

# Measuring and Monitoring the Adequacy of the Direct- Care Workforce and Impacts on Unmet Need: Landscape Scan of Data Sources and Opportunities for Future Research

Authors: Christina Wu, Grace Hong, and Mary Kaschak



# Table of Contents

- Executive Summary** ..... 2
  - Background.....2
  - Goals and Purpose.....2
  - Methods.....2
  - Findings.....3
  - Key Takeaways and Recommendations.....3
  - Conclusion.....5
- Background** ..... 6
  - Current Gaps in Workforce Data and Recent Federal Action.....7
- Goals and Purpose**..... 9
- Methods**..... 9
- Findings** ..... 10
  - Availability of Workers ..... 11
  - Gaps in Services and Supports..... 13
  - Wages and Compensation ..... 15
  - Stability.....19
  - Consumer Experiences ..... 20
  - Summary of Current Data Sources on Workforce Dimensions..... 25
  - Considerations for Self-Direction ..... 30
- Key Takeaways and Recommendations** .....30
- Conclusion** ..... 32
- Acknowledgments**..... 33
- Funding Statement** ..... 33
- How to Cite This Brief**..... 33
- Contact Us** ..... 33
- Appendices** ..... 34
  - Appendix A | List of Organizations Represented in Focus Groups and Interviews ..... 34
  - Appendix B | Interview Guide ..... 36

# Executive Summary

## Background

Direct-care workers (DCWs) play a critical role in supporting the daily activities of millions of older adults and individuals with disabilities who need long-term services and supports (LTSS) in the United States. Reports from the field indicate that the combination of high demand for services and high turnover of workers who provide them has resulted in a severe workforce shortage in the LTSS sector; however, it is impossible to quantify the number of vacant direct-care positions nationwide given the inadequacy of existing workforce data. Furthermore, data on the impacts of workforce shortages on individuals who need LTSS, such as unmet need, is virtually nonexistent.

## Goals and Purpose

Long-Term Quality Alliance (LTQA), in collaboration with the Community Living Policy Center (CLPC) at Brandeis University, conducted an initial exploratory study with two primary goals:

- 1) To **assess the current landscape** of data sources to measure and monitor access to and adequacy of the direct-care workforce (DCW) and highlight promising practices; and
- 2) To **explore potential data sources for a future pilot study** to test new ways of measuring and monitoring access to and adequacy of the DCW (e.g., test data collection and analysis with select group of plans and providers).

Our research to date has culminated in this policy brief, which summarizes findings and outlines recommendations for potential workforce-related data sources that can be better leveraged to measure adequacy of the DCW and assess the impacts of unmet need.

## Methods

To inform this exploratory study, we conducted six focus groups and four key informant interviews with managed-LTSS health plans, home-care providers, self-direction experts, fiscal intermediaries, state-association representatives, and other

policy experts and advocates. We also conducted desk research for review of: state contracts; data collection tools and accompanying reports; federal regulations, guidance, and other policy documents; and other relevant literature identifying state activities and best practices in workforce data collection.

## Findings

Our research explored currently available data in the five following domains: availability of workers; gaps in services and supports; wages and compensation; stability; and consumer experiences.



## Key Takeaways and Recommendations

Our key takeaways and recommendations for future research, policy, and practice are outlined below.

**Table 1. Key Takeaways and Recommendations**

Key Takeaway	Recommendation
There is potential in electronic visit verification (EVV) to identify gaps in care due to workforce capacity issues; however, much is unknown.	Conduct a landscape scan of EVV systems across states, including assessment of the accuracy of data, and identify best practices and recommendations for standard reporting measures, including missed-shift reporting and reason codes.
The availability of data on the	<ul style="list-style-type: none"> <li>▪ Conduct a pilot study testing the ability to link</li> </ul>

