Report on
A Key Informant Survey on
Data Sources on LTSS Needs and Services Use of
Adults with Disabilities Under Age 65

February 23, 2018

Introduction

The purpose of this project is to develop recommendations for data collection that will assist policy-makers in addressing the long-term service and support (LTSS) needs of working age adults with disabilities. In this first phase of the project we conducted Key Informant interviews with expert researchers in the fields of disability and LTSS for working age adults. 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 and their strengths and weaknesses
- Methods for accessing these data
- The key questions that researchers would like to answer, but cannot answer given existing data resources.

In addition, we received important information about data collection trends, both in terms of definitions and foci for people with serious mental illness and for trends in national disability data collection overall. Below we report our findings.

Individuals interviewed, current position and research/population focus

We interviewed 14 experts in the field of data and research related to working age adults with disabilities in 11 conference calls. These included a team of 4 experts from Mathematica Policy

Research (Carey Appold, Carol Irvin, Jody Schimmel Hyde and Dave Whittenberg), Charles Lakin, Steve Kaye, Andrew Houtenville, Ronald Manderscheid, Richard Kronick, Sarah Ruiz, Ronald Kessler, Lisa Iezzoni, Jae Kennedy and John Tschida. More detailed information about each of these informants including their current positions is appended to this report. This group included two individuals whose primary research focus is on individuals with intellectual or developmental disabilities, two researchers whose focus is on people with serious mental illness, three researchers with a focus on physical disability or mobility impairment and the remaining seven individuals reported that their research focus was explicitly cross-disability. Following these key informant interviews, we spoke with two additional informants with expertise in the LTSS needs and sources of funding for people with serious mental illness, Richard Frank and Kevin Martone.

Other environmental scans

Most of the key informants were not aware of any other environmental data scans, similar to the scan we are conducting now. However, several other scans with some overlapping characteristics were mentioned. These include:
- Mathematica's 2011 report on Disability Data in National Surveys (2011) prepared for ASPE - Gina Livermore is first author. The report is a review of disability-related data from existing national surveys to assess the need for fielding another national disability survey (this scan does not specifically address the availability of LTSS-related data).
- A Report from AHRQ on "Future Directions for Community-Based Long-Term Care Health Services Research: Expert Meeting Summary June 20-21, 2000" which reviewed existing survey data at the time.
- A report from the DEHPG 2014 LTSS Research Summit prepared by Mathematica that summarizes the findings from DEHPG grant programs organized by eight attributes of LTSS systems and identifies critical research gaps.
- The Committee on National Statistics of the National Academy of Sciences was reported to have put together a scan on HCBS data in 2003-2004 (still searching for this).
- Interagency Committee on Disability Research: Disability Data -- https://www.icdr.acl.gov/resources/disability-data -- an online compendium of data resources with links to websites for the resources. The online listing Is kept current.
- "Compendium of Health Data Sources for Adults with Intellectual Disabilities, 2011" funded by the CDC, conducted by HSRI and UMass Boston with Alexandra Bonardi as the lead author.
- "National Quality Inventory Survey of State HCBS Programs" prepared by Medstat and HSRI for CMS in 2004. The report summarizes the results of a nationwide survey of state waiver program quality assurance/quality improvement systems.

- "Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services" – an environmental scan in 2010 by AHRQ of existing and potential measures of HCBS in client functioning, client experience, and program performance.
- "Sources for Employment and Disability Data" – a list of links to data sources for estimating employment for individuals with disabilities maintained by the ADA National Network.

Data sources/references used by Key Informants

Key Informants identified nine national surveys and four administrative datasets that they commonly used to conduct disability research. These are described below, and are followed by lesser known or more localized study descriptions.

Major Data Sources

The Survey of Income and Program Participants (SIPP) is a national, longitudinal household survey conducted by the Census Bureau of people age 15+. The current panel was launched in 2014 based on the 2010 Census. SIPP is designed to evaluate the effectiveness of government-sponsored programs and asks questions about employment, income, living arrangements, social program participation and eligibility, health insurance coverage, and demographics. It uses the 6 generic disability questions but also asks about severity. The SIPP can be used to look at the potential size of the population that is eligible for the federal personal assistance benefits and it provides some information about the kinds of services people are getting, including unpaid help. The sample is about 40,000 and it is also linked to Social Security Disability Insurance records so you can get primary diagnoses. The SIPP was more useful in the past than it is now, and informants do not know if it will be fielded again. One informant remarked that it is probably the richest data source ever on disability. It has a public use file but linking it to SSA is challenging. (JK, SK, AH, MPI, RF)

