LONG-TERM
QUALITY ALLIANCE

Environmental Scan: Data Resources Available to Determine the LTSS Needs of Working Age Adults with Disabilities

EXECUTIVE SUMMARY

Currently, our understanding of the population that needs and uses long-term services and supports (LTSS) is largely derived from studies of people age 65 and older. However, nearly half of all individuals with functional needs are adults younger than 65. This younger population has a wide variety of disabilities and LTSS needs.[1,2]

The Long-Term Quality Alliance, with support from The Commonwealth Fund, conducted an environmental scan of the data resources available to understand the scope, need, use and cost of long-term services and supports (LTSS) by adults under the age of 65 in the United States.

This environmental scan was designed to describe the information that is available to understand these needs and to identify its limitations. The scan is part of a process intended to lead to recommendations for research priorities that will generate the information needed to support improvements in LTSS for adults under age 65 with functional needs.

For this scan, we reviewed 26 data sources: 11 national surveys, of which 9 are ongoing but 2 are no longer in use; 7 multi-state but not national surveys; and 8 administrative datasets, 4 of which are administered nationally and 4 of which are compiled by Universities or consortia that collect data from individual states.

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[1] Analysis by LTQA of data from the 2016 American Community Survey 1-Year Estimates show 7.6 million adult community residents "with self-care difficulty," of whom 3.7 million (49 percent) are between ages 18 and 64. Another 0.2 million adults under age 65 are residents of nursing facilities.

[2] A disability is typically considered an impairment – either physical, mental, or cognitive. A functional limitation is in inability to independently perform activities of daily living (ADLs) and/or instrumental activities of daily living (IADL) such that an individual must either accommodate the limitation or have assistance performing that function. The American Community Survey identifies 21 million Americans age 18 to 64 with a disability, only about 18% (3.7 million) of whom have substantial "self-care difficulties".

This is what we found:

1. <u>Current national surveys provide little detail on adults under age 65 with disabilities or the nature of their disabilities, and almost no data on LTSS needs or service use.</u>
    a. There are seven (7) national surveys that collect prevalence information on adults with disabilities under age 65 and have large enough sample sizes to stratify the population with disabilities. By far, the largest sample (2,390,000) is in the annual American Community Survey (ACS), which is unique in that it also includes people living in institutions.
    b. Almost all of the national surveys use a standard set of 6 "disability questions," which ask about a mix of impairment and function (hearing, sight, cognition, ambulation, dressing/bathing, and doing errands alone). These questions do not capture the variety of conditions that are disabilities, or the host of functions that are included in Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs). They also provide no information on the severity of limitation or the accommodations or supports needed to function.
    c. The most extensive information on adults with disabilities came from two national surveys conducted over 15 years ago. The NHIS-Disability Supplement (NHIS-D) in 1994-5 was designed to provide detailed information on adults with disabilities and has been the basis for several hundred studies. The National Co-Morbidity Survey (NCS), conducted in 1990-2 and 2001-2 was a study of mental health prevalence and needs conducted twice over a decade. These studies have not been replicated and are now too dated to support any contemporary analysis.
    d. Many of the national surveys exclude some categories of adults with disabilities, either people who cannot answer survey questions themselves, or who live in places (institutions, prisons, shelters) that are not part of the sampling frame, or people who only use cellphones.

2. <u>Recent trends are moving away from collecting useful, detailed information on disability and LTSS need.</u>
    a. The NHIS is shifting in 2019 from surveying households as a unit to surveying individuals, which will result in a loss of information better collected from households on the cognitive or other limitations of its members.
    b. The Survey of Income and Program Participation (SIPP), the best source of data on the population with disabilities among the current national surveys, is not scheduled to be administered again.
    c. The consistent use now across the major national surveys of a standard set of six "disability questions" to measure the prevalence of disabilities, limits the collection of data that could support a more robust understanding of the LTSS needs of the younger population with disabilities.

3. <u>Data on the LTSS needs and service use and cost for adults under age 65 with disabilities is inadequate, for several reasons:</u>

a. Only three of the national surveys that cover the under 65 population with disabilities go beyond the 6 standard "disability questions" and gather any additional detail on LTSS need or use. The LTSS data in these three surveys is limited.
b. Detailed data on disability and LTSS need is available for some subpopulations (I/DD, SMI/SUD). But specific information on LTSS need and use is not uniformly available for all subpopulations.
c. Assessments could yield the most useful information on functional limitations and LTSS need, but there is no national administrative data set that aggregates assessment data.
d. Medicare collects assessment data on individuals who use post-acute care (not LTSS) covered by Medicare (the MDS instrument is used for Skilled Nursing Facilities (SNFs) and the OASIS instrument for home health services). The data is limited to the subset of adults with disabilities under age 65 who qualify for Social Secure Disability Insurance. These databases are not publicly available.
e. Medicaid home-and community-based services (HCBS) use a wide range of state developed or adopted assessment instruments with no consistency in data items across instruments, making it impossible to produce national data.
f. Administrative data sets, particularly the MAX, provide data on LTSS use and cost for individuals with disabilities who are eligible for services. This data is generally not linked to functional assessment data States collect. Comparable information on use and cost of LTSS services is not available for people with LTSS needs who do not receive government-subsidized services. As a result, we do not have good information on why adults with disabilities who have LTSS needs do not get government services and whether they rely on unpaid caregivers or pay out-of-pocket for services.

4. <u>The best sources of information on the LTSS needs, use and unmet need for the under 65 adult population with disabilities are:</u>
    - **The Survey of Income and Program Participation (SIPP),** a national survey that collects ADL and IADL information, any assistance that people receive and if this assistance is paid or unpaid. However, this survey does not collect information on unmet need and there is no plan to administer it again.
    - **The Medicare Current Beneficiary Survey (MCBS),** a national panel survey of Medicare beneficiaries that asks about ADLs, IADLs, the need for assistance with ADLs, housework, meals or transportation and if these needs are met. It also samples people living in group quarters and institutions. The sample size for the survey is small, however, and only a portion of respondents are under age 65.
    - **The Health and Retirement Survey (HRS),** a national panel survey of people age 50 and older, that collects extensive information about ADLs, IADLs, LTSS needs and unmet needs. The HRS also samples people living in institutions and group quarters after the initial interview. However, the survey is not inclusive of the majority of people in our age range of interest.
    - **The National Core Indicator Survey (NCI)and National Core Indicator Survey – Aging and Disability (NCI-AD)** are both excellent sources of LTSS information on population subsets. Both are administered at the state level to a small sample of program participants in state or

county-funded disability services. The NCI-AD is still very new and only a small number of states are collecting information to date.