<p>direct-care workforce varies significantly by state, plan, and provider (e.g., particular value-based purchasing arrangements between a specific plan and provider).</p>	<p>workforce data (e.g., missed-shift reporting, referral-acceptance rates) to individual-level LTSS user data in partnership with a plan or provider in a state with more systematic reporting.</p> <ul style="list-style-type: none"> <li>▪ Encourage states to promote plans and providers to develop more value-based purchasing agreements to drive investments and improvements in the direct-care workforce and evaluate efforts.</li> </ul>
<p>While a few states are more advanced in their data collection, most states lack basic data on the direct care workforce.</p>	<p>Encourage states to administer a survey to collect workforce data from providers, such as the National Core Indicators—Intellectual and Developmental Disabilities (NCI–IDD) and National Core Indicators—Aging and Disabilities (NCI–AD) State of the Workforce Surveys. Encourage states to collaborate across their departments of health, labor, and economic development to develop workforce data-collection infrastructure and dashboards with real-time data on direct-care workers.</p>
<p>More information is needed on what measures would make sense in a self-direction model compared to a traditional agency model.*</p>	<p>Convene fiscal management services (FMS) providers, self-direction experts, and advocates to better understand what will be feasible and meaningful in terms of data collection on the workforce within a self-direction model.</p>
<p>Federal standard occupational classification (SOC) codes for direct-care workers are not clearly defined in the current LTSS context, limiting our ability to collect standardized data.</p>	<p>Conduct a study compiling definitions of direct-care workers across states to inform future revisions to federal SOC codes that better reflect DCW competencies, settings, and populations served.</p>
<p>More research is needed to understand and demonstrate</p>	<p>Conduct studies to evaluate the impacts of DCW shortages on upstream costs to payers from</p>

the impacts of the direct-care workforce shortage on medical costs.	increased inpatient care and on downstream costs from increased acute events that could have been avoided with greater workforce capacity.
---	--

*\* In a self-direction model, the participant or designated representative assumes decision-making authority over the services they receive—including over who provides the services and how services are provided—and manages their services with a system of supports. In a traditional agency model, services are provided by a qualified provider agency, which has full authority and responsibility for hiring and supervising staff.*

## Conclusion

Our focus groups, interviews, and desk research underscored limited efforts to systematically collect standard data on direct-care workers and their impacts across the country. While a few states have taken proactive steps to require Managed Long Term Services and Supports (MLTSS) health plans and LTSS providers to measure and report data related to direct-care-workforce availability, gaps, wages, and stability, most states lack basic data. As a result, our research suggests that we are currently unable to quantify the shortage of direct care workers and assess how these workforce shortages impact individuals with LTSS needs. Our report highlights future recommendations for research, policy, and practice that aim to advance efforts to improve standardized data collection and reporting, understand more fully the impacts of direct-care workforce shortages, and drive critical investments in the direct-care workforce.

## Background

Direct-care workers (DCWs) play a critical role in supporting the daily activities of over 12 million older adults and individuals with disabilities who require long-term services and supports (LTSS) in the United States.<sup>1</sup> In 2021, approximately 2.6 million DCWs provided care in people's homes, 648,000 provided care in residential settings (i.e., group homes and assisted living), and 471,000 provided care in nursing homes.<sup>2</sup> DCWs assist older adults and people with disabilities due to physical, cognitive, developmental, and behavioral conditions so that they may complete self-care and other daily tasks. While their jobs require a wide range of technical and interpersonal skills, these essential workers receive low pay and limited benefits and experience high rates of injury.<sup>2</sup> They typically work part-time hours for multiple employers and have irregular work schedules. Direct-care workers are predominantly female (87%) and people of color (59%), and just over a quarter (27%) are immigrants. Most (53%) have a high school education or less.<sup>3</sup>

The number of Americans ages 65 and older is projected to nearly double from 52 million in 2018 to 95 million in 2060, ultimately comprising 23% of the population in the United States.<sup>3</sup> As the U.S. population ages and people live longer with disabilities and chronic conditions, the number of individuals with significant disabilities is projected to grow from 7.6 million in 2020 to almost 14.7 million in 2065.<sup>4</sup> The number of older Americans requiring nursing home level of care will increase by 50% from 1.2 million in 2017 to 1.9 million in 2030.<sup>3</sup> Today, an individual turning 65 has almost a 70% chance of needing LTSS in their remaining years.<sup>5</sup>

---

<sup>1</sup> It's Time to Care: A Detailed Profile of America's Direct Care Workforce. (2020). PHI. <https://www.phinational.org/caringforthefuture/itstimetocare/>

<sup>2</sup> Direct Care Workers in the United States: Key Facts. (2022; September 6). PHI. <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/>

<sup>3</sup> Mather, M., Jacobsen, L., & Pollard, K. (2019; July 15). Fact Sheet: Aging in the United States. Population Reference Bureau. <https://www.prb.org/resources/fact-sheet-aging-in-the-united-states/>

<sup>4</sup> Johnson, R., & Dey, J. (2022). Long-Term Services and Supports for Older Americans: Risks and Financing. Office of the Assistant Secretary for Planning and Evaluation. <https://aspe.hhs.gov/reports/ltss-older-americans-risks-financing-2022>

