine prescribed by a doctor; need or use medical care, mental health, or educational services more than is usual for most children of the same age; are limited or prevented in any way in their ability to do things most children of the same age can do; or need or get special therapy, such as physical, occupational, or speech; and in each case if it is because of any medical, behavioral, or other health condition; if the condition has lasted or is expected to last 12 months or longer; and if the need, use, or limitation has lasted or is expected to last 12 months or more. Questions ask if children have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling and if this problem has lasted or is expected to last 12 months or longer.

Respondents are asked if a doctor, health care provider, teacher, or school official has ever told them their child had a learning disability; if the child currently has a learning disability; about the severity of the learning disability; and if the child receives or needs any special adaptations or accommodations in school or day care.

Questions ask if children have ever been diagnosed with attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD); autism, Asperger's disorder, pervasive development disorder, or other autism spectrum disorders; any developmental delays that affect their ability to learn; or Tourette Syndrome; and in each case if they currently have the problem; the severity of the problem; how many times in total they have seen a health care provider in the past 12 months because of their condition(s); and the reason for not seeing a health care provider if they did not. Questions also ask if children diagnosed with ADD or ADHD are currently taking medication for ADD or ADHD.

Questions address whether respondents have concerns about their children's learning, development, or behavior; how concerned they are about their children's general behavior; ability to

getting along with others; ability to do things independently; and ability to learn pre-school or school skills

Questions provide information about whether during the past 12 months (for children at least 12 months old) or since birth (for children younger than 12 months) health care providers asked if respondents had concerns about their children's learning, development, or behavior or had respondents fill out a questionnaire on specific concerns about their children's development, communication, or social behaviors. The survey includes information about whether the questionnaire asked about respondents' concerns or observations about how their children interact with respondents and others; and how their children behave and get along with respondents and others. Questions solicit information about whether children have any developmental problems for which they have an individualized family service plan or individualized education program and about whether children's behavior limits respondents' ability to find child care.

Other Health and Disability Measures

Questions ask parents of children with special health care needs if their child's medical, behavioral, or other health conditions interfere with their ability to participate in play with other children; go on outings; make friends; attend school on a regular basis; or participate in sports, clubs, or other organized activities.

Questions ask respondents to describe their children's health in general; the condition of their teeth; and whether children received certain immunizations. The NSCH asks if children's health limits respondents' ability to find child care.

Questions ask if children have any kind of health care coverage; if children are insured by Medicaid or children's health insurance plan; if there was a time children were not covered by any health coverage in the past 12 months for children at least 12 months old and since birth for younger children; if there was any time children were covered by any health coverage in the past 12 months for children at least 12 months old and since birth for younger children; if the health insurance offers benefits or covers services that meet children's needs; if the insurance allows children to see the health care providers they need; if children's parents pay any money for children's health care out-of-pocket; and how often these costs are reasonable.

Respondents are asked if there is a place children usually go when they are sick or need health advice; what type of place it is; if children have a personal doctor or nurse; if anyone helps respondents coordinate children's care among the different doctors or services they use; how satisfied respondents are with communication among children's health care providers; and whether health care providers communicate with children's school, special education program, or vocational education program and how satisfied respondents are with this communication.

Questions ask how many times during the past 12 months (for children at least 12 months old) or since birth (for children younger than 12 months) children saw a health care provider for preventive medical care; dentist for preventive dental care; if children saw a specialist; if respondents or a doctor thought children needed to see a specialist; how much of a problem it was to get the care from the specialists children needed; if there was a time when children needed health care but it was delayed or not received; what type of care was delayed or not received; if children needed a referral to see any doctors or receive any services; how much of a problem getting referrals was; if respondents felt they could use extra help arranging or coordinating children's care; how often respondents got as much help as they wanted arranging or coordinating care; how often health care

providers spent enough time with children; how often children's health care providers listened carefully to respondents; how often health care providers are sensitive to families' values and customs; how often respondents got the specific information they needed from children's health care providers; how often health care providers made respondents feel like partners in their children's care; and how often children have been injured and required medical attention and where the injury occurred.

Respondents with children 6 to 17 years of age are asked how many days children missed school because of illness or injury; how many times children's schools have contacted respondents about a problem their children were having with school in the past 12 months; and if their children have a health problem, condition, or disability for which they have an individualized family service plan or individualized education program.

Respondents are also asked about the general status of their own health.

Topic Areas

Questions solicit information about child and family demographics; children's physical and mental health status; early childhood-specific information (0-5 years); middle childhood and adolescent-specific information (6-17 years); health insurance status and type of coverage; family health and activities; access to and use of health care services; parental health status; medical homes; and parent's perceptions of neighborhood characteristics.

Links to Administrative Data

The NSCH is not linked to administrative data.

Potential Uses for Disability-Related Research

The NSCH allows estimates of the prevalence of certain disabilities among children in the U.S. It can help researchers understand the relationship between the development and treatment of children's disabilities and factors such as access to health care, family relationships, family stability, parental health, neighborhood condition, income, and race and ethnicity.

Other Notable Features

In 2011, questions will also ask parents of uninsured children from some households about their awareness of, experience with, and interest in enrolling in Medicaid and the state children's health insurance program.

Sources of Information About the Survey

<http://nschdata.org/content/LearnAboutTheSurvey.aspx>

<http://www.cdc.gov/nchs/slits/nsch.htm>

<http://nschdata.org/Dataquery/SurveyAreas.aspx?yid=2>

<http://www.norc.uchicago.edu/projects/ByFocusArea/Health/National+Survey+of+Childrens+Health.htm>

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NATIONAL SURVEY OF FAMILIES AND HOUSEHOLDS (NSFH)

General Purpose

The NSFH was designed to provide a broad range of information on family life to serve as a resource for research across disciplinary perspectives. The design permits the detailed description of past and current living arrangements and other characteristics and experiences, as well as the analysis of consequences of earlier patterns on current states, marital and parenting relationships, kin contact, and economic and psychological well-being.

Sponsoring Agencies

The first wave of the NSFH was sponsored by the National Institute of Child Health and Human Development, U.S. Department of Health and Human Services. The second and third waves were jointly sponsored by the National Institute of Child Health and Human Development and the National Institute on Aging.

Sampling Universe

The NSFH used a multi-stage probability sample of those age 19 and older living in households. Students away at college and those living in military housing but tied to a sampled household were eligible for interview. Minority groups, single parent families, families with step children, cohabitators, and recently married couples were oversampled. Within each sampled household one person 19 years old or older was randomly selected as the primary respondent. Information was gathered from the primary respondent, their spouse or partner, and the householder if he or she is not already accounted for. In the first follow-up year information was collected from the primary respondent, their spouse or partner, their spouse or partner at the time of the first survey if different, and a focal child who was living in the household at the time of the first survey. In the second follow-up year information was gathered from the primary respondent, their spouse or partner at the time of the first survey, and a focal child.

Sample Size

The first wave of the NSFH used a sample of 13,007 households. Interviews were conducted with 10,007 primary respondents in the second wave, as well as 12,067 other family members. A total of 10,154 interviews were conducted in the third wave.

Regional and State-Level Estimates

The NSFH does not support regional or state-level estimates.

Longitudinal Data

The NSFH collected follow-up information from households covered in 1987-88 interviews in 1992-94 and 2001-2003.

Frequency of Data Collection and Year(s) Fielded

The NSFH was fielded in 1987-88, 1992-94, and 2001-2003.

Physical Health, Sensory, and Communication Disability Measures

If respondents reported that a member of the household, or anyone who had been a member in the past 12 months, needed assistance or care because of a disability or chronic illness, they were asked if the individual had difficulty climbing stairs; caring for personal needs such as dressing, eating, or toileting; or moving around inside the house.

Mental Health and Disability Measures

The NSFH contains information on whether children have seen a therapist or doctor for emotional or behavioral problems.

It also includes information on how often respondents felt bothered by things that did not usually bother them; not felt like eating; felt they could not shake off the blues even with help from family and friends; had trouble keeping their mind on what they were doing; felt depressed; felt that everything was an effort; felt fearful; slept restlessly; talked less than usual; felt lonely; felt sad; or felt like they could not get going. Questions also addressed whether anyone in the household had problems with drug or alcohol abuse.