National Health Interview Survey (NHIS) is conducted annually by the National Center for Health Statistics(NCHS) and is one of the largest in-person household health surveys. It looks at health insurance for working age adults with disability, measures of functioning, activity limitations, access to and use of health services, where people live, how they live, and their transportation. It provides some information about service needs, but not if those needs are met. Another drawback is that you cannot compare states. There was a particularly useful disability supplement (NHIS-D) done once as an expanded questionnaire administered for two consecutive years in 1994-5. It is a rich data source that has supported over 500 studies over the last 20 years. It is a particularly valuable source of information about people not in the service system, but is quite dated now. The NHIS has been redesigned for first use in 2019. The impending

methodological change of interviewing individuals rather than households is not good, a lot of disability will be missed. You can get supplements to the NHIS but the agency controls everything. NCHS is good at getting public releases out quickly. They have a user-friendly website with publicly available data files along with variable labels and statistical measures. They provide guidance on how to use the data. (AH, MPI, LI, JK, CL, SK, RF)

Medical Expenditure Panel Survey (MEPS) administered by the Agency for Healthcare Research and Quality (AHRQ) is a set of large-scale surveys of families and individuals, their medical providers, and employers across the United States. The Household Component collects data from a sample of families and 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 household interviews include demographics, health conditions, health status, service use and cost, access to and satisfaction with care, insurance, income, and employment on each member of the household. Key informants report that it is a little more complicated than the NHIS because they follow people over a longer period of time. As a result, they get a lot more information about expenditures and utilization. On the other hand, there is a time lag to receive the data and informants would prefer real time expenditures and a larger, more diverse sample. Data files are available on the AHRQ website. (JK, SK, LI).

American Community Survey (ACS) is administered by the Census Bureau annually and has a very large sample, 1/100. This short survey asks about occupations, education, veteran status, and housing. They have data on people in nursing homes, group homes, correctional facilities, but they do not let people look at the type of institution in the public use data files. They also do not use it themselves. The ACS uses the 6 generic disability questions but it does not tell you if the person needs LTSS, nor does it have information on service utilization. ACS is readily available on the Census Bureau website. (SK, JT, AH, MPI)

Current Population Survey (CPS) is a monthly survey done by the Census for the Bureau of Labor Statistics on people in the work force. The CPS looks at unemployment rates among people with disabilities. It does not include people in institutions, but it adds on modules that are incredibly rich such as community participation and is also linked to social security records. There is a list of supplements on line. You can get supplements added to the CPS but the agency controls everything (CL, SK, AH).

Behavioral Risk Factor Surveillance System (BRFSS) is sponsored by the Centers for Disease Control. It consists of telephone surveys that are conducted state by state to collect data about on health-related risk behaviors, chronic health conditions, and the use of preventive services. Historically, its disability questions have been very poor and it asks nothing about LTSS. SAMHSA gave the CDC money in 2002-3 to add the PHQ, a 9-item questionnaire that measures depression and anxiety, to the BRFSS. BRFSS also collects information on disability and well-being (SK, RM).

The National Co-Morbidity Study I and II (NCS) was conducted at Harvard, and funded by NIMH, NIDA and the W.T. Grant Foundation. The baseline study, 1990-92 was the first nationally representative mental health survey in the U.S. to use a fully structured research diagnostic interview to assess the prevalence and correlates of DSM-III-R disorders. In 2001-02, respondents of the baseline NCS were re-interviewed (NCS-2) to compute incidence and prevalence of mental illness. This was a national telephone probability sample of the US population age 18-death, showing that 20-25% of the population has mental illness, and it also includes how severe the symptoms are and the level of disability. These data are kept by Ron Kessler at Harvard and available on the website. There is no next cycle planned (RM).