5. <u>There are many questions about the LTSS needs of adults under age 65 with disabilities that cannot be answered from existing data sources. Much more data is needed, including data on</u>:
    - The full scope of LTSS need, by population subgroups and overall, for adults under the age of 65 with disabilities.
    - The incidence, duration and extent of this need.
    - The scope of unmet need, by population subgroups and overall.
    - The consequences of unmet LTSS need.
    - The cost implications of meeting these needs.

INTRODUCTION

The Long-Term Quality Alliance, under a grant from the Commonwealth Fund, conducted an environmental scan of the data resources available to understand the scope, need, use and cost of Long Term Services and Supports (LTSS) by adults under the age of 65 in the United States. Currently, our understanding of the characteristics of and need for LTSS is largely derived from studies of people age 65 and older. However, nearly half of all individuals with functional needs are adults younger than 65 who have a wide variety of disabilities and LTSS needs.[3] We have very little information on the LTSS needs of this younger adult population. The gap in knowledge between the older and younger adult populations has contributed to a disproportionate focus in policy and programming on the LTSS needs of older Americans. This environmental scan was designed to describe the information that is available to understand these needs and identify the limitations.

The scan is part of a process designed to develop recommendations for research priorities that will generate the information needed to support improvements in LTSS for adults under age 65 with functional needs. The first phase of the project consisted of key informant interviews with 14 disability researchers and experts in the field. Interviews were designed to elicit information about other environmental data scans, data sources used by key informants, and their strengths and weaknesses, other data sources that might be useful to our efforts, methods for accessing these data and the key questions that researchers would like to answer, but cannot answer given existing data resources.

The interviews generated a wealth of information on surveys, administrative databases, compendia, literature reviews, workshops, and other environmental scans that disability researchers and policy-makers use in their work. This report describes our findings: the current state of data available to describe the extent, diversity and level of LTSS need in the under-65 population, and the limitations of this information.

METHODS

We compiled information on 26 data resources, both survey-generated and administrative, as well as additional information on compendia, data scans, literature reviews, workshops and conferences provided by the initial 12 key informants. At the conclusion of the key informant stage, we decided to interview two additional experts in the field of community-based LTSS for people with serious mental illness and/or addiction in order to ensure inclusion of relevant data sources for these sub-populations and to ensure that we examined all data resources for the inclusion/exclusion of their service needs. Below we describe the work conducted to scan the survey and administrative data sources. Information

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[3] Analysis by LTQA of data from the 2016 American Community Survey 1-Year Estimates show 7.6 million adult community residents “with self-care difficulty,” of whom 3.7 million (49 percent) are between ages 18 and 64. Another 0.2 million adults under age 65 are residents of nursing facilities.

about the compendia, other data scans and literature reviews is described in the Appendix, and was used primarily to be certain that we did not miss any other relevant data sources.

LTQA developed an initial screening protocol to determine if a data source would be included in the scan. Inclusion criteria were broad – the data source had to include information on at least some individuals in the appropriate age range (18-65), and it had to include some question(s) or data element(s) that allow users to identify a person with a disability, broadly defined, or collect information of program participants who, by definition, have a disability as a result of receiving Social Security Income or disability services from a state agency. With the exception of a few very large national population-based surveys, the data source also had to address some component of LTSS.

LTQA then developed two survey instruments that were used to collect and catalogue information on each screened in data resource, one for survey instruments and a second for administrative data and compendia. Consistent information was collected on these resources. LTQA also identified unique features of each resource and its limitations in describing LTSS needs. The vast majority of survey questionnaires were available on-line and were downloaded for review. Documentation and methods were reviewed for both survey and administrative data, and interactive charts were explored for the administrative data sets. In a few instances where on-line documentation was insufficient, we obtained hard copies of data reports or followed up with telephone calls to the individuals responsible for oversight of the data repositories.

Information from the data sources was entered into an Excel spreadsheet, allowing easy comparison across surveys. Each survey was reviewed at least twice, first for general categories of information and secondly for more detailed information about LTSS need, use, unmet need and cost.

KEY FINDINGS

In order to use data for the purpose of describing and quantifying the LTSS needs of working age adults with functional limitations, policy-makers need the following information:

- How many people, nationally, have a functional limitation that requires LTSS?
    - Does the sampling methodology allow for people who cannot answer survey questions themselves, or who live in group quarters/institutions?
- Who are the subpopulations and are they all included in the sample?
- What functional limitations are described, and do they identify LTSS needs?
- Are these needs accommodated by equipment or assistive technology?
- What LTSS are used, and how are they provided (e.g. paid/unpaid caregivers)?
- What LTSS needs are unmet?
- What do LTSS cost?
- Is there longitudinal data that can help us understand the progression of need?

Using these questions as a guide, we reviewed 26 data sources: 11 national surveys, of which 9 are ongoing but 2 are no longer in use; 7 multi-state but not national surveys; and 8 administrative datasets, 4 of which are administered nationally and 4 of which are compiled by Universities or consortia that collect data from individual states. A summary of each data source and its strength and weaknesses begins on page 9.

PREVALENCE INFORMATION

Data Sources that provide a national estimate of the number of people age 18-65 with disability.
The national surveys funded by the Census Bureau or the Department of Health and Human services that use a national probability sample are the best sources of information about the prevalence of disability nationally. These include the National Health Interview Survey (NHIS), the Medical Expenditure Panel Survey (MEPS), the Behavioral Risk Factor Surveillance System (BRFSS), the American Community Survey (ACS), the Current Population Survey (CPS), the Survey of Income and Program Participation (SIPP), the National Survey of Drug Use and Health (NSDUH), and the Health and Retirement Survey (HRS). All of these surveys include over 67,000 people in their sample, with the exception of the MEPS which includes 34,000 people and HRS which includes 20,000 people. The National Co-Morbidity Survey (NCS) also falls in this category, as does the National Health Interview Survey Disability Supplement (NHIS-D), but neither has been administered in the past fifteen years and there are no plans to resume administration. All other data sources included in this scan are limited to participants of a particular program or agency and thus are not a nationally representative sample of people with disabilities.

Potential limitations in sample selection, despite the national scope.
In additional to obtaining a national sample, a survey to identify people with disabilities needs to include people with communication or cognitive limitations (who might not be able to answer questions themselves), people who live in group quarters, people who live in institutions and if conducted by telephone, people who only use cell phones. Although rarely included in national samples, surveys that help account for the functional status of people living in shelters or in prison, or serving in the military are also important.

Survey methodologies that allow for proxy responders and are administered at the household level, allowing one person to respond for all household members, help to ensure that individuals with communication or cognitive limitations are included in the sample and makes it more likely that people with serious mental illness or addiction will be identified. Of the seven surveys listed above, all but the BRFSS use household respondents to describe the functional status of all household members. However, it appears that the NHIS will be moving to an individual level survey rather than a household survey in the next year. Of the remaining surveys, all but the CPS conduct interviews of people living in group quarters, but the ACS is the only survey that includes people living in institutions. The BRFSS does use cell phones in its survey methodology, but only interviews individuals rather than households.