Cognitive and Intellectual Disability Measures

If respondents reported that a member of the household, or anyone who had been a member in the past 12 months, needed assistance or care because of a disability or chronic illness, they were asked if the individual had difficulty caring for personal needs such as dressing, eating, or toileting..

Other Health and Disability Measures

The NSFH contains information on the reasons individuals joined or left the responding household, including because the individual needed care or assistance due to a disability or chronic illness; moving in or out of a nursing facility; and receiving nursing care at home. Respondents were also asked if any member of the household, or anyone who had been a member in the past 12 months, needed assistance or care because of a disability or chronic illness, and if so their age; condition; relationship to the respondent; when they began to need assistance or care; whether they could be left alone and for how long; and whether they had difficulty working (asked of those age 16 or older); driving a car (asked of those age 16 or older); or doing household tasks (asked of those age 16 or older).

The NSFH includes information on how satisfied respondents were with their health and how it compared with the health of others of their age, as well as sources of income including Supplemental Security Income, Social Security Disability Insurance, private disability, and workers' compensation. Questions in follow-up surveys addressed health insurance coverage.

Topic Areas

The NSFH collected information on household composition; the respondent's household composition while growing up; marriage history; cohabitation history; children in the household; income; assistance and care provided to those in and out of the household; attitudes and opinions; residential mobility; employment history; child care arrangements; income and assets; dynamics within the household including financial dynamics, household responsibilities, and how different members of the household interact; and detailed background and demographic information.

Links to Administrative Data

The NSFH is not linked to administrative data.

Potential Uses for Disability-Related Research

The NSFH can be used to describe the dynamics of families in which one or more individuals has a disability which requires care or assistance; to track changes in household composition over time; and to examine the changes which occur in a family when a member experiences the onset of a disability.

Sources of Information About the Survey

<http://www.ssc.wisc.edu/nsfh/mod1/Housecomp1.txt>

<http://www.ssc.wisc.edu/cde/nsfhwp/nsfh1.pdf>

<http://www.ssc.wisc.edu/nsfh/design.htm>

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NATIONAL SURVEY OF SSI CHILDREN AND FAMILIES (NSCF)

General Purpose

The NSCF collected data on the health status; functional limitations; health care utilization; health insurance coverage; receipt of special education, transportation, and other services; household socioeconomic status; and housing characteristics of over 3,000 children who were receiving, had received, or were applying for Supplemental Security Income (SSI).

Sponsoring Agencies

The NSCF was sponsored by the Social Security Administration (SSA).

Sampling Universe

The NSCF used a sample drawn from the SSA's administrative records of SSI applicants and recipients. The study was limited to the noninstitutionalized population in the continental United States (residents of Alaska, Hawaii and the territories were not included in the survey). Information was gathered from a parent or guardian, or the beneficiary if they were age 18 or older, and included data on both the beneficiary and other members of the family.

Sample Size

The NSCF used a sample size of 3,203 children and young adults receiving SSI benefits and their families.

Regional and State-Level Estimates

The NSCF does not support regional or state-level estimates.

Longitudinal Data

The NSCF does not provide longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The NSCF was conducted once, from 2001 to 2002.

Physical Health, Sensory, and Communication Disability Measures

The NSCF gathered information on whether the child who received SSI: needed or used more medical care, mental health, or education services than most children; if the child needed or used medicine prescribed by a doctor; was limited or prevented in any way in their ability to do things children of the same age can do; needed or got special therapy; and if so if it was because of a medical, behavioral or other health condition, and if it had lasted or was expected to last 12 months or longer.

If the child had a current health condition or problem the survey collected information on whether they used any medical devices such as a glucose monitor or wheelchair; how well they heard

without a hearing aid; whether they experienced any difficulty seeing even with glasses or contact lenses; whether they needed help with personal care, and if so what activities required assistance (age 5 or older). Questions also addressed how many times in the previous 12 months they had seen a doctor or other medical professional; stayed overnight or longer in a hospital; been to a hospital emergency room; had surgery, and how much was paid by the family for physical health care for the child. Questions also asked whether they had delayed or gone without health care, dental care, or medication, and if so why.

Mental Health and Disability Measures

The NSCF gathered information on whether the child who received SSI: needed or used more medical care, mental health, or education services than most children; needed or used medicine prescribed by a doctor; was limited or prevented in any way in their ability to do things children of the same age can do; needed or got special therapy; and if so if it was because of a medical, behavioral or other health condition, and if it had lasted or was expected to last 12 months or longer.

The survey also asked if the child needed or got treatment or counseling for any kind of emotional or behavioral problem; and if so if the condition had lasted or was expected to last 12 months or longer; and if they were limited in any way in any activities due to that condition.

The survey also collected information on whether they had stayed overnight to receive treatment for mental health or substance abuse in the past 12 months, and if so whether for mental health or substance abuse, and how many times; if they had received outpatient treatment for mental health or substance abuse, and if so whether for mental health or substance abuse, how many times, and how much treatment cost the family.

Cognitive and Intellectual Disability Measures

The NSCF gathered information on whether the child who received SSI: needed or used more medical care, mental health, or education services than most children; if the child needed or used medicine prescribed by a doctor; was limited or prevented in any way in their ability to do things children of the same age can do; needed or got special therapy; and if so if it was because of a medical, behavioral or other health condition, and if it had lasted or was expected to last 12 months or longer.

If the child had a current health condition or problem the survey collected information on whether they used any medical devices; whether they needed help with personal care, and if so what activities required assistance (age 5 or older).

Other Health and Disability Measures

The NSCF asked whether a medical, behavioral, or health condition currently prevented recipients age 17 or older from working at a job or business or attending school; or limited the kind or amount of work or school they could participate in.

Questions also collected information on whether the child was covered by health insurance; the kind of coverage (for example Medicaid, private insurance from an employer); who paid for coverage; whether the individual was ever without health insurance coverage in the previous 12 months, and if so for how long; if the respondent had tried to get their insurance to pay for

something for the child but the insurer had refused to pay, and if so what for; whether the respondent had tried to get private insurance but been unable to, and if so why.

The survey collected information on whether school-age children were not going to school due to illness or disability; if they received special education services, and if so where and whether in a regular classroom, resource room, or separate classroom. If the child did not receive special education services the survey asked if the respondent had tried to get services for them, and if they were on a waiting list. The survey collected information on whether children under 3 were receiving early intervention services and if so where, and if not whether the respondent had tried to get services for them and if they were on a waiting list. The survey collected information on whether recipients age 14 or older had received any training in job skills, vocational education, or help finding a job; and if so what kind, where from, and how much; and if they were then receiving training. If the SSI recipient had not received training the survey asked if the respondent had tried to get training for them, and if they were on a waiting list. Questions also asked how likely the child was to attend school or training after they turn 18, and how likely they were to live independently. Recipients age 17 or older were asked if they had ever been referred to vocational rehabilitation services by SSA, and if so if they were accepted.

If the child had a current health condition or problem the survey collected information on how often and to what degree they were limited; how severe the problem was; how often their health needs changed; what their main condition was; how long they had had this health condition; how many days of work or school were missed in the previous 12 months because of illness or injury (age 17 or older); how many days they had been kept in bed more than half the day due to illness or injury (age 17 or older); whether they needed help with routine tasks such as preparing meals and managing money and if so what tasks (age 17 or older); whether family members provided any health care at home, and if so how much time they spent on it and how they were related; whether they received health care from others, and if so how much the family paid for it.

The survey also asked if they had an individual education plan or an individual written rehabilitation plan.

Topic Areas

The NSCF covered disability status and functional limitations; health care utilization; health insurance; education and training; other programs and services; impact on family; SSI experience; employment; work and child care; unearned income and assets; housing and transportation; and background information.

Links to Administrative Data

The NSCF is not linked to administrative data.

Potential Uses for Disability-Related Research

The NSCF allows researchers to estimate the number of children receiving SSI who are not receiving needed services; to examine the family dynamics of children receiving SSI; or to understand the use of other programs by families receiving SSI benefits for a child's disability.

Other Notable Features

The NSCF sample includes children and young adults receiving SSI as well as those who received SSI benefits in the past.

It is sometimes referred to as SSI-Kids.

Sources of Information About the Survey

<http://www.ssa.gov/disabilityresearch/nscf.htm>

Ireys, Henry, Daniel Kasprzyk, Ama Takyi, and Jennifer Gillcrist. Estimating the Size and Characteristics of the SSI Child Population: A Comparison Between the NSCF and Three National Surveys. Washington, DC: Mathematica Policy Research, 2004.

