White Paper:

Data Resources to Determine the LTSS Needs of Working Age Adults with Disabilities: Gaps and Recommendations

July 30, 2018

INTRODUCTION

About 13 million Americans need long-term services and supports (LTSS),[1] and nearly half are adults younger than age 65 who have a wide variety of disabilities and LTSS needs.[2] However, our understanding of the characteristics and needs of the LTSS population is largely derived from studies of people age 65 and older. We have very little information on the LTSS needs of this younger adult population. This 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 and makes it difficult to build an effective case for improvements in service delivery and financing of LTSS for adults under age 65 with disabilities.

The following report, funded by a grant from the Commonwealth Fund, summarizes the findings from a set of activities conducted to identify the data gaps concerning the extent and diversity of LTSS needs and unmet needs of adults under age 65, and makes recommendations for filling these data gaps.[3]

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[1] V. Nguyen (2017). Long-Term Services and Supports, Fact Sheet. AARP Public Policy Institute. The estimates were developed by AARP from the 2014 National Health Interview Survey and the 2014 American Community Survey 1-Year Estimates.

[2] 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.

[3] It should be noted that, while this project is focused on the adult under 65 population, there are important LTSS considerations for children with disabilities as well. As long as children are engaged in the educational system, a significant amount of data is collected about their functional and cognitive status and needs. The National Survey of Children with Special Health Care Needs is another invaluable source of information on children. Thus, while data

The first step in identifying the data needs and gaps consisted of key informant interviews with 14 disability researchers and experts in the field. The interviews were designed to obtain information about data sources used by researchers, 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. A list of these 14 key informants is provided at the end of this document. 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.[4]

In the second step of this process, we conducted an environmental scan to review the scope and adequacy of the data sources suggested by the key informants, as well as the methods used to obtain the information.[5] 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. From this scan we generated a report on 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. A summary of the thirteen data sets most frequently cited by researchers during our interviews is provided in Table 1, on the next page.

Thirdly, we convened an Advisory Panel of disability advocates and policymakers to review the findings of the environmental scan and provide feedback on the accuracy and implications of these findings, and to provide recommendations on strategies to fill the gaps. A list of the Advisory Panel members and their affiliated organizations is included at the end of this document. The information and recommendations provided in this report are based on a combination of a comprehensive documentation of LTSS-related data available today and input from the Advisory Panel, who identified important data gaps, policy questions that cannot be answered, and possible options for filling these gaps.

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gaps are not quite as extensive for children, once they exit the educational system there is a data cliff, and we need to be particularly mindful of this transition period.

[4] Long-Term Quality Alliance (2018). *Report on A Key Informant Survey on Data Sources on LTSS Needs and Services Use of Adults with Disabilities Under Age 65*. Available from: http://www.ltqa.org/wp-content/themes/ltqaMain/custom/images//Key-Informant-Report-2-23-18-Final.pdf

[5] Long-Term Quality Alliance (2018). *Environmental Scan: Data Resources Available to Determine the LTSS Needs of Working Age Adults with Disabilities*. Available from: http://www.ltqa.org/wp-content/themes/ltqaMain/custom/images//Environmental-Scan-Report-FINAL-05.14.18.pdf

Table 1: Overview of Key Data Sources Available to Determine the LTSS Needs of Working Age Adults with Disabilities

Data Source	Sampling		LTSS Need[6]		LTSS Use[7]	Unmet Need[8]
	Sample	Limitations	Functional Needs	Cognition		
NHIS[9]	General population sample: 87,500	No institutional, military, prisons.	◑	●	◐	◎[10]
NHIS-D	Individuals with disabilities: 32,788	No institutional, military, prisons. Last administered 1995.	●	●	●	●
SIPP	General population sample: 67,994	No institutional respondents.	◑	●	◐	◎
ACS	General population sample: 2,390,444	No LTSS information.	◐	◎	◎	◎
NSDUH	General population sample: 67,942	No institutional.	◐	◑	◐	◎
BRFSS	General population sample: 400,000	No group quarters, institutional, or proxy respondents.	◐	◎[11]	◎[11]	◎[11]
NCS	General population sample: 9,282	Last administered in 2003. No institutional or homeless individuals.	◑	◑	◐	◎
MCBS	Medicare beneficiaries: 15,000	Few respondents are under age 65.	◑	◑	◑	◑
MEPS	National subset of NHIS sample: 33,893	No institutional, military, prisons.	◑	◐	◑	◎
HRS	National probability sample: 20,000	No respondents younger than 50 years old.[12]	◑	●	◐	◑[13]
NCI	IDD service users: 17,682	Only people using publicly-funded services.	◎[14]	◐[15]	◑	◑
NCI-AD	People with physical disabilities: 5,921	Only people using publicly-funded services.	◑	◐[15]	◑	◑
MAX	Medicaid participants: 55,028,691	Only people receiving Medicaid benefits.	◎	◎	●	◎