Medicare Current Beneficiary Survey 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. It looks at changes in health status, expenditures, satisfaction with care, and health outcomes over time. Key informants reported that this survey is more complicated and expensive than the MEPS, NHIS or the SIPP. (LI, JK, RF)

Medicaid Analytic Xtract (MAX) is a research-ready data source for 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 and then combined by CMS. MAX is problematic in a number of ways, they run 3-5 years behind actual service use and there is limited information that is comparable state to state. MPI uses Medicaid administrative data, enrollment and claims data, using the national data that is housed at CMS. (CL, SK, MPI, RF)

Social Security Disability Insurance Data –there is a disability file that combines the data across 12 SSA files and it can be merged with some of the national survey data (the SIPP and ACS - with great difficulty, now almost impossible). This is a huge dataset that contains lifetime histories of people. The main drawbacks are that it does not include people with disabilities who do not receive public benefits and it is quite difficult to access the data and/or linking it to other datasets (MPI)

All Payer Claims Databases – there are 14 states that maintain state all-payer claims databases, and 5 more in the process of implementing them. These databases have information on all privately-insured individuals as well as beneficiaries of Medicaid. Researchers can request state-level Medicare data from CMS to add to the data. One Key Informant is using all-payer claims to study IDD (but not LTSS). There is an All Payer Claims Data association (APCD) with a website that provides links to state databases that can be acces online. Amanda Rikerd at NIDILRR is working on the code they use to identify people with DD and ID; AHRQ and the Canadians have also done work on this. They sometimes miss people who have never been seen by a doctor or

don't have the right codes but this is one source of administrative data that is not confined to single public or private program. (AH)

The Rehabilitation Services Administration (RSA) oversees all the state rehabilitation agencies and has good data for population-specific information. It is good for showing the heterogeneity of the population, benefit amounts, and impairments. Its population is broader than Social Security Disability Insurance or SSI/Medicaid beneficiaries because many vocational rehabilitation users are not on other public programs and many are looking for work. You can access these data by emailing a contact person at the Department of Education. It is not an onerous process. (MPI)

The National Survey on Drug Use and Health, conducted by SAMHSA, is an in-person survey conducted at the individual's place of residence or shelter. It excludes people living in institutions or in the military. 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. 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. (RF)

Smaller studies conducted by Key Informants

Mathematica: In their evaluation of the Money Follows the Person demonstration they looked at differences in LTSS needs and use. Program participant sample.

Kennedy: Internet based survey of adults with disabilities; survey of ILCs on benefit counseling, information and training needs.

Mandersheid: His organization publishes a monthly document called Under the Microscope which uses SSI data on people with serious mental illness, substance use disorders and developmental disabilities.

Other resources to review

Other potentially relevant data sources, not used directly by informants but known to them, included the following:

The National Core Indicator surveys, a collaboration between Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disability Services, provide information about IDD service users at the state level. Forty-two states participate and each state does an assessment of the medical needs, service use and quality of life on a sample of 400 people with IDD. These data are amalgamated into a national data set that is the best

data source for IDD service users that can be stratified by age, diagnoses and dozens of other variables. 20,000 individuals are in the database. The Core Indicators Project is branching out beyond the DD population with an aging and disability supplement to look at people with other disabilities, mental health and physical. This is mostly focused on the Medicaid population, although some states, including MN, are going beyond the Medicaid population. The supplement lives with the National Association of States United for Aging and Disability (NASUAD). Camille Dobson is the lead contact on this. More information and data can be found on the nationalcoreindicators.org website. (CL, SK, JT).

The **foundational reports in the DD world** that have been used in court cases in states that are not keeping up with getting people out of institutions include (CL, JT):

- The Residential Information Systems Project out of the University of Minnesota collects annual survey information from states on the number of people receiving services in different kinds of locations, service models, sizes, at home, state operated, relatives and public and private institutions. The Residential Community Assistance Project that Amy Hewitt is working on.
- The State of the States, a report out of the University of Colorado, focuses on expenditures for developmental disabilities.
- A report on day and employment supports is done by John Butterworth at the Institute for Community Inclusion at UMass Boston.

The Inter University Consortium for Political and Social Research (ICPSR), housed at the University of Michigan, is a repository for publicly available data, and starting next year all research funded by NIDILRR will have to be sent to them as part of their Terms and Conditions of Award. They have a disability data section with IDEA data and NHIS data, with funding from ACL and other agencies.

Health and Retirement Study from Michigan (funded by NIH, the National Institute on Aging) follows cohorts age 50 and older, refreshing them from time to some. They are some of the best minds in survey work. They have data on formal and informal long-term care.

National Academy of Sciences report on changing the definition of serious mental illness from an absence-based approach to a strengths-based approach, 2016 report #21920.

NIDILLR has large datasets on people with SCI and TBI. These are publicly available but you have to request them from the Project Directors who have the option to be involved in the research projects.

The **Hopkins longitudinal** study out of the National Institute on Aging

Truven did a report last year on the evolution of Medicaid expenditures over the years using Medicaid 64 and 372 data.