NATIONAL SURVEY OF VETERANS (NSV)

General Purpose

The NSV provides information for developing and planning U.S. Department of Veteran Affairs (VA) programs. The survey collects information from both active and veteran service members and their families.

Sponsoring Agencies

The NSV is sponsored by the VA.

Sampling Universe

The 2001 NSV used a nationally representative sample of noninstitutionalized veterans. Eligible respondents were identified through telephone screening interviews conducted in the U.S. and Puerto Rico. The sample was augmented by a random sample of veterans selected from the VA Compensation and Pension records and VA Health Care Enrollment files.

The 2009 NSV included military family members as a part of the sample for the first time in the history of the survey. Family members were surveyed along with active and veteran service members. Data, questionnaire, and final report for the 2009 NSV are not yet available.

Sample Size

The 2001 NSV interviewed 20,048 respondents.

130,000 screening surveys were mailed to households for the 2009 NSV to identify eligible respondents. 10,000 veterans are expected to participate in the 2009 NSV. Data, questionnaire, and final report are not yet available for the 2009 NSV.

Regional and State-Level Estimates

The NSV does not support regional or state-level estimates.

Longitudinal Data

The NSV does not collect longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The NSV has been fielded six times in 1978, 1979, 1987, 1993, 2001, and 2009.

Physical Health, Sensory, and Communication Disability Measures

The 2001 NSV collected information about any medical treatment over the previous year for specific physical, mental, and emotional conditions including eye or vision problems, a hearing condition that requires a hearing aid, cancer, diabetes, and HIV/AIDS.

The 2001 NSV collected information about difficulties in the last week with activities of daily living including eating, using or getting to the toilet, bathing or showering, getting dressed, controlling bladder or bowels, walking across a room, and getting in or out of chairs or bed. The survey also collected information about difficulties during the previous week with instrumental activities of daily living including preparing meals, managing money, using the telephone, doing light housework, shopping for personal items, shopping for groceries, or going places within or out of walking distance.

Mental Health and Disability Measures

The 2001 NSV collected information about any medical treatment over the previous year for specific physical, mental, and emotional conditions, including post-traumatic stress disorder and drug abuse or alcoholism.

The 2001 NSV collected information about difficulties in the previous week with instrumental activities of daily living including preparing meals, managing money, using the telephone, doing light housework, shopping for personal items, shopping for groceries, or going places within or out of walking distance.

Cognitive and Intellectual Disability Measures

The 2001 NSV collected information about difficulties in the previous week with activities of daily living including eating, using or getting to the toilet, bathing or showering, getting dressed, controlling bladder or bowels, walking across a room, and getting in or out of chairs or bed. The survey also collected information about difficulties during the previous week with instrumental activities of daily living including preparing meals, managing money, using the telephone, doing light housework, shopping for personal items, shopping for groceries, or going places within or out of walking distance.

Other Health and Disability Measures

All respondents were asked if they currently had a disability and for their VA disability rating on the 2001 NSV. If the respondent indicated a disability, the respondent was asked whether the disability was related to military service. Respondents were asked whether they had worked or were looking for work in the week prior to the survey. If the respondent did not work or look for work they respondent could select that this was due to a disability.

The 2001 NSV asked if respondents were covered by Medicare; Medicare managed care; a health maintenance organization; Medigap or Medicare supplemental health insurance; Medicaid; CHAMPUS; TRICARE; another government health care program; or private health insurance.

The survey asked all respondents to rate their health status from excellent to poor. The survey also collected information about health care service usage during the previous year, including emergency room visits, outpatient care, inpatient care, prescriptions, treatment for environmental hazards, psychiatric treatment or counseling, in-home health care, and prostheses. If the respondent indicated using any services during the past year, the survey collected information about how the respondent paid for services and if the VA provided care.

Respondents who did not utilize VA benefits in the last year for health care services were asked for reasons why VA benefits were not used. They could respond that they used other sources for

health care, that using VA benefits was inconvenient, that they were not aware of VA health benefits, or that they had concerns about quality of care compared to other sources.

The 2001 NSV included sections focusing on VA disability compensation and pension and vocational rehabilitation and employment services. The survey collected information about program participation, reasons for not applying, ease of receiving benefits, the importance of programs to respondents, and knowledge of the programs.

Topic Areas

Topics on the 2001 NSV included military service experience, health status, health insurance coverage, VA disability compensation and pension program, educational programs, vocational rehabilitation and employment services, home loan guaranty program, life insurance program, and burial plans.

Links to Administrative Data

The NSV is not linked to administrative data.

Potential Uses for Disability-Related Research

The NSV surveys can be used to evaluate the prevalence of service-related disabilities and compare the health status of veterans with and without disabilities. It can be used to model service usage and to explore the reasons why people do not utilize VA health benefits. The information in the survey can be used to model the impact of changes in VA policy on services for people with disabilities.

Other Notable Features

The NSV is conducted infrequently. The most recent NSV was fielded in 2009.

Sources of Information About the Survey

http://www.virec.research.va.gov/References/Links/VHACorporateDatabasesMonograph_2010.pdf

<http://www.virec.research.va.gov/DataSourcesName/NationalSurveyVeterans/2001NationalSurveyofVeterans.htm>

http://www.va.gov/VETDATA/docs/SurveysAndStudies/NSV_Methodology_Report.pdf

<http://www.census.gov/housing/userdata/public%20nsv/final%20report.pdf>

http://www.cdva.ca.gov/news/DocAndImages/Survey_Households.pdf

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NATIONAL SURVEY ON DRUG USE AND HEALTH (NSDUH)

General Purpose

The NSDUH is the primary source of information on the prevalence, patterns, and consequences of alcohol, tobacco, and illegal drug use and abuse in the general U.S. civilian noninstitutionalized population age 12 and older.

Sponsoring Agencies

The NSDUH is sponsored by the Substance Abuse and Mental Health Services Administration.

Sampling Universe

The NSDUH samples the civilian noninstitutionalized population aged 12 years or older residing within the United States, including those living in group quarters but not those without a fixed household address. Up to two members of each sampled household unit are selected to complete the interview, with those ages 12-25 oversampled.²⁰ The sampling algorithm is updated approximately every 5 years.

Sample Size

The NSDUH samples approximately 86,000 individuals each year.

Regional and State-Level Estimates

The NSDUH produces representative estimates for the 50 states and the District of Columbia.

Longitudinal Data

The NSDUH does not produce longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The NSDUH was first conducted in 1972, and has been fielded annually since 1991. Interviews are evenly spread throughout the year. Each respondent is interviewed once.

Physical Health, Sensory, and Communication Disability Measures

The NSDUH does not include information specific to physical disabilities.

Mental Health and Disability Measures

A section given only to adults includes information on whether the respondent has stayed overnight or longer for treatment or counseling for problems with emotions, nerves, or mental

²⁰ In some households no individual is sampled, as each person is selected separately.

health; the kind of facility at which it occurred; who paid; how much was paid; if the respondent has received outpatient treatment or counseling; where that occurred; who paid; how much was paid; use of prescription medicine; if treatment was ever needed but not obtained, and if so why; and whether the respondent has received treatment from other sources (herbalist, acupuncturist, chiropractor, spiritual or religious advisor, internet support or chat room, in-person support group, or hotline).

A similar section given only to adolescents includes information on whether, due to emotional or behavioral problems not caused by alcohol or drugs, the respondent has stayed overnight or longer in a hospital, residential treatment center, or foster care; visited a partial day hospital or day treatment program, mental health clinic or center, private therapist, psychologist, psychiatrist, social worker, counselor, pediatrician or other family doctor; or been visited by an in-home therapist, counselor, or family preservation worker; and in each case why they did so. Respondents are also asked whether treatment has been received in school or in prison.

The survey also contains a section on mental health, which includes information on how often the respondent feels nervous; hopeless; restless or fidgety; so sad or depressed that nothing could cheer them up; that everything is an effort; or down on their self, no good, or worthless. It also contains information on whether and to what extent they have had difficulty concentrating; difficulty going out of the house or getting around on their own; difficulty dealing with people they did not know well; difficulty participating in social activities; difficulty taking care of household responsibilities; difficulty taking care of responsibilities at work or school; or difficulty getting work done as quickly as needed; and whether they were able to do these things at all during the month in the past year in which their symptoms were worst. Questions also address whether the respondent contemplated or attempted suicide, and whether they received medical attention as a result.