FUNCTIONAL INFORMATION

Data sources that describe functional limitations that are inclusive and can identify LTSS need.
Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) are the most commonly used standard for assessing functional limitations, determining the need for home care and institutional

care, and determining eligibility for public benefits and programs. ADLs generally refer to self-care in the areas of bathing or showering, personal hygiene, getting dressed, toileting, eating, and functional mobility. IADLs include housekeeping, managing money, shopping, cooking, taking medications, using the telephone and going out of the house. ADLs and IADLs are also commonly used in survey research to identify people with disabilities although the wording to identify ADL or IADL limitations varies from one survey to the next.

In the interest of using a simpler and more standardized method of identifying disability, the federal government has recently mandated that a six-item set of questions (hereafter referred to as the 6 disability questions) be used to identify disability in many national surveys, including ACS, CPS, BRFSS, MEPS, NHIS, and SIPP. This does not preclude the possibility of additional question on disability and function in these surveys, but is beginning to replace more robust assessments of function. The six disability questions are:

1. Are you ([or is anyone in your household] deaf, or do you have serious difficulty hearing?
2. Are you [or is anyone in your household] blind, or do you have serious difficulty seeing, even when wearing glasses?
3. Because of a physical, mental, or emotional condition, do you [or does anyone in your household] have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
4. Do you [or does anyone in your household] have serious difficulty walking or climbing stairs?
5. Do you [or does anyone in your household] have difficulty dressing or bathing?
6. Because of a physical, mental, or emotional condition, do you [or does anyone in your household] have difficulty doing errands alone such as visiting a doctor's office or shopping?

While in many ways this standardization of disability data collection is good, allowing for comparison of people with and without disabilities in relation to many other characteristics, these 6 standard disability questions do a poor job of assessing the LTSS needs of people with disabilities. If no other functional questions are asked it is difficult to know the severity of the limitation. For example, a limitation might be something that is easily accommodated by equipment or periodic informal support. In addition, there are many other functional limitations that require assistance such as the inability to eat, toilet, or transfer from bed to chair. Finally, there are significant intellectual, developmental, or mental health conditions that make it difficult to work or perform other activities of daily living that may not be identified using these six questions.

Of the 8 national surveys described above, 7 ask the 6 disability questions, but the NHIS, SIPP, MEPS and HRS also ask about ADLs and IADLs. Thus, these surveys provide much more robust information about functional limitations and LTSS needs. In addition, many of the non-national or program-specific surveys also provide valuable functional information. These include the Medicare Current Beneficiary Survey (MCBS), the National Core Indicator –Aging and Disability (NCI-AD), the 3 Model Systems Databases on Burns, Spinal Cord Injury and Traumatic Brain Injury, the Home and Community Based Services Consumer Assessment of Health Plan Survey (HCBS CAHPS), and the Outcome and Assessment Information Set (OASIS). The OASIS is actually an administrative data set, but the information includes ADL and IADL assessments.

In addition to the 6 disability questions and questions about ADLs and IADLs, some of the surveys ask more in-depth questions about cognitive and intellectual disabilities and mental illness. For example, some surveys include the PHQ-9, a set of 9 questions that assess anxiety and depression, including the MCBS, NCS, HRS, and model systems studies. Others, such as the NHIS, BRFSS, and NSDUH, ask a few of these questions. Some of the studies ask extensive questions about memory and cognitive status, including the NHIS, MEPS, MCBS, SIPP, NCS, NCI-AD, and the 3 model systems studies. The BRFSS has an optional module devoted exclusively to cognition; states may choose to administer this module or not. The HRS includes extensive cognitive testing as part of its design. Notably, two of the largest national surveys, the ACS and the CPS do not include additional questions on mental health or cognition.

FUNCTIONAL NEEDS AND UNMET NEED

Data sources that describe needs accommodated by equipment or assistive technology

Some of the national surveys and more of the program-specific or multi-state surveys provided information about LTSS needs that are accommodated by the use of equipment, devices or adaptive technologies. These included the NHIS, MEPS, and SIPP for the national surveys, and the MCBS, NCI and NCI-AD, the HRS, the Spinal Cord injury model center, the HCBS CAHPS, the Adult Medicaid CAHPS and the OASIS for the other data sets.

Data sources that describe what LTSS are used, and how are they provided (e.g. paid/unpaid caregivers)

The Medicaid Analytic Abstract (MAX) is the most robust source of data about LTSS use and cost, with over 60 different LTSS items in the dataset. Unfortunately, the MAX does not include functional information, although it does include diagnoses. Other datasets are varied, with three of the largest national surveys – the BRFSS, the ACS and the CPS – containing no information on LTSS (note: the BRFSS optional module on cognition asks a few questions about LTSS, but the core survey does not). Twelve of the data sources include information on equipment use (NHIS, MEPS, MCBS, SIPP, HRS, SCI model system, NCI, MAX, HCBS CAHPS, Adult Medicaid CAHPS and OASIS). Six data sources contain information about personal assistance, in-home help, meals or chores (MEPS, MCBS, the TBI model system, the SCI model system, MAX, and the HCBS CAHPS), and five have information specifically about the receipt of assistance for ADLS (MEPS, MCBS, SIPP, HRS and OASIS). Information about whether this assistance is paid or unpaid is provided in SIPP, NCI-AD, HRS and the SCI model system data. Several sources have information about formal or informal care, including OASIS, MEPS, SIPP, HRS, and the NCI-AD.

Three of the data sources have information about the use of care or service coordination (NCI, NCI-AD, and HCBS CAHPS). Three of the data sources ask about peer services, support or specialists (the NSDUH, the NCS, and the HCBS CAHPS). Finally, the NSDUH and NCS both ask about a range of mental health or addiction support services including spiritual advisors, chat rooms, self-help groups, hot lines and drop in centers. However, none of the other national surveys, program-specific surveys, or population-specific surveys ask any questions about behavioral health LTSS.

Data sources on unmet LTSS needs

Many of the national and multi-state surveys ask about unmet need for medical, dental, or mental health care or drug treatment, but questions about unmet need for LTSS are more problematic and quite variable. Only one of the national probability surveys, the HRS, collects robust data on unmet LTSS needs and these data are limited by the age (50+) of the sample.[4] The MCBS asks Medicare beneficiaries if they have difficulty with different functions and if someone helps them with this function, thus unmet need can be derived from responses from people who receive Medicare benefits. The NCI, OASIS, and HCBS CAHPS ask several questions along the lines of "Did you need a service? Did you get the service?" and the NCI-AD asks about services that might help if a person's needs were not met. The BRFSS optional module on cognition asks about unmet need for cognitive support and the Adult Medicaid CAHPS asks two questions about unmet need for ADL support.

