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Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



ASSESSING THE NEED FOR A NATIONAL DISABILITY SURVEY: FINAL REPORT

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Office of the Assistant Secretary for Planning and Evaluation

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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, the agencies that provided input to the study, or Mathematica.

ACRONYMS

ACS	American Community Survey
Add Health	National Longitudinal Study of Adolescent Health
ADL	Activities of Daily Living
AHS	American Housing Survey
ASPE	Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services
ATUS	American Time Use Survey
B&B	Baccalaureate and Beyond Longitudinal Study
BLS	Bureau of Labor Statistics, U.S. Department of Labor
BPS	Beginning Postsecondary Students Longitudinal Study
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention, U.S. Department of Health and Human Services
CE	Consumer Expenditure Survey
CMS	Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services
CPS	Current Population Survey
DOL	U.S. Department of Labor
ECLS	Early Childhood Longitudinal Survey
EPA	U.S. Environmental Protection Agency
FAEP	Federal Advisory Expert Panel
HHANES	Hispanic Health and Nutrition Examination Survey
HHS	U.S. Department of Health and Human Services
HOS	Medicare Health Outcome Survey
HRS	Health and Retirement Study
HSLS	High School Longitudinal Study
HUD	U.S. Department of Housing and Urban Development
IADL	Instrumental Activities of Daily Living

ICDR	Interagency Committee on Disability Research
ICF	International Classification of Functioning, Disability, and Health
IES	Institute of Education Sciences, U.S. Department of Education
IRS	Internal Revenue Service, U.S. Department of the Treasury
LSOA	Longitudinal Study of Aging
MCBS	Medicare Current Beneficiary Survey
MEPS	Medical Expenditure Panel Survey
NBS	National Beneficiary Survey
NCHS	National Center for Health Statistics, U.S. Department of Health and Human Services
NCS	National Comorbidity Survey
NCVS	National Crime Victimization Survey
NELS	National Education Longitudinal Study
NHANES	National Health and Nutrition Examination Survey
NHATS	National Health and Aging Trends Study
NHES	National Household Education Survey
NHIS	National Health Interview Survey
NHIS-D	National Health Interview Survey on Disability
NIA	National Institute on Aging, U.S. Department of Health and Human Services
NLSY97	National Longitudinal Survey of Youth 1997
NLTCS	National Long Term Care Survey
NLTS	National Longitudinal Transition Survey
NLTS 2012	National Longitudinal Transition Survey 2012
NLTS2	National Longitudinal Transition Study 2
NNHS	National Nursing Home Survey
NS-CSHCN	National Survey of Children with Special Health Care Needs
NSCF	National Survey of SSI Children and Families
NSCH	National Survey of Children's Health
NSDUH	National Survey on Drug Use and Health
NSFH	National Survey of Families and Households
NSV	National Survey of Veterans
ONC	Office of the National Coordinator for Health Information Technology

PALS	Participation and Activity Limitation Survey
PSID	Panel Study of Income Dynamics
RSA	Rehabilitation Services Administration
SAMHSA	Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services
SCF	Survey of Consumer Finances
SILJ	Survey of Inmates in Local Jails
SIPP	Survey of Income and Program Participation
SISCF/SIFCF	Survey of Inmates in State and Federal Correctional Facilities
SSA	U.S. Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
SSN	Social Security Number
TAG	Technical Advisory Group
UI	Unemployment Insurance
VA	U.S. Department of Veterans Affairs
WIA	Workforce Investment Act

EXECUTIVE SUMMARY

Purpose of the Report

This is the final report of a project that assesses the need for developing and fielding another national disability survey data collection effort. It presents the findings from three principal project activities designed to assess whether existing data are sufficient to answer key disability-related research questions identified by the staffs of various federal agencies, and options for addressing the unanswered questions, including the pursuit of a national disability survey. These activities include:

- Obtaining feedback from federal and state agencies regarding their disability data needs and unanswered questions,
- Reviewing the disability-related information that is available in 40 existing national surveys, and
- Obtaining ideas and feedback from experts on disability data and research regarding how to address existing limitations in national disability data.

The summary provided in this report includes a review of existing disability data collection efforts and their limitations, and discusses a wide range of potential options to address these limitations. While the general purpose of the project is to assess the need for a national disability survey, we do not offer conclusions or recommendations regarding whether a national disability survey is warranted and if so, what its specific nature should be. Rather, this report provides objective information intended to be a resource for staff of the U.S. Department of Health and Human Services (HHS) and other federal agencies to inform their discussions and consideration of options for addressing their disability-related data needs, including the decision whether to conduct a new national disability survey.

Current State of Disability Data

Review of Existing National Surveys. Key findings from a review of 40 national 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.
- The National Health Interview survey (NHIS) and Survey of Income and Program Participation (SIPP) are frequently used to address disability-related issues because they contain a relatively large amount of disability content, are

representative of the national household population, and include large samples of people with disabilities.

- A concerted effort is being made to use a uniform set of disability indicators across surveys. The six-question series included in the American Community Survey (ACS), Current Population Survey (CPS), American Housing Survey (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 Panel Survey of Income Dynamics and Health and Retirement Study represent the most extensive efforts in that they regularly interview individuals from the time of sampling until death.
- 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 are also in the works. The National Longitudinal Transition Survey 2012 will provide new longitudinal information on transitions from school to work, and the National Health and Aging Trends Study will monitor changes in daily life and activities throughout the aging process of Medicare beneficiaries over age 65.
- Consumption, finances, expenditures, transportation, environmental barriers, accommodations, and community supports are the general topic areas least commonly addressed for people with disabilities in the surveys we reviewed.
- Administrative data have been linked with several of the national surveys. The most frequently linked administrative data sources are from Social Security and Centers for Medicare and Medicaid Services (CMS) programs, which have been linked with several health-focused national surveys.

A final key 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.

Disability Data Limitations. A number of limitations of existing disability data were identified by state and federal agency staff, Technical Advisory Group (TAG) members, and through our review of national surveys. Principal among these include:

- Disability measurement is inadequate. The health and functional measures used to identify people with disabilities vary markedly in concept, detail, and quality across surveys. Except for the surveys that focus on health, most do not capture in-depth information on the health issues and functional limitations experienced by people with disabilities. Measures corresponding to mental, emotional, cognitive, and intellectual disabilities were identified as being particularly poor.
- Sample sizes are small. Small numbers of people with disabilities in the large, general population surveys limit the ability to examine subgroups of people with disabilities. Analysis of residents of specific regions, states, or substate geographic areas is also limited due to small sample sizes.
- Administrative data are inaccessible. Administrative data are often hard to access due to legal, privacy, and security concerns, and data-sharing agreements are sometimes difficult to obtain. Linking the data across sources is also problematic because of technical issues and resource constraints.
- Quality is poor for some data. Respondent reports of program participation are believed to be inaccurate. Proxy responses and stigma related to disability also might contribute to poor data quality.
- Disability topics are inadequately addressed. Topics believed to be inadequately addressed include: disability onset and dynamics; program participation and the adequacy of support; supports needed to live in the community and environmental barriers to community participation; supports needed to obtain and maintain employment; disability-related expenditures; and health care access among employed people with disabilities.
- Data are not timely. Many sources of disability-related data are old or are produced very infrequently.
- There is inadequate longitudinal data. Existing longitudinal data fail to reasonably identify persons with disabilities and do not provide a lifetime perspective on disability.

Incremental Options for Addressing Disability Data Limitations

There are a number of ways that existing disability data collection efforts could be strengthened to address data gaps and limitations. Here, we describe a variety of strategies that build on existing data collection efforts, and thus, might be considered incremental in nature.

Increase Awareness of Existing Data. The perception of several TAG members was that a lot of good disability-related data exists, but that knowledge and use of some data sources are limited. Improving available information about existing data and making it easier for federal and state agency staff to access it is one potential way disability data limitations might be addressed. Reports that summarize a great deal of information in a format that is easily accessible, are one way this can occur and periodic cross-agency panels or work groups that exchange information about the nature and limitations of disability data are another.

Improve Disability Measures in National Surveys. Although disability is a difficult concept to define and measure, efforts to develop a succinct but comprehensive set of questions to identify people with disabilities have great potential value. Such efforts led to a six-question series developed by an interagency work group, which is becoming the new standard for identifying disability in national surveys. Despite the considerable efforts to develop these questions, however, they appear to not capture a significant number of people. Though not without its limitations, the addition of the six common questions across surveys was viewed as an important first step. While supportive of efforts to use a common set of disability questions, TAG and Federal Advisory Expert Panel (FAEP) members believed that complementary efforts were important and needed to be pursued. These include: preserving the ability to produce trends by at least temporarily including old disability questions when new questions are added; conducting research to better understand who is being captured by the six-question disability series; and strategically adding disability questions to selected surveys that will provide information to inform the findings from other surveys that do not include the additional questions.

Facilitate Increased Use of Administrative Data. There are many possibilities for enhancing the use of administrative data. Several appealing options include the following:

- Maintain and strengthen efforts to link survey and administrative data. Survey and administrative data linkages currently exist for many national surveys, and additional efforts in this area are an important way to address many disability data limitations. An example of a new effort would be to develop a match between the ACS and Social Security, Medicare, and Medicaid data. Improving the match rates in the survey-administrative data links conducted by the National Center for Health Statistics (NCHS) is another means of strengthening such efforts.

- Maintain and strengthen efforts to match administrative data across agencies. Cross-program data linkages would be useful for developing a better understanding of how the target populations of programs overlap and the extent to which service needs are met or are duplicative. Many interagency data use agreements are already in place; developing more of these and creating multilateral agreements would expand access to administrative data. Creating a stand-alone data workroom is another possibility. The workroom would provide access to data without personal identifiers that are linkable to data from numerous program sources.
- Make greater use of Unemployment Insurance (UI) records. Employment and earnings information collected by states for the UI program are reported quarterly and, as such, represent the most frequent and consistently collected administrative data source on employment and earnings. Developing linkages to federal administrative data or survey data and making the UI data accessible for more research purposes would address some of the disability data limitations surrounding the issue of employment.
- Develop the capacity to use electronic health records. The emerging use of electronic health records offers future opportunities to use these data on their own or to supplement other data for disability research and policy purposes, but work needs to begin now to facilitate this. Of particular importance is developing a standard set of items that measure disability and functioning. Social Security's current efforts to identify people with disabilities who meet their programs' disability criteria from such records might provide a good foundation for a broader effort to develop measures of disability and functioning from such records.
- Improve general accessibility. Greater accessibility could be achieved through improved documentation, technical assistance, and the creation of variables that are useful for research as opposed to program administration purposes. Access also could be facilitated through the use of a contractor to administer data use agreements (under a model similar to that used by the CMS's Research Data and Assistance Center).

Improve Collection of Longitudinal Information. Options for improving longitudinal data include collecting such information using event history calendars or diaries, and asking retrospective questions (for example, about key events surrounding disability onset). Improving the ability to efficiently measure and interpret changes in disability status over time might also lead to disability questions being added to existing longitudinal surveys. New or enhanced longitudinal survey efforts could also provide information on other unanswered disability-related questions. A new effort could sample people who apply to a program and who exit from the same programs. A more ambitious approach would be to develop a longitudinal disability sample. The SIPP could be used to identify respondents with disabilities and these respondents could be followed for an extended period (for example, 10 years).

Enhance Disability-Related Content in Existing Surveys. Inclusion of a basic set of disability questions in all surveys is the most important way disability-relevant content in national surveys could be improved. Among surveys that already include questions to identify people with disabilities, FAEP and TAG members believed it would be useful to add content related to: disability severity and onset, program participation and service use, barriers to independent living, work accommodations, accessible public transportation, assistive technology, disability-related costs, and the emotional and social impacts of disability.

Augment Samples in Existing Surveys. There are several possible ways to augment survey samples and address issues related to small sample sizes of people with disabilities:

- Pool data across survey years. This is a useful means for increasing sample sizes when data have been collected consistently over time. The Medical Expenditure Panel Survey (MEPS), NHIS, CPS, and SIPP are good candidates for pooling multiples years to increase sample sizes.
- Modify survey sample frames and methods to identify more people with disabilities in surveys. The exclusion of people residing in group quarters or institutions may inadvertently omit a large number of people with disabilities. Improvements in the manner with which surveys interview respondents might also help to identify more people with disabilities.
- Purposefully augment existing survey samples with individuals in the subpopulation of interest. An example is Social Security’s collaboration with the Census Bureau to include an additional sample of Social Security disability beneficiaries in the 2001 SIPP.
- The addition of the six-question disability series to federal surveys might also offer future opportunities to augment sample sizes in surveys that obtain their samples from larger national surveys. The screener questions from the parent survey could be used to augment samples of people with disabilities in the supplemental survey.
- Oversample from identifiable groups with high disability prevalence. The SIPP used this approach to oversample low-income households. For example, use ACS data pooled across years to identify small geographic areas where disability prevalence is relatively high, and then oversample those areas for the SIPP or NHIS.

Field Periodic Supplements. Adding a topical supplement to an existing national survey is a useful approach when a large amount of new information is required or when there is a need to study a specific subpopulation that cannot be easily identified with existing information. An existing, large national survey would act as the screener and this “parent” survey would also provide additional information that enhances the

supplement. Three general models for fielding topical supplements to existing surveys are currently used and offer models for adding disability-related content:

- Topical modules are supplementary questionnaires administered during a longitudinal survey that contains information on other topics, such as employment. The planned disability supplement to the CPS is an example.
- Topical question batteries are sets of questions that can be added to a core survey questionnaire but, unlike topical modules, are only asked of a subsample. An example of this is the Behavioral Risk Factor Surveillance System, where topical supplements can be used in concert with the core national survey and administered in a single interview.
- Topical surveys appear to be stand-alone surveys, but in fact derive their samples from a parent survey and so are essentially extensive topical modules of the parent survey. For example, the MEPS sample is derived from the NHIS. The supplemental interviews are conducted separately from the original interviews but the data from the original survey can be combined and used with the topical survey data.

Conduct Periodic Surveys of Subpopulations. Over half of the 40 surveys reviewed for this report represent surveys of subpopulations. The need for these types of surveys is driven by the specific information needs of particular agencies and the inability of general population surveys to identify or include in their samples sufficient numbers of individuals for which disability information is needed. Most subpopulation surveys focus on those already in a subpopulation, rather than those transitioning into or out of the subpopulation, such as applicants. Hence, adding special surveys that start with transitioning populations might be of considerable value (for example, transitions from education to employment, changes in residences, or from institutional to and from noninstitutional settings, entry to and exit from public programs, and across changes in health care systems).

Designate a Lead Agency or Group to Coordinate Disability Data Efforts. Designating a lead organization or agency to advocate for and coordinate disability data improvements efforts was perceived to be necessary. Proposed organizations include the HHS Office of the Assistant Secretary for Planning and Evaluation, the NCHS, the Office of Management and Budget, and the National Institute on Disability and Rehabilitation Research.

Addressing Disability Data Limitations with a National Disability Survey

Another approach to addressing the disability data limitations would be to design and conduct a national survey focused specifically on disability issues and populations. Pursuing such an option might be desirable if: pursuit of other, more incremental options

are infeasible or do not adequately address the disability data limitations considered to be of significance to federal agencies; there is a desire to collect a large amount and wide variety of data; and there is a goal to make disability issues more prominent and to establish an ongoing mechanism for periodically and consistently collecting data to assess the experiences and economic well-being of people with disabilities. Potential features of such a survey include the following:

Purpose. There are many different data limitations a national disability survey could be designed to address and the primary purpose of the survey will dictate its design features. Potential purposes include: providing a broad range of detailed information about disability and acting as the gold standard for general population prevalence and disability measurement; focusing on a subgroup neglected in other surveys; providing important disability-related information not captured in existing surveys; and ensuring periodic and consistent collection of key information on people with disabilities.

Stand-alone versus Supplement. A basic decision to be made with regard to conducting a national disability survey is the choice to establish a stand-alone survey or create a supplement to an existing survey. The only national disability survey ever conducted in the United States, the National Health Interview Survey on Disability (NHIS-D), was a supplement to an existing survey. Relative to a stand-alone survey, this approach imposes lower costs and burden and has the benefit of providing comparison data for people without disabilities at no additional cost. However, deriving a sample from an existing survey imposes the sampling and administration methods on the new survey. A stand-alone survey offers the opportunity to tailor sampling and administration methods to better capture people with disabilities who may be excluded from existing surveys.

Frequency of Administration. Ideally, data collection would occur frequently, perhaps annually or biennially, which would allow for an analysis of trends and short-term changes in the experiences of people with disabilities. An alternative model would be to administer a core set of questions on a regular basis with a more comprehensive disability survey occurring less frequently (for example, every 5-10 years).

Population Coverage and Level of Estimates. A national disability survey provides the opportunity to improve on data limitations related to the population sampled. Possible opportunities to improve or modify data collection in this respect include:

- Sample all Americans, including people who reside in the community, group quarters, and institutions, as well as those who are homeless.
- Improve coverage of people with disabilities and their families. Such information might be important in understanding the support system available to respondents with disabilities.

- Include all age groups and disability questions that are appropriate for different ages. The inclusion of all age groups in one survey would be important to a national disability survey intended to provide information on disability across the life cycle.
- Oversample or create new surveys focused on disability subpopulations neglected in other surveys. This could include people making transitions, racial and ethnic minorities, people with rare disabling conditions, and employment subgroups.
- Create a survey with a sample size large enough to produce state or local-level estimates. This will assist states in obtaining basic prevalence rates, assessing access to and unmet need for services, and understanding the impacts of state-level policies and programmatic changes.
- Focus on communities as the unit of observation. A focus on communities, rather than on individual experiences and perspectives, might be valuable for purposes of gathering information about the community environment, including supports for people with disabilities and how the environment affects outcomes for individual consumers.

Longitudinal Data. A longitudinal survey can address disability-related issues that cannot be addressed by other means (for example, capturing information about the dynamics of disability and the characteristics and outcomes of key transitions). Longitudinal information about working-age people with disabilities is particularly scarce. In collecting longitudinal data, panel length and survey frequency must be balanced against financial costs and the risk of sample attrition. Alternative methods to collecting longitudinal data include the use of retrospective questions and linkages with administrative data.

Disability Measures. A national disability survey could address problems with the inconsistency and quality of disability measures. A step to ensure consistency across other surveys measuring disability is to include the six-question series used to identify disability in the ACS, AHS, and CPS, which appears to be the new standard for identifying disability. Including other measures of disability as well would allow for a better understanding of which individuals are being identified and overlooked by the six-question series. A battery of more detailed questions to measure onset, severity, functioning, underlying causes of disability, and use of accommodations and supports could also be included. Short general health scales, such as the SF-12 and more detailed SF-36, might also be included to assess how these scales operate in the context of disability.

Topical Content. A national disability survey could potentially cover a wide variety of general topics, including health, health care, education, employment, program participation, participation in an array of social activities, housing, disability services, supports, and quality of life. A new data collection effort could also address disability-

specific topic areas, such as the role of the surrounding environment and transitions in and out of federal disability programs. Finally, a national disability survey could reach beyond a cursory level of understanding to know more about the motivation behind outcomes.

Links to Administrative Data. A national disability survey, regardless of its other features, would significantly benefit from linkages with administrative data. People with disabilities participate in public programs at high rates; creating linkages with administrative data from federal programs, particularly the Social Security disability programs, Medicare, and Medicaid, would provide accurate historical information on program participation and usage.