<sup>5</sup> How Much Care Will You Need? (2020; February 18). Administration for Community Living. <https://acl.gov/ltc/basic-needs/how-much-care-will-you-need>

While direct-care worker supply has been a challenge for many decades, the COVID-19 pandemic has both highlighted the need for workers and exacerbated longstanding challenges, including low wages, high turnover, and an increasing demand for home-care services that is far outpacing current supply. To meet rising demand for LTSS, the direct-care workforce is expected to add 1.3 million more new jobs from 2018 to 2028 and to fill nearly 7 million additional jobs during the same period, as existing workers move into other occupations or exit the labor force.<sup>2</sup> Furthermore, the population of working-age adults (i.e., adults of ages 18–64) is projected to remain static, meaning fewer potential paid and unpaid caregivers will be available to support the growing population of older adults with their LTSS needs.<sup>2</sup>

## **Current Gaps in Workforce Data and Recent Federal Action**

Reports from the field indicate that high demand for LTSS coupled with high worker turnover has resulted in a severe workforce shortage in the LTSS sector; however, it is impossible to quantify the number of vacant direct-care positions nationwide given the inadequacy of existing workforce data.<sup>6</sup> Data on the impacts of workforce shortages on individuals in need of LTSS—impacts such as unmet need—is virtually nonexistent. Many fundamental barriers to data collection and analysis exist, including insufficient data infrastructure for the collection of employer-level data (including demographic data), imprecise federal industry and occupational classification codes, and limited implementation of workforce quality measures in policy and practice.

Recognizing the need for federal action on the DCW crisis, the Centers for Medicare and Medicaid Services (CMS) has taken several actions in the past several years to better understand workforce data and drive improvements in workforce capacity. In its guidance on the implementation of Section 9817 of the American Rescue Plan Act of 2021 (ARPA), CMS identified several workforce development-related activities for which states could use the enhanced federal medical assistance percentage (FMAP), with some states using funds to support data collection and data-infrastructure development. For instance, Wisconsin is using ARPA funds to conduct surveys on its DCW and Arizona is using funds to develop a bidirectional

---

<sup>6</sup> Scales, K. (2021). It Is Time to Resolve the Direct Care Workforce Crisis in Long-Term Care. *The Gerontologist*, 61(4), pp. 497-504.

<https://academic.oup.com/gerontologist/article/61/4/497/5898205>



database that the state, managed-care organizations (MCOs), and providers can use to enter workforce data and to monitor trends.<sup>7,8</sup>

In May 2023, CMS released the Ensuring Access to Medicaid Services proposed rule, which contained several provisions on workforce data collection and transparency, including reporting DCW payment and gaps in care.<sup>9</sup> Most recently, in September 2023, CMS released a proposed rule on Minimum Staffing Standards for Long-Term Care (LTC) Facilities and Medicaid Institutional Payment Transparency Reporting.<sup>10</sup> The proposal would require public reporting on the percentage of Medicaid payments for services in facilities spent on compensation to DCWs and support staff, in alignment with the transparency provision focused on home- and community-based services (HCBS) providers in the Medicaid Access rule.

While the proposed rules, if finalized, reflect progress on data collection and transparency, opportunities remain to improve standardized collection of workforce data on critical measures of workforce capacity and stability (e.g., longevity, turnover, impacts on consumers). Of note, the Medicaid Access rule proposes collecting data on percentage of authorized hours that the individual receives, but subject matter experts have noted that authorized hours may not be an accurate measure of need. Thus, further study is needed to better understand and test meaningful measures of workforce adequacy and access as well as approaches to collecting these data in a standardized way.

---

<sup>7</sup> American Rescue Plan Act: Medicaid HCBS Direct Care Workforce Reform and Analysis. Wisconsin Department of Health Services. (Last revised October 4, 2023.)

<https://www.dhs.wisconsin.gov/arpa/hcbs-directcareworkforce.htm>

<sup>8</sup> Arizona Health Care Cost Containment System (AHCCCS) Spending Plan for Implementation of the American Rescue Plan Act of 2021, Section 9817. (2022; January 19).