Data sources on LTSS costs

The best source of data on LTSS costs is the Medicaid Analytic Xtract (MAX), with over sixty different home and community based waiver services included, as well as Medicaid state plan LTSS, group homes, ICF-MR and skilled nursing facility costs. With the implementation of the Transformed Medicaid Statistical Information System (T-MSIS), CMS's ability to generate more detailed, consistent, and timely service use and cost information should improve greatly in the near future.[5] However, this information will only be available for people who are enrolled in the Medicaid program. The all-payer claims databases may have LTSS services if Medicaid is part of the database. On an aggregate level, the RISP and two State of the State data sources have information on service expenditures for people with disabilities, including their LTSS.

Longitudinal data sources

Ideally, the data used to estimate the need, use and cost of LTSS will be longitudinal, allowing the analysis of trends over time and the impact of the aging process on LTSS need of people with disabilities. Only a few of the data sources in the scan are longitudinal: the MEPS, HRS, and the three Model Systems datasets for the surveys; and the RISP, State of the States, OASIS for the administrative datasets. Other surveys or administrative datasets may collect data over time on the same individuals or programs, but have not been used for longitudinal analysis.

SUBPOPULATIONS AND CO-OCCURING NEEDS

Intellectual and Developmental Disability

Where the large, national household surveys generally fall short in addressing functional needs, several smaller, population-specific surveys and administrative datasets contain rich detail. For example, if you are interested in understanding the LTSS needs and service use among people with *intellectual or developmental disabilities*, the NCI survey has detailed information on nearly 20,000 people with IDD in 46 states, including LTSS use, need and unmet need. The RISP and State of the States administrative

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[4] The NHIS asks one question about mobility – "Do you use any help or equipment to get around?" If the person responded previously that they had difficulty getting around, then unmet need for this function could be inferred, but there are no other questions about unmet need.

[5] T-MSIS is the replacement for MSIS and will add valuable information on LTSS and improve the turnaround time on public access, but this is still in the process of being rolled out and is not yet available for all states.

datasets contain information on aggregate service use and cost for people with IDD, and the MAX has information on Medicaid HCBS data for this population. The limitation of all these data sources is that they only collect information on people currently served by state and county systems and thus may miss people with significant needs who live with family caregivers or people who are over income for Medicaid benefits.

Mental Illness and Substance Use

If you are interested in knowing more about *people with serious mental illness or addiction*, the National Comorbidity Study was an excellent source of information, but is now over 15 years old. The National Survey on Drug Use and Health is also a good resource, with information on a wide range of mental health conditions, alcohol and drugs, as well as LTSS in the behavioral health field which are markedly absent from any of the other surveys. Questions about peer support, spiritual advisors, chat rooms, self-help groups, herbalists, hot lines and drop in centers do not appear elsewhere, other than one question in the HCBS CAHPS about peer specialists. While the NSDUH contains a great deal of information on the severity of mental illness and addiction and the impact on daily living, it does not contain any of the ADL or IADL questions, nor any questions about LTSS need or use other than services that address mental health or addiction.

Physical Disability

For people interested in looking at more robust data for people with low prevalence but significant *physical disabilities,* the three model systems databases contain highly detailed information on sizable samples of people with burns, traumatic brain injury, and spinal cord injuries. The OASIS contains similarly detailed information about home care users, many of whom have physical disabilities. Finally, the NCI-AD contains valuable information on the subset of people with physical disabilities who are served in skilled nursing facilities, Medicaid waiver programs, Medicaid state plan programs and state-funded programs. The main limitation of all these data sources is that they are not nationally representative samples, but rather samples of people who participate in specific programs in a few states or locations. However, the NCI-AD is increasing the number of states that collect and contribute data to the national repository.

Co-occuring Disabilities

An important shortcoming in many of the program-specific data sources is the lack of information about co-occuring disabilities. For example, people with serious mental illness may also have physical limitations, but the national surveys that collect substantial information about mental health status often do not include questions about ADLs or IADLs. Similarly, some of the surveys of people with IDD or physical disabilities may include very little information on mental health or addiction. The program-specific data sources, in particular, often confine questioning to a particular disability, rather than examining the needs of the individual as a whole.

OTHER DATA SOURCES

A few other data sources have targeted information about specific services or populations which have not received much attention thus far. The Rehabilitation Services Administration hosts the RSA-911, an administrative database that receives data from all state vocational rehabilitation programs on services provided by these agencies and the clients they serve. Vocational rehabilitation services are cross disability rather than disability specific, and they are an important component of LTSS that are not included in many other data sets. The two CAHPS surveys – HCBS and Adult Medicaid – contain interesting information on Medicaid beneficiaries with disabilities. The HCBS has detailed LTSS information but results are not yet publicly available. The Adult Medicaid CAHPS asks less about LTSS but does include a couple of questions about unmet need, and is structured in such a way that it is possible to compare the experiences of Medicaid adults with disabilities to the experiences of people who qualify for Medicaid for other reasons.

Finally, one other important national survey deserves mention, the National Health Interview Survey – Disability Supplement, administered in 1994-1995. This survey asks nearly every LTSS question contained in any other survey including extensive questions on LTSS need, use and unmet need, the provision of help by paid/unpaid caregivers, formal/informal caregivers, accommodations provided, and if the person is on a waiting list for any kind of residential program or home care program, or is looking to move to receive more assistance. The survey also includes many questions on social activities, vocational rehabilitation services and transportation needs. As such, it is the best source of population-based disability data ever collected in the United States. The main limitation of this survey is that the data are more than 20 years old.

CONCLUSIONS

- These data sources are inconsistent in their measures of disability, with some using the 6 disabilities, others using ADLs and IADLs, some using both, and the administrative datasets using program eligibility as a proxy for disability. To the extent consistency is being promoted, the 6 disability questions are neither inclusive nor the best indicator of functional limitation or need for LTSS.
- The large national surveys that are the best at identifying the population because of the household methodology and the inclusion of ADL and IADL questions still have important limitations: the NHIS is moving to individual rather than household methodology, the MEPS has the smallest sample size of the national studies which may lead to underrepresentation of important populations, the MCBS is limited to Medicare beneficiaries, and the SIPP is being discontinued.
- Many of largest and most comprehensive datasets have the least information on functional limitations, LTSS needs, or LTSS use.
- Data on LTSS unmet needs is fairly non-existent, and where it does exist it is highly variable from one data source to the next.
- The richest datasets on LTSS service needs and use are found in population-focused studies (especially the trilogy of NCI, State of the States, and Residential Information Systems Project) or the studies of program participants. LTSS needs vary substantially from one sub-population to the next, and with this information typically housed in program-specific datasets, it is very difficult to form a comprehensive national picture.

