LTSS Need, Receipt, and Unmet Need in the Washington State Population Age 18-64 with Disabilities

Final Report
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Contents

1. Introduction

Nearly half of the people who need Long-Term Services and Supports (LTSS)[1] in the U.S. are adults age 18 to 64 with disabilities. We know a lot about the LTSS needs of older adults but very little about the LTSS needs of these "working age adults." This younger group is diverse, with a wide array of disabilities – the lack of data on their needs hinders efforts to adequately plan services for them.

To remedy this problem, Long-Term Quality Alliance (LTQA) set out in 2018, with support from The Commonwealth Fund, to search for any available information on younger adults with disabilities. Completing an Environmental Scan of existing data resources, LTQA convened a panel of leading researchers and national stakeholder organizations to detail the gaps in data and recommend strategies to fill them. One of the recommended strategies was to partner with an interested state government to develop and test an approach that would combine new survey data with data from existing state administrative records.

In 2020, LTQA invited proposals for a pilot project from interested states and selected Washington State to collaborate on this initial pilot. In partnership with the Washington State Aging and Long-Term Services Administration (ALTSA) and the Community Living Policy Center (CLPC) at Brandeis University, with support from The Commonwealth Fund, LTQA designed an approach that would analyze data from:

- Supplemental questions about LTSS need and use added to the 2021 Behavioral Risk Factor Surveillance System (BRFSS) Survey administered in Washington State;
- A unique model to predict LTSS need, developed for this project by the Washington State Department of Social and Health Services (DSHS) Research and Data Analysis Division (RDA); and
- Linked Medicare and Medicaid claims records for calendar year 2018, along with data from the Comprehensive Assessment Reporting Evaluation (CARE) Assessments on beneficiaries receiving LTSS.

Data collected and analyzed over the last two years are brought together and presented in this Final Report on the Washington State pilot project. The Report is both a description of the pilot with a documentation of its methods, and a presentation of the data analysis that describes the LTSS needs and service use of "working age" adults with disabilities.

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[1] Long-Term Services and Supports (LTSS) are the array of types of assistance that people who have long-lasting or permanent functional limitations need in order to perform daily activities. These activities include Activities of Daily Living (ADLs) which are activities related to personal care, such as bathing or showering, dressing, getting in and out of bed or a chair, walking, using the toilet, and eating; and Instrumental Activities of Daily Living (IADLs), which are complex skills necessary for independent living such as: using the telephone, shopping, preparing meals, housekeeping, using transportation, taking medication, and managing finances.

2. Methods

Research Questions

This study aims to answer three sets of research questions:

1. LTSS NEED - What is the prevalence, nature, and severity of LTSS need among the Washington State population of adults under age 65 with a disability?
2. LTSS RECEIPT - What portion of the adult under age 65 LTSS need population is receiving LTSS? How much of it is provided through Medicaid? For those receiving Medicaid LTSS, in what settings are they receiving services and what is the severity of their need?
3. UNMET LTSS NEED - What is the prevalence of unmet LTSS need in the population of adults under age 65 with disabilities? What are the characteristics of the population with unmet needs? What is the size of the Medicare/Medicaid-eligible population "at risk" of needing but not currently using LTSS? What factors may account for their unmet needs?

Data Sources

This pilot used a multi-tiered methodological approach to answering the research questions, based on the analysis of three different data resources[2] (Figure 1):

1. **Population survey data** from the 2021 Behavioral Risk Factor Surveillance System (BRFSS) Survey for the Washington State population, including data on LTSS met and unmet needs from a special LTSS supplement to the core national survey;
2. **Washington State administrative data** including linked Medicare and Medicaid claims records for 2018 and data from the CARE Assessments on beneficiaries receiving LTSS.
3. **A predictive risk model** developed by Washington State Department of Social and Health Services (DSHS) Research and Data Analysis Division (RDA) using data from the linked 2018 Medicare and Medicaid files.

Figure 1: Various Data Sources for LTQA Washington State LTSS Data Pilot

Population Survey Data (BRFSS)	State Administrative Data	Predictive Risk Model

•Demographic Information
•Core Survey Disability Questions
•LTSS Supplement
	•Linked Medicare and Medicaid Claims including Medicaid LTSS
	  •Medicare only
	  •Dual eligible
	  •Medicaid only
	•CARE Assessments for Medicaid LTSS recipients
		•Predictive model of probability of LTSS need using linked Medicare-Medicaid claims

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[2] Details on these sources and the data analytic methods are provided in the Appendices to this report. Note that for some analyses to address the research questions, more than one of the sources (e.g., BRFSS Data, Predictive Risk Model, State Administrative Data) may apply.

Analytic Approach

The findings section is organized into several subpopulations nested within one another in order to illustrate how various concepts of disability and LTSS need relate to one another in the Washington State population. The subpopulations/levels of analysis are briefly defined below and in further detail in the corresponding sections (Table 1):

Table 1: Description of Subpopulations/Levels of Analysis and Corresponding Data Source

	Description	Data Source
1. Disability	Individuals identifying as having a physical, mental, and/or emotional condition that could limit their ability to function independently.	2021 BRFSS Core Disability Questions
2. LTSS Need	Individuals identifying as needing assistance with ADLs[3] ("self-care") or IADLs[4] ("independent living").	2021 BRFSS LTSS Supplement
3. LTSS Receipt	Medicare and/or Medicaid beneficiaries with LTSS need identified as receiving services; including settings for service receipt and severity of LTSS need.	2018 Washington State linked Medicare-Medicaid Files; 2018 CARE Assessments
4. Unmet LTSS Need	Individuals identifying as not receiving enough or any supports for their LTSS needs.	2021 BRFSS LTSS Supplement
5. Predicted Need	Medicare and/or Medicaid beneficiaries who are not receiving LTSS through Medicaid and who are at high risk of needing LTSS.	Washington State Predictive Model using 2018 linked Medicare-Medicaid Files

Figures 2 and 3 below illustrate how these various subpopulations relate to one another (e.g., overlap, nesting) (note: the size of each circle is to scale).

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[3] In the standard six disability questions used in the BRFSS as well as the American Community Survey and some health surveys, the question about needing help with dressing or bathing is used as a proxy for a broader set of activities of daily living (ADLs) – which are activities related to self-care.

[4] The question in the core BRFSS about difficulty doing errands alone is used as a proxy for a broader set of instrumental activities of daily living (IADLs) – which are complex skills necessary for independent living.

Figure 2: Disability, LTSS Need, and Unmet Need Among Washington State Residents Age 18-64

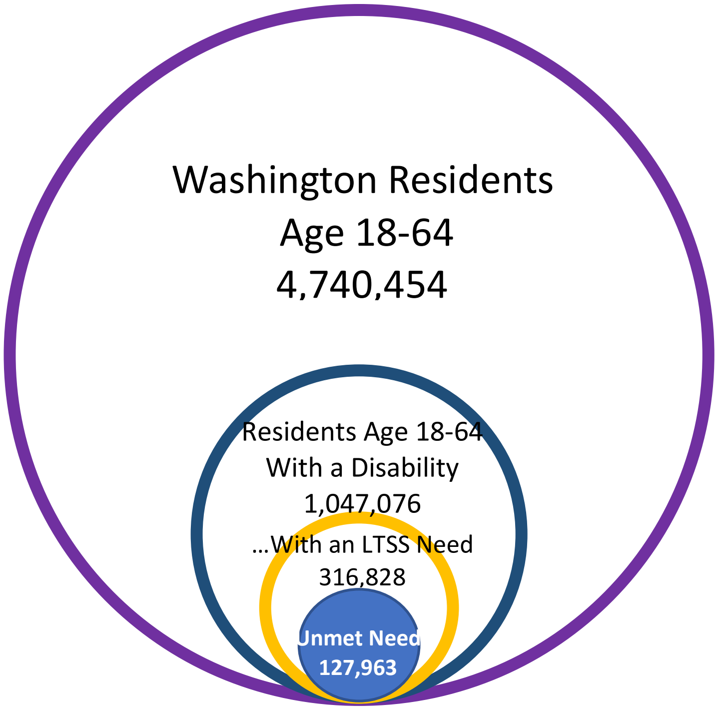
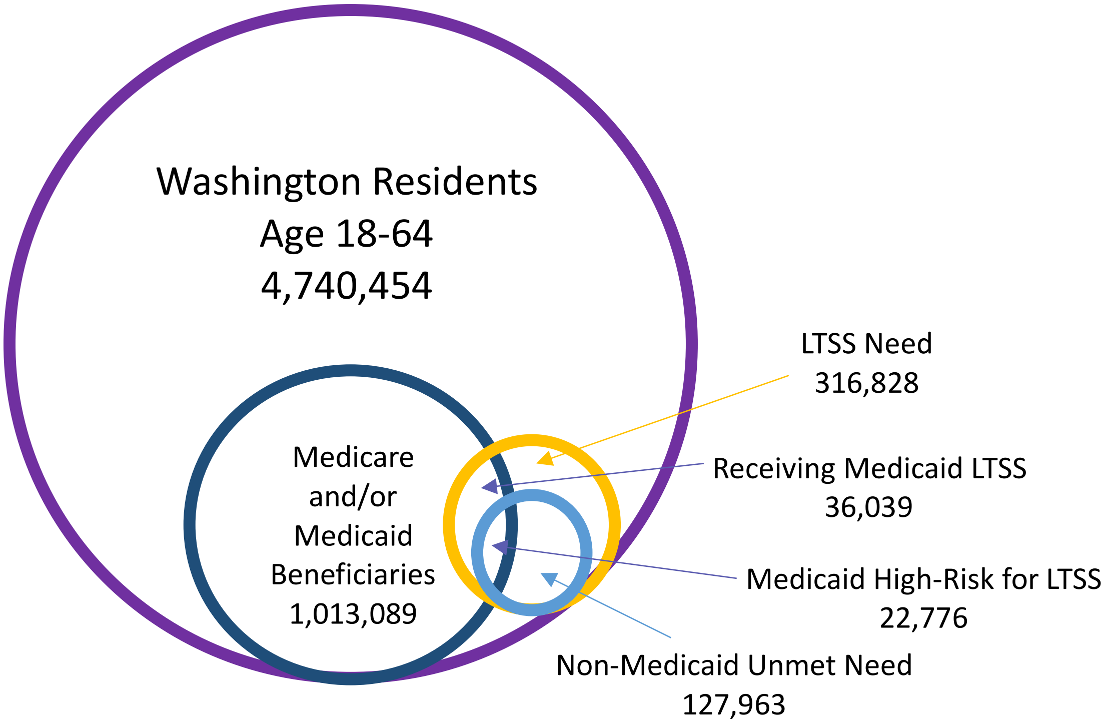


Figure 3: Medicare and/or Medicaid Beneficiaries, LTSS Need and Receipt, Unmet Need, and Predicted LTSS Need Among Washington State Residents Age 18-64



3. Findings

To contextualize the findings, we first need to describe the Washington State population and how it compares to the U.S. population as a whole. Among residents ages 18-64, the Washington State population is similar to the U.S. national population in terms of age and gender distribution (Slides 1 and 2).