The NSDUH also contains a section on depression, which includes information on whether the respondent has, most of the day for a period of several days or longer, most of the day for two weeks or more, or most of the day every day, felt sad, empty or depressed; felt discouraged or hopeless; or lost interest or became bored with activities that are normally enjoyable; and if so whether during any of these periods the respondent also experienced any of these other depression symptoms; how severe and long lasting each feeling was during those periods; if the respondent was unable to carry out daily activities as a result or experienced changes in sleeping, eating, energy, concentration, or feeling bad about themselves; and if the respondent thought about, planned, or attempted suicide.

The survey also includes information on use of tobacco, alcohol, marijuana, cocaine, crack cocaine, heroin, hallucinogens, inhalants, pain relievers, tranquilizers, stimulants, and sedatives. Questions address whether respondents have used a particular substance; how often; how long it has been since they used the substance; and how old they were when they first used it. A noncore section asks other questions about substance use, which in 2010 included methods of using heroin; methods of using cocaine; use of methamphetamine; use of a needle to inject drugs; and use of a variety of drugs not specifically queried earlier. Questions also address whether and how often the respondent experiences a variety of symptoms of substance abuse and dependence, including needing to use an increasing amount to achieve the same effect; craving the substance; experiencing withdrawal symptoms; giving up activities; having physical health problems caused or made worse by substance use; and getting in trouble with the law.

The NSDUH also includes information on treatment received for alcohol and drug use, including the location of the facility and whether treatment was inpatient or outpatient; whether

additional treatment was needed; which substance or substances treatment was needed or received for; reasons for not getting needed treatment; time spent in treatment; who paid or is paying for treatment (private insurance, Medicaid, Medicare, other public program, own funds, a family member, courts, military health care, or an employer); and the age at which treatment was first received.

Cognitive and Intellectual Disability Measures

The NSDUH does not include information specific to cognitive or intellectual disabilities.

Other Health and Disability Measures

The NSDUH includes information on the number of hospital visits in the past year; conditions the respondent has been diagnosed with; whether the respondent is covered by Medicare, Medicaid, military health insurance or private health insurance; whether that insurance covers treatment for alcohol abuse or alcoholism, drug abuse, or mental or emotional problems; and whether the family receives Supplemental Security Income or Social Security or Railroad Retirement payments. When asked about their work activity, respondents can answer that they did not work in the past week because they are disabled.

Topic Areas

The NSDUH covers illicit drug use; tobacco and alcohol use; risk and protective factors; dependence, abuse, and treatment; sources of drugs; mental health; and demographics.

Links to Administrative Data

The NSDUH is not linked with administrative data.

Potential Uses for Disability-Related Research

The NSDUH can be used to estimate the need for treatment facilities for mental health and substance use problems in particular areas; to track changes in drug use patterns; and to estimate the substance use of people who are not working due to a disability.

Other Notable Features

The NSDUH interview consists of core and noncore sections. A core set of questions remains in the survey every year and comprises the first part of the interview. Noncore questions make up the remainder of the interview. The core consists of initial demographic items and questions pertaining to the use of tobacco, alcohol, marijuana, cocaine, crack cocaine, heroin, hallucinogens, inhalants, pain relievers, tranquilizers, stimulants, and sedatives. Topics in the remaining noncore sections include (but are not limited to) injection drug use, perceived risks of substance use, substance dependence or abuse, arrests, treatment for substance use problems, pregnancy and health care issues, and mental health issues. Noncore demographic questions address such topics as immigration, current school enrollment, employment and workplace issues, health insurance coverage, and income. Some of the noncore portions of the interview, including health insurance coverage and employment, have remained in the survey, relatively unchanged, from year to year.

Sources of Information About the Survey

<http://www.oas.samhsa.gov/NSDUH/2k7NSDUH/appA.htm>

<http://www.oas.samhsa.gov/nsduh/2k10MRB/2k10Q.pdf>

PANEL STUDY OF INCOME DYNAMICS (PSID)

General Purpose

The PSID provides information on the economic, social, and health factors affecting U.S. families over generations. It collects data on expenditures; income; health status; experiences related to drug use, housing and neighborhood conditions, education, and employment; and behavior.

Sponsoring Agencies

The PSID was originally sponsored by the U.S. Department of Commerce. The primary funding source is now the National Science Foundation, with additional funding from numerous federal agencies. The PSID is administered by the Survey Research Center at the Institute for Social Research at the University of Michigan.

Sampling Universe

The PSID uses two independent samples: an equal probability sample of households from the 48 contiguous states and a national sample of low-income families. The second sample selected about 2,000 low-income families with heads under the age of sixty residing in standard metropolitan statistical areas in the North and area that were not standard metropolitan statistical areas in the South from the Survey of Economic Opportunity. The PSID core sample combines the cross-sectional and low-income samples. Only household heads and their spouses are surveyed, but they provide information about other family members. While individuals living in group quarters were not part of the original sample, the PSID follows sample members whether they remain their original household, move to another household, or enter group quarters.

Sample Size

The PSID used a sample of 4,800 families in 1968, and the sample size increased to more than 9,000 families in 2009. By 2009 the PSID had collected information on a cumulative total of about 70,000 individuals.

Regional and State-Level Estimates

The PSID does not produce estimates at regional or state levels.

Longitudinal Data

The PSID follows individuals in the original sample over their lifetimes, even as family members leave their homes to establish new households of their own.

Frequency of Data Collection and Year(s) Fielded

The PSID has been fielded since 1968 when the original sample was selected. The PSID interviewed sample members every year from 1968 to 1997, and then began conducting interviews biennially. As respondents' children form their own independent family units, the PSID continues to interview them and members of their new family unit. In order to better reflect changing

demographics, an additional 2,000 families were added to the sample from 1990 to 1995, 441 additional families were added in 1997, and another 70 were added in 1999.

Physical Health, Sensory, and Communication Disability Measures

Questions ask respondents if they have any physical or nervous condition that limits the type or amount of work they can do and if it limits the type of work, the amount of work, or both; for their height and weight; and if they had difficulty seeing, even with glasses or prescription lenses, before the age of 17.

The survey asks if, because of a health or physical problem, respondents have any difficulty bathing or showering; dressing; eating; getting in or out of bed or a chair; walking; getting outside; or using the toilet; if someone usually helps them with any activities in which they are limited; and if they usually use special equipment to do each activity. Questions ask if, without personal assistance or assistive equipment, they have any difficulty preparing meals; shopping for personal toilet items or medicines; managing money; using the telephone; doing heavy housework; or doing light housework; and if so, if the limitation is due to a health or physical problem.

The PSID asks if respondents have ever been diagnosed by a health professional as having a stroke; heart attack; coronary heart disease, angina, or congestive heart failure; high blood pressure or hypertension; asthma; chronic lung disease; diabetes or high blood sugar; arthritis or rheumatism; cancer; or any other serious or chronic condition, and if so how old the individuals were when they first were diagnosed; if it got much worse for a month or longer in the past 12 months or since it was first diagnosed if it has not been 12 months since diagnosis (for strokes and heart attacks, individuals are asked instead if another stroke or heart attack occurred over the same time frame); and how much the condition limits their normal daily activities.

The PSID asks questions about individuals' health before the age of 17. It asks about the quality of their health; if they ever missed a month or more of school because of a health problem; if they ever had measles, mumps, or chicken pox; and if their parents or guardians smoked. They were also asked if they ever had asthma; diabetes; a respiratory problem or disorder; a speech impairment; an allergic condition; heart trouble; chronic ear problems or infection; epilepsy or seizures; severe headaches or migraines; stomach problems; or high blood pressure, at what age they were diagnosed with each problem, and until what age they had each problem.

Mental Health and Disability Measures

The PSID asks if respondents have ever been diagnosed by a health professional as having emotional, nervous, or psychiatric problems. If so, the PSID asks how old the individuals were when they first had the problem or were diagnosed; if the severity increased for a month or longer in the past 12 months or since it was first diagnosed if it has not been 12 months since diagnosis; and how much the condition limits normal daily activities. If individuals have an emotional, nervous, or psychiatric problem they are asked to identify their specific disorder.