- Cost information is limited to administrative datasets that are generally not linked to functional assessment information. The MAX and Medicare databases are confined to program participants. All-payer claims databases are not confined to a single payer, but it is unlikely that any payer other than Medicaid covers much in the way of LTSS other than equipment and adaptive devices.
- Unfortunately, the two most robust datasets on disability, the NHIS-D and the National Co-Morbidity Study, have long since been discontinued, and a third relatively rich source of data, the SIPP, is not scheduled to be administered again.

APPENDIX 1: SUMMARY OF DATA SOURCES

NATIONAL SURVEYS

National Health Interview Survey (NHIS) is conducted annually by the census, the National Center for Health Statistics (NCHS) and is one of the largest in-person household health surveys, with a sample size of 35,000 households representing 87,500 people. This survey includes people who live in group quarters, but not people who live in institutions such as nursing homes. Because it asks one individual in a household to answer questions about the health and functioning of everyone in the household, it is able to capture information about people with cognitive disabilities or serious mental illness or substance use disorders who are not likely to be answering survey questions. In addition, it is more likely to obtain information about other cognitive limitations and serious mental illness. The survey obtains good information about functional limitations, including Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). It asks fairly extensive questions about intellectual disability, cognitive limitations, a range of other physical limitations, and covers a wide range of diagnoses, including depression and mental illness. It also provides good information about the degree of limitation. The NHIS has been merged with Medicare data, and therefore cost and utilization information is available for those respondents who are Medicare beneficiaries, but Medicare does not generally cover LTSS. Limitations of the NHIS include the lack of information about specific LTSS service use other than equipment or adaptive technology, nor does it address unmet need. The NHIS has been redesigned for use in 2019, with a methodological change from interviewing households to interviewing individuals, which will result in missing a fair amount of disability, particularly for those with cognitive impairments.

National Health Interview Survey on Disability (NHIS-D) was an in-depth disability supplement to the NHIS administered for two consecutive years in 1994-5. The supplement contains detailed questions about the types of LTSS people with disabilities need and receive including personal assistance, home care, meals, housework, transportation, group home services, Independent Living Center services, vocational rehabilitation and care coordination. It asks if help is received from formal or informal care givers, paid or volunteer helpers, and asks about social activities, disability accommodations and a wide range of unmet service needs. The NHIS-D asks about residential accommodations and the types of services provided in the residence. The survey asks if the individual is on a waiting list for a group home, residential services or home and community-based waiver services or is planning to move to get more help. This incredibly rich disability data source has supported over 500 studies over the last 20 years, but is limited in that the data is now more than 20 years old and much has changed in the world of disability since then.

The Survey of Income and Program Participants (SIPP) is a national, longitudinal household survey conducted by the Census Bureau of people age 15 and older designed to evaluate the effectiveness of government-sponsored programs. Like the NHIS, it asks about all members of the household, with a sample size of 29,825 people representing 67,994 individuals. The current panel was launched in 2014 based on the 2010 Census. It asks about ADLs or IADLs, as well as the six generic disability questions. In addition, it asks specifically about serious mental illness, mental retardation, developmental disability, Alzheimer’s and other cognitive limitations. It provides some information about the degree of limitation and the impact on independent living, as well as any assistance with ADLs and IADLs that people receive. We can tell from the data if this assistance is formal or informal, paid or unpaid. Limitations of the SIPP include the limited information on LTSS use other than equipment or assistance with ADLs, and the lack of any information about unmet LTSS needs. In addition, according to key informants, there is no current plan to field this survey again, even though it is one of the richest data sources on disability.

American Community Survey (ACS) is administered by the Census Bureau annually and has the largest sample of any of the surveys, 2,390,000 people including those who live in group quarters, correctional facilities and institutions. Interestingly, they do not let people look at institutional arrangements in their public use data files nor do they use it themselves. This short survey asks about occupations, education, veteran status, and housing, but the only information pertaining to disability is the 6 generic disability questions. The limitations of the ACS are significant; it does not ask about the severity of disability, ADL or IADLs needs, LTSS need or use, or unmet need. In addition, the survey does not ask any questions about diagnoses, cognitive limitations or mental health.

Current Population Survey (CPS) is a monthly survey conducted by the Census for the Bureau of Labor Statistics on people in the work force and unemployment rates. Another household survey of people ages 15 and older, it has a sample size of 54,000 households representing 106,000 people, but it excludes those living in group quarters or institutions. The Census Bureau adds on modules periodically that include information on community participation and can be linked to social security records. A one-time disability supplement in 2012 captured information on workplace accommodations. Like the ACS, the limitations of the CPS include the absence of information on the severity of disability, ADL or IADLs needs, LTSS need or use, or unmet need. In addition, the survey does not ask any questions about diagnoses, cognitive limitations or mental health.

The National Survey on Drug Use and Health (NSDUH) is a SAMHSA-sponsored in-person survey conducted annually at the individual's place of residence, shelter, or other group quarters. It is administered by states, with a sample of 67,942 nationally. The sample excludes people living in institutions or in the military but it does include a portion of the homeless population. It contains information on the prevalence and consequences of alcohol, illegal drug use and mental illness, as well as treatment, in people age 12 and older. The survey also asks the six disability questions, a few questions about cognitive status and includes most of the PHQ-9 questions for anxiety and depression. The survey also asks about the use of peer support and other mental health/addiction support services such as Alcoholics Anonymous. The NSDUH asks about unmet need for mental health or addiction treatment. It uses audio computer-assisted self-interviewing (ACASI) for the more sensitive questions in order to increase the honest reporting of drug use or mental illness. The main limitations of the NSDUH are that it does not collect detailed information about physical function or LTSS needs, service use or unmet need for physical or intellectual disability.

Behavioral Risk Factor Surveillance System (BRFSS) is an annual telephone survey sponsored by the Centers for Disease Control. The BRFSS uses both landlines and cell phones in its survey methodology. Another large survey, with 400,000 respondents, it is conducted of one person randomly selected in each household and does not include people living in institutions or group quarters. The survey is conducted state by state, with a core module on health-related risk behaviors, chronic conditions and the use of preventive services that are conducted in all states. Supplemental modules are available to be conducted at the state's discretion. The core module includes the 6 disability questions and diagnostic information, but little else related to disability. Two optional modules, a cognitive module and a caregiver module, provide extensive information about cognitive impairments, LTSS need and unmet need, and caregiver responsibilities respectively. According to one key informant, SAMHSA gave the CDC money in 2002-3 to add the PHQ-9 that measures depression and anxiety, to the BRFSS, but the current version only appears to include a few of the nine questions. Limitations of the BRFSS include the lack of information about people living in group quarters and the single respondent per household, which makes it difficult to capture information about cognitive impairments unless the supplement is conducted. Further limitations include the absence of information on LTSS use or unmet need.