◎ – No data, ◐ – Simple and/or limited data, ◑ – Moderate quantity and/or detail of data,

● – Extensive and/or very detailed data

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[6] LTSS Need includes difficulties with ADLs and IADLs, whether the respondent needs help with various activities such as mobility or transportation, and cognitive limitations such as memory loss, dementia, or confusion.

[7] LTSS Use includes whether respondents receive assistance with ADLs/IADLs, use special equipment to accommodate their LTSS needs, or receive either formal or informal in-home care.

[8] Unmet Need addresses whether the respondents have LTSS needs which are not addressed by services, supports, or equipment.

[9] Changing to individual survey in 2019

[10] NHIS asks only 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.

[11] BRFSS only asks about cognition, LTSS use for cognitive difficulties, and unmet LTSS need in an optional module which states may or may not administer.

[12] Excludes people living in group quarters or institutions at intake, but will follow-up with study participants if they later move to group quarters or institutions.

[13] Specific to the functional need

[14] While NCI does not ask about functional status or LTSS needs in their survey, a certain level of need is implicit in IDD program eligibility.

[15] NCI and NCI-AD ask very few questions about cognitive function, but a certain level of need is implicit in IDD program eligibility.

LIMITATIONS OF CURRENT DATA

Limited definitions of disability

There are no current national surveys that capture information on the full array of physical, developmental, intellectual, cognitive, sensory, and mental disabilities for the adult population under age 65. According to our key informants, national surveys are moving away from using functional assessments to identify disability and instead rely upon a set of 6 questions that have been developed to identify disability.[16] While the use of standard questions provides greater consistency in how disability is defined across surveys, the 6 questions focus on only a few selected areas of disability and functional limitation and do not capture many areas of disability, such as mental health or cognitive disabilities, that can result in functional limitations and LTSS need. The surveys that do focus on mental health or cognitive impairment do not capture other areas of disability or functional need.

Limited understanding of LTSS

The environmental scan revealed that existing data sources provide only some of the information we need to identify LTSS needs, use, and unmet needs, with no single source providing all the information that is needed.[17] Surveys tend to rely upon a limited set of self-reported questions that ask about the need for assistance with ADLs or help around the house, but unless they are designed to study mental health or substance use, they do not ask about peer specialist or self-help groups. As noted above, this is another example of the siloed lens through which LTSS needs are examined in survey data. While some administrative datasets, in particular the Medicaid Analytic Xtract, include extensive information about LTSS service utilization and cost, this information is only available for people who receive Medicaid-covered services. In addition, none of the administrative datasets contain any information about the receipt of unpaid care, the need for services that are not available in that location, or the existence of other unmet needs.

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[16] These six 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?

[17] Long-Term Quality Alliance (2018). *Environmental Scan: Data Resources Available to Determine the LTSS Needs of Working Age Adults with Disabilities*.

Limited information on co-occurring disabilities

As noted by the Advisory Panel, historically we have defined people with disabilities in terms of subpopulations and their specific delivery systems, and this is reflected in the way many surveys are designed. It is important not to lose sight of these important sub-populations, but it is also essential to capture information about people with co-occurring disabilities whose needs cannot be met by a single delivery system. The environmental scan found that many of the program-specific data sources lacked information about co-occurring disabilities. For example, people with serious mental illness may also have physical limitations, but the surveys that collect 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.

LTSS data on aging population does not include younger adults

The environmental scan revealed that the most comprehensive surveys on LTSS needs, use, and unmet needs focus on older adults and use age 65 as an arbitrary dividing line. The National Health and Aging Trends Study (NHATS) only surveys people age 65 and older. The Health and Retirement Survey (HRS), another national longitudinal survey with good data on LTSS needs and use, begins at age 50 in order to follow this population into old age. This survey does not include people with disabilities under age 50. It also does not include people living in group quarters or institutions during initial data collection. Its sample between age 50 and 65 is too small to provide meaningful data on subpopulations of people in this age range with disabilities.