Kaiser Family Foundation has good information about people on waiting lists for services although states vary widely in how they collect this information. They also have good information about Medicaid expenditures.

"The State of the States in Intellectual and Developmental Disabilities" is an annual publication compiled from an annual survey of 51 state programs with state-level data on services use and federal and state spending.   It provides longitudinal data: 2017 is the 11th edition. The project is funded by the Administration on Intellectual and Developmental Disabilities, compiled by David Braddock at the Coleman Institute for Cognitive Disabilities in Boulder, CO, and distributed by the American Association of Intellectual and Developmental Disabilities.

The **CAHPS HCBS survey** is conducted by states or health plans, administered in idiosyncratic ways. Each state has its own gatekeeper for the survey and they are limited to program participants. The CAHPS for LTSS might get at unmet need for LTSS in a way that other CAHPS get at unmet need for medical services (MPI)

Data from health plans, particularly the data arm of United, Optum, and perhaps Centene or Anthem, or the managed behavioral health care plans that pay for both Medicaid and state mental health agency-funded services) (JT, KM).

Commonwealth Care Alliance data – trying to look at LTSS use and match that with functional status, but having difficulty due to missing data (LI).

The ACES (Adverse Childhood Events) study, done first by Kaiser Permanente and now by CDC ran a sample of 19,000 children to see what happens to them as adults (RM)

The OASIS might be useful (minimum data set) (LI, RK).

Evelyn Bromet at SUNY Stoneybrook created **a population registry for people with serious mental illness** in Westchester County, she went to all the shelters and community mental health centers and tried to keep track of people. She has the best data about the true prevalence of mental illness as anyone (RK2).

SAMHSA block grant applications may have some information on LTSS needs on a state by state basis.

Comments and reflections on the overall state of data, trends in data collection, and definitions over the past 20-30 years

Key Informants were nearly unanimous in deploring the current state of disability data, describing it as piecemeal, lacking in generalizability, or, if based on national probability samples, too broad to capture the information we need to know. Since the NHIS disability supplement in the mid-1990s there has been nothing comparable that captures information on the population as a whole, including service needs on a broad basis. Further, the trend seems to be that the government is moving away from subsidizing, fielding and analyzing national data on disability. Key Informants also consistently underscored the lack of information on long-term services and supports (LTSS) needs and use in the national surveys.

Key Informants pointed out that the number and variability of surveys with information on younger adults with disabilities created a problem. Each survey presents a different snapshot and the body of information coming from the surveys has not been consolidated into any overall national picture of disability. Why have 7 different epidemiological surveys, why not put them altogether in one survey? SAMHSA, CDC, NIH they all have their own surveys. The national surveys have limits in their ability to measure and characterize the scope of the younger adult population with disabilities. For example, national surveys are just beginning to use cellphone numbers for phone interviews, without which they miss a large portion of the population without conventional landline phones - particularly those with disabilities.,

The most extensive data on people with disabilities comes from government program files (including Medicare and Medicaid). However, these databases do not include data on individuals with disabilities who are not in the programs or who are on a waiting list.

Impairment and functional status data are missing from many of the surveys and that is what you need to get information on LTSS needs; diagnoses are not sufficient.   Most of what we know about disability and LTSS from the large national surveys is basic and not detailed or subdivided enough to have much value in program development or in addressing some of the more important research questions.

The most extensive detail on disability and long-term services and supports comes from Medicaid expenditure data. It only applies to a subset of adults with disabilities, and it does not include housing, employment or other supports not covered by Medicaid.   It is also important to know more than someone's functional status, and to know something about their community activities and life.

Extended longitudinal data is hard to find, but is important in understanding LTSS need because people's status changes, especially with progressive conditions. And you need more than functional status, you also need community activities and life.

We have no good population base to estimate need. The NHIS is the best, but it is still lacking, especially for utilization. It has been merged with Medicaid and Medicare data, but you have to go to the data centers to use it, and that is very difficult. It also only includes people on Medicaid and Medicare, and many states are not sending waiver data to MAX.

How do you survey homeless people if you are surveying individuals or households? How do you survey people with dementia, chronic alcoholics, people with bipolar disorder, drug dependence, or anxiety if surveying individuals? What about people in prison, many of whom have mental illness? Doing these surveys right is hard work, you need to use a network approach by sampling households or relatives.

There is more detail on substance use than on mental health. Impairment and functional status data are missing from many of the surveys and that is what you need to get information on LTSS needs; diagnoses are not sufficient.