Washington State is slightly less diverse than the U.S. population as a whole (Slide 3). The State population has a larger White Non-Hispanic proportion of the population than the general U.S. population age 18-64. Its largest racial-ethnic groups are Hispanic and Asian. Black adults are underrepresented in the population compared to the national average. Indigenous people (American Indian or Alaska Native (AI/AN), and Native Hawaiian or other Pacific Islander (NHOPI)) are a more prominent part of the Washington State population, though still less than five percent in total.

Washington State's White population age 18-64 is older than its non-White population. The Hispanic young adult population is the youngest, with more than 20 percent of this age group falling between age 18 and 24, with sharply declining numbers in each subsequent age cohort. Young Black and Native American adults are the next youngest groups with nearly 20 percent of their working age adults in this youngest age group and a similarly steep decline in numbers with advancing age cohorts. By contrast, the White population is much older, with an even distribution across their nine 5-year age cohorts (Slide 4).

Washington State also has a smaller share of its population (9.5 percent) living in non-metropolitan (rural) counties than the nation as a whole (13.9 percent). Its metropolitan population is concentrated in 9 counties, mostly concentrated around Puget Sound (Slide 5).

3.1 DISABILITY

<u>Nearly one-in four Washington State residents age 18-64 have a disability</u>

Nationally, using the results of the 2019 BRFSS, 23.3 percent of Americans age 18 to 64 living in the community have a disability[5]. The prevalence of disability in the Washington State "working age" population, from the 2021 BRFSS, is 22.1 percent (Slide 6) – only slightly below the national average. In Washington State, this rate equates to an estimated 1,047,076 adults age 18-64 in the State with a disability[6].

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[5] Disability for survey purposes is measured using the six standard disability questions from the American Community Survey (ACS-6) which are now used in most national surveys including the BRFSS survey. People with disabilities living in institutions or incarcerated are not included in the surveys. See Appendix B for more detail.

[6] While several national surveys now include the six standard disability questions, the disability rates estimated from different surveys are quite different. Using the same six questions, in 2019 the estimated disability rate from the ACS was 10.5 percent compared to 23.3 percent estimated from the 2019 BRFSS (M. Mitra, et al. Addressing

All of these individuals have a physical, mental, and/or emotional condition that could limit their ability to function independently. These functional limitations include:

- Partial or full loss of sight
- Partial or full loss of hearing
- Serious difficulty concentrating, remembering, or making decisions (cognition)
- Difficulty walking or climbing stairs (mobility)
- Difficulty dressing or bathing (self-help)
- Difficulty shopping or doing errands alone (independent living).

Almost all of these adults (19.5 percent of the population in the age group 18-64) have a limitation in cognition, mobility, self-help, independent living or a combination of these. The most prevalent of these is difficulty with cognition (13.2 percent) followed by mobility (7.6 percent) (Slide 7).

When compared to people age 18-64 who do not have disabilities, those with disabilities are more likely to be Female, White, and living in a non-metropolitan (rural) area (Slide 8).

- **Gender:** While females are the minority in the population without disabilities (47.5 percent), they are a majority in the population with disabilities (54.6 percent).
- **Race/Ethnicity:** About a third of the Washington State population are people who identify as a race or ethnicity other than White ("non-White"). The proportion of people who are non-White is smaller among people with disabilities (30.8 percent) than among people without disabilities (33.0 percent) (Slide 8). More substantial differences can be seen among Hispanic and Asian groups. In Washington State, Hispanic residents constitute a larger proportion of the population with disabilities than of the population as a whole (17.1 percent compared to 13.7 percent), while Asian residents represent a smaller share of the population with disabilities than of the population as a whole (5.5 percent compared to 12.0 percent) (Slides 9 and 10).
  These differences are noteworthy: while the rates of disability are higher than the population average (22.1 percent) among Hispanic (27.4 percent), AI/AN (34.0 percent) and Black (23.8 percent) Washington residents, they are substantially lower among Asians (10.0 percent) (Slide 11).
- **Urban/Rural:** Only 9.5 percent of Washington's population age 18-64 lives in a non-metropolitan (rural) county. Those with disabilities are slightly more likely to live in a rural county (10.4 percent) than those without disabilities (9.2 percent), but the difference is quite small (Slide 8).

Health Equity and Reducing Health Disparities for People with Disabilities in the United States. Health Affairs 41, NO. 10 (2022): 1379–1386). Accessed at: https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00499

3.2 LTSS NEED

Many of those who have disabilities need assistance to perform routine daily activities that require physical, mental, or emotional ability they may lack – activities like getting out of bed, bathing, dressing, walking, shopping for food, fixing meals, or handling finances. Some may be able to change how they do these activities, use special devices or equipment, or get assistance from an attendant, a family member, or a personal care worker. While much of this care is provided by unpaid family members or friends, many people with disabilities need paid care. As arranging care becomes more difficult due to demographic shifts that shrink the number of family members and growing shortages of paid direct care workers, many are going without the care they need.

LTSS are the array of types of assistance that people with functional limitations that are long-lasting or permanent will need to help them with ADLs ("self-care") or IADLs ("independent living").

One-third of those age 18-64 with disabilities need help with self-care or independent living
Overall, 77.9 percent of the population age 18-64 in Washington State does not have a disability – 15.4 percent have a disability with no need for LTSS, and 6.7 percent have an LTSS Need (Slide 6).

A third (32.7 percent) of Washington State residents age 18 to 64 with disabilities (6.7 percent of the total population in the total age group, Slide 6) need assistance with ADLs, IADLs or both in order to remain safely in their home or the community (Slide 12). This equates to an estimated 316,828 people age 18-64 in the State.

- A small percentage of the population in this age-group (0.5 percent) needs help only with one or more ADLs.
- Far more (4.2 percent) need help only with one or more IADLs.
- Another two percent of this age-group need help with both ADLs and IADLs.

Characteristics of People with LTSS Needs

Functional limitations arise when an individual's disabilities prevent them from performing routine activities of daily living (ADLs and IADLs) without assistance. LTSS are the services and supports an individual with functional limitations needs to continue living independently or, if preferred or necessary, in a residential or institutional environment.

Based on the 2021 BRFSS Survey Washington State LTSS Supplement, 316,828 people in Washington's general population age 18-64 have LTSS needs.   A small number of these (23,783) need help only with ADLs. About a third (93,283) need help with both. Most need help only with IADLs (199,763) (Slides 6 and 12).

While all people with ADLs or IADLs require assistance to meet their daily functional needs, Medicaid does not typically fund services and supports for people with IADLs only. People assessed with needs for assistance with ADLs will receive help with IADLs. Other federal and state funded services may be available for older (60+) adults who need assistance with IADLs alone, but these services are not provided for adults under age 60 with similar needs.

Disability and LTSS Need

With an older population (age 65 and older), advancing age, with its effects on physical and cognitive abilities, is often the major factor contributing to an individual's functional limitations. For a younger population (age 18-64), while age may still be a factor, functional ability and the need for LTSS are more likely related to the type and degree of disability an individual has. Intellectual and Developmental Disability (I/DD), substantial physical disability, and brain injury and cognitive loss often directly affect functional capacity, whereas individuals whose primary diagnosis is mental illness or behavioral health are more likely to function without assistance, although they may need ongoing treatment for their illness or disorder.

A high proportion of adults under age 65 with disabilities have multiple, co-occurring disabilities – with mental and behavioral health issues compounding the functional challenges for those with physical disabilities. An analysis of Washington State Medicare and Medicaid linked claims files (described later in this Report) will provide a more thorough look at the disability characteristics of the current population receiving LTSS through the State Medicaid program.

Rates of LTSS Need in the Population Age 18-64:

Overall, women, rural residents, and White, Black and Native Americans are the most likely to need LTSS (Slide 13). Based on an average of 6.7 percent of the Washington State population age 18-64 needing LTSS,

- Women (8.5 percent) and rural residents (8.1 percent) have above average rates,
- Whites have a rate slightly above the average (7.4 percent). Some non-White racial/ethnic groups have even higher rates of LTSS need (Black (9.1 percent), AI/AN (10.5 percent) and NHOPI (10.9 percent)); while other groups have low rates (Hispanic (5.5 percent) and Asian (2.5 percent). With the exception of White and Hispanic rates, rates for these other race/ethnicity groups are based on small numbers of survey respondents and have high standard errors.
- Low income is highly-related to LTSS Need. The rate of LTSS need is over 16 percent among Washington residents with annual incomes below $35,000, but less than 5 percent for those with incomes above $50,000 a year (Slide 20).

Comparison of the Populations With and Without LTSS Needs

Adults under age 65 who have an LTSS need are a very small subset of the larger population. They differ from the population without LTSS needs in that they are more likely to be female, to be White (as compared to non-White), and to live in a rural area. The differences between the two groups are noticeable (Slide 14).

- **Female**: While a little under half of people who do not need LTSS are women (48.7 percent), more than 60 percent of those who do need LTSS are women (63.5 percent).
- **White:** The population with an LTSS need has a much higher proportion that is White (74.6%) than the population that does not have an LTSS need (67.1 percent).
- **Rural:** A higher proportion of those who need LTSS reside in rural areas (11.9 percent) than those who do not need LTSS (9.7 percent),

Age of Onset of Disability of those with LTSS Needs

A quarter of the adults age 18-64 with LTSS Needs acquired their disability at birth or during their childhood. A large portion of these likely have intellectual or development disabilities, autism, or other conditions that were evident at birth or became evident in early childhood. Three-quarters of those with LTSS needs, however, acquired their disability during their adult years. (Slide 15).