The survey asks if respondents smoke cigarettes; how many cigarettes they smoke per day on average; if they ever smoked cigarettes; if they ever drink any alcoholic beverages; how often they drank on average in the last year; how many drinks they had on days they drank; and on how many days in the last year they had five drinks or more if they are male or four drinks or more if they are female.

The survey asks how often in the past 30 days respondents felt so sad nothing could cheer them up; nervous, restless or fidgety; hopeless; that everything was an effort; or worthless; if these feelings occurred more or less often in the past 30 days than was usual; how much more or less often they occurred; how much these feelings interfere with their life or activities; how many days out of the past 30 days they were totally unable to work or carry out their normal activities because of these feelings; and how many of the remaining days out of the 30 they were able to work but had to work less because of these feelings.

The survey asks if individuals had depression, drug or alcohol problems, or any other emotional or psychological problems before the age of 17; at what age they were diagnosed with each problem; and until what age they had each problem.

Cognitive and Intellectual Disability Measures

The PSID asks if respondents have ever been diagnosed by a health professional as having a permanent loss of memory or mental ability, or a learning disorder. If so, the PSID asks how old the individuals were when they first had the problem or were diagnosed; if it got much worse for a month or longer in the past 12 months or since it was first diagnosed if it has not been 12 months since diagnosis; and how much the condition limits their normal daily activities.

Other Health and Disability Measures

The PSID asks if respondents are not working because they are permanently or temporarily disabled; if they missed work in the past year because they were sick or because someone else was sick, and how much time they missed; if they received any income in the past year from Supplemental Security Income; other welfare funded by local and state governments; Social Security benefits for their own or a family member's disability; veterans' disability; or workers' compensation, who it was received for, how much they received, and in which months they received the income. The PSID includes information on the total amount of health care expenditures paid for by individuals and family residing with them during the last two years, with and without costs covered by insurance. It asks how much the family paid out-of-pocket for nursing home and hospital bills; doctor, outpatient surgery, and dental bills; and prescriptions, in-home medical care, special facilities, and other services.

The PSID asks respondents about the quality of their health in general, and how it compares with the last time they were interviewed. They are asked if they were patients in a hospital overnight or longer at any time during the past year and if so how long they were in the hospital.

The survey asks if any of the other family members residing with respondents are in poor health and who those family members are.

Topic Areas

Core topics include income sources and amounts; poverty status; public assistance in the form of food or housing; other financial matters including taxes and inter-household transfers; family structure and demographics; labor market work; time spent doing housework; housing; geographic mobility; socio-economic background; and health.

Supplemental topics include housing and neighborhood characteristics (1968-1972, 1977-1987); achievement motivation (1972); risk tolerance (1996); child care (1977); child support and child

development (1997, 2002); job training and acquisition (1978); retirement plans (1981-1983); health status, health expenditures, health care of the elderly and parent's health (1986, 1990, 1991, 1993-1995, 1999-2003); financial situation of parents, time and monetary help to and from parents (1980, 1988); wealth (1984, 1989, 1994, 1999-2003); education (1995); military combat experience (1994); immigration history (1997); time use (1997, 2002); and philanthropic giving (2001-2003).

Links to Administrative Data

PSID data collected in 2001 have been linked to Health and Retirement Study data collected in 2000. PSID data also are linked to Census data, allowing for the addition of data on neighborhood characteristics for the geographic areas in which panel individuals and families reside.

Potential Uses for Disability-Related Research

Because the PSID has followed families over generations since 1968 it provides an opportunity for researchers to study the development of disabilities over individuals' lifetimes from birth to adulthood. Because respondents' children are followed when they start their own households, researchers can gain a better understanding of the effects of upbringing and genetics on the development of disabilities within families. Additionally, the PSID collects data on pairs of siblings, allowing researchers to control for variables, such as family income level, family events, exposure to drugs, and thus better isolate the factors contributing to disabilities.

Other Notable Features

In 1990, 2,000 Latino households, including families originally from Mexico, Puerto Rico, and Cuba, were added to the sample to keep it representative despite changing immigration patterns. The Latino sample was dropped after 1995 because the sample did not include the full range of post-1968 immigrants (especially Asians). A supplemental sample consisting of 441 immigrant families was added in 1997, and an additional 70 immigrant families in 1999, for a total of 511 families.

Sources of Information About the Survey

<http://psidonline.isr.umich.edu/data/>

SURVEY OF CONSUMER FINANCES (SCF)

General Purpose

The SCF is a survey of household finances. The survey collects information on income, expenditures, savings, and use of financial institutions and services in U.S. households.

Sponsoring Agencies

The SCF is sponsored by the Federal Reserve Board and the Statistics of Income Division at the U.S. Department of Treasury.

Sampling Universe

The SCF uses an area probability sample of households. To account for income distribution and mitigate non-response bias, the SCF adds an additional sample of wealthy households selected from tax returns.²¹ The head of household, age 18 or older, completes the survey on behalf of the entire household.

Sample Size

The SCF uses a national sample of about 4,500 households.

Regional and State-Level Estimates

The SCF does not provide regional or state-level estimates

Longitudinal Data

The 1989 SCF re-interviewed a subset of the 1983 sample. However, the current SCF does not revisit households included in previous samples.

Frequency of Data Collection and Year(s) Fielded

The SCF began in 1983 and is fielded every three years.

Physical Health, Sensory, and Communication Disability Measures

The SCF does not collect information specific to physical health, sensory, and communication disabilities.

Mental Health and Disability Measures

The SCF does not collect information specific to mental health and disability.

²¹ The supplemental sample excludes the individuals named on the Forbes 400 list of richest Americans.

Cognitive and Intellectual Disability Measures

The SCF does not collect information specific to cognitive and intellectual disability.

Other Health and Disability Measures

The SCF collects information about general health status, life expectancy, and smoking habits for the respondent and spouse. When asked about their work status, respondents may answer that they are disabled. Sample members who report an absence from work due to a disability are asked when they became disabled, and if they are looking for work or expect to return to work. The employment status for respondents who report a disability is recoded into the following categories: working and disabled; disabled and expecting to return to work; disabled and looking for work; retired and disabled; disabled and not expecting to return to work.

The SCF asks if respondents are covered by private health insurance, Medicare, or Medicaid; and if they receive income from Supplemental Security Income, other types of welfare, disability benefits or military disability benefits.

Topic Areas

Topics covered in the SCF include economic expectations and use of financial institutions; credit attitudes and credit cards; principal residence and lines of credit; real estate and loans to others; businesses; vehicles; loans; attitudes about saving and investing; financial assets; work and pensions; income; taxes; income expectations; inheritances and charity; demographics; and health.

Links to Administrative Data

The SCF is not linked to administrative data.

Potential Uses for Disability-Related Research

The SCF can be used to evaluate the assets and liabilities of people who are not working due to disability. It can be used to compare the types and levels of expenditures of people with and without disabilities. Researchers can explore whether changes in income are attributed to a disability, or if savings decisions are impacted by life expectancy or health status.

Sources of Information About the Survey

<http://www.federalreserve.gov/pubs/oss/oss2/2007/scfoutline.2007.pdf>

<http://www.federalreserve.gov/pubs/oss/oss2/2007/codebk2007.txt>

<http://www.federalreserve.gov/pubs/oss/oss2/scfindex.html>

<http://www.federalreserve.gov/pubs/oss/oss2/papers/isi.2007.pdf>

SURVEY OF INCOME AND PROGRAM PARTICIPATION (SIPP)

General Purpose

The purpose of the SIPP is to collect information about the sources and amounts of earned and transfer income, labor force participation, program participation and eligibility, and general demographic characteristics. This information is collected to help measure the effectiveness of existing federal, state, and local programs; to estimate future costs and coverage for government programs; and to provide statistics on the distribution of income and measures of economic well-being in the country.

Sponsoring Agencies

The SIPP is sponsored by the U.S. Census Bureau.

Sampling Universe

The SIPP uses a multistage-stratified sample of the U.S. civilian noninstitutionalized population of all ages. Since the 1996 survey it has oversampled low-income households. Data are collected on all household members regardless of age.

Sample Size

The SIPP sample size varies by panel, and is largest in recent years. It ranges from 12,400 to 45,000 households, or approximately 26,040 to 94,500 individuals assuming an average of 2.1 individuals per household.