There are several advantages and drawbacks to conducting a national disability as a means for addressing existing disability data limitations.

Advantages. A national disability survey provides the flexibility to design a comprehensive survey that moves beyond the current level of coverage of disability-related issues. The key advantages of a national disability survey include:

- As a new data collection effort, it could be designed to specifically address particular existing data limitations.
- A national disability survey would be focused on disability and thus would be open to many questions, including those that may be of relevance only to people with disabilities.
- Statistics would be based on a single set of disability identifiers.
- In a new national disability survey, the identification of people with disabilities who are often overlooked (for example, people with specific disabilities, with difficulties responding to a particular survey format, or living in institutional settings) could be prioritized.
- A national survey has the potential to provide a complete life cycle perspective on disability, which seem to be missing from existing data.
- An ongoing national disability survey would ensure regular and consistent information over time about the experiences and well-being of people with disabilities and in doing so, inform disability issues and policies and make them more prominent.

Disadvantages. Although theoretically appealing, the reality of a national disability survey comes with several disadvantages. Disadvantages of a national disability survey include:

- It is potentially expensive to design and field.

- There might be significant political and practical challenges in attempting to coordinate, design, and implement a large undertaking.
- There is too much potential topical disability-related content to be incorporated in one survey. A survey lengthy enough to cover all relevant content would be prohibitively long, unless questions were spread across topical modules in a longitudinal survey.
- If designed to cover a broad set of topic areas, rather than focused on filling an existing information gap, might be viewed as duplicative of existing efforts.
- If designed as an extensive supplement to an existing survey, the parent survey may be averse to adding extensive screening questions or changing the sampling method to identify people with disabilities who may be overlooked.
- If designed as a stand-alone survey, comparative information on people without disabilities would either be unavailable or would require an even larger sample size.

Conclusions and Potential Next Steps

A substantial amount of survey and administrative data relating to disability is currently collected in the United States and significant progress has been made in improving the nature of the disability-related data collected. But despite this progress, important limitations to existing disability data persist. In this report, we have provided numerous ideas for ways in which disability data limitations might be addressed. Some potential next steps include:

- Conducting analyses to better understand the advantages and limitations of the six-question disability series with the intent of developing ways to improve the standard measure.
- Facilitating the use of linked survey and administrative data by developing procedures to improve match rates, improving documentation, and developing summary variables useful to administrative data users.
- Pursuing opportunities to develop the capacity to use electronic health records for disability-related purposes by engaging an organization involved in health information technology advancement to support such an effort and developing the means to identify people with disability in health records.
- Encouraging those responsible for existing national surveys to reassess their sampling frames and data collection methods to determine if there are ways to

increase the likelihood that people with disabilities will be captured in national surveys.

- If HHS and other agencies are interested in pursuing a national disability survey, the critical next step is to define the specific scope and purpose of the survey.

A national disability survey can address many existing disability data limitations, but there also are numerous incremental means to do so. Final decisions regarding which specific disability data collection efforts to pursue will be determined by federal policy makers and program administrators whose agencies' needs are diverse. It is unlikely that any single effort would address all limitations and disability data needs. But there are many possible strategies for ameliorating current disability data limitations and there is considerable room for multiple efforts, large and small.

I. INTRODUCTION

A. Purpose of the Report

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

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

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

This is the final report of a project that assesses the need for developing and fielding another national disability survey data collection effort. It presents the findings from three principal project activities designed to assess whether existing data are

sufficient to answer key disability-related research questions identified by the staffs of various federal agencies, and options for addressing the unanswered questions, including the pursuit of a national disability survey. These project activities include:

- Obtaining feedback from federal agencies regarding their disability data needs and unanswered questions,
- Reviewing the disability-related information that is available in existing national surveys, and
- Obtaining ideas and feedback from experts on disability data and research regarding how to address existing limitations in national disability data.

Our summary includes a review of existing disability data collection efforts and their limitations, and discusses a wide range of potential options to address these limitations. In developing the list of options, we did not constrain them based on potential costs, feasibility, or practicality. Our goal was to document a variety of ways that disability data limitations could be addressed without making judgments about which would be most feasible or desirable. Feasibility and desirability are subjective concepts that can change quickly in response to many factors, including technology, political will, available resources, and the needs of program administrators and policy makers. Efforts that seem difficult or impractical today could become achievable in the future.

While the general purpose of the project and this report is to assess the need for a national disability survey, we do not offer conclusions or recommendations regarding whether a national disability survey is warranted and if so, what its specific nature should be. Rather, this report provides objective information intended to be a resource for the U.S. Department of Health and Human Services (HHS) and other federal agencies to inform their discussions and consideration of options for addressing their disability-related data needs, including the decision whether to conduct a new national disability survey.

B. Sources of Information

Below, we describe the sources used to develop the information presented in this report.

1. Input from Government Agencies

Staff from 26 federal agencies and five state-level organizations provided responses to a set of questions related to their use of disability-related data, unanswered disability-related program and policy questions, subpopulations for which more information is desired, and efforts they have undertaken to address existing data limitations. The questionnaire and a list of agencies that provided responses are shown in Appendix A.

In identifying the agencies and staff to be solicited for input, we attempted to cast a broad net and include all federal agencies responsible for disability-related programs and policies. We also sought input from several federal agencies that have data collection, reporting, and program monitoring responsibilities. Although the federal agency perspective was the focus of our information collection activities, we also solicited input from a few state-level organizations. Once the list of target agencies was developed, specific individuals were identified to be contacted via email to provide input. These individuals were identified through the project team members' contacts in the disability field as well as through Internet searches and suggestions from federal staff and disability researchers. The large majority of agencies contacted provided input; only six of 37 agencies contacted did not respond.

Following receipt of the written input, we convened a Federal Advisory Expert Panel (FAEP) for a one-day meeting. The purpose of the meeting was to present the information collected on the nature of the disability data needs of federal agencies and limitations of existing data, and to obtain input on promising disability data improvement options that might be considered by HHS in coordination with other federal agencies. Representatives from 13 of the federal agencies that submitted written input accepted invitations to be members of the FAEP and participated in the meeting. Prior to the meeting, a summary of the federal and state input was distributed to FAEP members for review. A summary of the FAEP proceedings is provided in Appendix A.

2. Review of Existing Disability Survey Data

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 the Office of the Assistant Secretary for Planning and Evaluation (ASPE) and other federal agency staff.

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

- The survey was federally-sponsored and national in scope.
- It 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 and the unaddressed issues identified by the federal agencies.

We identified 40 surveys that met these requirements.¹ A tabular, quick-reference summary of the features of the 40 surveys reviewed is provided in Appendix B; more detailed text summaries of each survey are provided in a companion report (Livermore et al. 2011b).

3. Technical Advisory Group

A final source of information for our assessment was a Technical Advisory Group (TAG) convened for the project. The TAG was comprised of federal and nongovernment experts in the areas of disability data, research, and policy issues. The purpose of the TAG was to provide feedback on the findings from the FAEP meeting and the disability data review, and offer their ideas about specific options that might be pursued to address current disability data limitations. A one-day meeting was convened for this purpose. A summary of the proceedings of the TAG meeting is provided in Appendix C.

C. Report Organization

The remainder of the report is organized as follows:

- In Chapter II, we discuss the concept of disability and disability measurement, provide an overview of the disability data landscape based on our review of the 40 national surveys, and describe limitations of the existing disability data from the perspective of the federal agencies that provided input on their data needs.
- In Chapter III, we discuss various approaches to addressing disability data limitations that build on existing data collection efforts.
- In Chapter IV we discuss options for conducting a new data collection effort by means of a periodic national disability survey, focusing on key design features and considerations for such a survey.
- We provide conclusions and a discussion of potential next steps in Chapter V.

¹ Due to resource constraints, a small number of surveys that met these general requirements were not reviewed. In the discussion of the surveys presented in Chapter II, we note instances of surveys that meet the above criteria and/or were identified as being used by federal staff but were not included in our review.

II. CURRENT STATE OF DISABILITY DATA

In this chapter, we describe the current disability data landscape. We begin with a general discussion of the concept of disability, and then describe the findings of our review of 40 national surveys. The final section discusses a number of limitations of existing disability data as identified by staff of federal and state agencies.

A. Disability Framework and Nomenclature

To guide discussion related to disability, we turn to the International Classification of Functioning, Disability, and Health (ICF) to provide a framework for the concept of disability (WHO 2001). The ICF model draws on the medical and social models of disability, describing disability as the result of an interaction between health conditions and environmental factors. According to the ICF model, disability can occur at any of the three levels of functioning: body or body part (impairment), the whole person (activity limitation), and in a societal context (participation restrictions). The presence of disability is further dependent on contextual influences, including environmental and personal factors. Environmental factors such as physical structures, technological aids, laws and policies, and social attitudes may alleviate or contribute to disability at each level. Similarly, personal characteristics such as age, education, coping styles, and occupation may lead one person with a health condition to be regarded as having a disability while another person with the same condition is not regarded as having one. The levels of disability defined in the ICF model do not necessarily build upon one another. That is, it is possible to have an impairment but not a participation restriction, and vice versa. For example, a person with HIV with no impairments or activity limitations may be denied employment based on his health condition, creating a participation restriction (Weathers 2009).

The concepts defined in the ICF model are similar to those defined in a model of disability developed by Nagi (1965). Nagi posits that disability is the manifestation of a health limitation in a social context. Nagi explains that “not all impairments or functional limitations precipitate disability, and similar patterns of disability may result from different type of impairments and limitations in functions.” Both the ICF and Nagi models acknowledge the importance of the environment in determining disability, and recognize that disability can occur on several levels. The difference between the two models is in terminology and the boundaries at which various levels of disability are defined (Mathiowetz and Wunderlich 2000).

Translating the concepts developed by the ICF and Nagi models into a standard set of survey questions to identify disability is difficult. In general, capturing the complexity of disability in a concise set of questions to be included on a survey is challenging. Further, conceptual models of disability differ from the many programmatic definitions of disability; the Interagency Committee on Disability Research (ICDR) documented 67 different administrative definitions of disability (CESSI 2003). Due in

large part to the lack of a uniform definition of disability, definitions of disability on surveys vary as well, as is documented in the following section.

B. Findings from a Review of National Surveys

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. We provide an overview of the 40 national, federally-sponsored surveys we reviewed for this study, focusing on the disability-related content. While numerous data sources provide information about people with disabilities, no single source provides comprehensive data on all issues of interest to ASPE. Our review is intended to illustrate the kinds of information available and the variation across existing survey data sources to provide a context for considering options designed to improve disability data. 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 B. Detailed summaries of each survey are provided in a companion report (Livermore et al. 2011b).

TABLE II.1. Surveys Reviewed	
National Household Surveys	
1. American Community Survey (ACS)	11. National Health Interview Survey (NHIS)
2. American Housing Survey (AHS)	12. National Household Education Survey (NHES)
3. American Time Use Survey (ATUS)	13. National Survey of Families and Households (NSFH)
4. Behavioral Risk Factor Surveillance System (BRFSS)	14. National Survey on Drug Use and Health (NSDUH)
5. Census	15. Panel Study of Income Dynamics (PSID)
6. Consumer Expenditure Survey (CE)	16. Survey of Consumer Finances (SCF)
7. Current Population Survey (CPS)	17. Survey of Income and Program Participation (SIPP)
8. Medical Expenditure Panel Survey (MEPS)	
9. National Crime Victimization Survey (NCVS)	
10. National Health and Nutrition Examination Survey (NHANES)	
Surveys on Health, Disability, Aging, and Long-Term Care	
1. Health and Retirement Study (HRS)	8. National Long Term Care Survey (NLTC)
2. Longitudinal Study of Aging (LSOA)	9. National Nursing Home Survey (NNHS)
3. Medicare Current Beneficiary Survey (MCBS)	10. National Survey of Children with Special Health Care Needs (NS-CSHCN)
4. Medicare Health Outcomes Survey (HOS)	11. National Survey of SSI Children and Families (NSCF)
5. National Beneficiary Survey (NBS)	
6. National Comorbidity Survey (NCS)	
7. National Health Interview Survey on Disability (NHIS-D)	
Surveys on Youth, Education, and Transition	
1. Baccalaureate and Beyond Longitudinal Study (B&B)	6. National Longitudinal Study of Adolescent Health (Add Health)
2. Beginning Postsecondary Students Longitudinal Study (BPS)	7. National Longitudinal Survey of Youth 1997 (NLSY97)
3. Early Childhood Longitudinal Survey (ECLS)	8. National Longitudinal Transition Study 2 (NLTS2)
4. High School Longitudinal Study of 2009 (HLS)	9. National Survey of Children's Health (NSCH)
5. National Education Longitudinal Study (NELS)	
Other Surveys	
1. National Survey of Veterans (NSV)	3. Survey of Inmates in State and Federal Correctional Facilities (SISCF/SIFCF)
2. Survey of Inmates in Local Jails (SILJ)	

We identified several additional surveys that we did not review but which met the criteria for inclusion in our review described in Chapter I and/or were identified as being used by the federal and state staff that provided input to this study.²

In what follows, we provide a summary of the 40 surveys reviewed for this study, focusing on the population coverage and frequency of administration, disability-related content, the inclusion of longitudinal data, and links between the surveys and administrative data sources. The final two sections describe several new survey efforts and provide some general observations about the nature and content of the 40 surveys, respectively.

1. Coverage and Frequency

a. Ongoing National Household Surveys

The 17 surveys in this group are representative of all or most of the United States population. These surveys are conducted on a regular basis and represent the core of the government's national data collection efforts to monitor the characteristics, health, and well-being of the United States population.

Most ongoing national surveys cover the household or noninstitutional population, though the ACS (since 2006), AHS, Census, and the 1996 MEPS also cover certain nonhousehold or group quarters populations. The nonhousehold population is important to consider with respect to disability data because people with disabilities are disproportionately represented in this group (She and Stapleton 2009). Most ongoing national surveys include individuals of all ages in their samples, but in many cases a single household member provides information on all other family members, and in several instances children under a particular age are excluded.

Surveys in this category are fielded regularly, some annually and others less frequently (for example, every 4-8 years). Most have data available from 2007 or later. All but one (the PSID) can generate time-series data. About half of these surveys support estimates at regional or state levels.

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

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 multiple sources on this topic for calendar years 2004 and later.

² 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.

Seven of the 11 surveys produce time-series data and six of them 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 Supplemental Security Income (SSI) and Social Security Disability Insurance (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 and/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.

c. Surveys on Youth and Education

All of the surveys in this group 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 9th grade. Nearly all have been fielded relatively recently; with the exception of the NELs, which was last fielded in 2000, data are available from 2007 or later. 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. The B&B focuses on college graduates, BPS on college freshmen, HSLs on those enrolled in 9th grade, NELs on those enrolled in 8th 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, the NLSY97 used a similar age cohort--youth ages 12-16--and followed transitions to adult outcomes that were similar to the NLTS2.

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

d. Other Surveys

The three surveys in this group 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 none of them support state or regional estimates.

The NSV is focused on collecting information for developing and evaluating U.S. Department of Veterans Affairs (VA) programs. It uses a sample of veterans and, starting in 2009, active members of the military as well as their families. The SILJ and SISCO/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

a. Ongoing National Household Surveys

With a few exceptions, the ongoing national household surveys collect information that permits users to identify people with disabilities. However, the level of detail available in the identifying questions and the amount of other disability-related topical information contained in these surveys varies. 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, environmental barriers, accommodations, and whether the respondents are considered by themselves or others to have a disability.

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 in 2009 and to the CPS in 2008. As a result, the surveys can now 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. Also, because these questions were recently added, they can only be used to track short-term trends.

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 basic 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 a wider variety of measures of health status and disability.

The CE and SCF are two surveys in this group with very little disability-related information. These surveys collect disability information only in the context of income and expenditures. In both cases, respondents are asked about disability income (for example, SSDI, 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.

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.

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

Because they are specifically designed to provide information related to disability and health, the 11 surveys we reviewed in this group 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 job accommodations, barriers to work and use of U.S. Social Security Administration (SSA) work incentives, 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 disability-related 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 into the sample. The NCS asks a detailed battery of questions related to psychiatric and physical disabilities.

c. Surveys on Youth, Education, and Transition

Information on physical and functional limitations, mental and emotional disorders or symptoms, and employment appear in each of the nine surveys we reviewed that were focused on youth and education. Seven of the nine surveys collect information about learning disabilities, which is relatively uncommon in surveys of other populations. None of these surveys collects information on disability-related expenditures and only two cover issues related to substance use, abuse, and dependence, or transportation.

Disability content in the 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 the NLTS2 is much more extensive than in the other education-focused surveys. It 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 National Surveys

All three surveys in this group 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. Disability information collected by the NSV includes ADL limitations and instrumental activities of daily living (IADL) limitations, as well as VA disability ratings, sources of health insurance, and medical services used. The SILJ and SISCO/SIFCF include detailed sections on drug and alcohol abuse and dependence and on other mental health issues. Some information about physical health and physical limitations is also collected in these surveys. Finally, none of these surveys addresses cognitive impairment or developmental disorders, social participation or interpersonal interaction, use of or need for personal assistance, bed days, household expenses, or transportation.

3. Longitudinal Survey Data

Of the 40 surveys we reviewed, 22 of them are longitudinal or have some longitudinal component. Certain groups have more longitudinal coverage than others; for example there are several longitudinal surveys on youth (Add Health, NLSY), even more specifically focused on students (B&B, ECLS, HSLs, BPS, NELS, NLTS), and several covering older individuals and seniors (HRS, LSOA, NLTCs). Longitudinal surveys focused on subpopulations, such as those receiving Medicare (HOS, MCBS), and on specific topic areas such as health care use (MEPS), crime and victimization (NCVS), and spending habits (CE) also exist. Surveys that address income and economic well-being for the general population, such as the PSID and SIPP, also include extensive longitudinal information.

Of the 22 surveys that contain longitudinal data, seven follow sample members for 1-4 years (B&B, CE, HOS, MEPS, MCBS, NBS, NCVS, SIPP); five follow sample members for roughly 5-10 years (BPS, ECLS, LSOA, NCS, NLTS2), and the remainder contain longitudinal data covering periods of more than 10 years (AHS, HRS, HSLs, NELS, NLTCs, Add Health, NLSY97, NSFH, PSID). Follow-up interviews occur as frequently as quarterly (CE), or as infrequently as a single follow-up interview occurring 10 years after initial interview (NCS).

The AHS, PSID, and HRS are unique in that they have consistently and frequently collected data on sample members for a very long period of time. The AHS follows housing units, rather than individuals, but has followed the same sample of housing units every other year since 1985. Both the PSID and HRS follow individuals from sampling until death, interviewing them every other year--the PSID since 1968 and the HRS since 1992.

4. Administrative Data

Administrative data, alone or linked across programs or with survey data, are an important source of information for addressing disability program and policy issues. Administrative data can address three important limitations of survey data. First, they can often be used to create longitudinal administrative files to assess issues related to the dynamics of disability and program participation over time. Second, administrative data are the best source of information on the participation of people with disabilities in public programs and the characteristics of that participation--information that may be lacking in detail and subject to error in respondent-reported survey data. A final advantage of using administrative data is that they can be collected without posing additional burden on respondents because such efforts make use of data already being collected.