Met and Unmet LTSS Needs

Most Washington State residents in the 18-64 age group with LTSS needs (59.6 percent) report that they are receiving the help that they need. However, a quarter of them (an estimated 83,514 residents) report they are receiving help, but not enough; and 14 percent (an estimated 44,449 residents) report that they receive no help (Slide 16). An estimated 316,828 Washington State residents age 18-64 need LTSS and of these 127,963 are not getting sufficient help.

The group with LTSS needs age 18-64 are more likely to be female and rural than the overall population with disabilities or the larger state population (Slides 17, 18, 19).

- Among the LTSS needs group who report they are “getting enough help”, 64.4 percent are female and 11.3 percent are living in a rural area (Slide 19).
- Those who report they are “getting some help, but not enough” are more female (66.4 percent) and more rural (15.5 percent) than the group that are getting the help they need (Slides 17 and 18).
- The group “not getting any help” is more male (females are 55.3 percent) and more urban (rural is 8.1 percent) than the group that are “getting enough help” (Slides 17 and 18).

Low income is associated with the greatest LTSS need and the greatest unmet LTSS need. People of working age with disabilities and LTSS need are likely to have very low incomes as a consequence, and people with a history of low income are more likely to have complex health problems, disability, and LTSS need (Slide 20).

- The rate of LTSS need in the age 18-64 population with annual household income below $35,000 (16.5 percent of the population) is double that of the rate for the population overall (6.7 percent). Half of those with LTSS needs who have incomes below $35,000 have unmet needs (8.2 percent of the population in this income group).

- The rates of LTSS needs and of unmet needs decline substantially with each increase in income group.
    - The rate of LTSS need in the group with incomes between $35,000 and $50,000 is 7.1 percent and only 3.0 percent has unmet needs.
    - Only 3.0 percent of the population with incomes of $100,000 or more need LTSS and a little over a half-a-percent of the population has unmet needs.

3.3 LTSS RECEIPT

Individuals with LTSS needs, who are able to get the assistance they need, may get that assistance from unpaid family caregivers, from paid assistants they or a family member hire, or through a government program – most likely by qualifying on the basis of income and level of need – for Medicaid. In 2020 in the U.S, Medicaid accounted for 54 percent of all LTSS spending. The other half included 13 percent paid by families and individuals out-of-pocket, 8 percent by private insurance, and 26 percent by a variety of other public and private sources[7]. The $400 billion annual spending on paid LTSS was equivalent to the estimated $470 billion in value for unpaid caregiving for younger and older adults[8].

Medicare and/or Medicaid Beneficiaries

Medicare provides health coverage for virtually all Americans age 65 and older and for adults under age 65 who qualify for Medicare by virtue of their eligibility for Social Security Disability Insurance (SSDI). Low-income adults under age 65, whether they qualify for Medicare or not, may be eligible for Medicaid. Medicare covers acute medical care (hospital and physician costs) and post-acute skilled nursing facility (SNF) care, rehabilitation, and home health care for up to 100 days after hospital discharge – it does not cover LTSS or other non-medical services. Medicaid covers acute medical care as well but also covers LTSS provided in a nursing home or through home- and community-based services (HCBS). “Medicare-only” beneficiaries do not have coverage for LTSS. “Dual (Medicare+Medicaid) beneficiaries” and “Medicaid-only” beneficiaries are eligible to receive LTSS if they have functional limitations with a high-enough acuity to meet state requirements.

About one-quarter (22 percent) of Washington State’s population age 18-64 is currently enrolled in either Medicare, Medicaid, or both (“Dually-Eligible Beneficiaries”) (Slide 21).

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[7] P. Chidambaram and A. Burns. 10 Things About Long-Term Services and Supports (LTSS). Kaiser Family Foundation. September 15, 2022. https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/

[8] AARP – “Valuing the Invaluable 2019 Update: Charting A Path Forward. https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html

There are 174,299 residents age 18-64 enrolled in Medicare, which includes 83,144 dually-eligible beneficiaries, and 838,790 enrolled in Medicaid only (Slide 21 and 22). While nearly all older adult (age 65+) Medicaid beneficiaries are "Duals," only around 10 percent of younger adult (age 18-64) Medicaid beneficiaries– those with a disability and work history that would qualify them for Social Security Disability Insurance (SSDI) and Medicare -- are "Duals". Many others in this age group with disabilities qualify only for Medicaid.

Age – The Medicare population of adults under age 65 is an older population that has received Medicare coverage almost entirely by qualifying for Social Security Disability Insurance (which requires a prior work history). The Medicaid-only population is dominated by young low-income families with children and younger workers enrolling in Medicaid expansion coverage, with about half of all Medicaid-only beneficiaries in the 18-34 age group.

- Almost 10 percent of the Washington State population age 55 to 64 are Medicare beneficiaries (including dual beneficiaries) and 12.5 percent are Medicaid-only (Slide 23).
- Nearly a quarter (23.5 percent) of the Washington State population age 18-34 are Medicaid-only beneficiaries. Less than 1 percent are Medicare beneficiaries (Slide 23).

Gender – While the Washington State population is more evenly split, with females predominating (51 percent female), the Medicare and/or Medicaid beneficiary population is majority male by a wider margin (55 percent male) (Slide 24).

Race/Ethnicity – Black, Native, and Hispanic populations have higher rates of participation in Medicare and/or Medicaid than the Non-Hispanic White population (which heavily influences the average rate) (Slide 25):

- Native Hawaiian or Other Pacific Islander – though a small part of the Washington State population age 18-64, almost half (44 percent) of this group are enrolled in Medicare and/or Medicaid.
- American Indian/Alaskan Native – a third (30 percent) of the Native Americans in Washington State age 18-64 get their health coverage through Medicare and/or Medicaid.
- Black – a third (32 percent) of African-Americans in Washington State age 18-64 are enrolled in Medicare and/or Medicaid.
- Hispanic – a quarter (24 percent) of the Hispanic population in Washington State age 18-64 are covered through Medicare and/or Medicaid.
- Non-Hispanic White – a fifth (20 percent) of the White population is covered through Medicare and/or Medicaid.

The Asian population has a significantly lower rate of participation in Medicare and/or Medicaid than any other racial/ethnic group (Slide 25). Only 8 percent of Asians age 18-64 in Washington State are participating in Medicare and/or Medicaid. This rate of coverage through publicly-financed health insurance is less than half the average rate for the rest of the population. It suggests a significant difference in the reliance on public health insurance, potentially due to cultural differences and attitudes about relying on public programs or to unique access problems.

The high rates of participation among Hispanic, Black, and Native population groups in these programs is due, in part, to their younger age distribution in the population resulting in a high concentration of these younger adults in the Medicaid program (Slide 26).

Disability among Medicare and/or Medicaid Beneficiaries

More than half (60 percent) of Medicare and/or Medicaid Beneficiaries have a disability or complex condition – almost half of those have co-occurring disabilities (Slide 27 and 28).

Almost 40 percent of Medicare and/or Medicaid beneficiaries have no disability or complex health conditions identified (Slide 27). This reflects the fact that a large portion of the Medicaid population is young adults without disabilities or complex conditions who have coverage through Medicaid, including new enrollees purchasing Medicaid coverage through the Affordable Care Act's Medicaid expansion.

Over the last decade, Medicaid expansion has increased Medicaid enrollment by an average of 20.7 percent across all participating states as of 2021.[9] The expansion includes large numbers of young adults with disabilities who were previously not able to purchase health insurance and were not eligible for Medicaid.

Within the 60 percent of beneficiaries who have a disability or complex condition, the largest group are beneficiaries diagnosed with a mental illness, including 44.7 percent who have depression, anxiety or bipolar disorder and 5.8 percent who have serious mental illness (schizophrenia or psychosis). Substance use disorder (SUD) is also prevalent in the Medicare and/or Medicaid population overall, affecting a quarter of all beneficiaries.

About half (47.2 percent) of the beneficiaries who have a diagnosed condition have more than one condition (co-occurring disabilities) (Slide 28). The most common conditions that co-occur with others are mental illness (36.0 percent of beneficiaries with disabilities) and SUD (27.1 percent). Beneficiaries with a physical or functional disability that co-occurs with another disability (7.9 percent) and those with IDD that co-occurs with another disability (3.6 percent) are far less common.

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[9] https://www.macpac.gov/subtopic/medicaid-enrollment-changes-following-the-aca/

Medicaid LTSS Recipients

Of Medicare and/or Medicaid's 1,013,089 beneficiaries age 18-64, only 39,398 (3.9 percent) receive Medicaid LTSS (Slide 29).[10]

Dual and "Medicaid-Only" beneficiaries who are receiving Medicaid LTSS are a very small percentage (3.9 percent) of the total Medicare and/or Medicaid beneficiaries age 18-64. They are older, more female, and more likely to be White Non-Hispanic than Medicare and/or Medicaid beneficiaries overall.

Age – While Medicare and/or Medicaid adult beneficiaries under age 65 are a comparatively younger-adult population (44 percent are age 18-34), the subgroup receiving LTSS is – not surprisingly – an older population (37 percent are age 55-64) (Slide 30). Only 27 percent of the LTSS recipients are age 18-34, and most of these (78 percent) are receiving LTSS through Washington State's Developmental Disabilities Administration (DDA). Another 36 percent are age 35-54, with 60 percent receiving LTSS from the Aging and Long-Term Support Administration (ALTSA). The older LTSS recipients (age 55-64) are receiving LTSS almost entirely (86 percent) through ALTSA (Slide 31).

Gender – While males are the majority (55 percent) of the Washington State Medicare and/or Medicaid beneficiary population overall, the LTSS recipient population is majority (51 percent) female (Slide 30).

Race/Ethnicity – The population receiving LTSS has a higher percentage of White Non-Hispanic beneficiaries than the overall Medicare and/or Medicaid beneficiary population. The percent of Medicare and/or Medicaid beneficiaries in each racial/ethnic group receiving LTSS varies from 2 percent of Hispanic beneficiaries to 4.3 percent of Non-Hispanic White beneficiaries. Black and Native Hawaiian or Other Pacific Islander (NHOPI) beneficiaries have the next highest rates of receipt (3.7 percent and 3.5 percent respectively). Rates of LTSS receipt for Asian, American Indian/Alaskan Native (AI/AN), and Hispanic populations are less than 3 percent (2.8, 2.4, and 2.0 percent respectively) (Slide 32).