Both of these studies collect valuable longitudinal information and could conceivably be extended to younger adults with disabilities. If this were to happen, the Advisory Panel recommended modifying the survey instruments to capture information critical to understanding a younger adult population with disabilities. To capture data of value in addressing the needs of the under-65 population, surveys must ask about the expectations and desires of someone living with a congenital or lifelong disability with regard to factors such as accommodation, community engagement, employment, or housing options. Surveys must also be sensitive to variations in functional challenges associated with age, such as mental and cognitive functioning that manifests more commonly as serious mental illness and intellectual disability for younger populations, and as depression and dementia or other cognitive decline for older populations. An “age-neutral” approach to measuring the physical and mental conditions associated with disability and their functional implications would collect data that better covers disability and LTSS needs over a lifespan.

Data collection for older adults often focuses on the aging process and loss of physical and cognitive capacity (a ‘frailty model’). However, many people are growing old with lifelong or long-term physical and/or mental disabilities and associated LTSS needs and services. As people with developmental disabilities live longer and survive into old age, their LTSS needs are not superseded by the needs created by the aging process. These individuals do not easily fit into a delivery system that is built exclusively around the aging process and functional and/or cognitive decline based on the frailty model.

Insufficient sample sizes

Another key finding from the environmental scan was that surveys with sample sizes large enough to obtain meaningful data on subpopulations of the under 65 adult population provide the least information about LTSS needs, unmet LTSS needs, and consequences of leaving needs unmet. As noted below, the most detail about LTSS is found in surveys with much smaller samples or limited populations.

Extensive LTSS data is limited to specific sub-populations

Extensive information on LTSS needs and use can be found in a number of smaller, population specific data sources, but is not currently in a format that makes aggregation possible or cross-disability planning feasible. Some organizations collect extensive data on specific disability sub-populations, such as people with ID/DD, traumatic brain injury, or spinal cord injury. These focused data sets do not supply information that can be generalized to a broader population of adults with disabilities.

Administrative data is limited to those enrolled in public programs

Administrative data sets from public programs like Medicare and Medicaid have extensive information on LTSS needs and service use, though only for the population that is eligible for these programs and is using services.[18,19] Claims data on LTSS through the Medicaid program is available on a national basis and CMS is instituting new methods that will improve the quality and timeliness of the data. Medicare claims data does not include LTSS, but Medicare's national beneficiary survey provides robust information on LTSS needs in its eligible population.

Assessments, which could potentially provide another administrative data source on LTSS needs of the population receiving services through public programs, are currently very difficult to use. Assessment tools used in Medicare and Medicaid programs to determine eligibility and need for various services collect extensive data on LTSS needs. Some states are able to aggregate assessment data and match it with claims data. In general, however, the lack of standard data

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[18] Long-Term Quality Alliance (2018). *Report on A Key Informant Survey on Data Sources on LTSS Needs and Services Use of Adults with Disabilities Under Age 65*.

[19] Long-Term Quality Alliance (2018). *Environmental Scan: Data Resources Available to Determine the LTSS Needs of Working Age Adults with Disabilities*.

elements or questions in the wide variety of assessment instruments in use today prevents any constructive analytic use of the data on a large scale.

Administrative data sets, in general, miss large parts of the eligible population that are not receiving services either due to a failure to apply for services or caps that states place on program enrollment. They also miss large numbers of people with disabilities and significant functional needs who are not eligible for a public program. These individuals may receive unpaid care and/or may be paying out of pocket for care that is not covered by their health insurance, none of which is captured in any database.

QUESTIONS WE NEED TO ANSWER

Based on the significant limitations of past and current data sources listed above, there are several key questions we cannot answer in order to assess the needs of, and design services for, adults with disabilities under age 65. These important planning questions include:

The prevalence of overall disability, population subgroups, and co-occurring disabilities

- What is the overall prevalence and nature of sensory, physical, cognitive, and mental health disabilities among adults under the age of 65?
- What is the prevalence of various combinations of co-occurring disabilities?

Definition and description of functioning and need

- What types of LTSS needs are most prevalent in the various subgroups of disability and how do LTSS needs vary for different subgroups?
- What LTSS needs are unique to people with a specific type of disability (I/DD, physical health issues, behavioral health issues, sensory issues, and other disabilities)?
- What is the distribution of the population with LTSS needs by level of need?
- What are the expectations, and what is the quality of life, satisfaction with settings and services, and general satisfaction of people with LTSS needs? What are the leading factors that affect satisfaction?
- How does the nature of LTSS need change over time?