Regional and State-Level Estimates

The 2008 SIPP was designed to be representative within 20 states and the 2004 SIPP was designed to be representative within 33 states; previous panels were not designed to produce state-level estimates.

Longitudinal Data

SIPP panels follow households for longitudinal periods ranging from eight months to four years. Households that move continue to be interviewed if they can be located. Individuals 15 years and older who leave the household, but remain noninstitutionalized civilians, are interviewed in their new households, along with the other members of that household.

Frequency of Data Collection and Year(s) Fielded

In the original SIPP, administered from 1984 through 1995, new panels began yearly. Interviews began in October 1983 for the 1984 panel, and in each February starting in 1985. Panel members were divided into four groups that were interviewed every fourth month over the course of 32 months, for eight waves of data from each group. The first wave was interviewed in the first month of the panel, the second wave in the second month, and so on. Several panels were ended before all eight waves were completed due to funding issues.

The revised SIPP was first administered in 1996. Major changes to the design included four-year concurrent panels, oversampling of households with high poverty concentrations, and a larger

sample size. A four-year panel began in April 1996, a three-year panel began in February 2000 but was canceled after eight months due to budget problems, a three-year panel began in February 2001, and a four-year panel began in February 2004. A four-year panel began in September 2008, with the plan to reduce the sample size by approximately half for the fourth year.

Physical Health, Sensory, and Communication Disability Measures

Topical modules of the SIPP include information on illnesses and injuries; the use of mobility and hearing aids; and difficulty standing; sitting; stooping; and reaching overhead.

Topical modules also address difficulty seeing; hearing; speaking; lifting 10 or 25 pounds; pulling and pushing large objects; grasping; walking up stairs or a quarter mile; using an ordinary telephone; and the ability to perform these activities at all.

Topical modules of the SIPP also include information on difficulty experienced due to a physical or mental condition getting around inside the house; going out of the house; getting in and out of bed or a chair; taking a bath or shower; dressing; walking; eating; toileting; keeping track of bills (adults only); preparing meals (adults only); doing housework (adults only); taking medicine at the correct time (adults only); and whether the help of another person is needed to do these things.

Topical modules also include information on whether children have a physical or mental condition or a developmental delay that limits ordinary activities; a condition that affects their ability to move their arms and legs; to play; or limits their ability to do regular school work; and if they receive or have ever received special education services.

Mental Health and Disability Measures

Topical modules of the SIPP include information on difficulty concentrating, remembering, and making decisions.

Topical modules also address whether the respondent is frequently depressed or anxious; has trouble getting along with others; has difficulty concentrating; or has a hard time dealing with stress; and whether these conditions make it difficult or impossible to find or hold a job.

Topical modules of the SIPP also include information on difficulty due to a physical or mental condition going out of the house; taking a bath or shower; dressing; eating; toileting; keeping track of bills (adults only); preparing meals (adults only); doing housework (adults only); taking medicine at the correct time (adults only); and whether they need the help of another person to do these things.

Topical modules also include information on whether children have a physical or mental condition or a developmental delay that limits ordinary activities; a condition that affects their ability to play, or limits their ability to do regular school work; and if they receive or have ever received special education services.

Cognitive and Intellectual Disability Measures

Topical modules of the SIPP include information on whether the respondent has a learning disability; mental retardation; a developmental disability; Alzheimer's or another condition that

causes confusion and forgetfulness (adults only); attention deficit hyperactivity disorder (children only); or another developmental condition (children only).

Topical modules also address whether the respondent is frequently depressed or anxious; has trouble getting along with others; has difficulty concentrating; or has a hard time dealing with stress, and whether these conditions make it difficult or impossible to find or hold a job.

Topical modules also include information on whether children have a physical or mental condition or a developmental delay that limits ordinary activities; a condition that affects their ability to play, or limits their ability to do regular school work; if they receive or have ever received special education services, and whether they take medicine or receive treatment for attention deficit hyperactivity disorder.

Other Health and Disability Measures

Core questions of the SIPP include information on insurance coverage; receipt of disability benefits; eligibility or need for other programs due to a disability; and if respondents are unable to work due to a disability or other illness.

Topical modules of the SIPP include information on hospital stays, including the length and reason for visits; doctor visits and other medical expenditures; health care expenditures; general health status; health conditions; need for help with personal care, household activities, and basic errands because of a health condition; the type and source of that help. They also include details on health and physical conditions that might affect the respondent's ability to work, including the specific conditions, the condition that primarily limits the respondent's ability to work, when the condition began, whether the individual was working at the time, whether the condition was the result of an illness or injury, and if so where it occurred.

Topic Areas

Core questions, which are repeated in each wave, solicit information about income, eligibility for and participation in transfer programs, household and family composition, and labor force behavior.

Topical modules, which appear in select waves of some panels, include: adult well-being; children's well-being; functional limitations and disability; health and disability; health status and utilization of health care services; long-term care; medical expenses and work disability; work disability history; annual income and retirement accounts; assets and liabilities; real estate property and vehicles; reciprocity history; retirement expectations and pension plan coverage; school enrollment and financing; selected financial assets; shelter costs and energy usage; support for nonhousehold members; taxes; child care; child support agreements; child support paid; education and training history; employment history; job offers; work-related expenses; work schedule; extended measures of well-being; family background; fertility history; household relationships; marital history; migration history; eligibility for and reciprocity of public assistance; benefits; job search and training assistance; job subsidies; transportation assistance; health care; food assistance; electronic transfer of benefits; and denial of benefits.

Links to Administrative Data

The Census Bureau has created a number of linked files available on a restricted-access basis. These include a match between the 1984 panel and Social Security Administration (SSA) records that was available only to SSA analysts for a two-year period; a match between the 1984 panel and Internal Revenue Service (IRS) information, that was used within the Census Bureau; a match between the 1990 panel and IRS data that was used internally; and a match between partial data from the 1984 panel and data from eight federal and state programs that was used to check the accuracy of survey results. Matches between the SIPP and SSA records also are provided to SSA on a regular basis.

The SIPP Gold Standard project matched SIPP data from the 1990, 1991, 1992, 1993, 1996, 2001, and 2004 panels to IRS and SSA records and created synthesized data available as public-use files. The Gold Standard File is available for use at the Census Bureau. The synthesized data, called SIPP Synthetic Beta, can be accessed more easily, but also can produce misleading results. Researchers have the option of running programs on the SIPP Synthetic Beta and having their findings verified by the Census Bureau using the Gold Standard File. Plans call for the 2008 and future panels to be linked to national and state administrative data.

Potential Uses for Disability-Related Research

The SIPP provides data on income, work behavior, participation in programs including disability benefits, and the reasons for changes in program participation, including disability onset. It can be used to model the effects of changes in benefit eligibility rules; to determine the effect of disability onset on work behavior, earnings, assets, benefit receipt, and other components of well-being; and to better understand target populations such as those who retire before reaching full retirement age or who are uninsured.

Other Notable Features

SIPP disability measures are spread between several topical modules. The functional limitations and disabilities module is administered approximately twice a panel, the health and disability, medical expenses and work disability, and work disability history modules are administered approximately once a panel, and the health status and utilization of health care services module is administered two to three times a panel. Information on sources of income, program participation, and the presence of a work disability is collected at each interview and status is reported on a monthly basis.

The SIPP is in the process of again being redesigned. Major changes are expected to include annual interviews using an event history calendar and more extensive use of administrative data to verify and impute results as well as to add information not collected in the survey. Disability questions will be simplified as part of an effort to create a uniform set of questions that are used across a variety of surveys in several countries. Prototypes are currently undergoing field tests and refinement. While the redesign originally used the title Dynamics of Economic Well-Being, the survey will continue to use the SIPP title.

An additional sample of 2,447 known Social Security Disability Insurance and Supplemental Security Income beneficiaries were interviewed as part of waves 6 and 7 of the 2001 panel.

The Survey of Program Dynamics (SPD) collected information annually from 1997 to 2002 from members of the 1992 and 1993 panels, which ran until 1996. The SPD aimed to provide

information on actual and potential program participation in order to evaluate the effects of welfare reform legislation passed in 1996. Data on employment, income, program participation, health insurance and utilization, child well-being, marital relationships, and parents' depression was collected every year. Topical modules included a self-administered adolescent questionnaire and information on children's residential history and extended measures of well-being.