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[10] These counts (Medicare and/or Medicaid beneficiaries and LTSS recipients) are based on a person-year methodology. The number of LTSS months in a setting for each recipient is summed and divided by 12. Part-year residents are excluded from the enrollment counts. The resulting total of Medicare and/or Medicaid beneficiaries age 18-64 is 1,013,089, and the total of LTSS recipients is 39,398. These are different totals than were used in the predictive model (1,059,272 total Medicare and/or Medicaid beneficiaries and 36,039 total LTSS recipients), which are based on the counts of individuals in the analysis (i.e., not person-years). Inclusion/exclusion criteria include the following: Part-year residents are included. Medicaid: Need to have 6+ months of full benefit coverage. Medicare & duals: Need to have 6+ months of Fee-For-Service coverage (excludes Medicare Advantage). The exclusion of Medicare Advantage beneficiaries and inclusion of partial residents tend to offset each other.

As a result, White Non-Hispanic beneficiaries are a greater proportion of LTSS recipients (68.0 percent) than they are of Medicare and/or Medicaid beneficiaries not receiving LTSS (61.4 percent)[11] (Slide 33). Hispanic beneficiaries, on the other hand, are a substantially lower proportion of LTSS recipients (7.2 percent) than they are of non-LTSS recipients (13.9 percent). Asians and American Indians also are a somewhat smaller portion of LTSS recipients (3.1 and 2.5 percent respectively) than they are of non-recipients (4.1 and 4.4 percent respectively). On the other hand, Black beneficiaries and NHOPI beneficiaries have about the same percentage of both LTSS and non-LTSS groups (around 8 percent and 2.5 percent respectively).

LTSS recipients have a wide array of disabilities and complex conditions that result in functional limitations. A substantial proportion have co-occurring disabilities, most of which involve mental illness and other behavioral health conditions.

A variety of disabling conditions are prevalent among age 18-64 LTSS recipients (Slide 34: Just measuring the prevalence of specific conditions, LTSS recipients have a wide array of diagnosed conditions, with a very high prevalence of mental illness. The majority of recipients have more than one of these conditions:

- One-third of LTSS recipients have IDD as a primary diagnosis
- Half (48 percent) of LTSS recipients have a physical/functional condition
- Over half (56 percent) have a complex medical condition
- Nearly a quarter (21 percent) have a serious mental illness (SMI) (which includes Schizophrenia and Psychosis).
- Nearly three-quarters (72 percent) have a diagnosed mental illness other than SMI (which includes anxiety, depression, bi-polar disorder, and personality disorders).
- More than a quarter (28 percent) have a substance use disorder.

A large majority of LTSS Recipients have co-occurring disabilities (Slides 35 and 36):

- Seven-in-ten (69 percent) LTSS recipients have co-occurring disabilities.
    - IDD – Two-fifths (40 percent) of those with co-occurring disabilities have IDD as a primary diagnosis, with physical/functional, mental illness, and/or substance use disorder co-occurring.
    - Physical and Mental Illness – Another two-fifths (39 percent) have co-occurring physical/functional and mental illness.
    - Mental Illness and SUD – One fifth (21 percent) have co-occurring mental illness and substance use disorder.
- A third of LTSS recipients have a single diagnosis (Slide 35):

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[11] The percentages reported here are of LTSS recipients and Medicare and/or Medicaid beneficiaries who are identified by race or ethnicity in claims files. About 6 percent of Medicare and/or Medicaid beneficiaries and 9 percent of LTSS recipients have no reported race or ethnicity category.

  - Mental Illness – 12 percent of the LTSS recipients have only a mental illness. This includes 1 percent who are diagnosed with serious mental illness – I.e., schizophrenia or psychosis.
  - IDD – 6 percent of LTSS recipients have IDD as a single diagnosis.
  - Physical – 5 percent of LTSS recipients have a physical/functional limitation. Another 2 percent have a complex medical condition.
  - No Diagnosis – 5 percent have no diagnosis entered in their claims record.

A large proportion of Medicare and/or Medicaid beneficiaries age 18-64 who are not LTSS recipients have mental illness and/or other behavioral health conditions (Slides 37 and 38)– Nearly 60 percent of Washington State Medicare and/or Medicaid beneficiaries have some physical, mental, or other behavioral health condition of varying degrees of severity that, for most, do not result in functional limitations severe enough to qualify them for LTSS. For nearly half of non-LTSS recipients, their diagnosis is mental illness or substance use disorder or both in combination: mental illness (24 percent), substance use disorder (SUD) (7 percent), or co-occurring mental illness and SUD (15 percent). The other beneficiaries with a diagnosed condition have either a complex medical condition (6 percent) or a co-occurring physical and mental condition (4 percent).

Acuity

A large portion of LTSS Recipients age 18-64 have high levels of LTSS need:

All recipients of Medicaid-funded LTSS, whether in home-based, community/residential, or institutional care, have sufficiently high needs for assistance with daily living to qualify for Medicaid LTSS. In Washington State, to receive home- and community-based services (HCBS), beneficiaries must meet the qualifications for an “institutional level of care” on the basis of a comprehensive assessment of functional capacity and need for assistance and be approved to receive care through one of the State’s home- and community-based Medicaid authorities.

Washington State measures the acuity of need for LTSS on a scale that combines an ADL (activities of daily living) functional needs score, a CPS (cognitive performance scale) score, clinical complexity, and behavioral points score. Combinations of these scores are grouped into five numeric categories from low (5) to high (1) acuity of LTSS need[12].

ADL Scores (Slide 39): Washington State measures ADLs on a scale from 0 to 25 and higher, with 86 percent of the Medicaid LTSS recipients clustered below 20 on the scale. The majority (67 percent) of recipients are spread between 5 and 19 on the scale, with the largest percentage (26 percent) between 15 and 19.

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[12] See Appendix D for a complete description of Washington State’s assessment tools and scoring methods.

There is a substantial difference in the distribution of ADL scores for recipients receiving care in-home as opposed to a residential setting. Recipients receiving in-home care have high ADL scores, with the highest concentration (28 percent) between 15 and 19. On the other hand, recipients receiving community/residential care (e.g., adult family home, assisted living, and residential care) are concentrated at lower ADL scores: 55 percent having scores below 10. Particularly noteworthy is the difference in the portion of the recipients who have the lowest ADL category of scores (0-4): the percent of those receiving in-home care who are in this category (15 percent) is half that of the percent of those receiving residential care (34 percent).

Acuity Group Scores (Slide 40): Washington State combines the ADL, cognitive, clinical complexity and behavioral scores into 17 distinct groups ranging from lowest to highest need that are then grouped into five categories: comparatively low acuity (5) to highest acuity (1). The level of acuity is linked directly to the amount and intensity of services that are provided.

There is again a difference in the distribution of the acuity scores for in-home LTSS recipients and residential LTSS recipients. Residential clients are more concentrated at the lower level of acuity than in-home clients, while scores for in-home clients are concentrated in three middle-range categories – particularly the highest of the three. About half (53 percent) of residential clients are in acuity groups 5 and 4, while three-quarters (76 percent) of in-home clients are in acuity groups 4, 3, and 2.

Even at the highest level of acuity (group 1), Washington State serves more of this group of clients in their home (2,163) than in a residential setting (722).

Care Settings

Nearly all Washington State LTSS Recipients age 18-64 are receiving LTSS in their home or in community-based settings. The majority of Home- and Community-Based Services (HCBS) recipients receive their LTSS in the home.

Washington State provides LTSS in a variety of home-based, community residential, and institutional settings. Following on the landmark 1999 Supreme Court decision in *Olmstead*[13], Washington State now provides almost all Medicaid-funded LTSS for the 18-64 age group in home or community residential settings (Slide 41).

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[13] The Supreme Court decision in *Olmstead v. L.C.,* 527 U.S. 581 (1999) required public entities to administer programs "…in the most integrated, least restrictive setting appropriate to the needs of qualified individuals with disabilities." This has led to a substantial shift in the settings of care, particularly for adults under age 65 with disabilities, from institutional to home- and community-based care. In Medicaid, this has resulted in widespread use of Medicaid home- and community-based services (HCBS) waivers to provide services outside of Medicaid's mandated institutional settings.

The proportion of the Washington State Medicaid LTSS recipients served through Nursing Homes or other institutions is much lower in the 18-64 age group than it is in the 65 and older age group. For those 18-64, only 6.6 percent receive LTSS in institutional settings, while 20.9 percent of those 65 and older are in institutions.

A large majority of HCBS recipients age 18-64 (85.1 percent) are receiving their services and supports in their home rather than in community-based residential settings – a much higher percentage than for HCBS recipients age 65 and older (70.4 percent).

Service Utilization

Almost three-quarters of Washington State LTSS Recipients age 18-64 receiving in-home care are at an acuity level that translates to between 12 and 47 hours per week of personal care.

The number of base hours of personal care an in-home recipient can receive through the Washington State Medicaid HCBS is directly tied to the individual's assessed acuity level. For the majority (71.1 percent) of in-home recipients, the base care hours fall between 50 and 200 hours per month. Base hours are the starting point -- actual hours provided for a client are adjusted for that individual's circumstances, including the availability of unpaid caregiving and any exceptional needs an individual recipient may have (Slide 42).

3.4 UNMET LTSS NEED

Forty percent of Washington State Residents age 18 to 64 with LTSS needs have unmet needs:

For the population as a whole, an estimated 316,828 Washington State residents age 18-64 (7 percent of this age group) need LTSS and of these 127,963 (40.4 percent) are not getting sufficient help, including 44,449 (14.0 percent) who are getting no help at all (Slide 16).

Among Medicare and/or Medicaid beneficiaries, the Washington State predictive risk model identified 22,776 beneficiaries "at high risk of needing LTSS" in 2019-2020 (Slide 43).

Washington State developed predictive risk models to examine the most important factors associated with receipt of Medicaid LTSS among Medicare and/or Medicaid beneficiaries. Logistic regression models were used to predict initiation of LTSS receipt (i.e., LTSS entry) within two years. These models estimated the effect of a given factor on the probability of entering into LTSS receipt, controlling for the influence of other factors (adjusted odds). (See Appendix G for a more complete discussion of the models.)