Informants gave specific examples of how they think we are going in the wrong direction:
- Current changes in the NHIS, going from a family focus to an individual focus, will make it less useful because we will miss a fair amount of disability. People with cognitive disabilities, or serious mental illness or substance use disorders are not likely to be answering survey questions – but a family member might on their behalf. This is going away.
- The six standardized questions that are now used across many surveys to identify disability are so broad that they do not, for the most part, capture LTSS need. These questions are taking the place of ADL and IADL questions in previous surveys that did help identify service need.
- The SIPP, one of the most useful surveys, has stopped asking questions about specific ADLS and may be going away entirely.
- The National Co-Morbidity Studies in the early 2000's were used to compute incidence and prevalence of mental illness, but there is no plan to conduct another round.
- No one is compiling encounter data from Medicaid and merging it with SSA data any more.
- It is very difficult to access SSA data or link it to other data sources. An interagency agreement is needed to link datasets and you need champions on both sides at high levels to make this happen.

- Agency heads at NIMH are more interested in finding a cure for a particular disorder than conducting epidemiological studies.

Several informants mentioned the challenges of using different definitions of disability; although few wanted to spend time going down that path other than to mention the replacement of ADL and IADL questions with the six standardized questions. However, it may be relevant to note the major changes in the landscape of thinking about mental illness and disability. In the early 1990's there were three markers for identifying disability due to mental illness: the diagnosis, the level of disability (e.g. SSDI classification) and duration of at least one year. However, many people who do not qualify for SSDI are still disabled so in the mid 1990's they dropped that criteria to look a community functioning and also dropped the duration criteria. This definition is still used by the government. However, the mental health field has moved beyond this – it no longer looks just at community functioning but if an individual has a full life in the community as a recovered person.

Important questions we cannot answer due to the lack of adequate data

We asked Key Informants what areas of understanding of people with disabilities are limited by the lack of adequate data, and what are the top two or three questions you would like to answer if you had the data. The most frequently mentioned responses were (1) how do we measure and understand unmet need? And (2) how do we know what works the best?

Below are the combined responses to these two interview questions:

- What is it about LTSS that makes a difference to people, and which services in particular make a difference (e.g. is it personal assistance, meals on wheels?
- Are there certain supports that we can say definitely that they keep people in the community?
- Medicaid HCBS services have expanded greatly but are people doing better as a result?
- Are the factors that impact one group different from the factors that impact another group, and if so, how?
- What are mental disorders, exactly, and why do some people with a certain diagnosis respond to a given treatment while others with the same diagnosis do not?
- What is the long term natural history of common mental disorders – how many people have the condition, how long do they have it, what is the trajectory? Most mental illness is a long term chronic disorder but we treat so many disorders as acute episodes of illness.
- What parts of mental illness are amenable to change? We can probably get 85-90% of people helped if they stick with treatment, but many people stop after the first failure

because they are depressed. Can we do better at finding the right treatment for the right person right away?

- To what extent are poor people with disabilities suffering worse outcomes than people with money and why? Would like to understand the role of disparities, the social determinants of health, support services.
- What are people with disabilities doing in their day to day lives, and what are the factors that impede their ability to live life to their satisfaction? What are the barriers to and facilitators of satisfaction?
- What are peoples' preferences for the LTSS they would like?
- What is the relationship between paid and unpaid labor in personal assistance?
- What are the transactional costs of obtaining and retaining disability services and making it all work?
- More information on the need and use of LTSS – how we can replace high cost services with lower cost services such as personal assistance.
- How do you structure an LTSS service system to best meet people's needs at a reasonable cost?
- Who are the people who need, but do not receive services (x4)?
- How do unmet needs outcomes, and the ability to remain in the community?
- What is the experience of family members who are caring for children or adults with disabilities?
- What are the advantages/disadvantages of managed care and do people get better services? If so, why?
- How can we learn more about the ADL and IADL needs of people with disabilities who are not eligible for Medicaid and Medicare? And how are these individuals meeting those needs (if they are)?
- What is the severity of disability and age of onset? How do you find people before they have a disability?
- What are the physical and mental disabilities of people who survive an opioid overdose? What services do they need and how is this impacting already meager LTSS and rehabilitation services?
- How can we identify the social and physical determinants of health, and mobilize communities to do something about them?
- How can we get information on the functional status of people with serious mental illness where diagnoses and symptoms do not suffice (e.g. one person with schizophrenia and an addiction can hold down a job while another person with the same diagnoses can barely function)?
- How do outcomes differ for people served in integrated systems of care for mental health, substance use and primary care as compared to outcomes for people not in those systems? And what are the cost savings?