How LTSS needs are currently met

- What proportion of younger adults with disabilities with LTSS needs use paid care? How does this vary by disability subgroup? What other characteristics affect the use of paid care?
- What differences are there in the way services are provided (e.g., the settings, the types of providers, the role of family and paid caregivers) for each disability subgroup?

- To what extent are people with disabilities paying family caregivers or self-directing their services and supports?
- What role do unpaid family and friends play in personal assistance or other services?
- What is the availability of HCBS waivers and to what extent is the capacity of waivers exceeded for any specific subpopulation and/or waiver?
- What are the sources of payment for paid care? What adjustments are individuals and families making to afford paid care?
- What is the impact of payment out-of-pocket for LTSS on the economic status of the person with disabilities and their families? What is the relationship between the need for LTSS and spenddown to Medicaid eligibility?
- How many people have any form of insurance that covers these services, and how many people have exhausted this insurance?

Settings of services

- What are the settings in which people with LTSS needs reside or receive services? How well-integrated are adults under 65 with disabilities in these settings? What is the need/opportunity for rebalancing?
- What kind of facilities do people with disabilities live in? Group homes, nursing homes, family homes, shelters, prisons?
- What happens as caregivers themselves age?
- How many people resort to institutionalization because of the inability to finance in-home care?

The extent and impact of unmet LTSS need

- How many people applied for SSI or SSDI and were denied eligibility?
- Who are the people who need, but do not receive, paid and/or unpaid services and supports? What accommodations do they make for their disability as a result?
- How do these accommodations impact their activity, engagement, and well-being?
- How do unmet needs impact outcomes and the ability to remain in the community?
- What is the impact of unmet need and unpaid care on caregivers?
- What impact does unmet LTSS need have on tax dollars spent on public service use or productivity loss due to caregivers staying at home?
- What is the cost impact of services that exist but are insufficient?
- Is there a difference in the acute health outcomes between people with and without unmet LTSS need?

Longitudinal issues

- What is the duration of LTSS need for this population? What is the progression and duration of service use?

OBTAINING THE NEEDED INFORMATION

In order to obtain information about the national total number of people who have a functional limitation (broadly defined) that requires LTSS, the sample for a national survey needs to be large enough to ensure meaningful samples of subpopulations. It also requires a sampling methodology that asks about all members of a household, rather than a single person, to get information about people who cannot or do not answer for themselves, as well as proxy responses for people who may have moved or are unavailable. In addition, to obtain reliable information on disability, the sample must include people who live in group quarters and institutions, and ideally would include hard-to-reach populations in jails, prisons, and shelters, many of whom have disabilities.

The way disability is defined and measured needs to be more expansive and more specific in order to capture important details that affect LTSS needs and how services are delivered. Most national heath surveys include extensive questions about medical diagnoses, but rarely ask about conditions that are directly correlated with disability. A disability-focused survey needs to include information about diagnoses, particularly for cognitive or mental disabilities, such as cerebral palsy, bipolar disorder, serious depression, autism spectrum disorders, and other major conditions that are not typically included in more-general national surveys.

To learn about the LTSS needs for subpopulations, as well as for people with co-occurring disabilities, the survey instrument needs to go beyond traditional questions on ADLs and IADLs, and include questions that better capture functional needs of a range of people with disabilities, including I/DD impairments, mental health, and substance use. Along with information about functional limitations, a national survey needs to include information on socialization, community engagement, individual expectations and desires, employment, poverty, living situation, and satisfaction with life activities. This information is vital in terms of understanding life needs and satisfaction, and the relationship between functional limitations and quality of life.

In order to use LTSS need information for planning purposes, it is important to know the extent to which these needs are accommodated either by changes in lifestyle and activity, living environment, or through use of equipment or assistive technology. To the extent that people are receiving some form of LTSS, it is also vital to collect information about what LTSS are being used (including LTSS for mental health or substance use); what services are used most frequently; the settings of this care; the providers of care (paid/unpaid, agency or family/friend); and the role of self-direction, care management, and paid family caregivers.

Two of the largest information deficits today are the absence of information on unmet LTSS needs and LTSS costs. These should both receive thorough attention in any new survey, along with the impact of unmet need on community engagement, quality of life and on the national economy. LTSS cost information needs to be obtained from self-report for those individuals who are paying out-of-pocket for care or are receiving services through agencies that do not bill insurance companies (e.g. vocational rehabilitation programs), and where available, from Medicaid claims data or managed long-term care companies.