The analysis used linked Medicare-Medicaid data from 2013 to 2020. The models include a long list of factors, including: demographics; socio-economic status measures; utilization of disability-related durable medical equipment; potentially disabling central nervous system conditions; intellectual disabilities and developmental delays; sensory, cognitive, and mobility impairments; frailty-related diagnoses; medical comorbidities; mental illnesses; substance use disorders; and utilization of medical services.

The resulting model based on current recipients was applied to Medicare and/or Medicaid beneficiaries in 2018 not currently receiving Medicaid LTSS to generate predicted probabilities or risk scores for needing LTSS. The non-LTSS recipients were divided into two groups: those "at high risk of needing LTSS "and those "at low risk of needing LTSS," with the threshold for high risk set so that the average risk score for the high-risk group was equal to the average risk score for current LTSS recipients.

Of the total of 1,059,272 Washington State Medicare and/or Medicaid beneficiaries ages 18-64[14], only 3.9 percent are currently receiving LTSS, and another 2.2 percent are "at high risk of needing LTSS" (Slides 43 and 54).

In addition to 36,039 Medicare and/or Medicaid beneficiaries who are currently receiving LTSS, the model identified 22,776 beneficiaries (5,608 Medicare+Dual and 17,168 Medicaid only) "at high risk for needing LTSS"[15]. Being at high-risk does not guarantee that any particular individual will qualify to receive LTSS. Some high-risk individuals may continue to receive assistance from other sources (e.g., private pay, unpaid family help); some may not meet Medicaid long-term care financial eligibility requirements; and some, despite having LTSS risk factors, may not meet functional eligibility criteria.

The population "at high risk of needing LTSS" has a higher percentage of older, female, and White beneficiaries than are currently receiving LTSS.

The group of Medicare and/or Medicaid Beneficiaries "at high risk for needing LTSS" and not currently receiving LTSS is an older and more female population than current LTSS recipients.

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[14] These counts (Medicare and/or Medicaid beneficiaries and LTSS recipients) are based on the counts of individuals in the analysis (i.e., not person-years). Inclusion/exclusion criteria include the following: Part-year residents are included. Medicaid: Need to have 6+ months of full benefit coverage. Medicare & duals: Need to have 6+ months of Fee-For-Service coverage (excludes Medicare Advantage). The exclusion of Medicare Advantage beneficiaries and inclusion of partial residents tend to offset each other. The resulting total of Medicare and/or Medicaid beneficiaries age 18-64 is 1,059,272, and the total of LTSS recipients 36,039. These are different totals than were used in the administrative data analysis (1,013,089 total Medicare and/or Medicaid beneficiaries and 39,398 total LTSS recipients, which are based on a person-year methodology. The number of LTSS months in a setting for each recipient is summed and divided by 12. Part-year residents are excluded from the enrollment counts.

[15] Note that this analysis applies only to the 22 percent of working age adults who received health coverage through Medicare and/or Medicaid. Adults with other forms of health coverage and those without health coverage are not included.

This older age group has a higher percentage of White non-Hispanic beneficiaries than the younger group that is currently receiving Medicaid LTSS.

- **Age** – While more than a third (38 percent) of age 18-64 beneficiaries currently receiving LTSS are 55 and older, more than half (52 percent) of the beneficiaries "at high risk of needing LTSS" are in this older age group (Slide 44).
- **Gender** – Beneficiaries currently receiving LTSS are a majority female population (51 percent), a slightly larger majority of the population "at high risk of needing LTSS" would be female (53 percent) (Slide 45).
- **Race/Ethnicity** – While 69 percent of current LTSS recipients are White Non-Hispanic, 73 percent of those "at high risk of needing LTSS" are predicted to be in that race category (Slides 46 and 47).
    - Both Hispanic and Asian groups are less prevalent among those "at high risk of needing LTSS" than they are among current LTSS recipients:
        - Hispanic beneficiaries are 8 percent of those "currently receiving LTSS" but only 6 percent of those "at high risk of needing LTSS." They are, however, almost 15 percent of the group "at low risk for needing LTSS."
        - Asian beneficiaries are 4 percent of those "currently receiving LTSS" but only 3 percent of those "at high risk of needing LTSS." They are a slightly larger percentage (5 percent) of the low-risk group.
        - Black beneficiaries are a consistent 8 percent of every group.
        - AI/AN or NHOPI populations are substantially the same proportion of both LTSS recipients and the high-risk group, but a slightly higher proportion of the low-risk group.
    - The population that is "at low risk of needing LTSS" is more diverse than the population "at high risk of needing LTSS." White beneficiaries are only 60 percent of the "low risk" group, while Hispanic beneficiaries are nearly 15 percent and Asian beneficiaries about 5 percent of this group. While some of this difference is likely associated with age differences in the populations (an older average age for White beneficiaries compared to the much younger average age for Hispanic beneficiaries), other groups with similar age profiles (Black and American Indian beneficiaries) do not have the extreme variation in LTSS need that is evident for Hispanic beneficiaries.

The prevalence of specific diagnoses among those currently receiving LTSS and those "at high risk of needing LTSS" are similar.[16] For several of these diagnoses, nearly all of the beneficiaries with these conditions who are not currently receiving LTSS are "at high risk of needing LTSS" (Slide 48).

- "At Low Risk of Needing LTSS" – Half of the population (49 percent) "at low risk of needing LTSS" has no risk factor identified. This is likely a group whose eligibility for

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[16] The percentages in this discussion include "duplicate counts" of individuals. Each diagnostic category shows the total percent of beneficiaries receiving LTSS or at risk of needing LTSS in that category. Since beneficiaries may have multiple co-occurring conditions, these percentages add up to more than 100 percent.

Medicaid is not based on a disability[17]. For the half who have one or more risk factors identified, the categories "other mental illness" (37 percent), "substance use disorder (SUD)" (19 percent), and "complex conditions" (17 percent) account for nearly all of the disabilities for those who are not likely to have an LTSS need. This suggests that less-severe mental illness, substance use disorder, and complex medical conditions are not as frequently associated with functional limitations that may generate a need for LTSS.

- "At High Risk of Needing LTSS" – The high-risk group and group receiving LTSS both have high and relatively comparable prevalence of:
  - Physical/functional disability, including mobility impairments
  - Intellectual or Developmental disability (I/DD)
  - Cognitive disorders, including traumatic brain injury,
  - Schizophrenia and other psychotic disorders,
  - Anxiety, bipolar disorder, and depression
  - Epilepsy, MS, and Parkinson's, and
  - Alcohol and drug disorders

  - Specifically:
    - Mental illness – the disability category "other mental illness" is the leading diagnosis for beneficiaries "receiving LTSS" or "at high risk of needing LTSS" – affecting three-quarters of beneficiaries in these categories. Twenty percent have serious mental illness ("schizophrenia/psychosis"). In many cases, depression, anxiety, or bipolar disorder would not by themselves result in a functional limitation sufficient to require functional assistance. However, most of these mental health diagnoses are co-occurring with other disabilities that in a combination do result in serious functional limitations.
    - Physical/Functional disabilities – about half of beneficiaries receiving LTSS or "at high risk of needing LTSS" have a substantial physical or functional disability.
    - IDD – a third of beneficiaries "receiving LTSS" and a quarter of those "at high risk of needing LTSS" are diagnosed with IDD.
    - Complex conditions - very high percentages of both populations have advanced chronic conditions that in almost all instances co-occur with physical/functional, I/DD, and/or behavioral health conditions. While complex conditions rarely appear as a solo condition for LTSS recipients, when co-occurring with other conditions, they likely contribute to the functional limitations that require LTSS.

Beneficiaries age 18-64 who "receive LTSS" or are "at high risk of needing LTSS" have an exceptionally high rate of co-occurring disabilities (Slides 49, 50, 51).

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[17] Some portion of this group may be people who have a condition that was not diagnosed or the diagnosis was not entered in their records.

- Co-occurring disabilities – Two-thirds of beneficiaries "receiving LTSS" and "at high risk of needing LTSS" have co-occurring disabilities, underscoring the importance of inter-disciplinary approaches that integrate physical health, behavioral health, and supportive services for the adult "working age" population with disabilities (Slide 49 and 50).
    - IDD with other disabilities – about a quarter of those with co-occurring disabilities have a diagnosis of IDD along with physical/functional, mental, or other behavioral health issues (Slide 49).
    - Mental Illness and SUD – these conditions are prevalent co-occurring disabilities of Medicare and/or Medicaid beneficiaries in the 18-64 age group who are currently "receiving LTSS" or are "at high risk of needing LTSS." Only 3.5 percent of beneficiaries with co-occurring disabilities "receiving LTSS" and only 1.4 percent of those "at high risk for needing LTSS" do not have a mental or other behavioral health diagnosis (Slide 51).

A minority of working age adults "receiving LTSS" or "at high risk of needing LTSS" have a single diagnostic condition – which may be a serious mental illness, or a complex physical or chronic illness (Slide 50).

- Mental Illness only – In addition to the role mental and other behavioral health issues play as a co-occurring disability, another 14 percent of beneficiaries "receiving LTSS" or "at high risk of needing LTSS" have a serious mental illness ("schizophrenia/psychosis") or "other mental illness" as their only diagnosed condition.
- Physical/functional or complex condition only – Beneficiaries with physical or functional disabilities and no co-occurring mental or other behavioral health conditions account for only 6 percent of beneficiaries "receiving LTSS" and only 8 percent of those "at high risk of needing LTSS."
- Complex condition only – Another 3 percent of beneficiaries "receiving LTSS" and 5 percent of those "at high risk of needing LTSS" have only a "complex condition" which may be one of many serious physical or chronic health conditions that can lead to functional limitations needing LTSS.

4. Conclusion

States, in partnership with the federal government through the Medicaid program, are the only public financers of essential services and supports for people who, due to a disability or a chronic health condition, are unable to perform basic functions of daily living without assistance. When we think of long-term services and supports (LTSS) we typically think of older adults who develop physical and cognitive infirmities as they age. Nearly half of the population in need of LTSS, though, are adults who are "working age" – between 18 and 64 years of age. While there is an abundance of information on adults age 65 and older who need LTSS, there is very little information available on adults under age 65 who need LTSS.