Many of federal and state staff who provided input to this study reported having used administrative data that were linked with survey and/or other administrative data to address disability-related program and policy issues. Linked administrative data also were frequently noted by federal staff as a means for addressing limitations in survey data. In Table II.2 and Table II.3 we list the linkages that were identified by the federal staff who provided input to this study as well as through our review of national surveys. SSA and Centers for Medicare and Medicaid Services (CMS) administrative data appear to be the sources that have been most extensively linked to other data sources, likely due to the importance of the programs operated by these agencies to people with disabilities. SSA data are particularly important for purposes of identifying who among those in a survey sample or other program administrative data are beneficiaries of SSI or SSDI. A number of new administrative data linkages with survey data planned for the near future also are shown in Table II.2, including linkages between national surveys and Medicaid and Medicare Part D administrative data.

Although some of the linkages shown in Table II.2 were conducted for one-time or very specific purposes, many reflect ongoing efforts to link administrative and survey data and make it more widely available for use by researchers. An important example is the National Center for Health Statistics (NCHS) data linkage activities. Under a federal interagency agreement, several NCHS population-based surveys (including the NHANES, NHIS, LSOA, and NNHS) have been linked to data from one or more of the following administrative sources: SSA, Medicare, U.S. Environmental Protection Agency (EPA) air quality, and state mortality data. Because their sampling frames are derived from the NHIS, the MEPS and NHIS-D also can be linked to data from these administrative sources.

TABLE II.2. Administrative Data Linkages with Survey Data	
Administrative Data Source	Linkages to Survey Data
Education	
Financial aid application data from the Central Processing System	B&B, BPS
Federal student loan amounts from the National Student Loan Data System	B&B, BPS
School records	ECLS, NELS, NLSY97, NLTS2
Medicare	
Medicare records from the Inpatient file and Skilled Nursing Facility file	HRS
Medicare records from the Denominator file; Medicare Provider Analysis and Review file; the Carrier file; the Home Health Agency file, the Durable Medical Equipment file; the Hospice file and the Outpatient file	HRS, LSOA, MEPS (via NHIS), MCBS, NHANES, NHIS, NHIS-D (via NHIS)
Medicare Standard Analytic File	NLTCS
Other Health and Medical Data	
Birth defect data	NS-CSHCN
Medicaid Statistical Information System data	ACS, BRFSS
EPA air quality data	NHANES, NHIS
National Death Index (NDI)	HRS, LSOA, NHANES, NHIS, NNHS
U.S. Social Security Administration (SSA)	
Social Security benefit records: Earnings, Benefits, SSI, Summary of Earnings and Projected Benefits, Wage and Self-Employment Income	HRS
Master Beneficiary Record, Supplemental Security Records file, Payment History Update System, 831 Disability Master File, and special extract of summarized quarters of coverage from the Master Earnings File	LSOA, MEPS (via NHIS), NHANES, NHIS, NHIS-D (via NHIS), NNHS
SSA data unspecified	CPS, SIPP
Other	
Area Resource File (county-level records)	MEPS
Climate data from nearest climate station	Add Health
Census data	Add Health, PSID
U.S. Department of Housing and Urban Development (HUD) administrative data	AHS
Internal Revenue Service (IRS) data	HRS, SIPP
Records from Aid to Families with Dependent Children, food stamps, unemployment, workers' compensation, federal civil service retirement, SSI, Social Security and veterans pensions and compensation	SIPP (1984 panel only)
Weather data from nearest weather station	Add Health
Planned Future Linkages	
Climate data from nearest climate station	NHIS
Medicaid claims data	HRS, LSOA, NHANES, NHIS, NNHS
Medicare Part D Denominator File; Medicare Part D Event File; and Chronic Condition Warehouse Summary Files	NHANES, NHIS, NNHS
National Highway Planning Network traffic indicators	NHANES
National Institute of Diabetes and Digestive and Kidney Diseases information on end-stage renal disease	NHANES, NHIS, NNHS

TABLE II.3. Administrative Data Linkages with Other Administrative Data	
Administrative Data Source	Linkages to Other Administrative Data
CMS data unspecified	Area Resource File, Minimum Data Set, Home Health Outcome and Assessment Information Set, Online Survey, Certification and Reporting
Rehabilitation Services Administration (RSA-911)	SSA
SSA data unspecified	IRS, Medicaid Buy-in program data, RSA-911, multiple SSA administrative data sources in the Ticket Research File, state Workforce Investment Act (WIA) and Wagner Peyser program data, U.S. Department of Defense Retirement data, Veterans program data
Veterans Programs	Bureau of Labor Statistics (BLS) unemployment data, SSA
State Medicaid Buy-in Programs	SSA
State WIA and Wagner Peyser Programs	SSA

5. New Survey Efforts

While many of the surveys we reviewed 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.

a. 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, hearing aid, 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 countries.

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 (DOL 2010).

The SIPP, conducted by the Census Bureau, is in the process of 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. SSA is scheduled to deliver the questions for the survey to the Census Bureau in summer 2011.

b. New Data Collection Efforts

The U.S. Department of Education is sponsoring a new round of data collection called the National Longitudinal Transition Survey 2012 (NLTS 2012). The NLTS 2012 will build on 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 (Center on Population Aging & Health 2010; NHATS 2010).

6. Commentary on Existing Disability-Related Data

Some general observations based on our review of the 40 surveys and the comments on national survey data provided by federal and state agency staff 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, such as the CE, do not.
- Based on the state and federal input received, the NHIS and SIPP are the two surveys most frequently used by federal and state staff to address disability-related issues, likely because they contain a relatively large amount of disability

content, are representative of the national household population, and include large samples of people with disabilities.

- A concerted effort is being made to use a uniform set of disability indicators across surveys. The six-question series included in the ACS, CPS, AHS, and NHIS supplement is part of this effort. A new supplement in the 2011 NHIS, which will include a battery of questions related to disability, represents an effort to make more uniform, descriptive information on disability available across countries.
- Few surveys contain measures to specifically identify individuals with cognitive or intellectual disabilities. Measures to identify specific health conditions underlying disability also are uncommon.
- There are numerous surveys of specific subpopulations (for example, students, inmates, nursing home residents, and beneficiaries of specific programs) on a variety of disability-related topics. This likely reflects the specific data and information needs of particular agencies and the fact that the general population surveys do not contain large enough samples of individuals in these specific target populations.
- Many national surveys have longitudinal components, though most cover a specific subgroup rather than a general population. The PSID and HRS represent the most extensive efforts in that they regularly interview individuals from the time of sampling until death or loss to follow-up.
- New disability supplements to the SIPP and CPS will increase the information available on employment, economic well-being, and program participation.
- 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.
- Administrative data have been linked with several of the national surveys. The most frequently linked administrative data sources are from SSA and CMS programs, which have been linked with several health-focused national surveys.

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. We turn to this subject in the next section.

C. Limitations of Existing Data on Disability

Although extensive information pertaining to disability is collected through national surveys and program administrative data, the existing sources of data on disability have a number of shortcomings that limit their usefulness. Gaps and limitations of available disability-related data were identified by the staff of the state and federal agencies that provided input to this study. Table II.4 lists specific questions they noted as being unanswered due to disability data limitations. These cover a wide range of topics that we have organized into several broad topic areas: program participation, education, employment, housing and independence, quality of life, health, and health care.³

The inability to address the numerous unanswered questions identified by state and federal staff stems from a variety of limitations of existing disability data. These limitations relate to the manner in which disability is measured, small sample sizes, data accessibility, the quality of collected data, poor coverage of certain disability-related topic areas, and the frequency of data collection. In the sections that follow, we discuss the nature of these limitations.

TABLE II.4. Unanswered Questions Due to Data Limitations Identified by State and Federal Agencies	
Program Participation	
1.	How many people with disabilities participate in multiple programs and what are their characteristics?
2.	Is there duplication or fragmentation of services for those participating in multiple federal disability programs?
3.	What is the cost-effectiveness of services for which consumers use comparable benefits?
4.	What happens to persons with disabilities after they leave public assistance programs?
5.	What are the incentives that affect individuals' decisions to either apply or not apply for DI and SSI benefits?
6.	What are the major referral sources for Social Security disability programs?
7.	How many people would meet SSA's definition of disability if they were not working and/or chose to apply?
8.	How do community rehabilitation providers rate with respect to the impact of service delivery after accounting for disability severity?
9.	How can researchers model the behavior of the nonelderly Medicaid disabled population?
10.	Are food assistance programs meeting the needs of disabled households?
11.	What are the types and numbers of customers with disabilities being served by the One-Stop system?
12.	How effective are state and federal benefit counseling services?
13.	What is the total federal compensation paid to disabled veterans?
Education	
1.	How does educational performance vary by type of disability?
2.	What services and accommodations are used by students with disabilities and how effective are they?
3.	What are the characteristics of students with disabilities?
4.	What happens to children who receive special education services but do not receive adult developmental services?
5.	How do people with disabilities make transitions from education to employment?
6.	What effect has rehabilitation had on drop-out and graduation rates?

³ Many of the questions shown in Table II.4 differ somewhat from the actual questions provided by federal and state agency staff; they represent condensed questions, elaborated questions given the context of the respondent's feedback, and combinations of related questions from different agencies.

TABLE II.4. (continued)	
Employment	
1.	What are the characteristics of working people with disabilities?
2.	What is driving the lower labor force participation rates among people with disabilities?
3.	What enhances return to work and long-term job retention following return to work?
4.	What are the quarterly employment and earnings patterns of SSDI/SSI applicants and beneficiaries?
5.	What are the quality and level of employment and how do they compare to desired employment?
6.	What are the labor market outcomes following participation in education and training programs?
7.	How are period of military service and race related to disability among veterans?
Housing and Independence	
1.	What kinds of assistance and services are needed for independent living in the community?
2.	What are the income level and housing needs of persons with disabilities living in noninstitutional group quarters?
3.	How do young people with disabilities make arrangements for housing following transition to adulthood?
4.	What is the relationship between housing and disability?
Quality of Life	
1.	What is the relationship between disabilities and household food insecurity?
2.	What are the consumption and expenditure patterns of persons with disabilities?
3.	What are the outcomes and quality of life for people with disabilities?
Health Status	
1.	How do morbidity and mortality relate to disability?
2.	What are the state-level prevalence rates of specific conditions?
3.	How prevalent are comorbidities among people with disabilities?
4.	How prevalent are intellectual disabilities and how do they affect overall health status?
5.	How prevalent are mental health limitations, and are limitations underreported?
6.	How does disability policy affect the dynamics of mental illness?
7.	What are the dynamics of disability (spells, duration)?
8.	What are the prevalence rates of disability for foster youth?
9.	What are the oral health status and immunization rates among people with disabilities?
Informal and Formal Health Care	
1.	What are the characteristics of co-residing caregivers and how does this care affect outcomes?
2.	To what extent do people with disabilities receive informal assistance with specific activities?
3.	How do long-term care programs and policies affect families and their role in care?
4.	What are the characteristics of the provider networks of working people with disabilities?
5.	What are the health care needs of the employed people with disabilities (rather than "utilization")?
6.	What functional and other factors are related to potentially avoidable hospitalization?
7.	What are the patterns of morbidity and utilization rates among states with high penetration of managed care patients?
8.	What is the medication usage of people with disabilities?
9.	What are the health care usage patterns of individuals who transition across systems and environments?
10.	How does continuity of care over time affect health outcomes and functioning?
Health Care Costs and Quality	
1.	What is the cost-effectiveness of care in programs that serve dual-eligibles?
2.	Should capitation rates to Medicare Advantage plans be adjusted to reflect the functional status of their enrollees?
3.	How do costs and utilization in Medicaid vary by SSDI/SSI status and length of time enrolled?
4.	How can access to and satisfaction with care be improved for the Medicare population with disabilities under age 65?
5.	How do people with disabilities' experiences in and satisfaction with Medicaid home and community-based service programs vary across states?
6.	What are the experiences of people with disabilities in managed care?
7.	What is the quality of care of programs that serve dual-eligibles?
8.	How can populations of people with certain disabilities be identified for specific quality measurement?

1. Disability Measurement

The health and functional measures used to identify people with disabilities vary markedly in concept, detail, and quality across surveys. The lack of consistency across

surveys leads to widely different prevalence measures and an inability to identify a common target population for which information across surveys might be used to develop a comprehensive picture of people with disabilities and their circumstances. Staff of many agencies pointed out that comparisons across surveys and populations are difficult at the national level, and even more so when attempting to crosswalk from national data to state-level data. As one participant noted, “While there has been improvement in the standardization of disability screeners, there is still a lack of consistency in disability questions among surveys.”

Except for the surveys that focus on health, most do not capture in-depth information on the health issues and functional limitations experienced by people with disabilities. Many surveys ask only a small sequence of questions related to disability, such as whether the survey respondent faces a work disability or has a limitation in one of six common functional categories (hearing, vision, mobility, cognition, self-care, and independent living). State and federal agencies identified many other areas for which detailed disability information was lacking, including age of onset, disability permanence, severity, general health status, functional status, activity limitations, and underlying medical conditions. Further, difficulty identifying people considered to have disabilities under varying programmatic definitions of disability was noted. For example, staff of one agency commented, “The current six questions in the ACS and CPS do not contain the specificity that we need to identify individuals who might be eligible for our program.”

Measures corresponding to mental, emotional, cognitive, and intellectual disabilities were identified as being particularly poor. One agency noted that “People with intellectual disabilities [are] not routinely included in surveys, due to the issues of consent, mode of survey (telephone, in-person, mail, Internet), [and] question development.” Another agency expressed concern over not being able to estimate the prevalence of mental disabilities and substance use disorders.

One FAEP member also pointed out that surveys with the same disability questions sometimes produce prevalence estimates that are different. This might reflect differences in the context of the questions or differences in survey methodologies.

2. Sample Sizes and Subgroups

The federal and state agencies that provided input to this study identified a number of subgroups for which disability-related data were lacking, primarily because of small sample sizes in the national surveys, but in some cases because these groups simply cannot be identified in existing national surveys. These subgroups include the three primary age groups (youth, working-age persons, and seniors), veterans, homeless people, people with specific health conditions or types of disabilities, various demographic subgroups, people who are not in the labor force, participants in public programs, and those receiving or providing formal and informal care. Table II.5 lists the subpopulations that were specifically noted. In some cases agencies noted specific

unanswered questions for a subpopulation; in such cases the questions are listed in Table II.5. Otherwise, only the subpopulation is listed.

Small numbers of people with disabilities in the large, general population surveys limit the ability to examine subgroups of people with disabilities. For example, subgroup analyses by specific types of disabilities, and those focused on current and potential program participants, cannot be conducted in many cases. One agency respondent suggested that small sample sizes might be a consequence of the inability of the currently used measures to capture people with psychiatric and intellectual disabilities. Many disabling health conditions are relatively uncommon and small sample sizes make identifying people with specific types of disabilities difficult. Staff of another agency noted that small sample size issues are most severe for those under age 65 because disability prevalence is relatively lower for this population.

Analysis of residents of specific regions, states, or substate geographic areas is also limited due to small sample sizes. As one respondent noted, there are “insufficient sample sizes to conduct state-specific estimates on people with disabilities.” Others also noted that state or other geographic-level analyses of people with specific conditions, functional limitations, and in various programs such as Temporary Assistance for Needy Families and Medicaid are not possible.

TABLE II.5. Subgroups for Which Disability Data Are Lacking Identified by State and Federal Agencies	
Demographic Subgroups	
1.	Distribution of those with psychiatric disabilities by age and gender
2.	Race/ethnicity and male/female
3.	To what extent do the populations of persons with disabilities overlap with minorities and low-income populations? How are these populations geographically distributed?
4.	More general information on people in the following groups: <ul style="list-style-type: none"> - American Indians - Asian Americans
Age Groups	
Children and Youth	
1.	Children (adequate sample sizes, disability measures, and family characteristics)
2.	Institutionalized children with disabilities--more information about their health status
3.	Children with parents with disabilities
4.	Youth with disabilities transitioning from school to work
5.	Students with intellectual disabilities and postsecondary educational outcomes
Working-Age Individuals	
1.	Nonelderly persons with disabilities
2.	Dual-eligibles under age 65 with serious mental illness, relevant for states pursuing the Health Home option under the Affordable Care Act
3.	Ages 18-64: participation in managed long-term care, Medicaid Buy-in, and competitive employment
4.	What are the health trends of those under age 65? (to predict future outcomes when over age 65)
Seniors	
1.	Elderly persons with disabilities and specific health issues that would benefit by having services brought to them
2.	People with disabilities ages 55-70 and how they would respond to changes in SSA and Medicaid eligibility ages
3.	Older persons residing in nursing homes and/or other institutions who could work

TABLE II.5. (continued)	
Veterans	
1.	Veterans--homelessness, access to Social Security and SSI benefits, family economic characteristics
2.	Do VA benefits help veterans improve their health and well-being and return to work, among other outcomes?
3.	How and when do recent veterans seek benefit services from the VA?
Homeless Individuals	
1.	Homeless SSI/SSDI applicants and beneficiaries--income, resources, access to Social Security and SSI benefits
2.	Distribution of those with mental health disabilities by homelessness history
Specific Types of Disabilities	
1.	Analyze services for individuals with disabilities by disability type
2.	People with AIDS who would benefit by having services brought to them
3.	Distribution of those with psychiatric disabilities by major diagnostic category
4.	Analyze services for individuals with co-occurring medical conditions
5.	Participation in managed long-term care, Medicaid Buy-in, and competitive employment by type of disability
6.	Specific limitations among race and demographic subgroups
7.	One-Stop customers with nonvisible disabilities (mental illness, learning disabilities)
8.	More general information on people with the following conditions: <ul style="list-style-type: none"> - Spina bifida, nationally and at the state level - Paralysis and limb loss, nationally and at the state level - Deafness or hearing loss - Mental illness - Behavioral health issues - Intellectual disabilities - Acquired brain injury
Employment Subgroups	
1.	Competitively employed individuals with disabilities
2.	Institutionalized people with disabilities who could work
Program Participants	
1.	Disability programs and various populations they serve
2.	More information about Medicaid Buy-In participants
3.	More information about those participating in Medicaid home and community-based services waiver programs
4.	SSDI and SSI beneficiaries <ul style="list-style-type: none"> - What access problems do SSDI beneficiaries in the 24-month waiting period experience and do they affect health outcomes? - How do allowed and denied disability applicants differ in terms of their characteristics?
5.	What are the characteristics of and outcomes for beneficiaries who work?
6.	What are the characteristics of and outcomes for beneficiaries who leave the rolls due to medical improvement?
7.	What are the outcomes for and number of beneficiaries enrolled in other programs?
Long-Term Care and Informal Care Providers and Users	
1.	More information about caregivers
2.	Services provided by nonpaid caregivers
3.	More information about the family of respondents in disability surveys
4.	Capturing the characteristics, medical expenditures, and utilization for persons residing in institutional settings
5.	More information about long-term care settings, including receipt of care at home
6.	More information about managed long-term care users

3. Administrative Data Access

Federal and state agency respondents acknowledged that use of survey data could be bolstered by linkages with administrative data collected by the programs that serve people with disabilities. However, data access issues and difficulties associated with performing such linkages were identified as hindering that process. Administrative

data are often hard to access due to legal, privacy, and security concerns, and data-sharing agreements are sometimes difficult to obtain. For those who were able to obtain access to necessary data, linking the data across sources proved to be problematic for various reasons. For example, FAEP members noted working at agencies that did not have adequate staff, time, and resources to manage data linkages. One state agency noted that states lack technical assistance in accessing and linking federal data. A federal agency noted that these barriers are even greater for nongovernmental researchers.