Finally, we need a data collection strategy that includes longitudinal data collection, at least every five years, periodically refreshing the panel. Longitudinal data is crucial to help us understand the process of aging with a disability and what we can learn about the LTSS needs and desires of people, especially those with an acquired disability, as they age beyond 65. This information can help us better plan a comprehensive LTSS system over the life course and benefit populations of all ages with disabilities.

OPTIONS FOR MOVING FORWARD

The time is right to take a significant step forward in improving the availability and quality of information on the LTSS needs of the younger adult population with disabilities. We propose several options for action that are best organized in three tiers, defined in terms of how incremental or comprehensive the approaches would be. The most comprehensive approach would be to field an entirely new survey dedicated to disability and LTSS needs. The most incremental approach would be to assemble data that already exists, using new statistical techniques that could stitch it together to answer the most pressing policy questions.

A. Create a new comprehensive data source

There needs to be a comprehensive, current national data source covering the broad population of adults with disabilities. The ideal solution would be to start fresh and develop a new national survey with the full array of questions to elucidate the nature and evolution of the disability, the scope of functional limitations, and the need for and use of LTSS. A comprehensive survey would first identify the prevalence of disability in the under 65 adult population, including people who live in both group quarters and institutions, as well as the homeless and incarcerated populations. This survey would include a comprehensive assessment that identifies the spectrum of functional and cognitive limitations, using ADLs, IADLs, cognitive and mental health measures, and measures associated with integration and engagement. From this national survey, a subsample would be drawn and surveyed longitudinally every five years, refreshing the sample as needed. The second survey would address all of the issues raised in this paper including impact of unmet need, settings of care and the trajectory of LTSS need across the lifespan. These data would be merged with administrative datasets for the subset of the sample who are enrolled in publicly-funded programs.

B. Add on to an existing survey (NHIS, NHATS or HRS)

Another option is to modify an existing national survey to collect more detailed information on younger adults with disabilities and their LTSS needs. There are two possible approaches:

- *<u>Approach 1: Change existing survey instruments and/or approaches</u>*

Several existing surveys could collect better LTSS data if their instruments or methodologies were modified. For example, the National Health and Aging Trends Study (NHATS) or the Health and Retirement Study (HRS) sampling methodology could be changed to include people under the age of 65. With a broader age range, the NHATS supplemental caregiving survey could look at caregiving across the lifespan, providing greater insight into lifelong LTSS need and use. If the HRS or NHATS were used the questions would need to be revised to be age-neutral and incorporate a strengths-based assessment that appropriately reflects the spectrum of disability.

- *<u>Approach 2: Create an in-depth supplement for specific populations identified by broader national surveys</u>*

Add benchmark questions to a broad national survey to identify people with disabilities who might be missed using the 6 national disability questions or a deficit-focused ADL/IADL assessment, and then sub-sample that group with an in-depth questionnaire that includes the questions presented in this paper.

In either option, we would recommend including:

- An institutional sample
- A component for hard-to-reach populations, in jail, prison or shelters
- All of the questions presented above including those on unmet need, paid and unpaid caregivers, service locations, employment, community engagement and satisfaction with life activities
- Information about LTSS cost and source of payment
- A repetition at least every 5 years with the same cohort, refreshing the cohort as needed

C. Leverage Existing Data Sources

A third option is to leverage what we can from existing data sources, using a hybrid approach to integrate as much available data to identify LTSS need, use and unmet need, using advanced statistical techniques. This might start with the prevalence of disability as reported in the NHIS (if it continues to be a household sample) and compare this to the prevalence in HRS and SIPP. If vastly different, use the NHIS data as much as possible since the sample size is much larger. If it is similar, it might be possible to use the more detailed information available in either of the other two surveys. Then it might be feasible to match functional information from the NHIS with similar information in MCBS, MEPS, and HRS to identify LTSS needs, potential use, and unmet need. In addition, it might be possible to match information about function and diagnosis with information about community engagement, socialization, satisfaction with services, and quality of life from the NCI, NCI-AD, and HCBS-CAHPS. This information could be supplemented with information from the NSDUH and NCS to obtain similar information on people with mental health or substance use disorders. These data might be merged with MAX data and MLTSS data, where available, to identify service use and cost among those eligible for Medicaid, using this as a proxy for individuals with similar limitations.