This report comes from a pilot effort[18] to build and test a model that states can use, relying on a combination of affordable survey data collection and analysis of existing state Medicare and Medicaid administrative data files, to create a portrait of the state's population age 18-64 with LTSS needs, including those whose LTSS needs are partially or fully unmet.

The model combines data from three sources: a special Washington State supplement on LTSS to the 2021 Behavioral Risk Factor Surveillance System (BRFSS), claims records from the Washington State Medicaid Enrollment Files for CY2018, and Washington State's Predictive Risk Model based on combined Medicare and Medicaid Claims Records for 2018.

This analysis of the Washington State data is a first effort to capture the scope of what these databases in combination can tell us about the working-age LTSS need population in relation to the state's population as a whole and those in this age-group with disabilities. These three data resources offer opportunities for future researchers to dig more deeply into the characteristics of the population in need of LTSS, including those age 65 and older, and the nature of their met and either partially or fully unmet needs.

4.1 Conclusion on Key Findings

Key Findings

1. **<u>Need for LTSS</u>**
   - Nearly a tenth of the population age 18-64 (7 percent) identify needs for long-term services and supports (LTSS). This is one-of-every 3 people who have disabilities.
     - Of those who need LTSS, only about a third need assistance with activities of daily living (ADLs) -- and most of those need help with both ADLs and instrumental activities of daily living (IADLs). The largest share of those with LTSS needs (about 60 percent) only need help with IADLs, which often is not sufficient to meet state requirements for LTSS, although clients who qualify for LTSS based on ADLs can also receive assistance with their IADLs.
     - For Washington State, this equates to 1 million residents age 18-64 with disabilities and 316,828 people with LTSS needs, of whom 117,066 have higher levels of need (i.e., ADLs or both ADLs and IADLs).

   - The highest rates of LTSS need are among women (8.5 percent), rural residents (8.1 percent), and Black, American Indian and Alaska Native, and Native Hawaiian or Other Pacific Islander race/ethnicity groups (9.1, 10.5, and 10.9 percent, respectively)[19].

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[18] The Long-Term Quality Alliance (LTQA) collaborated with the State of Washington Aging and Long-Term Services Administration (ALTSA), with assistance from The Commonwealth Fund, to design and test this model.

[19] Percentages are omitted in the LTSS needs analysis for all of the race/ethnicity groups other than Non-Hispanic White and Hispanic due to the small number of BRFSS respondents identifying an LTSS need in all of the other race/ethnicity groups, resulting in a large confidence interval.

- Prevalence of LTSS need from the BRFSS data is higher-than-average among the non-Hispanic White population and lower-than-average among Hispanic and Asian populations. In-part, the lower LTSS need rate in the Hispanic population can be explained by the high number of the youngest adults in this group. The Asian population is not as young, though, and the other racial/ethnic groups that have similar age patterns to the Hispanic population appear to have high levels of LTSS need.[20]

- The Predictive Risk Model provides a more nuanced look at race and ethnicity. The group of Medicare and/or Medicaid Beneficiaries "at high risk for needing LTSS" and not currently receiving LTSS is an older and more female population with a higher percentage of non-Hispanic White beneficiaries than the younger group that is currently receiving Medicaid LTSS. Both Hispanic and Asian groups are less prevalent among those "at high risk of needing LTSS" than they are among current LTSS recipients. Hispanic beneficiaries in particular are far more prevalent in the group "at low risk of needing LTSS" than they are in either the group of current LTSS recipients or the group "at high risk of needing LTSS." Differences in prevalence of Asian, Black, and Native beneficiaries across all three groups are small.

Enrollment in Medicare and/or Medicaid

- Over 1 million Washington State residents age 18-64 (22 percent) are enrolled in Medicare and/or Medicaid.
    - Participation rates are higher than average for Native Hawaiian and Other Pacific Islander (44 percent), American Indian (30 percent), Black (32 percent), and Hispanic (24 percent) populations.
    - Participation rates are significantly lower for the Asian population (8 percent).

2. LTSS Receipt

Demographics of Medicaid LTSS Recipients

- Only 3.9 percent of Medicare and/or Medicaid beneficiaries age 18 to 64 receive Medicaid LTSS.
    - 27 percent of LTSS recipients are age 18-34 – the majority of whom (78 percent) are served through the Developmental Disabilities Administration (DDA)
    - A third (36 percent) of LTSS recipients in the middle age range (35 to 54) of whom 60 percent receive LTSS from the Aging and Long-Term Support Administration (ALTSA).
    - Another third (37 percent) of LTSS recipients are in the older age group (age 55-64), almost all (86 percent) of whom are served through ALTSA.

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[20] Conclusions on LTSS need from the BRFSS data on racial/ethnic groups other than the non-Hispanic White and Hispanic groups are based on small numbers of respondents and have a wide confidence interval.

- With regard to disparities in access to LTSS, data from the Predictive Model do not point to racial/ethnic differences in LTSS receipt or unmet LTSS need that would suggest any BIPOC group lacks access or is underserved.
    - The population that is currently “receiving LTSS” is more diverse, with a lower percentage of non-Hispanic White beneficiaries, than the population “at high risk of needing LTSS.” Both Hispanic and Asian beneficiaries are slightly more prevalent in the group “receiving LTSS” than they are in the group “at high risk for needing LTSS.” At the same time, both Hispanic and Asian beneficiaries are more prevalent in the group “at low risk of needing LTSS,” suggesting a younger age subpopulation or lower rates of disabling conditions.
    - Other racial/ethnic subgroups have roughly the same prevalence in all three LTSS receipt or need groups, a pattern that is inconsistent with disparities in access.

Disabilities of Medicaid LTSS Recipients

- LTSS recipients have a very high rate of physical or developmental disabilities co-occurring with mental illness and substance use issues.
    - Seven-in-ten (69 percent) LTSS recipients have co-occurring disabilities
    - Two-fifths (40 percent) of those with co-occurring disabilities have an Intellectual or Developmental Disability (IDD) as a primary diagnosis.
    - Another two-fifths (39 percent) have a co-occurring physical/functional disability and mental illness.
    - One-fifth have co-occurring mental illness and substance abuse disorder (SUD).

- A third of LTSS recipients have a single diagnosis – principally mental illness (12 percent), but 6 percent have IDD and 7 percent have a physical/functional disability or a complex medical condition.

Acuity of Medicaid LTSS Need[21]

- The majority (76 percent) of recipients of home- and community-based LTSS (HCBS) have acuity scores in the middle range (acuity groups 4, 3, and 2 (on a scale from 5 (low) to 1 (high)). About half (53 percent) of residential clients are in lower acuity groups (5 and 4}. Even at the highest level of acuity (group 1), Washington State serves more of this group of clients in their home than in a residential setting.

Settings for Receipt of Medicaid LTSS

- Nearly all LTSS recipients age 18-64 receive Medicaid LTSS in their home or in community residential settings. Only 6.6 percent are in nursing homes or other institutional settings.
- Of those receiving HCBS, 85.1 percent are receiving it in their home.

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[21] See Appendix D for a description of the Washington State CARE assessment tool and methods for scoring acuity of LTSS need. LTSS recipients are given an assessment of their functional capacity the amount of assistance they will need to complete critical daily activities. The State compute a composite acuity score ranked from 5 (lowest) to 1 (highest). These scores measure acuity of need as well as the intensity of services provided by the State.

- Washington State serves a large proportion of the highest acuity recipients in the home.

3. Unmet LTSS Need

- An estimated 316,828 Washington State Residents age 18-64 (6.7 percent of this age group) need LTSS. Of these, 127,963 (40 percent) are not getting all of the help they need: 83,514 (26 percent) not getting enough help, and 44,449 (14 percent) not getting any help.
- In the population enrolled in Medicare and/or Medicaid, 36,039 (3.9 percent of enrollees) are "receiving LTSS," and another 22,776 (2.2 percent of enrollees) are "at high risk of needing LTSS"[22].

Demographics of Unmet Need

- Among all residents age 18-64, the group "not getting enough help" varies some from the group "not getting any help." Compared to those who are "getting the help they need":
  - Those "not getting enough help" are more likely to be female (66.4 vs. 64.4 percent) and rural (15.5 vs. 11.3 percent).
  - Those "getting no help" are less likely to be female (females are 55.3 vs. 64.4 percent) and rural (rural are 8.1 vs. 11.3 percent).

- Income plays a significant role in both LTSS need and rates of unmet need.
  - The rate of LTSS need in the population age 18-64 with annual household incomes below $35,000 (16.5 percent) is more than double the rate in the population overall (6.7 percent).
  - Half of those with incomes below $35,000 with LTSS needs have unmet needs – (8.2 percent of the 18-64 year old population with incomes below $35,000).
  - Only 3.0 percent of those with incomes above $100,000 have LTSS needs and only 20 percent of those are not meeting their needs.

- Among Medicare and/or Medicaid beneficiaries, those not receiving LTSS but "at high risk of needing LTSS" have a higher percentage of older, female, and white beneficiaries than current LTSS recipients. Hispanic and Asian beneficiaries, in particular, would be less prevalent in the "at high risk of needing LTSS" group than among those "receiving LTSS."

- The population "at low risk of needing LTSS" is more racially and ethnically diverse than the population "at high risk of needing LTSS." Hispanic and Asian beneficiaries in particular are more prevalent in the low-risk group.

Disabilities among those with Unmet Needs

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[22] See Appendix G for a description of the LTSS predictive risk model used to predict LTSS need among those not receiving LTSS.

- The prevalence of specific categories of diagnoses is similar among those “receiving LTSS” and those “at high risk of needing LTSS”; in large part due to the model’s reliance on patterns of disability that correlate highly with LTSS need.
    - Three-quarters have mental illness, half have a physical/functional condition, and a third have IDD.
    - Two-thirds of those “at high risk of needing LTSS” have co-occurring disabilities, with mental illness and substance use disorder (SUD) co-occurring with other diagnoses.
    - Those “at high risk of needing LTSS” have higher rates of SUD and mental illness that beneficiaries “receiving LTSS.”
    - All beneficiaries with a diagnosis of IDD are either “receiving LTSS” or “at high risk of needing LTSS.”

Key Questions for Future Research

1) A large portion of the population with LTSS needs has identified only needs for assistance with IADLs. A high proportion of those with LTSS needs report they are meeting those needs. We do not have a way through our survey instrument to scale the level of need or determine how many in the population with LTSS needs (and especially unmet needs) would meet the threshold for publicly-funded LTSS.