Although administrative data sources appear to be used extensively by federal agencies, respondents noted a number of limitations associated with these data:

- **Difficulty accessing administrative data from other agencies.** Several respondents indicated that obtaining data-sharing agreements across agencies was sometimes difficult and time-consuming.
- **Difficulty with and lack of resources available for linking data.** Several respondents noted that linking data is a technically demanding and resource-intensive process. Even when access is granted, adequate documentation, resources, and technical expertise are required to successfully link and analyze the data.
- **Timing of the data.** A few respondents also mentioned that the quarterly or annual nature of some administrative data (for example, earnings data) make them much less useful than if the data were collected and reported more frequently. In addition, administrative data made available for use more widely are often released with a considerable time lag.

Another potential problem with attempting to link administrative data to survey data is that this is primarily done through the collection of Social Security Numbers (SSNs) from survey respondents; respondents may refuse to provide this sensitive information due to identity theft or other concerns. Even among those willing to provide SSNs for themselves or others in their households, missing or incomplete information may be an issue. High refusal rates or incomplete SSN information will affect the quality of survey-administrative data linkage. As an example, the NHIS files linked with SSA administrative data that are maintained by NCHS have match rates that declined fairly steadily over time, from 75 percent in 1994 to 46 percent in 2005 (NCHS 2009). The low match rates in the later years will certainly affect the perceived quality of the data by researchers, and require those using the data to conduct analyses to assess the extent to which “nonmatching” bias might affect the findings of their studies. The Census Bureau has developed a method to link data that does not require participants to provide their SSNs (O’Hara 2007), which we describe in the next chapter.

4. Data Quality

Federal and state agency respondents cited data quality concerns in conducting disability-related research. Several listed specific datasets for which they believed the data were inaccurate or inconsistent. As a result, one agency noted that they had deemed certain data sources as “insufficiently reliable for specific purposes.” Data was thought to be particularly poor for age and gender subcategories, people with psychiatric disabilities, veterans, those participating in Medicaid managed care, and people receiving employment support services. It was postulated that proxy responses and stigma related to disability might contribute to poor data quality.

During the FAEP meeting, the issue of data quality was raised with respect to respondent reports of program participation. One meeting participant noted that his agency had found self-reports of program participation to be inaccurate when compared against administrative data. The lack of administrative data linkages across multiple programs and with survey data inhibits the ability to assess program participation, duplication, and adequacy of the services and benefits provided by federal programs.

5. Survey Content

A number of subject areas were identified as being inadequately addressed for people with disabilities. Subject areas deemed lacking include consumption, long-term supports, family structure, and informal care. Data also were perceived to be lacking for people who are similar to those enrolled in programs but who are not enrolled, as well as for people who have exited a program. For example, one agency stated “We have administrative data to track persons with disabilities when they are on Medicaid; however, we do not have data when they are not on Medicaid. This makes it impossible, for example, to track persons’ well-being after exiting from Medicaid.” Other examples of inadequate survey content were reflected in the unanswered questions and subpopulations of interest identified in Table II.4 and Table II.5.

During the FAEP meeting, participants elaborated on particular subject areas raised as being inadequately addressed for people with disabilities. These include:

- **Program Participation and Adequacy of Assistance.** Participants noted a lack of information about the adequacy of income assistance programs for people with disabilities, and a lack of measures of material hardship, quality of life, and other outcomes that would allow an assessment of whether programs are meeting their objectives. Participants noted the difficulty of identifying people with disabilities participating in multiple public programs, and so issues related to adequacy, duplication, and fragmentation of services cannot be addressed.
- **Community Living.** Inadequate information about unmet service and support needs of people with disabilities was discussed in the context of the demand for accessible housing and more generally, in terms of what is needed to help those with significant disabilities live in the community. While there is some information

at the national level about housing accessibility and services to support community living, such information is absent at the local level. It was noted that information is lacking about the types of services that people with significant disabilities need to live in the community, or the availability of those services in local (urban and rural) areas. For example, supports that are either formally or informally provided, including personal care, assistance with household maintenance, accessible housing, accessible and reliable transportation, home modifications, assistive technology, and particular types of job accommodations.

- **Employment.** Information about how individuals with significant disabilities are able to stay employed is limited. Members also had an interest in having more information about specific employment barriers and the extent to which individuals with disabilities believe that they are employed at their full potential. Other employment issues discussed related to underemployment among those with postsecondary education, and how the employment of and use of services by people with disabilities is affected by economic changes.
- **Expenditures.** FAEP members noted a lack of information about the consumption and expenditure patterns of people with disabilities, primarily because of the lack of disability measures in the CE. Information on expenditures might be used to infer service needs and use in order to address some of the unanswered questions noted in the three preceding topic areas.
- **Health Care and the Affordable Care Act.** Members noted that we lack information about the experiences of people with significant disabilities enrolled in employer-sponsored health insurance, and so are unable to infer the extent to which new sources of coverage implemented under the Affordable Care Act will meet the needs of people with disabilities. More generally, it was noted that information on health care access, quality, and unmet needs for people with disabilities is severely limited by existing data.

6. *Timing and Trends*

Federal and state agency respondents raised several issues related to survey data frequency and timing. One issue relates to the timeliness of available data; one respondent suggested that for programmatic purposes, old data were no longer helpful or relevant. Another issue concerned the lack of current trend data as some surveys transition to new measures of disability. One agency stated that “new instruments... are too new to provide information on trends.” Finally, several responses indicated that the lack of longitudinal data is an issue. Where these data exist, one respondent noted that longitudinal datasets fail to “reasonably identify persons with disabilities.” As some disabilities might be temporary or episodic, their effects are sensitive to the timing of the

survey. FAEP meeting participants also noted that existing data do not provide a lifetime perspective on disability. Age and population-specific surveys often provide detailed information, but only for a relatively short window of time or only for older individuals. Accordingly, it is difficult to understand the dynamics of disability onset at younger ages and changes in severity and functioning over time.

III. ADDRESSING DISABILITY DATA LIMITATIONS WITH INCREMENTAL CHANGES TO EXISTING EFFORTS

The TAG members and federal and state staff who provided input for this study indicated a number of ways that existing disability data collection efforts could be strengthened to address data gaps and limitations. In this chapter, we describe a variety of strategies that could be used to address survey data limitations. As noted previously, in developing the list of options we did not constrain them based on potential costs, feasibility, or practicality. Our goal was to document a variety of ways that disability data limitations could be addressed without making judgments about which would be most feasible or desirable. The discussion in this chapter focuses on approaches that build on existing data collection efforts, and thus, might be considered incremental in nature. In Chapter IV, we discuss another possible strategy--fielding a new national disability survey.

A. Increase Awareness of Existing Data

The perception of several TAG members was that a lot of good disability-related data exists, but that knowledge and use of some data sources are limited. The 40 national surveys reviewed for this project offer a variety of disability-related data. These surveys collect information about people with disabilities that covers a wide array of topic areas with varying degrees of detail. The list of surveys reviewed is not exhaustive and it is likely that most program administrators, policy makers, and researchers are unfamiliar with the content of all national surveys that contain information about people with disabilities. It is possible that some of the perceived limitations in existing disability data and unanswered questions might simply be due to a lack of awareness that certain survey data exist, or that certain administrative data can be accessed by external agencies. Some of the data limitations and unanswered questions indicated by state and federal agency staff might be addressed if information about the content of relevant surveys was known or if the resources to analyse these data in the ways needed to answer disability-related policy issues were available.

Several Census Bureau efforts were noted as being underutilized, such as small area estimates, which can calculate prevalence rates at the school district level, and research data centers, where researchers can go to gain access to results run on restricted data. The Census is also developing synthetic data files, which use variable imputations to mask the identity of survey respondents while making previously sensitive data available to the public.

One TAG member also mentioned an opportunity to coordinate state data collection efforts to produce a large, national database. Dissemination of these efforts to

the research community might help many researchers answer questions currently perceived to be unanswerable with existing data.

Improving available information about existing data and making it easier for federal and state agency staff to access it is one potential way disability data limitations might be addressed. Reports such as those produced for this project, which summarize a great deal of information in a format that is easily accessible, are one way this can occur. The Rehabilitation Research and Training Center on Disability Statistics and Demography, funded by the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education, represents another effort to produce a variety of easily accessible information about and statistics from existing national data on people with disabilities. Periodic cross-agency panels or work groups that exchange information about the nature and limitations of disability data are other means that have been used. Examples of these include the ICDR, including its Interagency Subcommittee on Disability Statistics, and the Federal Interagency Forum on Aging Work Group on Data Needs. TAG members suggested organizing a disability statistics group, similar to the ICDR, which would hold monthly phone calls and periodic meetings to share information.

B. Improve Disability Measures in National Surveys

As outlined in Chapter II, national surveys include a variety of disability measures. Researchers have produced several theoretical frameworks to model disability, but translating these models into survey questions can be challenging. Although disability is a difficult concept to define and measure, efforts to develop a succinct but comprehensive set of questions to identify people with disabilities have great potential value. Such efforts led to a six-question series developed by an interagency work group, which is becoming the new standard for identifying disability in national surveys (Adler et al. 1999). These questions are now included in the CPS, ACS, AHS, and NHIS. In June 2011, HHS announced that, in response to new requirements in the Affordable Care Act, they have developed draft standards for the collection of survey data that, among other things, will require all federal surveys to include the six-question series on disability. The six-question series solicits information about hearing, vision, cognitive, ambulatory, self-care, and independent living disabilities.

Despite the considerable efforts to develop these questions, they appear to not capture a significant number of people that are identified by program administrators as having disabilities, and might miss others as well. In a recent paper, Burkhauser et al. (2010) find that in the noninstitutionalized population ages 25-61, the six-question sequence identifies only 65 percent of those who identify themselves as SSDI or SSI beneficiaries. They argue for the addition of a work-limitation question, similar to that used historically in the CPS, which by itself identifies approximately 84 percent of those reporting SSDI or SSI receipt in the 2009 CPS as having disabilities. Combining the six questions with the work-limitation question increases the percentage of beneficiaries identified as having disabilities to 92 percent.

It is important to note that this research uses self-reports of SSDI or SSI receipt, which might themselves be inaccurate. Follow-up research by Burkhauser and his co-authors will use CPS data matched to SSA data to validate self-reports of SSDI or SSI receipt and assess the extent to which the six-question series captures this population. They will also compare the SSA primary impairments of those captured by the various disability questions to the impairments of those not captured. This analysis will be able to assess the validity of a concern expressed by FAEP members: that the six questions do not adequately identify people with significant behavioral, emotional, and intellectual disabilities.

Though not without its limitations, the adoption of a common set of questions in surveys is nonetheless a positive contribution to the national disability data system. The addition of the six common questions across surveys was viewed by FAEP and TAG members as an important first step and suggests similar types of cross-survey questions could be developed in the future with effective collaboration efforts. While supportive of efforts to use a common set of disability questions in all federal surveys, TAG and FAEP members argued that complementary efforts were very important and needed to be pursued at the same time. These include:

- Preserving the ability to produce trends by at least temporarily including old disability questions when new questions are added. For example, retaining the work-limitation question in the CPS would be beneficial for producing long-term trends.
- Conducting research to better understand who is being captured by the six-question disability series, as well as who is not being captured. What types of impairments are and are not captured, and of what severity? What other characteristics distinguish those with disabilities who are captured from those who are not? Opportunities to study the six-question series will be available with data being collected for the 2010 and 2011 NHIS and the data planned for the re-designed SIPP. Since 2008 the NHIS has included the six-question series, along with numerous other measures of health and disability. Likewise, the re-designed SIPP will include the six-question series, a set of re-designed disability questions, and a module that will include questions contained in the former SIPP disability topical module that is being supported by SSA specifically to offer the opportunity to study the new SIPP disability questions and their implications.
- Strategically adding disability questions to selected surveys, such as a work-limitation question or questions designed to identify specific conditions (for example, psychiatric or intellectual). The intent is to add detail that will be useful for the survey itself, but also provide information that illuminates the findings from other surveys that do not include the additional questions.

The FAEP and TAG members recognized that it will never be possible to develop a small set of questions that will perfectly distinguish between the disability and

nondisability populations, nor even to reach agreement on who should be included in disability and nondisability populations. Instead, they think that the expanded use and better understanding of a consistent measure of disability would help answer a number of questions raised by federal and state agencies, despite the inherent flaws in any such measure. Notably, one agency commented, “To date, lack of standardization of the disability definition has made comparison across surveys difficult; there are even differences in the estimates of the number of people with disabilities.” The failure of the current system to consistently estimate statistics as basic as prevalence by any disability definition is a major shortcoming of existing data. At the same time, it is critically important to have a sophisticated understanding of any measure’s limitations, and to address those limitations through improvements in the measure when it is feasible to do so.

C. Facilitate Increased Use of Administrative Data

As discussed in Chapter II, administrative data sources are extensively used by federal and state agencies and, when linked with survey data, add a longitudinal perspective to cross-sectional data. Administrative data also provide more accurate and detailed information about program participation and service use than can be collected via survey. CMS and SSA administrative data linked with large national surveys are particularly likely to be useful for studying a wide range of disability program and policy issues, and important linkages already exist.

There are many additional possibilities for enhancing the use of administrative data. We describe several appealing options below.

1. Maintain and Strengthen Efforts to Link Survey and Administrative Data

As shown in Table II.2, survey and administrative data linkages currently exist for many national surveys, and additional efforts in this area are an important way to address many of the disability data limitations discussed in Chapter II. Examples of administrative files that have been made more widely accessible include the NCHS survey-administrative data linkage efforts, and SSA administrative data linked with the SIPP, made accessible through the SIPP Synthetic Beta data product. An example of a new effort that might be supported would be to develop a match between the ACS data and SSA, Medicare, and Medicaid data. Our understanding is that Census and SSA have already taken steps to test matching procedures. The ACS offers the largest sample sizes of all of the ongoing national surveys, and linkages with administrative data from these major programs would support state and community-level estimates for participation, benefit, health, service, and other measures of interest to researchers and administrators.

Improving the match rates in the survey-administrative data links conducted by NCHS would be another means of strengthening such efforts. O’Hara (2007) describes a method by which data can be linked to administrative records without the collection of

SSNs from respondents. Currently, households selected for the CPS are sent letters informing them that their data may be combined with other data sources, unless they request otherwise. Following the interview, the Census Bureau works with SSA to use information collected on a sample member's name, address, and date of birth to obtain a SSN. Using this method, O'Hara found that 89 percent of all adults had verified SSNs that could be used for matching in the 2006 CPS. For this method to be applicable to other surveys, it requires that a consent process be added to the interview, where respondents consent to providing access to information on their program participation and earnings.

2. Maintain and Strengthen Efforts to Match Administrative Data Across Agencies

Cross-program data linkages would be useful for developing a better understanding of how the target populations of programs overlap and the extent to which service needs are met or are duplicative. Many interagency data use agreements are already in place; developing more of these would expand access to administrative data. There are several examples of existing linkages that provide a template for developing further linkages across agencies. For example, within the next two years, SSA is planning to develop files of Medicare and Medicaid enrollment and claims records that can be linked to SSA's disability data. SSA and RSA have already developed linkable RSA records.

The current agreements we are aware of are all bilateral, though multilateral matches would be valuable in providing information on participation in more than two programs. We understand that SSA, CMS, and the U.S. Department of Education have developed a trilateral agreement but that it has not yet been executed. Its execution, along with SSA's data linking activities, would make it possible for approved researchers in the three agencies and their approved contractors to link Medicare, Medicaid, SSDI, SSI, and RSA records. Qualified SSA employees would also be able to link the IRS earnings records.

Another way to expand such efforts might be to develop a stand-alone data workroom, without personal identifiers, that contains linkable data from numerous program sources: SSA, CMS, earnings data, food stamps, HUD, Temporary Assistance for Needy Families, and perhaps others. This is essentially a component of the vision for the re-engineered SIPP, which has plans to incorporate greater use of administrative data in its design. Attaching selected data from these sources to the SIPP records would be valuable. Allowing restricted-access to a broader set of administrative data would also be useful for many other purposes, including production of basic statistics on the participation of individuals with disabilities in all government programs and longitudinal analysis of individuals as they pass through these programs.

3. *Make Greater Use of Unemployment Insurance (UI) Records*

Employment and earnings information collected by states for the UI program are reported quarterly and, as such, represent the most frequent and consistently collected administrative data source on employment and earnings. However, states vary in the extent to which they permit researchers or others to use state-level quarterly UI data, and while these data are currently made available to the Federal Government, they may only be used for very specific federal administrative functions. Developing linkages to federal administrative data or survey data and making the UI data accessible for more research purposes would address some of the disability data limitations surrounding the issue of employment.

4. *Develop the Capacity to Utilize Electronic Health Records to Address Disability Issues*

FAEP members noted that the emerging use of electronic health records might offer future opportunities to use these data on their own or to supplement other data for disability research and policy purposes. Participants acknowledged that use of electronic health records is not feasible at this point in time, but might be a potentially important source of data on disability in the future. It was also noted that, if we expect to be able to use these data for program and policy purposes, work needs to begin now, while the standards and content of electronic health records are still being developed.

Of particular importance is the development of a standard set of items that measure disability and functioning, for use in the identification of people with disabilities in health records. Such measures would also be useful to track changes in disability and functioning over time and in response to particular medical treatments and procedures. Currently, information about disability and functional limitations is not routinely collected in medical records, but as is the case with national survey data, having a basic means to identify people with disabilities is a critical step to being able to use a data source to address disability-related research and policy issues.

SSA is at the forefront of efforts to collect disability data from electronic records. They have established contracts with local health information networks under which they can request the electronic records of applicants for SSDI and SSI benefits, with the approval of the applicant. The availability of electronic records for an applicant reduces the time it takes SSA to collect medical records from months to minutes, and reduces the likelihood that SSA will need to order a consultative examination for the applicant because of missing information. Once SSA has the electronic record, SSA can more readily obtain information from the record than they can from a paper record, and can also store critical information from the record in an electronic record. Currently, only a small share of applicant records are collected electronically, but SSA is pushing to rapidly increase this share. SSA also has plans to develop a repository of electronic medical data on its applicants, to support program management and research.

While there exists an opportunity to shape the future of electronic health records for purposes of disability research, an institution is needed to spearhead and coordinate the effort. The Office of the National Coordinator for Health Information Technology (ONC) is a promising choice given its current involvement in the development of a nationwide health information technology infrastructure. Many of ONC's goals, such as improving the quality of health care and reducing health care costs, can be applied to people with disabilities. Other goals, such as promoting the management of chronic diseases, directly relate to people with disabilities. Further, ONC is currently involved in strategic planning of the health information technology infrastructure and thus, is well positioned to effectively advocate for disability-related improvements to the developing system.

A larger effort by the government to build an electronic health record repository would no doubt be of great value to researchers. SSA's efforts to identify people with disabilities who meet SSDI/SSI medical criteria from such records might provide a good foundation for a broader effort to develop measures of disability and functioning from such records. It is also possible that major health systems with relatively long-standing electronic health record systems (including the Veterans Health Administration) recognize the value of measuring disability and functional status of their enrollees, and are already doing so.