[https://azahcccs.gov/AHCCCS/Downloads/Initiatives/ARPA/AHCCCS\\_ARPA\\_HCBS\\_SpendingPlan.pdf?time=1696626235809](https://azahcccs.gov/AHCCCS/Downloads/Initiatives/ARPA/AHCCCS_ARPA_HCBS_SpendingPlan.pdf?time=1696626235809)

<sup>9</sup> Federal Register. Medicaid Program; Ensuring Access to Medicaid Services. 88 FR 27960. (2023; May 3). <https://www.govinfo.gov/content/pkg/FR-2023-05-03/pdf/2023-08959.pdf>

<sup>10</sup> Medicare and Medicaid Programs: Minimum Staffing Standards for Long-Term Care Facilities and Medicaid Institutional Payment Transparency Reporting (CMS 3442-P). (2023; September 1). CMS. <https://www.cms.gov/newsroom/fact-sheets/medicare-and-medicare-programs-minimum-staffing-standards-long-term-care-facilities-and-medicare>

## Goals and Purpose

Given the workforce shortage and the significant gaps in data illustrated above, there is a critical need to strengthen the system's ability to measure and monitor adequacy of the DCW. There is also currently very little public awareness of the magnitude of the DCW crisis. Quantifying the impacts of the workforce crisis on unmet need among individuals in need of LTSS may help to highlight the significance of the impact and bolster public support for critical investments in the DCW.

Long-Term Quality Alliance (LTQA), in collaboration with the Community Living Policy Center (CLPC) at Brandeis University, conducted an initial exploratory study to identify actionable solutions that work towards addressing these data gaps. This study was supported by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at the Administration for Community Living.

This study had two primary goals:

- 1) To **assess the current landscape** of data sources to measure and monitor access to and adequacy of the DCW and to highlight promising practices; and
- 2) To **explore potential data sources for a future pilot study** to test new ways of measuring and monitoring access to and adequacy of the DCW (e.g., test data collection and analysis with select group of plans and providers).

Our research to date has culminated in this policy brief, which summarizes findings and outlines recommendations for potential workforce-related data sources that can be better leveraged to measure adequacy of the DCW and assess the impacts of unmet need.

## Methods

To inform this exploratory study, we conducted six focus groups and four key informant interviews with:

- Managed LTSS (MLTSS) health plans
- Home-care providers
- Self-direction experts

- Fiscal intermediaries
- State-association representatives
- Policy experts and advocates

A list of the participating organizations and a sample interview guide can be found in [Appendix A](#) and [Appendix B](#).

We also conducted desk research to review state contracts; data-collection tools and accompanying reports; federal regulations, guidance, and other policy documents; and other relevant literature identifying state activities and best practices in workforce data collection.

Finally, we hosted an additional focus group to discuss the Medicaid Access proposed rule, which also helped to inform this brief.

## Findings

Through the interviews and focus groups, we sought to understand how MLTSS health plans, providers, state agencies, and other stakeholders are currently measuring and monitoring adequacy of the direct-care workforce in five key domains: availability of workers; gaps in services and supports; wages and compensation; stability; and consumer experiences.



We also aimed to assess the differences in workforce data collection and reporting between the traditional agency model and the self-direction model. Our key findings are summarized below.

## Availability of Workers

Understanding the availability of DCWs is a key step to ensuring that LTSS are provided to consumers in a timely, appropriate manner. Interview and focus-group participants stated that the extent to which health plans, providers, and Medicaid agencies collaborate to measure and monitor the availability of DCWs varies widely across and within states and involves the use of the following data sources:

- Payroll software;
- Service-authorization software;
- Scheduling systems; and
- Electronic Visit Verification (EVV) platforms.

With the exception of EVV systems, these data sources tend to be set up for internal operational purposes, which limits their ability to report these data to the state in a consistent way. EVV can be a strong mechanism for reporting to the state, but states vary significantly in how they are designing their system requirements and leveraging these data beyond the baseline 21st Century Cures Act requirements.

For providers, the frequency and scope of workforce data-collection and reporting depend largely on their specific agreements with health plans. Given the increased administrative burden of gathering and organizing workforce data, our interviews suggested that provider teams are primarily reporting more detailed workforce data in markets where this activity is required or compensated. In these markets, some providers are using data in EVV platforms to measure and report capacity—defined as the difference between authorized hours and staffed hours—and leveraging authorization software and scheduling systems to track referral-acceptance rates and measures of reliability. Value-based purchasing (VBP) agreements have also resulted in improved workforce data-collection efforts. However, as noted previously, the number of authorized hours may not be an accurate measure of hours needed, as in some states, the standard practice may be to authorize a higher number of hours initially to allow for greater flexibility in service hours delivered in the case of a future change in level of need.