2) Given the limitation on the number of LTSS supplement questions, we are also not able to determine how people are meeting their care needs – whether through family caregivers, out-of-pocket private payment, or public programs. More research is needed to scale the level of need and measure the availability and use of resources.

3) The populations with disabilities, in need of LTSS, “receiving LTSS,” and “at high risk of needing LTSS” have higher concentrations of Female, White, and Rural people than the population at-large. What factors contribute to this phenomenon in adults age 18 to 64. To what extent is isolation and lack of access to services in rural populations a factor in this higher level of need?

4) The Hispanic population has higher rates of disability but low rates of LTSS need. They have a higher-than-average rate of participation in Medicare and/or Medicaid, but substantially lower rates of receipt of LTSS. To what extent is this low rate of LTSS need a function of the younger average age of the Hispanic population and to what extent could it be a result of cultural differences? To what extent is the low rate of LTSS receipt a function of the younger age of the Hispanic population, or are there factors limiting access, such as immigration status?

5) The Asian population has very low rates of: disability, enrollment in Medicare and/or Medicaid, and receipt of LTSS and unmet need for LTSS. The pattern among Asians is substantially different than that of other racial/ethnic groups. To what extent do

cultural values or informal social supports play a role? What other factors may be contributing to these lower rates?

6) The population with very low household incomes have a high rate of LTSS Need along with a very high level of unmet need. The reverse is true at high levels of income – low LTSS need and low level of unmet need. While low income can be expected to associate with high levels of LTSS need – either contributing to or resulting from conditions that would cause high LTSS need – the high rate of unmet need may also suggest a lack of access to means-tested programs. What can we learn about the LTSS needs of this low-income population with unmet needs?

7) A high percentage of people with LTSS needs are meeting their needs. What proportion of this group is being served by public programs and what proportion is drawing on other resources, including paid and unpaid caregivers?

8) There is an interesting pattern of a higher percentage of women and rural residents in the group not getting all of the help they need and a higher percentage of men and urban residents in the group not getting any help. What characteristics of the population age 18-64 with disabilities may be contributing to urban men with LTSS needs not getting any help? Why are rural women more likely to get less help than they need?

4.2 Conclusions (Lessons Learned) on Methodology

Planning for services to meet the LTSS needs of adults age 18 to 64 with disabilities has been hampered by a lack of current national data on the LTSS needs and service use of this diverse population. Given the substantial cost involved in conducting a large national survey, LTQA set out to design and test an approach that would rely largely on existing state data resources. The Commonwealth Fund approved funding for a state pilot project and LTQA requested proposals from interested states, selecting two states to participate in the pilot: Washington and Texas.

The Methodology

The Washington State Department of Social and Health Services (DSHS) Aging and Long-Term Support Administration (ALTSA) and Research and Data Analysis Division (RDA) in partnership with LTQA and Brandeis University's Community Living Policy Center (CLPC), with support from The Commonwealth Fund, developed a methodology combining three data sources:

- BRFSS - state-specific questions added to the 2021 Behavioral Risk Factor Surveillance System conducted annually by the Centers for Disease Control and Prevention;
- Predictive Risk Modeling – a unique predictive model built by RDA to predict risk of needing LTSS among current non-recipients of LTSS in the population of Medicare and/or Medicaid beneficiaries.

- Administrative Data – Medicare and Medicaid administrative records that provide information on the demographic, health conditions, and services received (including LTSS) in the population enrolled in Medicare and/or Medicaid.

Strengths and Limitations of the Data Sources

1. BRFSS Supplement –
    - *Value* – The addition of supplemental LTSS questions on the 2021 BRFSS survey enables us to measure the scope of LTSS need – both met and unmet – in the total Washington State population. This provided the broader context within which we could do a deeper analysis of the subset of the State population that is enrolled in Medicare and/or Medicaid. For the age group we are interested in (adults age 18-64), Medicare and/or Medicaid beneficiaries make up less than a quarter of the age group (unlike the age 65+ population that is almost entirely enrolled in Medicare). The BRFSS survey data enables us to put the population with disabilities receiving Medicaid-funded LTSS in the context of a larger population with disabilities and LTSS needs.

    - *Strengths* -- the BRFSS was selected as the survey vehicle to collect data on LTSS needs for three reasons:
        - It is a large national health survey conducted annually by the CDC (400,000 adult interviews) with a separate state-specific sample in each state (around 14,000 in Washington in 2021).
        - It allows state health departments to add a limited number of optional questions for interviews conducted with state residents.
        - It collects rich health care data that can be valuable in understanding the LTSS needs of the working-age population with disabilities.

    - *Limitations* – the BRFSS was the best available vehicle, but not perfect. It misses some people with disabilities because it is a telephone interview of individuals 18 and older using randomly selected landline and cellphone numbers and it does not collect household information from the individual who is interviewed, and it does not reach individuals in institutions. In addition, some Washington residents included in the Washington State results who had out-of-state cellphone numbers were interviewed with a different state's instrument and so were not asked the Washington State supplemental questions (including our LTSS questions) but were later included with the Washington State survey responses. In addition, although the BRFSS interviews a relatively large sample in each state, LTSS need is rare in the working-age population, resulting in a small number of responses to some of the LTSS questions that made it difficult to do sub-group analysis (e.g., racial/ethnic groups, groups with LTSS needs not getting any help). With some sub-group analysis, the standard error for smaller groups was too great to report the results. Finally, the estimates of the population with a disability the come from the BRFSS are substantially higher than the estimates that come from the American Community Survey – using identical questions. There is a great need for improvement in the core disability questions that are asked, and at the same time, a need to test different approaches to administering the core questions to better understand and address the causes of the variability in resulting disability population estimates.

- *Value of the LTSS Supplemental Questions* – the supplemental questions enabled us to collect additional information on met and unmet LTSS need in the general population of adults ages 18 to 64. Given the length of the overall survey, we were limited in Washington to three supplemental questions. The questions were carefully designed to elicit information on the need for assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) and the extent to which individuals with needs were able to meet those needs; and – in support of state planning activities - the age of onset of the underlying disability. A comparison of responses to the LTSS need question with responses to two of the six Disability questions in the core survey that address functional limitations validated the phrasing of the supplemental question. In the future, dropping the first supplemental question would provide space for an additional question on the source and type of assistance for respondents saying they were getting some or enough assistance.

- *Alternative Supplemental Questions* – In the Texas BRFSS, the Public Health Department allotted more space for the LTSS supplement to the 2021 BRFSS and suggested a question design to minimize the time allotment needed to ask the supplemental questions. The Texas questions provided a test of alternative phrasing for the Washington questions as well more extensive probe into the extent and type of assistance received and the cost of care. When the analysis of the Texas results is complete, we will compare the LTSS question responses for the two surveys and draw conclusions on question design for future work on an LTSS module.

2. <u>Administrative Data</u>
    - *Value* – In this study, we worked with data from two types of administrative files: 1) claims data from the matched 2018 Medicare and Medicaid enrollment and claims files and 2) data on the acuity of LTSS recipient’s needs from the Washington State CARE Assessment Instrument administered to ALTSA community and DDA residential clients age 18 to 64 at the end of 2018. The combination of information on service recipients regarding their acuity of need and services received allows for a detailed analysis of the LTSS needs and service utilization of the working-age population with disabilities that receives services. In addition, the availability of extensive medical claims records in the Medicare and Medicaid claims files enabled us to group diagnosis and health condition categories into clusters of medical and behavioral health conditions for purposes of describing prevalence and co-occurrence of different condition categories in the disability and LTSS recipient and

need groups. The groups that were developed for this project are described in detail in Appendix F.

- *Advantages* – The Medicaid claims files are already available to states and they provide a rich source of information on the demographics, disabilities and health conditions, and services used by Medicaid beneficiaries – for beneficiaries who are receiving state-funded LTSS as well as those who are not. The linked Medicare-Medicaid files expand the population of non-LTSS users – although with the 18-64 age group this is a small increase in the size of the total population included – and provide more extensive health condition and health services data for the Dual Eligible and Medicare-only beneficiaries. Assessment data in general is something that all state LTSS programs collect, although the CARE Assessment instrument used in Washington State is unique to that State. Assessment data can be extremely valuable in understanding individual levels of severity of LTSS need and intensity of service delivery. Washington State's CARE assessment provides a very sophisticated scoring of the acuity of LTSS need that is directly linked to level of services. This kind of data provides an understanding of need and service use that is important in planning and delivering services.

- *Challenges and Limitations* – Both Medicare-Medicaid claims files and state assessment data enable a much greater depth of analysis of LTSS needs and services than survey data, but with a narrower breadth of application of the conclusions. Less than a quarter of Washington State residents age 18 to 64 receive their health coverage through Medicare and/or Medicaid – and this is a population that by definition skews toward a high prevalence of disability and a greater level of health care and LTSS need compared to the total population in this age range. The CARE Assessment data was available for only a subset of the total LTSS recipient population – those receiving Home- and Community-Based Services (HCBS) in a home or community residential setting, and for one-third of the population with developmental disabilities served in residential settings through the Developmental Disabilities Administration (DDA).

- Additionally, the Medicaid expansion created by the Affordable Care Act in 2010 enabled states to extend Medicaid coverage to low-income individuals and families whose incomes and/or assets would previously have been too high for Medicaid. Large numbers of individuals with disabilities were able to attain coverage through the expansion. In addition, Washington has a Medicaid buy-in program for people with disabilities who are working but have low incomes. As a result, there could be large numbers of "expansion" and "buy-in" Medicaid beneficiaries who would not be eligible for LTSS. We were not able for this study to analyze beneficiaries by these categories.

3. Predictive Modeling
   - *Value* – the predictive risk model created for this project by the DSHS Research and Data Analysis (RDA) Division allows us to identify the more important factors associated with entry into Medicaid funded LTSS. It also enables us to understand the scope and characteristics of the group of Medicare and/or Medicaid beneficiaries not currently receiving LTSS who have a high risk of needing LTSS. For our purposes in this study, we view this group as the group with "unmet LTSS needs". These are individuals who already have coverage through Medicare and/or Medicaid and have or are likely to develop the conditions that would meet state requirements for receiving LTSS. The model is particularly useful for exploring in detail issues around unmet need, including problems with access to services for different types of existing beneficiaries and estimating the potential for expansion in existing services.