5. *Improve General Accessibility*

As described in Chapter II, currently there is extensive use of administrative data, and many administrative data sources have been matched to both survey and other administrative data sources. But for a variety of reasons, these data are often technically or legally inaccessible to researchers. TAG and FAEP members suggested that administrative data should be released in a more timely manner and be made more user-friendly. Greater user-friendliness could be achieved through improved documentation, technical assistance, and the creation of variables that are useful for research as opposed to program administration purposes. It was also suggested that administrative data access could be facilitated through the use of a contractor to administer data use agreements (under a model similar to that used by the CMS's Research Data and Assistance Center). To maximize its value, any effort to build a multiagency data workroom would need to be accompanied by a substantial effort to make the data both technically and legally accessible to qualified researchers.

D. Improve Collection of Longitudinal Information

Linkages between survey and administrative data can provide longitudinal information to address some disability data limitations, but longitudinal survey data can also be useful for analyzing many issues that cannot be adequately addressed with administrative data alone. As noted previously, about half of the 40 national surveys we reviewed are longitudinal or have a longitudinal component. Longitudinal data can help researchers to understand the dynamics of disability in a way that is difficult to capture

in a cross-sectional survey. Disability is not a static condition; it may grow more or less severe over time, and limitations imposed by a specific condition may change as one's environment changes over time. Longitudinal surveys are generally more expensive to conduct than cross-sectional ones, both because data are collected over a longer period of time and because efforts must be made to locate sample members over time and minimize loss to follow-up. Budgetary pressures threaten the continuation of many federal efforts, including data collection. Creative methods to maintain longitudinal data collection in the face of limited finances are needed.

One option for a new survey or for existing surveys is to collect longitudinal information in a manner similar to that planned for the SIPP. The SIPP is in the process of undergoing a re-design, after which its interviews will be conducted annually instead of three times a year. To accurately account for the entire year, respondents will be given an event history calendar to aid in recall throughout the year. Similar methods could be adopted by cross-sectional surveys. For example, in addition to asking if a person has a disability, cross-sectional surveys would gain from also asking when the onset of disability occurred. Retrospective information about other important events surrounding the onset of disability could also be queried, such as consequences of disability onset for employment, income, health care use, and family well-being. Retrospective information about the availability and use of supports thought to mitigate the consequences might also be collected. Potential problems with collecting retrospective data include recall bias and the possible irrelevance of the information collected if the event of interest (like disability onset) occurred a long time in the past. Respondents might have difficulty recalling experiences, and the experiences themselves may no longer be relevant in the current social and policy context.

Another practical issue that would be associated with studying the dynamics of disability over time is developing measures to capture changes in health and disability status. Unlike factual information such as employment, income, program participation, service use, and other concepts typically measured in existing longitudinal surveys, disability is complex and multidimensional. Currently, little data are available on the validity and reliability of health and disability measures that might be collected via survey over time on the same individuals. Health scales, such as the SF-36, and functional limitation questions with four or five response categories may not be sensitive enough to capture substantive changes in disability status, and so might be of limited use in relating those changes to particular disability-related determinants and outcomes. Improving our ability to efficiently measure and interpret changes in disability status over time might lead to disability questions being added to existing longitudinal surveys.

New or enhanced longitudinal survey efforts could also provide information on other unanswered disability-related questions. Many unanswered questions identified by federal and state agencies focused on transitions. Several surveys monitor children with disabilities over time as they age into adulthood and others follow the elderly population as they retire and experience declines in functioning, but information about the transitions experienced by working-age individuals with disabilities (for example, surrounding disability onset, employment, and disability program participation) is less

available. One government respondent noted that it was difficult to answer the question, “What happens to persons with disabilities after they leave public assistance programs?”

The PSID has the potential to provide some information on these topics, but the sample sizes are too small to be able to analyze the incidence of many types of disability-related transitions. Although information on working-age individuals before and after they participate in government programs is lacking, the act of applying for a program creates an opportunity to identify individuals in transition who might be the target of data collection efforts. A new effort could sample people who apply to a program (for example, SSDI) and who exit from the same programs. These samples might be used to augment the samples of existing surveys in a manner similar to that described previously for Social Security disability program participants in the SIPP.

A more ambitious approach would be to develop a longitudinal disability sample from the SIPP itself. That is, the SIPP could be used to identify respondents with disabilities and particularly those who, during the SIPP period, experience the onset of disability or of a medical condition that puts them at high risk for disability. These respondents could be followed for a longer period (for example, 10 years). Similar to the MCBS, new subjects would be added every year (from the current SIPP) and subjects who had completed all interviews would leave. This approach would only work well if the new SIPP sample sizes are sufficiently large, the panels are fielded on a regular basis, and questions in SIPP that are key to selection of the disability sample are maintained over successive panels. In essence, a re-designed SIPP with a special disability sample could become a longitudinal national disability survey.

E. Enhance Disability-Related Content in Existing Surveys

A key issue is that many surveys have very limited and--at the extreme--no questions related to disability. In our correspondences with the staff of agencies that conduct research related to people with disabilities, one respondent suggested that disability be included in all surveys as a basic demographic characteristic, such as gender or race.

Inclusion of a basic disability variable in all surveys would open up a variety of topics to research on people with disabilities. For example, adding a concrete measure of disability to the CE would allow for studies comparing the spending habits of people with and without disabilities. The inclusion of disability questions in the 2009 AHS has added a new opportunity to use these data for disability research. As noted in Stapleton et al. (2009a), “Adding disability measures to surveys with poor or nonexistent measures is the most important way that disability-relevant content in existing national surveys can be improved.”

As mentioned previously, among surveys that already include questions to identify people with disabilities, many lack details on the severity of the disability or diversity of

conditions. Federal and state agency staff providing input to this study requested that information on disability severity, longevity, onset, and causes be included in more surveys. More information on people with disabilities could also be included by restructuring certain questions. Some surveys inquire about a respondent's ability to work and include disability only as a response option for a question about why the individual is not working. Including a separate work-limitation question, with inability to work as a response option, would increase the validity and usefulness of the measure. This restructuring could be applied to any question for which disability appears as one of many response options. Researchers would prefer use of a larger stand-alone battery of disability questions, but that would impose a greater burden on the respondents.

Inclusion of disability-related content, such as service use or barriers to independent living, is another important way to enhance existing surveys. People with disabilities have many unique needs and circumstances that might not be captured by standard questions targeted to people without disabilities. Questions related to work accommodations, accessible public transportation, assistive technology, disability-related costs, and the emotional and social impacts of disability are absent from most existing surveys but would improve the usefulness of surveys for studying disability issues. For example, including content related to vocational rehabilitation on all educational surveys would be useful to answering a question posed by one government agency: "What effect has rehabilitation had on drop-out and graduation rates?" Numerous examples of disability-related content that staff of federal and state agencies find are inadequate in existing surveys were noted in Chapter II (Section C.5).

F. Augment Samples in Existing Surveys

Federal and state agency staff indicated that one way they attempt to address issues related to small survey sample sizes is to pool data across survey years. This is an effective and efficient means for increasing sample sizes when data have been collected consistently over time and it is reasonable to presume that population distributions for relevant variables have changed little. To facilitate these types of analyses, NCHS provides weights and survey design adjustment information to use when multiple years of the NHIS are being pooled. Other surveys, including the MEPS, NBS, CPS, and SIPP are good candidates for pooling multiple years to increase sample sizes. For example, studies have pooled multiple years of the MEPS to study the health care expenditures of people with disabilities (Olin and Dougherty 2006), and multiple years of the NHIS to study SSDI beneficiaries in the 24-month waiting period for Medicare (Riley 2006; Livermore et al. 2010).

Modifications to survey sample frames and methods might also identify more people with disabilities in surveys. One respondent suggested, "Enhancements to survey sampling frames should be considered as a way to enhance sample size of people with disabilities in existing surveys." The exclusion of people residing in group quarters or institutions may inadvertently omit a large number of people with disabilities (She and Stapleton 2009). Improvements in the manner with which surveys interview

respondents may also help to identify more people with disabilities. People with disabilities may require additional follow-ups to successfully complete a survey compared to people without disabilities. Alternative measures for conducting the survey may be required, such as providing surveys in Braille or verbally for people with vision difficulties.

Another way to increase survey sample sizes so that particular subpopulations of people with disabilities might be studied is to augment the samples of existing surveys with such individuals. An example of this is SSA's collaboration with the Census Bureau to include an additional sample of SSDI and SSI beneficiaries in the 2001 SIPP. To increase the number of SSDI and SSI program participants available for analysis, SSA contracted with the Census Bureau to interview a sample of known SSDI beneficiaries and SSI recipients identified from SSA administrative records using the SIPP core questionnaire. This resulted in 2,447 additional interviews of known program participants. By adding this oversample of interviews to the 2,575 program participants already in the sample, the sample size of SSI and SSDI beneficiaries in the 2001 SIPP increased to a total of 5,022 (DeCesaro and Hemmeter 2008).

The addition of the standard six-question disability series to federal surveys might also offer future opportunities to augment sample sizes in surveys that obtain their samples from larger national surveys. For example, the MEPS obtains its sample from the NHIS. Sample sizes for working-age people with disabilities in the MEPS are fairly small, necessitating the pooling of data across years to study this population. With the addition of standard disability questions to both the NHIS and MEPS, sample sizes of people with disabilities in the MEPS could be augmented by using the disability questions as a screener in the NHIS, and oversampling NHIS respondents with disabilities in the MEPS. Several federal agencies noted unanswered disability questions related to health insurance, health care utilization, expenditures, and effects of the Affordable Care Act that could potentially be addressed with augmented samples and data from the MEPS.

Another option is for surveys to oversample from identifiable groups with relative high disability prevalence. In the past, the SIPP has used this approach to oversample from low-income households, and the HRS has used it to oversample African Americans. For instance, using ACS data pooled across years, it might be feasible to identify fairly small areas where disability prevalence is relatively high. Those areas could be oversampled for the SIPP.

G. Field Periodic Supplements

Adding a topical supplement to an existing national survey might be a useful approach when a large amount of new information is required or when there is a need to study a specific subpopulation that cannot be easily identified with existing information. In either case, an existing, large national survey could act as the screener. The existing "parent" survey would also provide additional information that enhances the

supplement, making an addition to an existing survey more efficient than conducting a stand-alone survey. The existing national survey to be used as the parent survey would need to include disability identifiers; otherwise, screening questions would need to be added. The inclusion of the six-question series on disability in additional federal surveys could expand the potential opportunities to use these questions as screeners for disability modules or supplements to existing national surveys.

Stapleton et al. (2009a) describe three general models for fielding topical supplements to existing surveys that are currently used in national surveys: topical modules, topical question batteries, and topical surveys. These models can be considered for purposes of conducting a national disability survey, which we discuss in Chapter IV.

Topical modules are supplementary questionnaires administered during a longitudinal survey that contains information on other topics, such as employment. The SIPP exemplifies this model because it is built around a core of labor force, program participation, and income questions designed to measure the economic circumstances of people in the United States. In addition, the survey was designed to provide a broader context for the analysis of income and program participation dynamics by adding questions on a variety of topics, such as living circumstances and personal assets, not covered in the core survey and that presumably do not change substantially during the short time intervals of the longitudinal data collection. Because the SIPP is designed to collect longitudinal information at relatively short intervals, it is unique in offering many opportunities to survey the same respondents and to spread the burden of collecting more detailed topical information. This is not the case with other large national surveys. Although repeated over time, most large national surveys are cross-sectional and thus offer only one opportunity to identify the subsample of interest and collect the additional topical information; this can substantially increase respondent burden if the topical supplement is large. The CPS, because it is fielded monthly, also offers multiple opportunities within a year to administer a topical supplement and has been used to do so quite frequently. The planned disability supplement to the CPS being developed by DOL is an example.

Topical question batteries are sets of questions that can be added to a core survey questionnaire but, unlike topical modules, are only asked of a subsample. An example of this model is the BRFSS, where topical supplements can be used in concert with the core national survey and administered in a single interview for a subgroup of people being interviewed. This approach differs from the SIPP topical module in that the topical question batteries are optional and selected for administration at the discretion of the states, which are responsible for administering the BRFSS. Under cooperative agreements with the Centers for Disease Control and Prevention (CDC), each state administers the core BRFSS questionnaire every year. In addition, each year the CDC offers a variety of approved topical modules that can be used by the states at their discretion and cost. States also are permitted to add their own sets of questions, subject to certain procedures and requirements, and at their own expense.

Topical surveys appear to be stand-alone surveys, but in fact derive their samples from a parent survey and therefore are essentially extensive topical modules of the parent survey. For example, the ATUS sample comes from the CPS, and the MEPS sample is derived from the NHIS. In each, supplemental interviews are conducted separately from the original interviews but the data from the original survey can be combined and used with the topical survey data. The NHIS-D also falls in this category, although unlike the other examples, the NHIS-D was designed as a one-time survey.

H. Conduct Periodic Surveys of Subpopulations

Conducting periodic surveys of specific subpopulations of policy interest, such as special education students, is an important way that disability data limitations are currently addressed. More than half of the 40 surveys reviewed for this report represent such surveys. The need for these types of surveys is driven by the specific information needs of particular agencies and the inability of general population surveys to identify or include in their samples sufficient numbers of particular individuals for which disability information is needed. Medicare beneficiaries, SSI and SSDI beneficiaries, nursing home residents, children, seniors, special education students, veterans, and prison/jail inmates are examples of subpopulations for which surveys have been conducted periodically in the past. Less frequent subpopulation survey efforts have focused on individuals with mental illness or intellectual disabilities, and homeless individuals. Subpopulations of particular interest to federal and state staff and for which disability data are thought to be inadequate are listed in Chapter II (Section C.2).

Most subpopulation surveys focus on those in a population, rather than those transitioning into or out of the subpopulation, such as applicants. The NLTS surveys are important examples of such a survey; the NLTS population is special education students who are at an age where they are about to transition out of the public school system into adulthood. As noted previously, however, state and federal agency staff indicated there is an information gap surrounding transitions from education to employment, changes in residences, or from institutional to noninstitutional settings (and vice versa), entry to and exit from public programs, and across changes in health care systems. Hence, adding special surveys that start with transitioning populations might be of considerable value. A survey focused on transitions would seek to capture people before and after they belong to a given subpopulation. In terms of program participation, potential survey respondents could be identified at the point of program application. The survey could ask retrospective questions at that point, then follow these individuals as they become enrolled in the program and continue to follow them after program exit. This would also create an opportunity to survey and compare accepted and rejected program applicants.

I. Designate a Lead Agency or Group to Coordinate Disability Data Efforts

Having an organization to spearhead disability data improvements efforts was viewed by TAG members as an important means to facilitate implementation of all of the options discussed above and also to garner support for a national disability survey (discussed in the next chapter) should one be deemed desirable. TAG members noted that significant improvements in data covering older individuals (via the HRS) were achieved through an active research community and strong relationships between the government and universities. Finding a way to mirror their success in the disability arena would facilitate disability data improvement efforts. Participants believed that the inclusion of the ACS six-question series in several surveys marked a rise in interest in improving disability data and that now is a good time to build on that momentum. Designating a lead organization or agency to advocate for and coordinate such efforts was perceived to be necessary. Proposed organizations include ASPE, NCHS, the Office of Management and Budget, and the National Institute on Disability and Rehabilitation Research.

IV. ADDRESSING DATA LIMITATIONS WITH A NATIONAL DISABILITY SURVEY

Another approach to addressing the disability data limitations described in Chapter II would be to design and conduct a national survey focused specifically on disability issues and populations. Pursuing such an option might be desirable if pursuit of other, less ambitious, options described in Chapter III are infeasible or do not adequately address the disability data limitations considered to be of significance to federal agencies. The marginal improvement options described in the previous chapter rely on the cobbling together of multiple data sources, which are based on contexts other than disability. A national disability survey can be designed to effectively reach many people with disabilities who may be missed in current surveys, include detailed information pertinent to understanding disability that may be absent from current surveys, and include all information in one source. The NHIS-D represents the only large-scale national disability survey ever undertaken in the United States general population. As noted previously, it is actually an extensive supplement to a major survey rather than a stand-alone survey, as it derived its sample through screening questions administered in the NHIS. This represents one model for conducting a periodic national disability survey, but other variants are also possible.

In what follows, we first describe potential design features of a national disability survey, focusing on aspects that address the existing disability data limitations. We conclude with a discussion of the advantages and disadvantages of conducting a national disability survey.

A. Potential Features of a Periodic National Disability Survey

A new, periodic survey focused specifically on disability offers significant potential because, in theory, it could be designed in any manner to address disability data limitations and not be hampered by the structure of existing data collection efforts. Attendees at the FAEP and TAG meetings supported the idea of such a survey but also expressed doubts as to its feasibility. There were also different ideas about how such a survey might be structured and what its content should be. In the sections that follow, we discuss a variety of potential features of a national disability survey. These features can be combined in various ways to yield hundreds of different options for conducting a national disability survey. It is not our intent to judge which options or combinations of options would be best for such a survey, but rather to discuss the issues and highlight potential advantages and disadvantages of particular survey features.

1. Purpose

There are many different data limitations a national disability survey could be designed to address and the primary purpose of the survey will dictate many of the specific design features of the survey. Potential purposes include:

- Provide a broad range of detailed information about disability
- Collect disability-related information not captured in existing surveys
- Act as the gold standard for general population prevalence and disability measurement
- Ensure periodic and consistent collection of key information on people with disabilities
- Focus on a subgroup of people with disabilities neglected in other surveys

We describe three examples of potential purposes of a national disability survey to illustrate some basic issues that might be encountered in developing the survey. These examples include: a small supplement to capture information not collected in other surveys; a longitudinal survey focused on working-age people with disabilities; and a large, ongoing survey that collects information on a wide variety of topics, similar in some respects to the NHIS-D.

Supplemental survey to capture nonexistent information. A small supplemental survey could be designed to focus on a narrow set of issues for which information is currently not collected in other surveys (for example, on issues related to barriers and supports to community living, disability-related service use, needs, and adequacy of existing programs). The survey could use one of the large national surveys (such as the NHIS or SIPP) for its sampling frame, and then be administered as a supplement separately from the core survey. The primary issues associated with this approach would be deciding on the focus of the survey, determining the parent survey and how the supplement would be incorporated, and obtaining funding for the effort. Of the three examples we discuss, this is likely the most feasible and least costly form of a disability survey.⁴

Longitudinal survey of working-age people with disabilities. Longitudinal information about working-age people with disabilities was identified as a key area where existing information is lacking. A longitudinal survey effort, similar in nature to the HRS, could be designed to focus on working-age individuals. Developing such a survey would involve considerable effort and require substantial resources to implement. In addition to determining the specific content of the survey, decisions would need to be

⁴ According to staff of the Aging and Chronic Disease Statistics Branch of NCHS, a 15-minute supplement to the NHIS would cost approximately \$10 million to administer to the entire NHIS sample, and a 20-minute supplement would cost about \$20 million. These estimates do not include development and testing costs. A supplement focused only on those identified as having a disability based on questions contained in other parts of the survey would include a substantially smaller sample, and presumably, could be administered for less than the cost of administering to the full sample. NCHS staff indicated that their survey costs have been increasing over time and that currently, the lead time for a supplement to be administered with the NHIS is three or four years.

made regarding whether the sample should include people without disabilities, follow-up intervals and methods to minimize and address attrition, duration of follow-up, and whether the survey could be administered as a supplement to an existing effort (like the HRS) to leverage the existing survey's infrastructure. Longitudinal survey efforts are generally much more complex and costly to implement than cross-sectional ones. Despite the complexity and potential costs associated with this survey, it might still garner support because it addresses a significant gap in existing disability data.