This approach would take advantage of data sources that have matured since the 1995 NHIS Disability Supplement but would mean foregoing any effort to survey hard to reach populations, collecting longitudinal information or obtaining robust information about service locations or preferences, or understanding the impact of unmet need on quality of life. In addition, there would be no opportunity to understand how LTSS for younger adults is financed, other than for those people receiving Medicaid-covered services.

Alternative strategy: A state-based approach

In the short-term, it may be more feasible to take a non-national or state-based approach to data collection rather than a national approach. One option is to pilot test a new national survey at the state level with one or more states, in order to test out the development of new survey questions and techniques before going national. Alternatively, it might be possible to pilot test data collection instruments with selected states that have expertise in service delivery and data collection for particular disability subgroups. State level data would be used to support research on specific issues as well as develop inferences on the national prevalence of LTSS needs, services use, and unmet needs. The pilot projects would help fine-tune survey instruments and could instruct a strategy to be implemented at the national level when funds can be raised for a national survey.

These four strategies are not mutually exclusive, and could be undertaken concurrently or in sequence. For example, state-based pilot surveys could serve as a starting point for building broader efforts such as creating a new national survey. Any future work in this area would also want to explore how other countries collect LTSS data to identify lessons we might learn from them to apply here.

RECOMMENDATIONS

Based on our thorough assessment of the information available and the gaps in existing data resources, we recommend:

1) Proceeding to define the ideal instruments for a comprehensive study of people with disabilities across the life span along with the LTSS needs for this population. While

immediate prospects for funding and fielding a large-scale longitudinal study are poor, and the challenges in today’s world of successfully executing a large national survey are great, there is value in defining at a more granular level the information that is needed. The exercise of constructing the ideal survey would provide a framework for more incremental and pragmatic approaches to improve the data available for research and policy analysis.

2) Developing and advancing a legislative proposal to appropriate funds to draw a sample of people with disabilities identified through a large national survey to receive a supplemental questionnaire with extensive questions on disability and LTSS need.

3) Preparing a compilation of what we know using advanced methods by employing multiple existing data resources and using novel data integration techniques to draw accurate inferences that can answer key policy questions; assessing residual data gaps and identifying ways for targeted data collection to fill those gaps, focusing on a subset of issues where high-quality data might be gathered.

4) Exploring opportunities to partner with a state or states to combine public and private funding to pilot test a comprehensive survey of disability prevalence and LTSS needs and services for a particular subgroup of the younger adult population with disabilities. The survey would be designed to fill data gaps that remain when inferences have been fully developed and validated using existing federal and state data resources. The approach would be intended to serve as a model for state-level analysis and understanding of LTSS needs.

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Key Informants

Charles Lakin, PhD	University of Minnesota
H. Steven Kaye, PhD	University of California – San Francisco
Andrew Houtenville, PhD	University of New Hampshire
Ronald Manderscheid, PhD	Nat'l Assn County Behavioral Health & Developmental Disability Directors
Richard Kronick, PhD	University of California – San Diego
Sarah Ruiz, PhD	Administration for Community Living (ACL)
Ronald Kessler, PhD	Harvard Medical School
Lisa Iezzoni, MD, MSc	Massachusetts General Hospital
Jae Kennedy, PhD	Washington State University
John Tschida, MPP	Association of University Centers on Disability (AUCD)
Richard Frank, PhD	Harvard Medical School
Kevin Martone, LSW	Technical Assistance Collaborative (TAC)
Carey Appold, MPH	Mathematica Policy Research
Carol Irvin, PhD	Mathematica Policy Research
Jody Schimmel Hyde, PhD	Mathematica Policy Research
Dave Whittenberg, PhD	Mathematica Policy Research

Advisory Panel Participants

Julia Bascom	Autistic Self Advocacy Network (ASAN)
Kelly Buckland	National Council on Independent Living (NCIL)
Joe Caldwell	National Council on Aging (NCOA)
RoAnne Chaney	Michigan Disability Rights Coalition
Camille Dobson	National Association of States United for Aging and Disabilities (NASUAD)
Esme Grant Grewal	ANCOR
David Machledt	National Health Law Program
Jennifer Mathis	Bazelon Center for Mental Health Law
Mary Sowers	Nat'l Assn of State Directors of Developmental Disabilities Services (NASDDDS)
Rick Surpin	Independence Care System New York (ICSNY)
Sarah Triano	Centene Corp.
John Tschida	Association of University Centers on Disability (AUCD)

LTQA Project Staff

G. Lawrence Atkins
Henry Claypool
Jared Hite
Carol Tobias

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