   - *Strengths* – The predictive model is applied to a linked Medicare and Medicaid claims file (linking beneficiary records in the two data files) which all states could obtain for this purpose. The linked files provide substantial health and disability condition and services utilization information on Medicare-only beneficiaries, Dual Medicare and Medicaid beneficiaries, and Medicaid-only beneficiaries. The predictive risk model enables a detailed comparison of beneficiaries receiving LTSS services with beneficiaries not receiving those services but highly likely to need them and beneficiaries with little or no likelihood of needing LTSS in the immediate future.

   - *Limitations* – The predictive model applies only to the Medicare and/or Medicaid beneficiary population – only 22 percent of adults age 18 to 64 in Washington State. People who have private insurance through work (including people with disabilities who are working) or who individually purchase private insurance, or who have no insurance but are not eligible for Medicare or Medicaid are not included in this predictive model. For this study, we rely on the results from the BRFSS supplement to understand the LTSS needs of the larger population. A second potential limitation is that the model requires a subjective decision on the appropriate risk score to use as a benchmark in separating "high risk" from "low risk" non-recipients of LTSS.

4. Combined Analysis
   - *Value* – It is important to put what we can learn from administrative data about the LTSS needs of working-age adults with disabilities in the larger context of the population of working-age adults as a whole. This is easier to do with the population age 65 and older, nearly all of whom are Medicare beneficiaries with extensive records in Medicare beneficiary and claims data. For the working-age adult population, the only source for this information is population surveys. Analyzing the LTSS needs and service use of current Medicaid recipients in the context of the predictive model results and the BRFSS survey results enables us to assess how well current services reach and meet the needs of the larger population with potential

LTSS needs and identify potential gaps in service that may need to be addressed by the State.

- *Advantages* – Working collaboratively with the LTSS experts in the State program unit and the data analysis experts in the State research and data unit, beginning in the design phase, made it possible to design and implement an approach to bring all of the disparate pieces of information together in a combined analysis at the end that has relevance for State planning purposes.

- *Limitations* – The most consequential limitations in the effort to combine data from different sources to draw a picture of the whole were the difficulty of assuring definitions related to LTSS need were the same across the data resources. In aligning the total working-age adult population's need for LTSS from BRFSS with the receipt of LTSS from State administrative data, the refinement that was missing in the BRFSS data was the severity or acuity of the LTSS need. BRFSS-based estimates of the population needing LTSS were likely to exceed the size of the population that would meet the State's eligibility criteria, since there was no question in the survey to determine the severity of functional limitation and no question for those reporting meeting their LTSS need on how they were doing it. An additional limitation was the inability to align the time periods for the various data resources. The BRFSS provided us with the freshest data – the interviews were conducted over a year from January to December 2021 and referred to events in the month prior to the interview. The predictive model results and the administrative data came from a database for calendar year 2018. The lack of alignment in time period may not have significant effect on the validity of the combination analysis, but it is a factor to keep in mind.

Takeaways from the Pilot Project

There are several lessons we have learned in the process of designing and testing this combined data approach about ways we could improve our information on the LTSS needs and service use of the population age 18-64.

Strengthen the LTSS Supplement

The information provided by the BRFSS supplement on LTSS need and service use was limited by the few supplemental questions (3 questions) we were allowed for the Washington State survey. The value of the supplement would be enhanced with more follow-up questions, despite the difficulty of making population estimates from the small numbers of interviewees in the 18-64 age range with an LTSS need that would answer questions about that need.

We are testing a different set of supplemental questions on LTSS need in the 2021 Texas BRFSS survey. In that survey, our LTSS supplement included 10 items, including questions on the type and amount of help people are receiving, whether it was paid or unpaid, and the source of payment. The analysis of the results from the Texas supplement is ongoing. We expect to have more comprehensive recommendations for a supplemental LTSS questionnaire once the analysis of the Texas survey is completed.

While the Texas supplement included questions that collected information on additional topics around respondents' receipt of help and costs, both the Washington State and Texas supplements included questions on LTSS need and unmet need. However, the questions were worded differently between the two supplements. The Washington State questions on LTSS need (i.e., ADLs, IADLs) resulted in similar estimates as the corresponding questions in the core BRFSS survey (i.e., American Community Survey (ACS) questions). The Texas questions produced some interesting results suggesting differences in interpretation of the questions that will be further analyzed and described in a separate report focused on the Texas BRFSS survey and LTSS supplement. Overall, using different questions between the two states allowed us to test different question designs and wording, which provides some preliminary lessons but also underscore the need for more robust cognitive testing of the questions by the CDC prior to inclusion in a national module.

Use Core Survey Disability Questions on LTSS Need to Allow More Supplemental Questions

In the Washington State survey results, the similarity of responses to two of the six disability questions on the core survey instrument that are related to functional limitations (Self Care and Independence) and responses to the two LTSS supplement questions about the need for assistance with ADLs and IADLs suggests that in future surveys the two Disability questions could be used to identify LTSS need in lieu of the two supplemental questions. This would provide more room for follow-up questions to those who identify an LTSS need – questions that could be used to determine the severity of the need and the assistance the individual was getting to the meet the need.

The six disability questions used in the core BRFSS survey are also embedded in the American Community Survey (ACS) and the National Health Interview Survey (NHIS), among other national surveys. As a result, basic information on prevalence of LTSS need along with a wealth of other information about people with LTSS needs could be available from other large national surveys. As we work to learn more about LTSS need in the working-age adult population, whether and how we are meeting these needs, and the nature of unmet LTSS needs, state administrators and researchers should be exploring state-level tabulations from these other national surveys.

Launch an Effort to Develop an LTSS Module for State BRFSS Surveys

Work to design a revised questionnaire, building on our learnings from the 2021 LTSS Supplemental questions, should contribute to an effort to secure federal agency sponsorship and funding for a BRFSS module on LTSS. The module would be a standard set of validated questions that states could elect to add to their state BRFSS survey. States that elect to use the LTSS module could contribute their results to the accumulating state-level data on the LTSS needs of the adult population in general, with special attention to the LTSS needs of the working-age adult population in the state. Over time, the accumulation of State-level data could contribute to a national understanding of the dimensions of LTSS needs in this population.

Provide States with Linked Medicare-Medicaid Claims Files

States that want to use matched Medicare-Medicaid claims files to explore LTSS service use have to purchase statewide Medicare data through 3rd party vendors. In addition to supporting state's access to statewide Medicare data at no cost, the Centers for Medicare and Medicaid Services (CMS) should make copies of linked Medicare-Medicaid files available to State Medicaid agencies at no cost, and through them to State research units and/or university research groups that contract with States to provide administrators with planning information. Washington state spent significant resources linking the files internally, and some states may not have this capacity.

Assist States in Developing and Using Predictive Models

The predictive model developed by Washington State for use in this project could serve as a template for other states to apply to their own Medicare-Medicaid matched claims files. Extensive documentation on the construction of the model and the choices made would help guide states with limited research and data analysis capabilities to replicate the model built for this project.

Adopt a Common Core Assessment Tool and Develop Analytic Tools

All states administer some form of assessment instrument to Medicaid beneficiaries seeking LTSS in order to determine their level of acuity and the appropriate type and level of LTSS Medicaid will provide. The data collected through these instruments could have great value for understanding in greater depth the level of acuity of beneficiaries seeking paid LTSS, the resources they have to meet their needs, and the type and amount of services the state is providing.

The State of Washington uses the CARE Assessment tool - which it developed - for all state HCBS waivers. Some other states have developed their own common assessment tools they use for all the state's HCBS waiver programs. A number of states use a single proprietary instrument – the InterRAI Home Care – but the assessment data is not available for analysis. In a number of states that contract with Medicaid Managed LTSS plans, each plan uses its own assessment instrument. There are also a number of states that use different assessment tools for different waiver programs.

Through the Testing Experience and Functional Tools (TEFT) Program, CMS has tested a set of functional assessment items they have been promoting with the states for use with HCBS waiver programs – the Functional Assessment Standardized Items (FASI). However, states have been slow to adopt FASI. More widespread adoption of a core assessment instrument would make it possible to develop a standard framework for states to incorporate analysis of severity of LTSS need and level of services required in the combined analysis of LTSS need and service use.

Bring Quality and Outcomes Data into LTSS Analysis

Almost all states collect data on the quality of services, experience of care, and outcomes for Medicare beneficiaries receiving HCBS. Most states collect data from a sample of beneficiaries through the National Core Indicators (NCI) and/or the National Core Indicators - Aging and Disability (NCI-AD) surveys to evaluate the experience of care. Alternatively, states may use CMS's HCBS-CAHPS for the same purpose. States could compile and analyze this data to provide a picture of the quality of services and beneficiary outcomes – as an additional component of the combined analysis of LTSS need and service use.

CMS announced in July 2022 a set of standardized quality measures for HCBS that states would be "strongly encouraged" to collect – either from Medicaid managed LTSS plans or from state HCBS program administrators -- and report annually. This data may be available in the public domain in the next few years and could be incorporated into a comprehensive report on LTSS need and service use.

Develop a State Toolkit for Combining State Data Resources to Support LTSS Planning

The experience with this pilot project with Washington State can be the basis for a toolkit documenting the selection and acquisition of data resources, the research design, research questions, development of the predictive model, and analysis of all three components. The data resources used for this project -- the BRFSS supplemental questions and the Medicare-Medicaid matched files – are available to all states. Extensive documentation of the methodology, predictive model design, learnings, and recommended adjustments would help states stand up a similar project without having to repeat the extensive design and testing activity required for the pilot project.

5. Appendices

See separate document for technical appendices:

- **Appendix A:** Crosswalk of Research Priority Areas and Available Data Sources to be Used
- **Appendix B:** Measuring LTSS Need Using the BRFSS
- **Appendix C:** Washington State's Administrative Data Sources
- **Appendix D:** Washington State Assessment Tools and Scoring Methods
- **Appendix E:** Washington State Long-Term Care Settings and Programs
- **Appendix F:** Categorized Conditions for Disability
- **Appendix G:** Predictive Model
- **Appendix H:** Summary of Prior Studies Related to LTSS Receipt