The National Co-Morbidity Study I and II (NCS) was funded by NIMH, NIDA and the W.T. Grant Foundation and conducted by Harvard University. The baseline study, 1990-92 was the first nationally representative mental health survey of people age 18 and over in the 48 contiguous states to use a research diagnostic interview to assess the prevalence and correlates of DSM-III-R disorders. In 2001-02, 9,282 respondents of the baseline NCS were re-interviewed (NCS-2) to compute incidence and prevalence of mental illness. The survey includes questions about ADLs and IADLs, cognition, the severity of mental health symptoms (including questions similar to the PHQ-9), equipment use and the level of disability. It also asks about the use of peer support and other mental health or addiction treatment supports such as the internet chat rooms, self-help groups, hotlines, spiritual advisors, and drop in centers. Limitations of the NCS include the absence of information about unmet needs for LTSS and the age of the data, over 15 years old. There is no next cycle planned for this survey.

NATIONAL PANEL SURVEYS

Medicare Current Beneficiary Survey (MCBS) is an ongoing survey of a nationally representative sample of the Medicare population, conducted by the Centers for Medicare & Medicaid Services (CMS) through a contract with NORC at the University of Chicago. The survey is conducted three times per year over the course of four years for a total of twelves surveys. The MCBS oversamples people under the age of 65 and people over the age of 80. With a sample size of 15,000, it also includes people living in group quarters and institutions and allows for proxy respondents. The survey of institutionalized individuals is conducted of their staff. The survey looks at changes in health status, expenditures, satisfaction with care, and health outcomes over time. The MCBS asks about both ADLS and IADLs as well as the six disability questions, a wide range of diagnoses, Alzheimer's, intellectual disability and other cognitive limitations, and psychiatric disorders. It also asks all but one of the questions from the PHQ-9 which is used to measure the severity of depression and anxiety. Survey respondents are asked directly if they need assistance with ADLs, housework, meals or transportation, and if their needs are met. In addition, there is a series of questions that ask the individual if they have difficulty with a particular task, and if someone helps them with that task. Survey datasets also include Medicare fee-for-service utilization and cost information. Public use data files are newly available, and there is a plan to add a care coordination module. A limitation of this dataset is that it is restricted to Medicare program participants, and thus the majority of respondents are over the age of 65, and although everyone in the sample under age 65 has a disability, it is only a subset of those with disabilities.

Medical Expenditure Panel Survey (MEPS) administered by the Agency for Healthcare Research and Quality (AHRQ) is a continuously administered set of surveys of families and individuals, their medical providers, and employers across the United States. The Household Component collects data from a sample of 13,000 households representing 33,892 individuals in selected communities across the United States, drawn from a nationally representative subsample of households that participated in the prior year's National Health Interview Survey. The survey consists of four interviews conducted over a period of 2 years and includes people living in group quarters but not institutions. The household interviews include a wide range of health conditions, ADLs, IADLs, the 6 disability questions, service use and cost, and access to and satisfaction with care, for each member of the household. It also asks about the severity of disability and the use of equipment or help, specifically home health, personal assistance and housework. The MEPS can be merged with NHIS data, which in turn is merged with Medicare data; thus some information about expenditures and utilization is available although it is unlikely that this information includes LTSS. Limitations of the MEPS include the absence of detail on mental health conditions (it does not ask any of the PHQ-9 questions), the lack of information about unmet need for LTSS and the time lag to receive expenditure data.

Health and Retirement Study (HRS) is a national panel study sponsored by the National Institute on Aging and the Social Security Administration, conducted by the University of Michigan. Data are collected every two years on cohorts age 50 and older until death, which are refreshed from time to time. The current sample consists of 20,000 individuals, and oversamples Blacks, Hispanics and people living in Florida. Participants and their spouses are recruited together, and originally have to live in a household, although follow up interviews may be conducted in an institution. The survey asks if the respondent was disabled as a child, and the reason for the disability, as well as questions about ADLs and IADLs, many questions about cognitive status, senility and Alzheimer's, includes extensive assessment of cognition, and most of the questions from the PHQ-9. The survey also asks if people receive help with any of their ADLs or IADLs, equipment use, formal and informal care, paid and unpaid care and the setting for this care. Finally, the survey asks many questions about unmet need, not for specific services but for specific types of assistance. The main limitation of the HRS is that the sample does not include people under the age of 50, over half of the people in the age-range of interest for this data scan.

MULTI-STATE (NON-NATIONAL) SURVEYS

The National Core Indicator Survey (NCI) is a collaboration between Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disability Services that provides information about IDD service users at the state or county level. The core indicators are measures used to assess the outcomes of services provided to individuals and families including employment, community inclusion, choice, and health and safety. Forty-two states voluntarily conduct an annual survey on a sample of at least 400 people with IDD, yielding a total sample of 17,682 individuals. Individuals are sampled from individual households, groups homes and institutions, and proxy responses are permitted for most questions. Each state conducts a standardized assessment of the medical needs, service use and quality of life on service users, which is supplemented by administrative data. Questions include a wide range of self-reported disabilities, including IDD and serious mental illness and many medical diagnoses. There are many questions about cognitive status, the severity of IDD and the level of staff support required. Specific questions about LTSS include the use of technology, respite, service coordination, transportation, environmental modifications, education, training, and questions about unmet need for a range of services. Limitation of the NCI include the absence of any questions about ADLs, IADLs, the 6 disability questions or the PHQ-9, and that the sample does not include people with IDD who do not receive publicly funded services through state or county IDD service systems.

National Core Indicator Survey (NCI-AD) – a spin-off of the NCI, the NCI-AD is a collaboration between National Association of States United for Disability and Aging and the Human Services Research Institute. It builds on the NCI model but surveys older adults and individuals with physical disabilities accessing publicly-funded services in skilled nursing facilities, Medicaid waiver programs, Medicaid state plans, and/or state-funded programs, or served by Older Americans Act programs. It is mostly focused on the Medicaid population, although some states are going beyond the Medicaid population. People with serious mental illness or IDD are excluded from this survey unless they are also participants in the programs administered above. A more recent initiative than the NCI, 20-25 states are currently signed on to participate, and data has been collected on a sample of 5,921 from the first seven states that joined the project. As with the NCI, individuals are sampled from individual households, groups homes and institutions, and proxy responses are permitted for most questions. Each state conducts an assessment of the medical needs, service use, consumer choice, and quality of life on service users, which is supplemented by administrative data. Questions are asked directly about physical disability, serious mental illness, and memory concerns, as well as ADLs and IADLs and cognitive status. The PHQ-9 is not used. LTSS questions include the use of equipment, assistive devices, transportation, home modifications, personal assistance, chore services, and companion services, and respondents are asked if these services are provided by a relative/nonrelative and are paid/ unpaid. Respondents are also asked specifically about services that might help if needs are unmet. The limitations of NCI-AD include the sample itself, which is limited to people receiving publicly funded services for physical disability rather than the universe of people with functional limitation due to physical disability and the newness of the survey – states are still signing on to participate and not much data is publicly available yet.