A large, ongoing survey on a wide variety of topics. Another potential purpose of a national disability survey would be to act as the primary and ongoing resource for disability-related information on the United States population. This survey would have a large sample, covering all ages and to the extent possible, all residential settings. It would cover a wide range of disability topics and be conducted on a periodic basis, with question modules being added or modified as disability-related information needs change. The survey would collect information on disability-related topics not addressed in other surveys, but also collect other general information available in existing surveys. The reason for doing the latter would be to ensure that the information is collected consistently over time for a sample defined in a uniform manner to which the survey is administered in a uniform fashion. An effort to develop such a survey would encounter similar issues as those noted for the previous two examples related to content, sampling, incorporation with a parent survey, and funding. In addition, obtaining support for such a survey might be more difficult if it is perceived as duplicating information that is already available from existing data collection efforts. While it might be more efficient to include certain types of disability-related content on a proposed national disability survey, existing efforts might be resistant to modifying their instruments for purposes of reducing duplication or otherwise enhancing the rationale for a new national disability survey.

2. Stand-alone versus Supplement

One of the most basic design decisions to be made with respect to conducting a national disability survey is identifying a target population. The target population for a stand-alone would have its own sampling frame and administration methods. Alternatively, a supplemental survey could build off an existing national data collection effort, such as efforts (for example, topical surveys) outlined in Chapter III.

Stand-alone Survey. Developing a stand-alone survey provides the opportunity to design all aspects of the sampling and administration methods. This is advantageous for a disability survey because some people with disabilities can be left out of existing data collection efforts because survey administration procedures fail to locate sample members with disabilities, adequately accommodate their participation in interviews, or too readily involve the use of proxy respondents when respondents with disabilities are encountered (Ballou and Markesich 2009). Administration methods for a stand-alone disability survey could be tailored to better capture people with disabilities and their experiences as reported by themselves, rather than by proxy interviewees.

A stand-alone survey offers the opportunity to create more extensive screening criteria if there are concerns about adding a significant number of questions to an existing survey for purposes of a supplement, or if the sampling frame of the existing survey is unlikely to identify sufficient numbers of individuals with rare types of disabilities. In a stand-alone survey, a set of disability screener questions could be developed to identify people with a variety of types and levels of disabilities for inclusion. Many surveys on which disability statistics are based contain only a limited set of questions to identify people with disabilities. However, screening potential sample members in a stand-alone survey may be burdensome as a large number of people without disabilities would have to be interviewed and screened out. Hence, the screener imposes some burden on a much larger number of potential respondents and would be costly to use.

To facilitate comparisons and place the findings in context, a sample of people without disabilities could also be included in the survey. If designed to have a longitudinal component (discussed further below), including a sample of people without disabilities would also allow the survey to track people who eventually experience disability or have a condition that is currently in relapse, giving the full perspective on the dynamics of disability.

Supplemental Survey. Adding a topical supplement or survey to an existing national survey might be a less burdensome and costly approach, but also poses significant constraints on the survey design relative to a stand-alone survey. Designing the national disability survey to be a supplement allows the effort to take advantage of the existing sampling frame and administration methods of the parent survey. While efficient, for these reasons this can impose some limitations. Like a stand-alone survey, the supplement would require a set of screener questions to identify a sample of people with disabilities. As noted in Chapter III, the addition of the six-question disability series to more federal surveys provides additional opportunities to use these questions as the screener questions to potential disability supplements. A significant advantage of a supplement over a stand-alone survey is that comparison data for a sample of individuals without disabilities is collected in the parent survey at no additional cost to the disability supplement.

Two data collection efforts serve as examples of national disability surveys; both were designed as supplements to existing national surveys. The NHIS-D, the only national disability survey ever conducted in the United States, was designed as a supplement to the NHIS, deriving its sample through screening questions administered in the NHIS. The NHIS-D has only been conducted once (fielded in 1994 and 1995), and collected cross-sectional information on over 32,000 people with disabilities. Depending on the age of the respondent, the NHIS-D collected information on disabling conditions, functional limitations, impacts of the disability on the family, development, employment, use of services and benefits, transportation and personal assistance needs, housing characteristics, environmental barriers, and participation in social activities.

Another example of this model is the Participation and Activity Limitation Survey (PALS), a national disability survey conducted in Canada. Like the NHIS-D, PALS is not a stand-alone survey as it screens potential participants based on an affirmative response to one of two questions on activity limitations in the Canadian Census.⁵ An analogous survey in the United States would use ACS respondents with disabilities as its sampling frame. Unlike the one-time NHIS-D effort, PALS is conducted every five years. The most recent version was conducted in 2006 and surveyed approximately 47,500 respondents (Statistics Canada 2007). PALS is a cross-sectional survey and collects detailed information on limitation type and severity, specialized equipment or aids, health care and social services, costs, unmet needs, barriers and accommodation to employment, education, retirement, housing, transportation, leisure, social interaction, discrimination, satisfaction, and stress.

Using an existing survey as a mechanism for identifying the population of interest is a more practical way to conduct a new survey of people with disabilities relative to conducting a stand-alone survey. Two potential candidates from which people with disabilities could be identified are the NHIS and ACS. The NHIS collects detailed information on health and will also include the standard six-question disability series. The NHIS identifies additional health conditions including but not limited to general health status, presence of ADL and IADL limitations, specific health conditions, and use of assistive equipment or personal assistants. Thus, the NHIS identifies more people with disabilities. The NHIS also has the advantage that it may be linked to several administrative data sources including the NDI, Medicare enrollment and claims data, and SSA administrative data.

The ACS has the advantage of size. The 2009 ACS conducted interviews with over 2 million Americans, a size large enough to support state-level estimates as well as estimates for smaller areas such as counties and Census tracts. The NHIS typically has about 87,500 individuals and does not support estimates below the state level. The ACS also samples individuals living in households, noninstitutional group quarters, and institutions, whereas the NHIS does not include those living in institutions. Disadvantages of the ACS relative to the NHIS are that it contains a limited number of disability questions that could be used as screeners, no other information about health and health care, and is not currently linked to administrative data sources. Another challenge is that to our knowledge, the ACS has not been used previously as a sample frame for a supplemental survey and there might be practical or legal impediments to doing so.

3. Population Coverage and Level of Estimates

If a national disability survey were to be developed, a number of decisions would need to be made regarding the specific population(s) to be sampled, which would dictate the population for which the estimates are representative. Below, we describe

⁵ Using the Census as a sampling base is not currently a possibility in the United States due to the removal of disability-related questions in the 2010 Census.

some of the factors that might be considered in deciding whether to develop a supplement or a stand-alone survey, and different options that could be pursued.

Residential Settings. To be fully nationally representative, a national disability survey should sample all Americans, including people who reside in the community, in group quarters, and in institutions, as well as those who are homeless. Many surveys fail to include people living in institutions, which may omit a large population of people with disabilities and thereby reduce their attractiveness as a potential parent for a supplemental disability survey. Based on ACS data, people living in institutions are 3.7 times more likely to have a disability as people living in noninstitutional settings (Brault 2009). For some demographic groups, the percentage of those with disabilities residing in institutions is extremely large. For instance, Stapleton et al. (forthcoming) report that over 23 percent of Black males with disabilities between the ages of 25 and 39 reside in group quarters, including 19 percent in institutions. Studies that have compared estimates of long-term care populations in various settings have found estimates to vary substantially across national survey sources due to a variety of sampling, administration, and methodological issues (Spillman and Black 2005; 2006). Rates of disability are also high among people who are homeless; 26 percent of homeless people are estimated to have a severe mental illness (SAMHSA 2011). Surveys dedicated specifically to these populations exist (such as surveys of inmates or people in nursing homes), but provide an uneven picture of these populations as the disability measures and topical questions vary across surveys. If consistent information is desired across residential settings, a national disability survey would need to rely either on the ACS sampling frame (the broadest available) or, alternatively, on a stand-alone survey to capture additional groups not covered by the ACS and other surveys, such as homeless people.

Individuals or Families. Another design decision relevant to population coverage relates to whether the unit of observation should be individuals, families, or both. Many of the existing surveys that focus on disability subpopulations typically include limited information about family circumstances or other family members. The large national surveys typically include more extensive information about all or most family members. A national disability survey attached to one of the large national surveys (like the SIPP, NHIS, or ACS) would contain substantial information about both individuals and families. If a stand-alone disability survey were to be designed, a decision would need to be made regarding how much information about the family members of individuals with disabilities would be collected. Such information can be very time and resource-intensive to collect, but might be important to understanding the support system available to respondents with disabilities.

Age Groups. Coverage of all Americans and interest in disability across the life cycle implies that people of all ages could be included in a national disability survey or certain groups could be oversampled, such as the working-age population. FAEP participants identified the current state of disability data as deficient in providing a lifetime perspective of disability. Age and population-specific surveys often provide detailed information, but only for a window of time. In addition, many surveys lack

disability measures appropriate for children. Accordingly, it is difficult to find useful data on disability onset and changes in functioning over time. The inclusion of all age groups, and of disability questions that are appropriate for different ages, would be important to a national disability survey intended to provide information on disability across the life cycle.

Specific Subpopulations. Aside from specific age groups (children, working-age, and elderly individuals), many existing disability surveys are fielded to cover specific subpopulations and help to provide information on people for whom little or no data are collected in larger and broader national surveys, primarily due to small sample sizes but also because of other factors. Surveys of subpopulations are an important tool for collecting data on populations that are overlooked or undercounted in other surveys. A national disability survey could be designed to oversample disability subpopulations neglected in other surveys. One group of interest might be people with disabilities who are making certain kinds of transitions. As noted previously, federal and state agency staff believed there is an information gap surrounding key transitions experienced by people with disabilities (for example, from education to employment, changes in residential settings, and entries to and exits from public assistance programs). A broader, longitudinal national disability survey focused on transitions could potentially capture people before and after they belong to a given subpopulation. FAEP respondents also noted a lack of disability-related information for racial and ethnic minorities, people with rare disabling conditions, and employment subgroups, all of which could be oversampled in the design of a national disability survey with appropriate screening questions.

State-Level Estimates. Small sample sizes of people with disabilities in existing national surveys limit the ability to study people with specific disabilities or to produce state or local-level estimates. The inability of many federal surveys to produce state-level estimates was noted as an important limitation of existing data at the TAG meeting. Without state-level data, it is difficult for states to get basic prevalence rates, assess access to and unmet need for services, or understand the impacts of state-level policies and programmatic changes. The BRFSS was noted as a possible vehicle for a national disability survey to support state-level analysis. As noted previously, the ACS is another option for this purpose because of its large sample sizes.

Communities. Thus far, the options discussed have focused on individuals with disabilities as the unit of observation. Another option for a national disability survey would be to have communities be the unit of observation in a manner similar to what was done for the Community Tracking Study conducted by Mathematica's Center for Studying Health Systems Change for the Robert Wood Johnson Foundation. As part of this study, data were collected from 12 metropolitan communities selected randomly from a stratified sample of national communities to be representative of the nation. Data were collected via site visits and interviews with staff of various types of health care institutions and providers, along with formal surveys of both consumer households and physicians. The goal of the project was to track changes in the health care system over time. Because little is known about the array of disability-related supports and barriers

at the community level, and because it is problematic to collect such information via a consumer survey alone, a focus on communities, rather than only on individual experiences and perspectives, might be valuable for purposes of gathering information about the community environment, including supports for people with disabilities and how the environment affects outcomes for individual consumers.

4. Frequency of Administration and Longitudinal Data

The frequency of administration and the extent of any longitudinal data collection are key considerations that interact with each other.

Frequency. The NHIS-D was conducted as a onetime disability survey to address unanswered disability-related questions at the time (1994 and 1995). Members of the FAEP and TAG agreed that waiting over 17 years between surveys (the minimum length of time between the NHIS-D and any subsequent national disability survey that might be conducted) is too long. Ideally, a national disability survey would be conducted more regularly (for example every 2-5 years). Regular administration of a core set of questions would permit analyses of changes in the status and experiences of people over time.

As a variant, a scaled-down version of a national disability survey could be administered on a more frequent basis (for example, every three years) with a more comprehensive disability survey administered less frequently (for example, every nine years). The comprehensive survey could take the form of the options described above (that is, have boosted sample sizes to support state or local-level estimates, contain a longer and more detailed battery of questions, and/or include oversamples of subgroups for which little or no data are typically collected, such as those residing in institutional settings or people with specific health conditions).

Longitudinal Data. The inclusion of longitudinal information is a key aspect of a national disability survey and the decision to include longitudinal data can affect decisions regarding survey frequency. FAEP and TAG members were in favor of collecting longitudinal data and thought it necessary to capture the dynamics of disability. FAEP and TAG members were also cognizant of the costs and other barriers to collecting longitudinal information. Although potentially less-expensive mechanisms can be used to capture a longitudinal perspective (for example, linkages with administrative data and the use of retrospective questions), the most direct way is to conduct a longitudinal survey. Panel length and survey frequency must be balanced against financial costs and the risk of sample attrition. The formats of the PSID and HRS, which follow sample members biennially from sampling until death, would be ideal if resources were not an issue. A long-running panel might be conducted with survey administration occurring relatively infrequently (for example, every five years). A less ambitious effort might involve a shorter-term panel, perhaps running for a period of five years with interviews conducted annually, to capture the shorter-term dynamics of disability.

Even in the context of a cross-sectional national disability survey, historical information can be collected through the use of retrospective questions. Basic information such as age, marital status, and employment status at disability onset could easily be collected through the use of such questions. Changes in disability status and associated outcomes occurring between onset and the survey, however, would be more difficult to capture. A sophisticated form of retrospective questions, such as that planned for use in the re-designed SIPP (described in Chapter III) might capture more detailed information.

5. Disability Measures

One of the key concerns mentioned by FAEP and TAG participants was the inconsistency and quality of measures of disability. A national disability survey could ideally address this limitation. The survey should minimally include the standard measure of disability that is common across national surveys. At this point in time, that standard appears to be the six-question series to identify disability in the ACS, AHS, and CPS, which seems likely to be promulgated in future federal surveys. Including the six-question series in addition to a battery of more detailed questions to measure onset, severity, and underlying causes of disability would provide an opportunity to analyze and better understand which individuals with disabilities are being identified--and which are missed--by the standard questions. Given the limitations of the six questions, development of a better understanding of disability measurement could be an important function and contribution of a national disability survey. The findings of such analyses might be used to develop better measures, or to develop cross-walks or weighting mechanisms for use with estimates based on data from surveys that include only the six-question series.

With respect to candidates for disability measures beyond the six-question series, FAEP and TAG participants expressed interest in including questions to identify behavioral, emotional, intellectual, and cognitive health conditions, measures of functioning, difficulty with specific activities, and work-limitations. Questions to identify specific conditions, the role of the environment in determining disability, use of accommodations and supports, and disability onset would also enhance current knowledge on disability. Short general health scales, such as the SF-12 and more detailed SF-36, might also be included to assess how these scales operate in the context of disability, and the extent to which they might be used to measure changes over time if longitudinal data on health and disability were to be collected.

6. Topical Content

Because disability can affect many aspects of life, a national disability survey could potentially cover a wide variety of topics, including health, health care, education, employment, program participation, participation an array of social activities, housing, disability services, supports, and quality of life. Many of these topics are covered in existing surveys, some in great detail. However, information is fragmented, with most surveys focused only on certain subgroups or certain topics. For example, the HRS

provides detailed information on accommodations, but only for those age 51 or older. A national disability survey provides the opportunity to collect in-depth information on the many topic areas relevant to people with disabilities.

There remain topics for which little or no information is available for people with disabilities. The extensive list of unanswered questions and topic areas where federal and state staff considered information to be inadequate (provided in Chapter II) offers potential areas of focus for a national disability survey. As discussed previously, current surveys do an incomplete job of covering people with disabilities as they make transitions. However, in written responses and during the advisory panel proceedings, very few questions related to transitions surrounding retirement were raised. This suggests that existing surveys, such as the HRS, do an adequate job of capturing these types of transitions. The HRS may serve as a model for surveys capturing other populations during other types of disability-related transitions.

Survey information on the role of the surrounding environment is especially limited. Information related to the type, amount, effectiveness, and cost of supports and modifications at home, at work, and in the community are needed, and might be topics addressed in a national disability survey. Similarly, more detailed information related to environmental barriers to participation in all life activities is needed.

The reasons behind many disability-related outcomes are unknown, while a deeper level of understanding is desired. Federal and state agency respondents cited unanswered questions related to incentives affecting individuals' decision to apply or not apply for public assistance programs and successful versus unsuccessful attempts to gain and retain employment. Understanding the motivation behind such decisions may help programs become more effective and efficient.

7. Links to Administrative Data

A national disability survey, regardless of its other features, would significantly benefit from links with administrative data. People with disabilities participate in public programs at high rates; creating linkages with administrative data from federal programs would provide accurate historical information on program participation and usage.

Administrative data from SSA and CMS programs seem the most likely candidates for linkages with national disability survey data, both because people with disabilities participate in SSI, SSDI, Medicare, and Medicaid, and because linkages between survey data and these sources are currently undertaken. If a national disability survey were conducted as a supplement to the NHIS, these linkages, along with linkage to the NDI, would occur essentially automatically through the existing efforts of the NCHS restricted data center, assuming those efforts continue in the future. Linkages with other types of administrative data, including earnings data and data from program administered by the states, would also be useful. Past Census Bureau surveys (the CPS and SIPP) have been linked to IRS earnings data; that might be a reason to consider using a Census survey as the sampling frame for a national disability survey.

B. Advantages and Disadvantages of a National Disability Survey

There are many factors and tradeoffs to consider in weighing the value of developing a periodic national disability survey versus utilizing other means that leverage existing data collection effort to address disability data limitations. Here, we discuss some of the advantages and disadvantages of conducting a national disability survey.

1. Advantages

A primary advantage of a national disability survey is that, as a new data collection effort, it could be designed to specifically address particular existing data limitations. As existing surveys have specific focuses, adding questions of interest outside of the topic areas of these surveys seems unlikely. Another important advantage over other options stems from the fact that statistics would be based on a single set of disability identifiers and obtained from data that were collected using a single methodology. Even if consistent disability indicator questions were used across different national surveys, differences in how the surveys are administered inevitably would lead to differences in the estimates and characteristics of the population of people with disabilities identified.

In a new national disability survey, the identification of people with disabilities who are often overlooked (for example, people with specific disabilities, with difficulties responding to a particular survey format, or living in institutional settings) could be prioritized. For existing surveys that do not cover people in such populations, changes to the sampling framework and implementation will be costly and may reach beyond the realm of moderate modifications. Although the cost will be lower relative to a new, stand-alone survey, it may be difficult to convince the agencies that oversee these surveys to make such changes.

A national survey would also have the potential to provide a complete life cycle perspective on disability, which seem to be missing from existing data. Several current surveys, such as the HRS, provide ample disability-related information, but only for a specific age group (the elderly). Other surveys focus on children and education, such as the NLSY. Few surveys provide a breadth of detailed disability-related information on all age groups.

Support for a national disability survey was expressed by the majority of FAEP and TAG participants. One participant noted that the United States is one of the only industrialized nations without a national disability survey, to which another responded that it was time for an “ambitious project” in the United States. Administrative data, survey data, and efforts to advance the state of disability research were described as fragmented. A combined national project has the power to unify the fragmented system and to provide a wide array of information on people with disabilities without having to link across or otherwise use data from numerous surveys.