Sources of Information About the Survey

<http://www.census.gov/sipp/usrguide/sipp2001.pdf>

<http://www.census.gov/sipp/dews.html>

<http://www.census.gov/spd/overview.html>

http://www.census.gov/sipp/SSB_Codebook.pdf

Citro, Constance F. and John Karl Scholz, Ed. Reengineering the Survey of Income and Program Participation. Washington DC: The National Academies Press, 2009.

DeCesaro, Anne and Jeffrey Hemmeter. Characteristics of Noninstitutionalized DI and SSI Program Participants. Research and Statistics Note No. 2008-02, January 2008. Available at [<http://www.ssa.gov/policy/docs/rsnotes/rsn2008-02.html>].

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SURVEY OF INMATES IN LOCAL JAILS (SILJ)

General Purpose

The SILJ collects information on individual characteristics of jail inmates, including current offenses and detention status, characteristics of victims, criminal histories, family background, gun possession and use, prior drug and alcohol use and treatment, medical and mental health history and treatment, vocational programs and other services provided while in jails, as well as other personal characteristics.

Sponsoring Agencies

The SILJ is sponsored by the Bureau of Justice Statistics, U.S. Department of Justice.

Sampling Universe

SILJ data are collected through personal interviews with a nationally representative sample of inmates in local jails. For the 2002 survey jails were selected from those enumerated in the 1999 Census of Jails. Those with a large number of inmates had a higher probability of selection than jails with small inmate populations. A sample of inmates was then selected from these jails.

Sample Size

The SILJ interviewed 6,982 individuals in 417 jails in 2002.

Regional and State-Level Estimates

The SILJ does not produce regional or state-level estimates.

Longitudinal Data

The SILJ does not produce longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The SILJ has been conducted in 1978, 1983, 1989, 1996, and most recently in 2002.

Physical Health, Sensory, and Communication Disability Measures

The SILJ asks respondents if they have ever had cancer; or had a heart problem; and in each case if so what kind, if they still have it, and if they have seen a health care professional for it since admission to jail. The survey also asks of they have ever been unable to move parts of their body; had high blood pressure; had a stroke or brain injury; had diabetes or high blood sugar; had problems with their kidneys; had arthritis or rheumatism; had asthma; been told they had cirrhosis of the liver; been told they had hepatitis; or been told they had a sexually transmitted disease; and in each case if so if it is still a problem and if they have seen a health care professional for it since admission to jail.

The SILJ includes information on respondents' height and weight. The survey asks respondents if they have difficulty seeing ordinary newsprint, even when wearing glasses; if they have difficulty

hearing a normal conversation even when wearing a hearing aid; if they have a speech impairment; and if they use a cane, walker, hearing aid, or other device to help with daily activities.

Mental Health and Disability Measures

The SILJ asks at what age respondents first started drinking; how often they drank in the year before being admitted to jail; if they had been drinking at the time of the offense; and if so what, how much, and for how many hours; if they have ever felt they should cut down on drinking; if people have ever annoyed them by criticizing their drinking; if they have ever felt bad or guilty about drinking; if they have ever had a drink first thing in the morning to steady their nerves or get rid of a hangover; if they have ever driven a vehicle after having too much to drink; and if so if they have had an accident after drinking.

The survey asks if respondents have ever gotten into situations while or after drinking that increased their chances of getting hurt; had arguments with family or friends after drinking; or lost a job because of drinking. It asks whether in the year before being admitted to jail they had job or school trouble; got arrested or held at a police station; or got into a physical fight due to drinking. The survey asks whether in the year before being admitted to jail the respondent often drank more or longer than they intended to; wanted or tried to cut down on drinking but were unable to; spent a lot of time drinking or getting over the bad effects of drinking; were kept from doing work, going to school, or caring for children due to drinking; gave up activities in which they were interested in favor of drinking; continued to drink even though it was causing emotional or psychological problems; problems with family, friends, or work; or physical health or medical problems; found that their usual number of drinks had less effect than it used to; felt bad effects of drinking after cutting back or stopping drinking; or often drank or took another drug to get over or avoid the bad effects of alcohol. These questions are also asked about drug use.

The SILJ asks if respondents have ever used heroin; other opiates; methamphetamine; another amphetamine without a prescription; methaqualone without a prescription; barbiturates without a prescription; tranquilizers without a prescription; crack; cocaine other than crack; PCP; ecstasy; LSD or other hallucinogens; marijuana or hashish; other drugs; or inhaled or sniffed substances to get high. For each case in which respondents have used the substance the survey asks whether they ever used it at least once a week for at least a month; whether they used it during the month before their arrest; and how often they used it during that month. They are asked if they were under the influence of drugs at the time of their offense, and if so which; the source of their drugs in the month before arrest; and if they have ever used a needle to inject drugs.

The survey asks respondents if they have ever attended a drug or alcohol treatment program, and if so what kind; if they have ever attended programs while in jail or on parole; if they have attended programs during their current stay in jail, and if so if it is required or is offered in exchange for good or gain time.

The survey asks if, during the last year, respondents have lost their temper easily; been angry more often than usual; hurt or broken things on purpose out of anger; thought a lot about getting back at someone; had difficulty feeling close to friends and family; had periods when they felt that they talked or moved more slowly than usual; had periods when they couldn't sit still; had periods when their thoughts raced; thought that other people were able to control their brain and thoughts; had an increase or decrease in activity; slept more or less than usual; had more or less of an appetite than usual; gave up hope for their life or future; had negative or frightening thoughts; felt that other people could read their thoughts; been more or less interested in sex than usual; felt that no one

cared about them; had periods of feeling numb; had a feeling things didn't seem real; seen things other people said were not there; heard voices other people couldn't hear; or felt that anyone other than corrections staff were spying on or plotting against them. It also asks if they have been told by a professional that they have a depressive disorder; manic-depression, bipolar disorder, or mania; schizophrenia or another psychotic disorder; post-traumatic stress disorder; another anxiety disorder; a personality disorder; or another mental or emotional condition; and if so when they were most recently told that. They are asked if they take medicine prescribed by a psychiatrist or other doctor because of an emotional or mental problem; have been admitted overnight to a mental hospital, unit, or treatment program; have received counseling or therapy from a trained professional; or have received other mental health services, and if so if they were receiving the service during the year before their arrest and if they have received it since being admitted to jail. Respondents are asked if they have considered or attempted suicide.

The survey asks respondents if a mental health condition keeps them from participating fully in work, school, or other activities.

Cognitive and Intellectual Disability Measures

The SILJ survey asks respondents if they have a learning disability.

Other Health and Disability Measures

When asked if they were working before admission to jail respondents can report that they were not working due to a medical condition, ill health, physical or mental disability. Respondents are also asked if they consider themselves to have a disability, and if they have ever been enrolled in special education.

The survey asks whether, in the month before admission, the respondent received Social Security or Supplemental Security Income; or workers' or veterans' compensation. It also asks if they have ever received income from Social Security as a result of a retirement, survivors, or disability benefit; and if they have ever received Supplemental Security Income.

Topic Areas

The SILJ collects information on current offenses and detention status; pretrial release and trial; current sentence; incident characteristics; criminal history; socioeconomic characteristics; alcohol and drug use and treatment; medical conditions, mental health, and disabilities; and jail programs and activities.

Links to Administrative Data

The SILJ is not linked to administrative data.

Potential Uses for Disability-Related Research

The SILJ can be used to estimate the prevalence of disability among jail inmates; to compare substance use, abuse, and dependence between the incarcerated and general population; and to describe the presence and need for targeted health care and treatment programs within jails.

Other Notable Features

Recent modifications include enhanced questions on medical and mental health histories of inmates and a sample design modification to ensure a representative sample of juveniles being held in local jails.

Sources of Information About the Survey

<http://bjs.ojp.usdoj.gov/index.cfm?ty=dcdetail&iid=274>

<http://bjs.ojp.usdoj.gov/index.cfm?ty=pbdetail&iid=1128>

SURVEY OF INMATES IN STATE AND FEDERAL CORRECTIONAL FACILITIES (SISCF/SIFCF)

General Purpose

The SISCF and SIFCF collect data on inmates of state and federal prisons to assist policymakers in assessing needs and remedying deficiencies in the nation's correctional institutions.