The **CAHPS HCBS (Home and Community Based Services) survey**, part of the Consumer Assessment of Health Plan Providers and Systems family, was designed to gather standardized information about Medicaid recipients' experience and satisfaction with their Home and Community Based Services. The Centers for Medicare and Medicaid Services funded the development and pilot testing of this survey by individual state Medicaid programs or their contracted health plans from 2010 through 2016. Each state has its own gatekeeper for the survey and it is limited to Home and Community Based Service Waiver program participants over the age of 18. Disability is assessed by virtue of program participation, as well as by questions concerning ADLS and IADLs. The survey also asks about cognitive status, as well as the use of LTSS including personal assistance, homemakers, behavioral health specialists (peers), case management, the frequency and reliability of this assistance, transportation, safety, and community engagement. The limitations of this data source are the inconsistence means of administration, the fact that it is not national in scope and its restriction to Medicaid beneficiaries.

Nationwide Adult Medicaid CAHPS (NAM), funded by the Center for Medicaid and CHIP Services (CMCS) and administered by NORC, was a one-time survey of Medicaid beneficiaries age18 and over not residing in institutions. The survey was conducted by mail with telephone follow up in 46 states and the District of Columbia in 2014-15. The NAM also includes administrative data submitted by states and health plans. The 272,679 person sample was stratified into 4 groups, including 76,704 respondents were eligible for Medicaid as a result of a disability and were not covered by Medicare and a second group who were dually eligible for Medicaid and Medicare (many of whom are likely to be over age 65). The other two groups consisted of adult Medicaid beneficiaries who were not eligible for Medicaid as a result of a disability. The NAM assesses access to care, barriers to care, and experiences with care across delivery systems. It asks the 6 disability questions as well as questions about cognitive status, but does not ask the PHQ-9. The NAM asks two questions about unmet need, one about need for bathing help that was not received, and the other about need for help getting out of the house that was not received. Limitations of the NAM include the absence of any questions about LTSS service use (it only asks about medical service use), the sparse information about unmet need and its restriction to Medicaid beneficiaries.

MULTI-STATE (NON-NATIONAL) PANEL STUDIES

Burn Injury Model System National Database (BMS) is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and housed at the University of Washington. This is one of three prospective longitudinal multicenter research studies funded by NIDILRR included in this scan because it is a very rich source of data on a subpopulation of people with disabilities who are often under-represented in larger national studies but may have significant functional limitations. There are currently 3,757 individuals in this database who were, at study enrollment, a patient with a specified burn injury being treated at one of the NIDILRR-funded Burn Model System Centers in Washington state, Texas or Massachusetts. Data include surveys and administrative data that are collected at intake, 6, 12 and 24 months post burn episode and then every 5 years thereafter. The survey includes questions about most ADLs and IADLs, mental health, most question in the PHQ-9, alcohol and drug use, amputations, many other physical conditions, and asks about LTSS service needs. Limitations of the BMS include the absence of questions about LTSS use other than adaptive equipment to help with driving, or unmet LTSS need. In addition, the sample is limited to one condition and is not nationally representative of people with that condition.

Traumatic Brain Injury Model Systems National Database (TBIMS) is funded by NIDILRR and housed at Craig Hospital in Englewood, CO. This is a prospective longitudinal multicenter research study of people age 16 and older admitted to one of 19 TBI Model System facilities with moderate to severe brain injury. The 19 centers are located in 14 different states, and 16 are currently enrolling new study participants. Data include surveys and administrative data, including physical examination, and are collected at discharge from acute care, 1, 2 and 5 years, and every 5 years thereafter. Approximately 15,000 people have enrolled in the study. The survey asks questions about ADLs and IADLs, cognitive status, mental health (PTSD, bipolar disorder), alcohol and drug use, and the PHQ-9 questions. Functional status is also assessed using the Functional Independence Measures (FIM), an 18-item measure of physical, psychological and social function as well as the individual’s response to rehabilitation, and the Supervision

Rating Scale which measures often an individual receives supervision. LTSS needs for ADLs, IADLs, mobility assistance, personal assistance, housework, transportation and equipment are asked directly. The survey also asks if personal assistance help or equipment are received, and asks where the individual is living and with whom. Limitations of the TBIMS include the lack of a nationally representative sample of people with traumatic brain injury. In addition, it is not clear from the on-line codebook if the survey asks about unmet LTSS.

National Spinal Cord Injury Model Systems Database (SCIMS) is funded by NIDILRR and housed at the University of Alabama at Birmingham. This is a prospective longitudinal multicenter research study of people admitted to one of 19 Spinal Cord Injury Model System facilities with a spinal cord injury caused by an external traumatic event. The 19 centers are located in 16 different states, and 14 are currently enrolling new study participants. Data include surveys and administrative data, including physical examination, and are collected at intake, 1, and 5 years, and every 5 years thereafter. Approximately 32,722 people have enrolled in the study. The survey asks questions about ADLs and IADLs, cognitive status, mental health (PTSD, depression, anxiety), alcohol and drug use, and the PHQ-9 questions. Functional status is also assessed using the FIM and the ASIA impairment scale which classifies motor and sensory impairment in spinal cord injuries. The survey asks if the person is living in a house, a group home or a facility. LTSS needs for ADLs, IADLs, personal assistance, mobility, assistive technology, and transportation are asked directly. The survey also asks how many hours of personal assistance help is received and if it is paid or unpaid, and if equipment and transportation assistance are received. Thus, if LTSS needs are identified, but no personal assistance, equipment or transportation is received, some level of unmet need can be derived. Limitations of the SCIMS are similar to those of the two other Model Systems data sources, it is not a nationally representative sample of people with spinal cord injury.