2. Disadvantages

The creation of a national disability survey is associated with several disadvantages and potential challenges. The primary concerns related to such an effort are the potential expense and difficulty in design and implementation. The NHIS-D was large, costly, and complex. It involved funding from and coordination across numerous federal agencies. Decisions regarding who is responsible for funding and development, the topics to include, sample sizes, how the sampling frame is to be derived, and how the survey will be administered would need to be negotiated among the various sponsors. TAG participants expressed concern about funding and coordination as well. The group noted that securing the funding for such a large project would be difficult, and disability advocates may not be in favor of federal spending on survey research, preferring instead that the resources to be devoted to programs and services.

Problems arise for both a stand-alone survey and a supplement. If not connected with an existing national survey, comparative information on people without disabilities would either be unavailable or the sample would need to include people without disabilities, thereby substantially increasing the sample size and cost of the survey. A longitudinal survey excluding people without disabilities would be limited in its ability to gain a lifetime perspective on people with disabilities, as disability onset would not be captured. This limitation may be somewhat addressed by the use of retrospective questions related to disability onset, but it will be difficult to capture detailed information around this transition due to issues related to memory recall (particularly for individuals who have been living with a disability for an extended period of time and for those with substantially limited memories).

If connected with an existing national survey, addition of the disability supplement would need to be negotiated with the sponsors of the parent survey, and disability screening questions would likely need to be added. Parent survey sponsors might be averse to adding extensive screening questions to an existing survey if it poses a risk that answers to other questions in the survey will systematically differ from those in earlier or later rounds because of changes in the context of those questions.

There is too much potential topical content for a national disability survey to incorporate it in one survey. As mentioned by one of the FAEP participants, there is interest in more than just the health of people with disabilities. Accordingly, a survey intending to capture the many effects of disability would need to include a large number of topics. However, this would lead to a survey that would likely be prohibitively long, which may lead to a low completion rate and be expensive. This could be addressed in longitudinal survey through topical modules, or in a large cross-sectional survey via random use of some question modules across respondents.

Of all of the approaches described for addressing disability data limitations, a national disability survey is perhaps the most ambitious. It is difficult to imagine, however, that a periodic national disability survey alone could meet the needs and

address all the unanswered questions raised by federal and state agency staff, given the wide range of issues and subpopulations they encompass. Yet such a survey might provide important data to address a subset of issues deemed to be of the highest priority.

V. CONCLUSIONS AND POTENTIAL NEXT STEPS

A substantial amount of survey and administrative data relating to disability is currently collected in the United States. The 40 national surveys and associated administrative data sources we reviewed contain a wealth of information about people with disabilities of all ages covering a wide range of topics. Further, in recent years significant progress has been made in improving the nature of the disability-related data collected. A standard set of disability measures has been added to the ACS, AHS, and CPS, and there are current plans to include these measures in all federal surveys. Linkages between national health surveys and a variety of administrative data sources have been undertaken and are made widely accessible to potential data users through the NCHS restricted data center, and plans for the re-designed SIPP call for increased use of administrative data sources. Several new efforts are underway, including a disability supplement to the CPS, a new longitudinal study of youth, additional disability questions added to the 2011 NHIS, and a new longitudinal study of Medicare beneficiaries over age 65.

Despite the substantial progress in recent years, important limitations to existing disability data persist. These include inadequate disability measures in many surveys, particularly as they relate to behavioral, emotional, and intellectual disabilities and disability severity; small sample sizes of existing surveys that limit the ability to analyze subgroups, such as program participants or people experiencing disability-related transitions; access to administrative data hampered by privacy, technical, and resource issues; lack of coverage of certain disability-related topic areas related to the characteristics of disability and its onset, program participation, community supports and services needed and used by people with disabilities, and disability-related expenditures; and lack of longitudinal information to characterize the dynamics of disability across the life cycle, and in particular, during transitions experienced by the working-age population with disabilities.

In this report, we have provided numerous ideas for addressing the disability data limitations identified by federal and state agencies. Although they were presented in terms of what might be achieved by means of incremental changes to existing data collection efforts versus conducting a periodic national disability survey, these general strategies should not be viewed as mutually exclusive alternatives. Many of the incremental options described warrant pursuit whether or not a national disability survey is developed. Although final decisions regarding which specific disability data collection efforts to pursue will be determined by federal policy makers and program administrators, here we offer some potential next steps and in doing so, highlight efforts that seem to be of highest priority.

A. Priorities and Potential Next Steps for Incremental Methods

1. *Improve Disability Measures in National Surveys*

A fundamental step towards improving existing disability data is to improve the disability measures included in national surveys. The inadequacy or absence of disability measures is widely viewed as a major shortcoming of available data, and steps to address this limitation have already begun. A June 2011 announcement out of HHS stated that, in accordance with the Affordable Care Act, a standard measure of disability must be included in all federally funded surveys. This standard measure is the six-question series used to identify disability in the ACS.

As the six-question series will become the standard measure of disability in many surveys, steps should be taken to understand who is identified and who is overlooked by these measures. Efforts to compare the six-question series to self-reported measures of disability have already been conducted and comparisons to administrative data are currently underway. Opportunities to better understand the new standard set of disability measures also exist in the 2011 NHIS and re-designed SIPP, both of which include measures of health and disability in addition to the six-question series. Analyses of these data sources with the purpose of improving the six-question series should be conducted. Subsequent to creating a profile of people for whom the six-question series misclassifies, additional questions could be developed to supplement the standard questions.

2. *Facilitate Use of Administrative Data*

Continuing to support and promote linkages between survey and administrative is an important means of improving disability data. Through the efforts of NCHS, survey-linked administrative data has become more available. As such efforts become more common, the means for conducting linkages might become more mechanized and expectations for conducting such linkages might become more commonplace. Some specific efforts could be undertaken in the short-term. One is to improve the match rates in existing linkages. Innovative new techniques for doing so are being developed and should be adopted when possible. Another is the creation of summary variables that would be useful to data users and that will help improve both data quality and ease of use. Finally, improved documentation and technical assistance are paramount to successful use of administrative data.

Another near-term focus would be to pursue opportunities to develop the capacity to use electronic health records for disability-related research purposes. To take advantage of this potential new resource, action needs to occur now while the standards for electronic health records are being developed. Of immediate importance is developing a measure or indicators that could be used to identify disability in health records. Once an identification strategy has been developed, lobbying for inclusion in health records can commence. Obtaining the support of an organization already

involved in the development of electronic health records, such as the ONC, is another key next step.

3. *Improve Samples in Existing Surveys*

Making the most of existing survey data includes ensuring that people with disabilities are not omitted. The methods used to collect data can affect the sample of people who respond. A potential next step would be to encourage those responsible for existing national surveys, especially those that are currently relied upon to provide extensive information about people with disabilities, to reassess their data collection methods and determine if there are ways to increase the likelihood that all people with disabilities are able to participate. Existing surveys might consider using assistive technology or mixed methods (for example, telephone, paper, computer, and in-person interviews). Sampling frames should also be reassessed, with the possibility of including nonhousehold and group quarters populations, which often are excluded from sampling frames. This would serve to increase available data on a population with high disability prevalence and for whom little information is typically collected.

B. Potential Next Steps for Developing a National Disability Survey

If HHS and other agencies are interested in pursuing a national disability survey, the critical next step would be to define the specific scope and purpose of the survey. A national disability survey would be most useful if it addressed specific disability data limitations that cannot be easily addressed by other, more incremental means, but there might be other reasons to focus the survey on particular topics or subpopulations. The limitations that seem most difficult to address with incremental methods relate to modifying the sample design and population coverage to include people with disabilities in a variety of residential settings, and the collection of longitudinal information to capture disability dynamics and transitions, particularly for the working-age population. A survey that addresses either or both of these limitations would require a significant amount of effort to design and execute, and would represent a significant departure from current efforts.

The process of identifying the scope and purpose of the survey might involve a series of meetings among HHS staff and selected representatives from other agencies. A standing work group might be created for this purpose. The survey purpose ultimately agreed upon will require a strong rationale in order to gain internal and external support. Thus, the early activities of the work group might include: defining the broad purpose of the survey and its rationale, developing a list of specific questions the survey data are intended to address, and documenting the reasons why these questions cannot be addressed with existing data. Once the scope and purposes have been sufficiently defined and supported with a strong rationale, the work group meetings could continue to be the platform for decision making regarding funding mechanisms, design features, and content.

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APPENDIX A. FEDERAL AND STATE AGENCY FEEDBACK ON DISABILITY DATA NEEDS AND LIMITATIONS

A. Questions for Federal and State Disability Policy Stakeholders

Current and Past Disability Data Needs and Uses

1. What are the disability-related policy/program/research questions that are important to your agency?
2. Does your agency have specific legislative, regulatory, or other needs for disability data? If so, what are they?
3. What sources of data have been used to address the above disability-related questions and information needs?
 - What, if any, survey data does your agency use?
 - What, if any, administrative data does your agency use?
4. Have you used merged survey and administrative data for addressing questions like those noted above and if so, how have you used these data?

Addressing Disability-Related Data Gaps and Limitations

5. Are there any disability-related program or policy questions that are important to your agency/program(s) but which you cannot address due to data limitations? If so, what are those questions?
6. What is the nature of the data limitations that prevent your agency from addressing the above questions (e.g., limitations related to lack of access to administrative data matched to survey data or to data from other agencies, small survey sample sizes, inadequate survey content, infrequent data collection)?
7. What strategies, if any, have you used in the past to address such limitations?
8. Are there any disability-related studies or initiatives that your agency would like to conduct, but have not done so due to data limitations? If so, please describe.
9. Are there any subpopulations of interest to your agency (e.g., individuals in specific age groups, with specific types of disabilities, residing in particular institutional settings), but about which little is known because of data limitations? If so, please describe the group and the kinds of information you wish were available.

10. What kinds of data would be most useful to address the important unanswered questions or otherwise help your agency in disability-related program and policy activities?
11. Is your agency planning or in the process of developing any new disability-related survey or administrative data collection efforts?
12. Please provide any additional thoughts or comments you have related to the nature and availability of data to address disability-related program and policy issues.

B. List of Agencies That Provided Input

1. Administration on Aging
2. Agency for Healthcare Research and Quality, Center for Financing, Access, and Cost Trends
3. Bureau of Labor Statistics
4. Census Bureau, Housing and Household Economic Statistics Division
5. Center for Health Care Strategies
6. Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability
7. Centers for Medicare and Medicaid Services
8. Congressional Budget Office, Budget Analysis Division, Long-Term Modeling Group and the Income Security Unit
9. Congressional Budget Office, National Security Division
10. Connecticut Department of Rehabilitation Services
11. Maryland Rehabilitation Services
12. National Center for Health Statistics
13. National Council on Disability
14. National Institute of Health, National Institute on Aging

15. National Institute of Mental Health
16. Substance Abuse and Mental Health Services Administration
17. University of Massachusetts, Disability Health and Employment Policy Group within the Center for Health Policy and Research & Shriver Center
18. U.S. Department of Agriculture, Economic Research Service
19. U.S. Department of Education, National Institute on Disability and Rehabilitation Research
20. U.S. Department of Education, Office of Safe and Drug-Free Schools
21. U.S. Department of Education, Office of Special Education Programs
22. U.S. Department of Education, Office of the Undersecretary
23. U.S. Department of Education, Rehabilitation Services Administration
24. U.S. Department of Health and Human Services, Immediate Office of the Secretary, Office on Disability
25. U.S. Department of Housing and Urban Development, Office of Policy Development and Research
26. U.S. Department of Labor, Employment and Training Administration
27. U.S. Department of Labor, Office of Disability and Employment Policy
28. U.S. Department of Transportation, External Civil Rights Program
29. U.S. Government Accountability Office, Education, Workforce and Income Security
30. U.S. Social Security Administration
31. Wisconsin Department of Human Services, Office of Independence and Employment

C. Summary of FAEP Meeting Proceedings

The Federal Advisory Expert Panel (FAEP) meeting for the *Assessing the Need for National Disability Survey* project was held in May 2011. Prior to the meeting, input was solicited from 31 federal agencies and state organizations. This input covered the

current disability data uses of federal and state agencies, unanswered question and disability-related data gaps, and agency-specific efforts to address data shortcomings. The purpose of the meeting was to: expand on the disability-related questions that were identified as being important to participants' policy and program efforts that remain unaddressed because of data limitations; discuss the limitations of existing survey data that hinder their efforts; and discuss potential solutions to the limitations.

The meeting included three discussion sessions: (1) disability-related questions that remain unanswered due to data limitations, (2) limitations of existing data, and (3) options for improving disability-related data. Each of the three sessions began with a brief summary of the pre-meeting input provided by federal and state staff, followed by a discussion of additional topic areas not identified prior to the meeting and the importance of various suggestions. The sections that follow summarize the meeting discussion.

1. Disability-Related Questions that Remain Unanswered Due to Data Limitations

Prior to the meeting federal and state organizations were asked to complete a questionnaire regarding their experiences with disability-related data (see Section A of this Appendix). Two of the questions solicited information about unanswered disability-related program or policy questions and disability-related initiatives that have not been conducted due to data limitations. Responses included issues related to program participation, education, employment, housing/independence, quality of life, health status, and health care. In a separate question, respondents also indicated that data was lacking for several subgroups defined by age, other demographic characteristics, veterans, homeless individuals, specific types of disabilities, employment subgroups, program participants, long-term care users, and informal care providers and users.

FAEP members echoed many of the topics that had been identified prior to the meeting. Education, particularly postsecondary education, questions remain unanswered despite a general sense of the abundance of surveys containing information on disability and education. Even more questions about employment were discussed. In the pre-meeting input, health care was the topic for which the most unanswered questions were identified. During the meeting, health care issues were discussed again, with a focus on care quality and access. Below, we highlight specific topics of discussion.

Program Participation and Adequacy of Assistance. Throughout the discussion, unanswered questions about public programs were mentioned several times. Participants identified a lack of information about the adequacy of income assistance programs for people with disabilities (including veterans), and a lack of measures of material hardship, quality of life, and other outcomes (such as employment) that would allow an assessment of whether programs are meeting their objectives. At a more basic level, participants noted the difficulty of identifying people with disabilities participating in multiple public programs, and so issues related to adequacy, duplication, and fragmentation of services cannot be addressed. Members

also noted an interest in understanding how program take-up rates change during an economic downturn and subsequent recovery.

Community Living. The issue of unmet service needs of people with disabilities was discussed in the context of the demand for accessible housing and more generally, in terms of what is needed to help those with significant disabilities live in the community. FAEP members noted that, while there is some information on the national level about housing accessibility and services to support community living, such information is needed at the local level. It was noted that we simply do not have information about the types of services that people with significant disabilities (i.e., those who need a nursing level of care) need to live in the community, or the availability of those services in local (urban and rural) areas. The inability of the American Community Survey (ACS) to provide local-level estimates of disability prevalence until the 3-5 year estimates become available (in 2012) was noted as contributing to the lack of data at the local level.

Employment. FAEP members noted a lack of information about how individuals with significant disabilities are able to stay employed. For example, what are those who are successfully employed doing to get their needs met? What types of programs and services (private or public) do they utilize? Members also had an interest in more information about specific employment barriers and the extent to which individuals with disabilities believe that they are employed at their full potential. Other employment issues discussed related to underemployment among those with postsecondary education, and how the employment of people with disabilities is affected by economic changes.

Expenditures. FAEP members noted a lack of information about the consumption and expenditure patterns of people with disabilities. If information on expenditures were available, it might be possible to infer service needs and use from these data to address some of the unanswered questions noted in the three preceding topic areas. A primary reason for the lack of expenditure information is the lack of disability measures in the Consumer Expenditure Survey.

Longitudinal Perspectives. FAEP members noted that existing data do not provide a lifetime perspective on disability. Age and population-specific surveys often provide detailed information, but only for a relatively short window of time or only for older individuals. Accordingly, it is difficult to understand the dynamics of disability onset at younger ages and changes in severity and functioning over time.

Health Care and the Affordable Care Act. Members noted that we lack information about the experiences of people with significant disabilities enrolled in employer-sponsored health insurance, and so, are unable to infer the extent to which new sources of coverage implemented under the Affordable Care Act will meet the needs of people with disabilities. More generally, it was noted that the ability to assess the health care access, quality, and unmet needs for people with disabilities is severely limited by existing data.

Discussion during the first portion of the meeting was focused on unanswered questions more so than inadequately-covered subpopulations. Attendees did reiterate calls for data on homeless individuals, those with behavioral or emotional disabilities, and those residing in group quarters.

2. *Limitations of Existing Survey Data*

Shortcomings of existing data that were identified by federal agencies and state organizations before the meeting include: poor and inconsistent measures of disability, small sample sizes, difficulty accessing and linking administrative data, poor data quality, inadequate survey content, and timing issues. During the meeting, all of these limitations were noted.

Disability Measurement. Some participants expressed the need for a standard, threshold measure of disability to be used across all federal surveys. There was some disagreement about the extent to which such a standard definition would be useful, however. One participant noted that even when using the same questions, different populations are identified because of differences in survey context, sampling, and administration. In addition, there is general disagreement about what constitutes disability. One participant shared news that the U.S. Department of Health and Human Services is supporting a requirement that the six-question series currently used to identify people with disabilities in the ACS (as well as the Current Population Survey and the American Housing Survey [AHS]) be included in all federally-sponsored surveys. Problems with these questions were noted, however. In particular, they likely fail to identify a large number of people with significant behavioral, emotional, and intellectual disabilities. Participants noted that developing a better understanding of who is captured by the six-item ACS measure and how it might be improved is critical. The evolution of the six-question sequence was questioned by one participant, and if promulgation of the measure is being advocated, this participant and others believed it important to understand what it is measuring and if it can be improved.

Other issues related to disability measurement that were discussed included the need to measure disability severity, developing a better understanding of the specific health conditions that are likely to result in disability, and incorporating the International Classification of Functioning, Disability, and Health (ICF) concepts into disability measures (both survey and clinical measures). It was also noted that, even if using a standard definition of disability, disability concepts need to be applied differently by major age group.

Data Quality. The issue of program participation was raised again during the discussion of data limitations. One participant noted that his agency had found self-reports of program participation to be inaccurate when compared against administrative data. The lack of administrative data linkages across multiple programs inhibits the ability to assess program participation, duplication, and adequacy.

Other issues were also raised by participants. Small sample sizes limit the ability to do subgroup analysis, particularly on people with specific disabilities or at the state and local levels. Lags in data availability make it difficult to produce timely reports. Participants also again noted that longitudinal disability-related data was lacking, especially long-term longitudinal data.

3. Options for Improving Disability-Related Data

In the background materials provided for the meeting, several options for improving disability data were described. These include: increasing awareness and use of existing data, improving disability measures, collecting longitudinal information, increasing survey and administrative data linkages, enhancing disability-related content, fielding periodic survey supplements, augmenting samples in existing surveys, conducting periodic surveys of subpopulations, and fielding a periodic national disability survey. Several of these options received recognition at the meeting, but little discussion. The meeting discussion generally focused on the topics below.

Increasing Access to Administrative Data. Options for improving access to administrative data described included: improving documentation for administrative data; facilitating data sharing, which might be done by having government agencies link administrative and survey data, then de-identify the data and make it publicly available; making administrative data available more timely; facilitating access to administrative data (for example, through the use of a contractor to administer data use agreements under a model similar to that used by the Centers for Medicare and Medicaid Services' Research Data and Assistance Center); improving match rates between survey and administrative data; and increasing linkages between survey and administrative data (for example, doing so with the ACS).