Sponsoring Agencies

The SISCF is sponsored by the Bureau of Justice Statistics, U.S. Department of Justice. The SIFCF is sponsored by the Bureau of Justice Statistics and the Federal Bureau of Prisons, U.S. Department of Justice.

Sampling Universe

The SIFCF uses a nationally representative sample of sentenced federal inmates held in federally-owned and -operated facilities. The SISCF uses a nationally representative sample of state prison inmates. Prisons are identified from the Census of State and Federal Correctional Facilities and records of new prisons opened since the previous Census. Inmates are then sampled from selected prisons. Personal interviews are conducted with inmates from June through October of each survey year.

Due to the large proportion of drug offenders in the federal system, to ensure a large enough sample of non-drug offenders an oversample of inmates was selected, from which 1 of every 3 drug offenders was retained.

Sample Size

The 2004 SISCF used a sample of 14,499 individuals in 287 prisons. The 2004 SIFCF used a sample of 3,606 individuals in 148 prisons.

Regional and State-Level Estimates

The SISCF and SIFCF do not support regional or state-level estimates.

Longitudinal Data

The SISCF and SIFCF do not produce longitudinal data.

Frequency of Data Collection and Year(s) Fielded

The SISCF and SIFCF were fielded simultaneously using the same survey instrument in 1991, 1997, and 2004. The SISCF was previously conducted in 1974, 1979, and 1986.

Physical Health, Sensory, and Communication Disability Measures

The SISCF and SIFCF ask respondents if they have ever had cancer or had a heart problem, and in each case if so what kind, if they still have it, and if they have seen a health care professional for it since admission to prison. The surveys also ask if respondents have ever been unable to move

parts of their body; had high blood pressure; had a stroke or brain injury; had diabetes or high blood sugar; had problems with their kidneys; had arthritis or rheumatism; had asthma; been told they had Cirrhosis of the liver; been told they had Hepatitis; or been told they had a sexually transmitted disease; and in each case if so if it is still a problem and if they have seen a health care professional for it since admission to prison.

The SISCF and SIFCF collect information on respondents' height and weight. The surveys ask respondents if they have difficulty seeing ordinary newsprint even when wearing glasses; if they have difficulty hearing a normal conversation even when wearing a hearing aid; if they have a speech impairment; and if they use a cane, walker, hearing aid, or other aid to help with daily activities.

Mental Health and Disability Measures

The SISCF and SIFCF ask respondents if they have ever taken medicine prescribed by a psychiatrist or another doctor due to an emotional or mental problem; if they were taking it anytime in the year before their arrest; if they were taking it at the time of the offense for which they are in prison; and if they have taken medication for an emotional or mental problem since they were admitted to prison.

Respondents are asked at what age they started drinking; if they drank during the year before their arrest, and if so how often; if they had been drinking at the time of the offense for which they were arrested, and if so for how many hours, what, and how much. They are asked if they have ever felt they should cut down on drinking; if people have ever annoyed them by criticizing their drinking; if they have ever felt bad or guilty about drinking; if they have ever had a drink first thing in the morning to steady their nerves or get rid of a hangover; if they have ever driven a vehicle after having too much to drink; and if so if they have had an accident after drinking.

The surveys ask if during the year before admission to prison respondents ever got into situations while or after drinking that increased their chances of getting hurt; had arguments with family or friends while or after drinking; or lost a job because of drinking. They ask whether in the year before being admitted to prison respondents had job or school trouble; got arrested or held at a police station; or got into a physical fight due to drinking. The surveys ask whether in the year before being admitted to prison respondents often drank more or longer than they intended to; wanted or tried to cut down on drinking but were unable to; spent a lot of time drinking or getting over the bad effects of drinking; were kept from doing work, going to school, or caring for children due to drinking; gave up activities in which they were interested in favor of drinking; continued to drink even though it was causing emotional or psychological problems; had problems with family, friends, or work; had physical health or medical problems; found that their usual number of drinks had less effect than it used to; felt bad effects of drinking after cutting back or stopping drinking; or often drank or took another drug to get over or avoid the bad effects of alcohol. These questions are also asked about drug use.

The SISCF and SIFCF ask if respondents have ever used heroin; other opiates; methamphetamine; another amphetamine without a prescription; methaqualone without a prescription; barbiturates without a prescription; tranquilizers without a prescription; crack; cocaine other than crack; PCP; ecstasy; LSD or other hallucinogens; marijuana or hashish; other drugs; or inhaled or sniffed substances to get high. For each case in which respondents have used the substance the surveys ask whether they ever used it at least once a week for at least a month; whether they used it during the month before their arrest; and how often they used it during that month. They are asked if they were trying to get money to buy drugs at the time of their offense; if

they were under the influence of drugs at the time of their offense, and if so which; the source of their drugs in the month before arrest; and if they have ever used a needle to inject drugs.

The surveys ask respondents if they have ever attended drug or alcohol treatment programs, and if so what kind; if they have ever attended programs while in prison or on parole; if they have attended programs during their current stay in prison, and if so if it is required or is offered in exchange for good or gain time.

The surveys ask if, during the last year, respondents have lost their temper easily; been angry more often than usual; hurt or broken things on purpose out of anger; thought a lot about getting back at someone; had difficulty feeling close to friends and family; had periods when they felt that they talked or moved more slowly than usual; had periods when they couldn't sit still; had periods when their thoughts raced; thought that other people were able to control their brain and thoughts; had an increase or decrease in activity; slept more or less than usual; had more or less of an appetite than usual; given up hope for their life or future; had negative or frightening thoughts; felt that other people could read their mind; been more or less interested in sex than usual; felt that no one cared about them; had periods of feeling numb; had a feeling things didn't seem real; seen things other people said were not there; heard voices other people couldn't hear; or felt that anyone other than corrections staff were spying on or plotting against them. They also ask if respondents have been told by a mental health professional that they have a depressive disorder; manic-depression, bipolar disorder, or mania; schizophrenia or another psychotic disorder; post-traumatic stress disorder; another anxiety disorder; a personality disorder; or another mental or emotional condition; and if so when they were most recently told that. They are asked if they take medicine prescribed by a psychiatrist or other doctor because of an emotional or mental problem; have been admitted overnight to a mental hospital, unit, or treatment program; have received counseling or therapy from a trained professional; or have received other mental health services, and if so if they were receiving the service during the year before their arrest and if they have received it since being admitted to prison. Respondents are asked if they have considered or attempted suicide.

The surveys ask respondents if a mental health condition keeps them from participating fully in work, school, or other activities.

Cognitive and Intellectual Disability Measures

The SISCF and SIFCF ask respondents if they have a learning disability.

Other Health and Disability Measures

The SISCF and SIFCF ask if respondents were taking prescription medication when they were admitted to prison, and if so if they have continued to since. If respondents were not working at the time of their arrest they can answer that this was because of a medical condition, ill health, physical or mental disability. Respondents are also asked if they consider themselves to have a disability, and if they have ever been enrolled in special education.

Respondents are asked if they received Social Security; Supplemental Security Income; or workers' or veterans' compensation payments during the month before their arrest; and whether they have ever received income from Social Security as a result of a retirement, survivors, or disability benefit; or from Supplemental Security Income.

Topic Areas

The SISCF and SIFCF collect information on inmates' current offense and sentence; criminal history; family background and personal characteristics; prior drug and alcohol use and treatment programs; gun possession and use; and prison activities, programs and services.

Links to Administrative Data

The SISCF and SIFCF are not linked to administrative data.

Potential Uses for Disability-Related Research

The SISCF and SIFCF can be used to follow the presence of and need for specialized health care and substance abuse programs in prisons over time; to estimate the prevalence of disability among the incarcerated population; or to compare the prison experiences of those with and without disabilities, or those with different kinds of disabilities.

Other Notable Features

With each round of the survey, the questionnaire has been modified in order to capture information on evolving issues in criminal justice and topics of the greatest interest to users. Recent modifications include enhanced questions on medical and mental health histories of inmates.

Sources of Information About the Survey

<http://www.icpsr.umich.edu/icpsrweb/NACJD/sisfcf/>
<http://bjs.ojp.usdoj.gov/index.cfm?ty=dcdetail&iid=273>
<http://bjs.ojp.usdoj.gov/index.cfm?ty=dcdetail&iid=275>
<http://bjs.ojp.usdoj.gov/content/pub/pdf/pptmc.pdf>

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