ADMINISTRATIVE DATA SETS

Medicaid Analytic Xtract (MAX) is an administrative data source housed at the Centers for Medicare and Medicaid Services (CMS) that contains Medicaid data on eligibility, service utilization and claims payment in the 50 states and District of Columbia. Source information is reported by each state to CMS on a quarterly basis. Because of the variation in state Medicaid programs, the state data are converted into a national standard via the Medicaid and CHIP Statistical Information System. The source data for the MAX has historically been the Medicaid Statistical Information System (MSIS) data reported from states to CMS, but that is being replaced by the Transformed Medicaid Statistical Information System (T-MSIS) for 2014 and during this transition consistent information is not available in all states. Over 55 million people were included in the 2010 dataset. The most recent year in which data is available for all states and the District of Columbia is 2012. State Medicaid programs differ in the types of LTSS services they offer and how they report these services, analyzing HCBS at the national level has been challenging. CMS worked with Truven Health Analytics to develop an HCBS waiver services taxonomy which includes 18 categories and over 60 services. Beginning in 2010 HCBS services and costs are reported in the MAX using this taxonomy. Limitations of the Max include the fact that as an administrative dataset, there is no information about functional status, only diagnostic information, and there is no assessment of level of disability, LTSS need or unmet need. Although the sample size is large, it is confined to those individuals who are eligible for Medicaid services by virtue of their low income, the threshold for which varies state by state. Finally, there is a significant time lapse between the point when services are provided and the data is submitted, cleaned, merged and released. However, with the implementation of T-MSIS, it is expected that both the quality of data and the timeliness of its release will improve greatly.

Social Security Disability Insurance Data –The Social Security Administration (SSA) produces Chart books, Fact Sheets, Public Use Data Files and Statistical Compilations about the people served by the SSA's programs and the benefits they receive, including people under the age of 65 who received benefits under the Blind and Disabled program. One of the datasets combines data from 12 SSA files. It is a huge dataset that contains lifetime histories of people and has been merged with national survey data from the SIPP and ACS in the past, but is now very difficult to access or link to other datasets. The National Beneficiary Survey, most recently conducted in 2015 by Mathematica, contains information about 4,062 SSDI and SSI program participants age 18-full retirement age, and their characteristics, health, program and service participation, employment interest and activity, job characteristics, and benefits. It includes information on ADLs, IADLs, other functional limitations, diagnoses, equipment use, employment services, training, services needed but not received. It also asks about other services such as personal assistance, special equipment or devices, or help with transportation that would be helpful in supporting the individual's employment. This is not information that is available in the administrative datasets. The main limitations of the SSA data are that they do not include people with disabilities who do not receive public benefits and the raw data is very difficult to access or link to other datasets.

The Rehabilitation Services Administration – 911 Data is housed at the Department of Education and contains information provided by every state rehabilitation agency on the demographic and programmatic characteristics of each person who exited the Vocational Rehabilitation (VR) program in that fiscal year. Information contained in the RSA-911 data include the type of disability, services provided the VR and SE programs, the cost of services provided, and employment outcomes. The type of disability includes a range of sensory/communication impairments, physical impairments, and mental/cognitive impairments. Services documented include information and referral, assistive technology, personal assistance, counseling, guidance, self-advocacy, skills training, transport, interpreter, and employment support. The population in this database is broader than Social Security Disability Insurance or SSI/Medicaid beneficiaries because many vocational rehabilitation users are not receiving benefits from other public programs and many are looking for work. Limitations include the restriction of the sample to those seeking vocational rehabilitation services and the fact that while aggregate data reports are available and interactive queries can be performed on R-911 data, the entire dataset cannot be downloaded without special permission.

The Residential Information Systems Project (RISP) is an administrative dataset that includes longitudinal information on LTSS for people with intellectual and developmental disabilities. Housed at the University of Minnesota's Institute on Community Integration, data is collected via an annual survey administered to states on residential information for people with IDD. Data collected include the number of people receiving services in different kinds of locations – at home, with relatives, state operated facilities, and public and private institutions – as well as service models, sizes and expenditures. The survey also includes information on the waiting lists for waiver services. Limitations of the data source include its restriction to services provided by state programs and the aggregate nature of the information.

The State of the States is an administrative dataset that includes longitudinal information on services for people with intellectual and developmental disabilities who receive services in state and county-funded systems. Housed at the University of Colorado, and funded in part by the Administration on Intellectual and Developmental Disabilities (AIDD) it contains nationwide financial and programmatic trend data on programs, services and costs. These data are collected through surveys administered to states. In addition to providing information on the number of people served in different residential options and the cost of this care, State of the States also provides information on family supports, supported employment, supported living, and personal assistance. The limitations of State of the States are similar to those of RISP.

Cross Disability State Spending is another administrative dataset housed at the University of Colorado that includes longitudinal information submitted by states on services for people with intellectual and developmental disabilities, mental health needs (MH), and physical and sensory disabilities. This study was funded by AIDD and NIDILRR. Data was collected on the annual costs of care during fiscal years 1997-2013 in each state for health care, income maintenance, special education, long-term care, and total disability spending. Data can be accessed through interactive charts on their website. The limitations of this data source are similar to those of the State of the States, and it does not appear that more recent data has been collected.

All Payer Claims Databases – All Payer Claims Databases have been developed by fourteen states, with five more states in the process of implementing them. The All Payer Claims Database Council (APDC) is a voluntary collaborative of government, private, non-profit, and academic organizations whose goal is to improve the development of state-specific all payer claims databases, share practices across states and help disseminate information. The APCD Council is convened and coordinated by the Institute for Health Policy and Practice at the University of New Hampshire and the National Association of Health Data Organizations. The APCD databases have information on all privately-insured individuals as well as Medicaid beneficiaries. Researchers can request state-level Medicare data from CMS to add to the data. The APCD website provides links to state databases that can be accessed online. People at AHRQ, NIDILRR and the Canadians have worked on codes that can be used to identify people with IDD in the databases. Although claims data sometimes miss people who have never been seen by a doctor or do not have the right codes on their claims, this is one source of administrative data that is not confined to single public or private program. Limitations of the All Payer Claims databases are that each dataset is different, making aggregation impossible at this point in time. In addition, any LTSS data would only be available in the Medicaid files, if it is included at all.

Outcome and Assessment Information Set (OASIS) is designed to measure changes in a Medicaid or Medicare home care patient's health status over time. Home care agencies submit socio-demographic, environmental, support system, health status, functional status, and health service utilization data on their patients to CMS at the start of care, 60-day follow ups and discharge, as well as surrounding an inpatient admission. Assessments are conducted by registered nurses or licensed therapists on patients age 18 and older, and include many diagnoses, conditions, severity of illness, vision, hearing, speech, and pain. ADLs and IADLs are assessed, as well as many neuro-behavioral conditions. OASIS data includes information about whether functional needs are accommodated and the use of LTSS including in-home supports, agency support, equipment use, paid and unpaid help, formal and informal assistance. It documents unmet need by asking if assistance is needed and if it is received. These data are housed at CMS, and outcome, process and avoidable events reports are available on their website. Although the OASIS is a rich source of data, it is limited to people who use home health services from a Medicaid/Medicare certified home care provider. Reports compiled from OASIS data are available on the CMS website; access to the data itself requires a formal data request to CMS.