Improving Disability Measurement. Participants discussed the development of a standard, reliable definition of disability that captures the appropriate population. There was no consensus regarding an appropriate definition, but many participants stressed the importance of developing the definition through a conceptual model that accounts for one's environment, such as the ICF model of disability. It was also noted that the context of disability varies greatly with regard to age; separate disability definitions based on age (children, working-age, and elderly) may be more appropriate than one definition applied to all age groups. One participant was a strong proponent for disability being defined in terms of severity, as opposed to a threshold. This participant suggested that a four-level system of severity be implemented: (1) not limited, (2) somewhat limited, (3) limited, (4) completely unable to perform the given activity. Another suggestion was to add questions to the National Health Interview Survey (NHIS) that would allow for an assessment of the six-question disability measure and determine who is and is not being captured.

Other Options. Other suggestions offered by participants included:

- Support more and longer-running longitudinal surveys, but many cited concerns with costs related to longitudinal data collection and low response rates. Using retrospective questions in cross-sectional surveys to elicit longitudinal-type information and increased linkages with administrative data were viewed as more practical options, although they have their own limitations.
- Develop and disseminate information about existing data, in a manner similar to that done through the Aging Forum report on older Americans.
- Find ways to make greater use of electronic health records or other encounter data to supplement existing data. Participants acknowledged that use of electronic records is not feasible at this point in time, but may be a potentially important source of data on disability in the future. It was also noted that, if we expect to be able to use these data for program and policy purposes, work needs to begin now, while the standards and content of electronic health records are still being developed, to ensure that the appropriate information is incorporated.

4. Summary

FAEP participants discussed a wide variety of topics reflecting the different data needs of their agencies. Notably absent from the open discussion of options was the suggestion to field a new national disability survey as a solution to the data shortcomings. When the group was asked to consider this option and discuss potential topics to be included if such a survey were to be conducted, the suggestions offered included the following:

- Access to and quality of health care, including the specific services that are covered by insurance and the gaps/unmet needs.
- Unmet service needs and the extent to which the existing system of supports fails people with disabilities in terms of supporting employment, community living, and independence.
- Environmental and accessibility factors that affect disability and disability severity.
- Subjective well-being, measures of quality of life, and measures of self-determination.
- Measures of disability that could be used to assess and improve existing survey measures.

The lack of discussion of a national disability survey should not be interpreted to mean that participants were not interested in that option. The options discussed were

raised primarily based on the discussion that occurred during the first session. In addition, the focus of the meeting was not on the options, but rather, on the policy and program issues that remain unaddressed due to data limitations. The discussion of options to address the data limitations was the focus of a Technical Advisory Group (TAG) meeting of academic researchers and representatives from government agencies involved in producing survey data that was held in June 2011 (see Appendix C for a summary of the TAG meeting).

APPENDIX B. TABULAR SUMMARY OF SURVEYS

Note to Readers about Appendix B

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 project. Rather, they are intended to portray the large and multidimensional variation across the 40 surveys in terms of their frequency of administration, nature of their samples, topic areas, and how health and disability concepts are measured. For more information about each survey, the reader is referred to the detailed survey summaries that are provided in the companion report (Livermore et al. 2011b).

TABLE B.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 B.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 B.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 B.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
Seniors (65+)		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 B.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	X
Transportation		X	X	X ³²

TABLE B.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 B.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 B.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 B.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	2008-09	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 B.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 Current Population Survey (CPS) interview. Income for all others is imputed from the CPS.
8. Sample excludes military personnel living on base.
9. Disability information, except for work disability, is not available at state or regional levels, due to small sample sizes.
10. Only available for the insurance component of the survey.
11. Disability information, except for work disability, is not available at state or regional levels, due to small sample sizes.
12. Only available for the insurance component of the survey.
13. In the interview survey of the CE.
14. Disability payments are grouped with other types of income.
15. In supplements only.
16. In the diary survey of the CE.
17. A study of Hispanic populations (HHANES) was conducted in 1982-84.
18. Regional estimates are provided from 1979-2004 for counties selected for the National Crime Victimization Survey (NCVS) sample in the 40 largest metropolitan statistical areas.
19. Different modules are fielded in different years, so the time span covered varies by topic.
20. A national longitudinal study, the National Health and Nutrition Examination Survey (NHANES) I Epidemiologic Follow-up Study, was jointly initiated by National Center for Health Statistics and NIA in collaboration with other agencies from 1982-1992.
21. In the NCVS crime report, asked if the respondent reports a crime in the initial questionnaire.
22. Only in NHANES III and Continuous NHANES.
23. Only in Continuous NHANES.

24. Those who are described as away at school or away in the armed forces are eligible for sampling.
25. The Panel Study of Income Dynamics (PSID) uses two independent samples. One is a national sample of low-income families.
26. Access to care data are available from 1991 to 2008. The cost and use data are available from 1992 to 2006.
27. Supplement on Aging (SOA) I and II.
28. SOA II.
29. Questions included in the SOA I and II and the Longitudinal Study of Aging (LSOA) II. Baseline survey collects information on any instances of difficulty remembering or confusion. LSOA II includes a section with questions about cognitive abilities.
30. SOA II includes detailed questions on both home and personal assistive devices.
31. Detailed questions on household expenditures are included in the economic supplement.
32. Transportation to and from medical care.
33. The National Comorbidity (NCS; 1990-1992) includes a supplemental sample of students living in campus group housing.
34. NCS (1990-1992) surveyed persons age 15-54; NCS-A (2001-2002) surveyed persons age 13-17.
35. Only selected Ticket to Work participant samples were followed longitudinally.
36. Information appears in core NHIS, not in the NHIS-D (National Health Interview Survey on Disability).
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 7th-12th 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 postsecondary education institution.
46. Asked on the B&B:93/03.
47. Employment of parents.

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

APPENDIX C. TECHNICAL ADVISORY GROUP INPUT ON OPTIONS FOR ADDRESSING DISABILITY DATA LIMITATIONS

The Technical Advisory Group (TAG) meeting for the *Assessing the Need for National Disability Survey* project was held in June 2011. The meeting included two discussion sessions: (1) the extent to which data limitations identified by federal and state agencies overlap with the TAG feedback and (2) options for improving disability-related data. Each session included discussion of additional topic areas not identified prior to the TAG meeting and the importance and feasibility of various suggestions. The sections that follow summarize the discussions that took place during the TAG meeting.

A. Unanswered Questions and Data Limitations

Prior to the meeting, TAG participants were asked to review *Disability Data in National Surveys*, a draft report summarizing the written input provided by federal and state agencies and describing 40 surveys with disability-related content. Participants were also asked to review a memorandum summarizing the proceeding of a May 2011 FAEP meeting. The first session began with a brief presentation that summarized the pre-meeting input regarding unanswered disability-related questions, inadequately addressed subgroups, and data limitations. Unanswered disability-related questions were presented as broad topic areas including program participation, education, employment, housing/independence, quality of life, health status, and health care. Similarly, inadequately addressed subgroups were defined by age, other demographic characteristics, veterans, homeless individuals, specific types of disabilities, employment subgroups, program participants, long-term care users, and informal care providers and users. Finally, the presentation provided details about noted data limitations, including poor and inconsistent measures of disability, small sample sizes, difficulty accessing and linking administrative data, poor data quality, inadequate survey content, and timing issues.

The consensus among TAG participants was that the unanswered questions, inadequately-covered subgroups, and data limitations identified by federal and state agencies were mostly accurate and valid concerns. Participants also acknowledged that the issues identified were varied and often disjoint from one another, and that it would be challenging to determine the overlapping data needs and priorities in determining which data improvement options to pursue. Specific issues discussed during the session are summarized below.

1. Unanswered Questions

Program Participation. Several topics related to program participation were mentioned by TAG members. One member perceived program participation to be the

topic area for which accessible data were most lacking and for which incremental changes to existing survey data might be least likely to address. Specifically, program take-up rates were mentioned as receiving inadequate data coverage. With available data it is difficult to identify which segments of the population are eligible for various programs, making it impossible for program administrators to predict demand, assess whether their programs are reaching the intended target populations, and estimate unmet need. The inability to assess program effectiveness and outcomes was also identified as an issue due to a lack of data. Although it was noted that such topics might be addressed using the Survey of Income and Program Participation, TAG members acknowledged that information is still lacking with regard to many programs that serve people with disabilities, such as vocational rehabilitation. In addition, TAG members indicated that addressing program-specific policy and research questions through survey data may not be the most feasible approach.

Community Living. One participant discussed data limitations related to community living. He stressed that community living applies to all age groups and goes beyond simply program participation, noting that most surveys do a poor job of measuring variables that broadly represent this domain, such as family circumstances and local resources. The issue will continue to grow in importance with the increase in the size of the United States population requiring assistance to remain living in the community.

Transitions. TAG participants noted that the lack of consistency in samples and disability measurement across multiple data sources makes it difficult to follow individuals as they make transitions. Identifying program participants before enrollment (when interventions may be particularly fruitful), and capturing the dynamic process of disability were mentioned as being nearly impossible to do with existing data. Following children with disabilities for long periods after they leave school was also discussed as being necessary but not done currently.

2. Data Limitations

Disability Measurement. Throughout the discussion, issues related to the measurement of disability were mentioned several times, echoing earlier feedback from federal and state agencies. Omission of a basic set of disability measures from federally funded surveys was regarded as problematic among meeting attendees. In surveys that include measures of disability, TAG participants lamented that little information beyond the basic measure is typically collected. Participants described measures of severity as being noticeably absent in most surveys. Participants also noted the inability of existing measures to identify psychiatric and cognitive disabilities well. There was discussion of the six-question disability sequence used on the ACS, and its likely promulgation to other federal surveys given the requirement under the Affordable Care Act that a disability demographic be included in federal surveys. Participants agreed that having a standard disability measure like the six-question sequence was critical, but many had concerns about who the current questions were identifying as having disabilities and

several suggested that more work should be done to understand and improve the standard measures.

Timing Issues. Several issues related to data timing were mentioned during the meeting. The first was the lack of longitudinal data covering people with disabilities, making it difficult to understand the dynamics of disability across the lifespan and to measure episodic recoveries and relapses. One participant suggested that this information might be ascertained by piecing together the experiences of larger samples over shorter time frames as opposed to following individuals over long periods of time. Delays in the release of data were also noted as a shortcoming, contributing to difficulty assessing current events, such as the impact of the recession on people with disabilities.

Small Samples. The inability of many federal surveys to produce state-level estimates was noted as an important limitation of existing data. It was mentioned that for many programs, such as Medicaid, there is direct involvement of states in the provision of services, and the nature of the programs varies substantially across states. Without state-level data, it is difficult to get basic prevalence rates, assess access to and unmet need for services, or understand the impacts of state-level policies and programmatic changes. The Behavioral Risk Factor Surveillance System (BRFSS) was noted as a possible vehicle for improving disability data to support state policy issues.

B. Options for Improving Disability-Related Data

TAG participants suggested a number of constructive options for improving disability-related data. The second discussion session began with a brief summary of options for improving disability-related data that were discussed in the draft report. These options include: increasing awareness and use of existing data, improving disability measures, collecting longitudinal information, increasing survey and administrative data linkages, enhancing disability-related content, fielding periodic survey supplements, augmenting samples in existing surveys, conducting periodic surveys of subpopulations, and fielding a periodic national disability survey. Below is a summary of discussion surrounding the aforementioned options as well as another option proposed by TAG members.

Improving Disability Measurement. Disability measurement was identified as a major limitation of disability-related data, but several options were proposed to improve on this metric. There was agreement that all federally funded surveys should include measures of disability. Most TAG members believed that there should be at least one standard measure applied consistently across all surveys. There was less agreement about what the measure of disability should be. Many members expressed discontent with the ACS six-question series, citing failure to adequately identify people with behavioral health conditions, aspects of cognition, social functioning, and mobility problems. One participant pushed for research to validate the six-question series, and another discussed developing a completely new set of questions to identify people with

disabilities, perhaps based on the WHO classification of disability. It was noted that substantial research had already been conducted to validate the six-question series and one participant believed that starting over with completely new measures was unnecessary and a waste of resources. Regardless of their views on the quality of the six-question series, participants agreed that the recent addition of these questions to several surveys is a positive step for the state of disability-related data. Those who were unhappy with the measure suggested that surveys should include additional questions to identify people with disabilities. Examples of additional questions include those used to identify behavioral health conditions, measures of functioning, difficulty with specific activities, and work-limitations. Opportunities to assess the six-question series in the future using the NHIS and the re-designed Survey of Income and Program Participation (SIPP) were noted, as both of these surveys will include the ACS six-question series in addition to a larger set of health and disability measures. Another suggestion was to include measures of disability that relate to program definitions. However, several participants noted the large number of definitions of disability and thought that approach would be infeasible, and one noted that the design of the six-question ACS series was intended to capture this in a very broad fashion.

Increasing Access to Administrative Data. TAG participants noted that several limitations of existing disability-related data could be eased with use of administrative data. Administrative data related to program participation is generally considered to be more accurate than survey data. Participants suggested that comparisons of administrative and survey measures could serve as a check of data accuracy and potentially alleviate concerns about survey measure validity. Administrative data also provide a longitudinal perspective on program participation without having to repeatedly interview respondents. One participant expressed that his ideal administrative data system would be similar to those in Scandinavian countries, where cross-program linkages are more frequently conducted, but recognized that this was unlikely due to privacy concerns. In order to make administrative data more accessible, TAG members suggested that administrative data should be made more user-friendly, perhaps through improved documentation, technical assistance, or the creation of variables that are useful for research as opposed to program administration purposes. Even if a national disability survey were to be established, one participant suggested that a cross-sectional survey would benefit from links to administrative data such as earnings records. However, only those individuals participating in a given program are included in administrative data.

Increasing Awareness and Use of Existing Data. The perception among several TAG participants was that a lot of good disability-related data exists, but that knowledge and use of some data sources are limited. Several Census Bureau efforts were noted as being underutilized, such as small area estimates, which can calculate prevalence rates at the school district level, and research data centers, where researchers can go to gain access to results run on restricted data. The Census is also developing synthetic data files, which use variable imputations to mask the identity of survey respondents while making previously sensitive data available to the public. One participant also mentioned the opportunity to coordinate state data collection efforts to produce a large,

national database. Electronic health records were cited as having potential for research in the future, but currently have a long way to go in terms of standardizing content in a way that would be useful for research. Dissemination of these efforts to the research community might help many researchers answer questions currently perceived to be unanswerable with existing data. One suggestion was to organize a disability statistics group, similar to the former Interagency Committee on Disability Research, which would hold monthly phone calls and periodic meetings to share information.

Field a National Disability Survey. Although the majority of meeting attendees agreed that a lot could be done with existing data, the group supported the idea of fielding a national disability survey. One participant noted that the United States is one of the only industrialized nations without a national disability survey, to which another responded that it was time for an “ambitious project” in the United States. Administrative data, survey data, and efforts to advance the state of disability research were described as fragmented. A combined national project was identified as having the power to unify this fragmented system and to provide a variety of information on people with disabilities without having to link across many surveys, which may not be feasible. A national survey would also have the potential to provide a lifetime perspective of disability that seems to be missing in current data.

TAG members had varying ideas about the ideal national disability survey. The National Health Interview Survey on Disability (NHIS-D) was described mostly as a random collection of disability-related questions that were unaddressed by the surveys that existed at the time. It was suggested that a future disability survey be more focused and have an overarching theme. Inclusion of information on specific conditions and program effectiveness was considered necessary by one member. There was disagreement about the ideal frequency of a national survey, but many participants noted that longitudinal data were needed. The model of the National Cancer Institute, which funds a 15-minute supplement to an existing survey every five years, could be adopted. Others suggested that a longer time frame would be sufficient, such as a large national survey conducted every 10 or 20 years. Yet others wanted a yearly survey, perhaps with boosted samples every 10 years to provide state-level estimates. One participant said his ideal survey would be similar to the longitudinal Health and Retirement Study (HRS), but inclusive of all age groups, or minimally, the younger age groups not covered by the HRS. Many TAG participants liked the NHIS-D model of using an existing survey as the basis for sampling; the NHIS and Medical Expenditure Panel Survey (MEPS) were suggested as potential starting points. Another suggestion was to take advantage of the event history calendar that will become a part of the re-designed SIPP. The calendar allows respondents to indicate important milestones that might be the cause or consequence of specific events for which SIPP data are collected. Question prompts specific to disability could be added.

Several obstacles to a national survey were mentioned. There was skepticism about the potential to keep people in a longitudinal survey over extended periods of time. It was also noted that a stand-alone survey targeted to people with disabilities would not allow for comparisons to people without disabilities. One participant pointed

out that there is interest in more than just the health of people with disabilities; the affect of disabilities on all aspects of life are important to consider. Accordingly, a disability survey would need to include a large number of topics. Another participant agreed and noted that it is the responsibility of each government agency and survey to include disability measures and content. Finally, there was concern about funding. It was noted that securing the funding for such a large project would be difficult and disability advocates may not be in favor of federal spending on survey research, but rather, would prefer the resources to be devoted to programs and services.

Designate an Agency to Coordinate Efforts. Having an organization to spearhead efforts was mentioned during discussion of each of the above options. TAG members acknowledged that improvements in data covering older individuals were achieved through an active research community and strong relationships between the government and universities. Finding a way to mirror their success in the disability arena would facilitate disability data improvement efforts. Participants believed that the inclusion of the ACS six-question series in several surveys marked a rise in interest in improving disability data and that now is a good time to build on that momentum. One TAG member called for capacity building and suggested that funding research on people with disabilities and disability-related data might help towards this end. Designating a lead organization or agency to advocate for and coordinate such efforts was perceived to be necessary. Proposed organizations include the Office of the Assistant Secretary for Planning and Evaluation, the National Center for Health Statistics, the Office of Management and Budget, and the National Institute on Disability and Rehabilitation Research.

C. Summary

Input received from federal agencies with program and policy responsibilities, federal agencies with survey and statistical responsibilities, state agencies, private contractors, and academic researchers received via written survey, an FAEP meeting, and a TAG meeting suggests that there are many limitations to existing disability-related data. These limitations span many topical areas and have a variety of sources. However, the discussions that occurred during the TAG meeting suggest that significant improvements could be made through relatively modest and well coordinated actions.

The most ambitious effort to improve disability-related data discussed during the TAG meeting was the fielding of a national disability survey. Participants acknowledged that while attractive, frequent cross-sectional national disability surveys or one longitudinal national disability survey would require significant resources. Still, if funding were made available, most TAG members showed a great deal of enthusiasm for this option.

ASSESSING THE NEED FOR A NATIONAL DISABILITY SURVEY

Reports Available

Assessing the Need for a National Disability Survey: Final Report

Executive Summary <http://aspe.hhs.gov/daltcp/reports/2011/NatIDSes.shtml>

HTML <http://aspe.hhs.gov/daltcp/reports/2011/NatIDS.shtml>

PDF <http://aspe.hhs.gov/daltcp/reports/2011/NatIDS.pdf>

Disability Data in National Surveys

HTML <http://aspe.hhs.gov/daltcp/reports/2011/DDNatISur.shtml>

PDF <http://aspe.hhs.gov/daltcp/reports/2011/DDNatISur.pdf>

To obtain a printed copy of this report, send the full report title and your mailing information to:

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