- What LTSS services are effective in community settings as compared to institutional or correctional settings?
- What are the long-term effects of early intervention for mental illness? Is it effective in preventing the need for more intensive services later on?
- What is the difference in outcomes for people whose LTSS needs are met as compared with people whose needs are not met?

Other researchers mentioned during the interviews

- Mark Salzer at Temple re: people with serious mental illness
- Brian Burwell at Truven
- David Stapleton at Mathematica knows about social security and Medicaid data
- Medicaid data experts: Todd Gilmore at UCSD, GEN Associates in Cambridge, Steve Crystal at Rutgers, and the person who created the first tape to tape data and then the MACS data at CMS, ask MacPac who this is.
- Ruth Katz at ASPE (now at LeadingAge)
- Kathleen Merikangas at NIMH can tell us more about the National Co-morbidity study
- Evelyn Bromet at SUNY Stoneybrook
- Sharon Normand, Health Policy Dept. at Harvard Medical School and Tom McGuire, a health economist in Ron Kessler's Dept. work with big claims datasets for SMI
- Sarah Galantowitz (now at Abt Associates, previously at Truven) did an inventory on quality measures and HCBS services.
- Suzanne Gruyere's work on employment at Cornell.
- Mark Olfson, professor of psychiatry at Columbia, uses administrative databases to count heads, piecing together Medicaid, Medicare and MEPS (RK2).
- Data from the VA System (Trish from the Interagency Committee on Disability Research (JT)
- Ted Lutterman at the National Association of State Mental Health Program Directors' research arm knows a lot about mental health and data (KM).

Specific recommendations

In addition to providing valuable information about data resources and insight into the inadequacy of existing datasets, Key Informants had several specific suggestions about steps that could be taken to change this situation:

- The Health and Retirement Study from Michigan (funded by NIH, the National Institute on Aging) follows people age 50 and older. They could be asked to start at a younger age.

- A recommendation to NIMH: If you do conduct a 1200 person sample every year instead of 12,000 once every 10 years, this is a very small, manageable study that would give you up to date information. It would only be 100 people/month or 25 people/week. Then the people could be re-interviewed for a small incentive that you give them right away and called back a few days later. Piggy back this onto the NHIS or the SAMHSA survey. You get an incredibly high response rate doing this, and you can get information about other household members. The entire thing could be done by 4 half time graduate students and cost next to nothing.

- Jean Hall and Noelle Kurtz worked on the Health Reform Monitoring Survey (JK) at the Urban Institute. They created a standing panel of people they could re-interview over time, and paid them for their time. This is similar to market research and we could do something similar for disability research because the Urban Institute sample of people with disabilities was fairly small. And if the sample were diverse enough, it could be used to study many different issues, rather than having to recruit a new survey sample for every study.

Appendix 1: Key Informant Information

Name	Current Position	Affiliation
Charles Lakin	Director, Rehabilitation Research and Training Center on Community Living/Institute on Community Integration	University of Minnesota
Steve Kaye	Professor, Institute for Health & Aging	University of California, San Francisco
Andrew Houtenville	Research Director, Institute on Disability	University of New Hampshire
Ronald Manderscheid	Executive Director	National Association of County Behavioral Health & Developmental Disability Directors (NACBHDD)
Richard Kronick	Professor, Dept. of Family Medicine and Public Health	University of California, San Diego
Sarah Ruiz	Senior Scientist and Program Officer	Administration for Community Living (ACL)
Ronald Kessler	Professor of Health Care Policy	Harvard Medical School
Lisa Iezzoni	Director, Mongan Institute Health Policy Center	Massachusetts General Hospital
Jae Kennedy	Professor and Chair, Department of Health Policy and Administration	Washington State University
John Tschida	Associate Executive Director for Research and Policy	Association of University Centers on Disability (AUCD)
Richard Frank	Professor of Health Economics	Harvard Medical School
Kevin Martone	Executive Director	Technical Assistance Collaborative (TAC)
Carey Appold	Senior Researcher	Mathematica Policy Research
Carol Irvin	Director of Health Research and Senior Fellow	Mathematica Policy Research
Jody Schimmel Hyde	Senior Researcher	Mathematica Policy Research
Dave Whittenberg	Director of Social Security and Disability Studies	Mathematica Policy Research