For health plans, our research indicated that the frequency and scope of data collection is often determined by health-plan agreements with states. Some states (e.g., Tennessee) outline specific requirements regarding workforce data-collection and reporting in their contracts with MLTSS health plans. To meet contractual network-adequacy requirements and gauge workforce availability, some health plans are engaging directly with providers to collect data on capacity. For example, one health plan shared that it regularly surveys residential facilities about open beds to assess their capacity to accept referrals. Some health plans are also investing in efforts to improve data infrastructure to facilitate data reporting; for example, Elevance Health partnered with the University of Minnesota to develop the Direct Support Workforce Solutions Portal, through which organizations can enter their workforce data and track

## Electronic Visit Verification (EVV)

EVV is a tracking system used to verify home health visits. Section 12006(a) of the 21st Century Cures Act mandated that states implement EVV for all Medicaid personal-care services by January 1, 2020 and for home-health services by January 1, 2023, though many states requested good-faith effort exemptions and delayed implementation by one year.

To be compliant, EVV systems must capture the type of service performed, individual receiving service, date of service, location of service delivery, individual providing service, and time the service begins and ends.

EVV has great potential to help ensure accountability for timely services delivered to consumers, but states must balance this with additional administrative burden to providers and workers.

For more information, see <https://www.medicaid.gov/medicaid/home-community-based-services/guidance/electronic-visit-verification-evt/index.html>.

and assess key elements of their workforce, including in relation to state and national benchmarks where available.<sup>11</sup>

### **Innovation Spotlight:** **Pay-for-Performance Contracts**

Some plans have engaged providers in **pay-for-performance (P4P)** arrangements with specific goals for access and reliability. Under these contracts, providers are using the additional funds they receive to flow them through field staff, to offer recruitment and retention dollars, and to incentivize staff to pick up more shifts. To meet performance metrics, staff may be encouraged to work better as a team and to fill in for each other when needed.

One provider shared that it has preferred provider relationships with a few payers. Under these P4P agreements, providers and, in turn, DCWs are receiving enhanced care-coordination rates—a per member per month capitated amount on top of wages. This has resulted in medical cost savings, improved care coordination, and increased efforts to address social determinants of health barriers.

## **Gaps in Services and Supports**

The growing demand for LTSS, paired with significant direct-care workforce shortages, has resulted in care gaps across long-term care settings. Our research suggests that there are currently no nationally standardized processes for collecting and reporting on measures related to gaps in services and supports, and health plans, providers, and states again vary in their ability to identify and address care

---

<sup>11</sup> *New Web Application to Provide Easy-to-use Tools to Improve Direct Support Workforce Recruitment and Retention Practices.* (2022; December). <https://ici.umn.edu/news/new-web-application-to-provide-easy-to-use-tools-to-improve-direct-support-workforce-recruitment-and-retention-practices>

gaps in real time. The Medicaid Access proposed rule aims to introduce some standard reporting requirements and, if finalized, would require states to report annually on several measures related to access to LTSS. Proposed measures include the number of people on the waiting list, average amount of time spent on the waiting list, average amount of time elapsing between service approval and service receipt, and percentage of authorized hours that the individual receives.

In the absence of national standard reporting requirements, we learned that some health plans and providers are using the following data sources to measure and monitor gaps in services and supports for LTSS consumers:

- EVV platforms; and
- Plan care-management systems and other internal databases.

In certain states that are taking concerted steps to improve workforce data collection and have built requirements into their contracts with Managed Care Organizations (MCOs), plans and providers are leveraging EVV platforms to assess measures of gaps in services and supports such as time between LTSS consumers' authorized start date and the date of their first visit, percentage of authorized service hours that has been provided, and number of missed shifts. Some plans are also using care-management systems and/or other internal databases to further assess care gaps by following up on referrals to services and tracking partial shifts.

However, we heard from several interviewees and focus-group participants that monitoring measures of gaps in services and supports using these data sources alone may not tell the full story. For example, the percentage of authorized service hours that has been provided may not be a reliable metric as service hours are not always directly correlated with level of need (e.g., individuals may be initially authorized a greater number of hours to allow for flexibility in case their level of need changes). Additionally, missed shifts may be caused by inadequate worker capacity, but they may also be the result of an LTSS consumer being hospitalized, going on vacation, or refusing services. To address the latter concern, some states (e.g., Pennsylvania) are requiring providers to report reason types for missed shifts through EVV platforms. Examples of reason types include: unable to staff, call outs, hospitalized, family refused or deferred, etc. While reason codes present an opportunity to clean the data to better understand care gaps, more research is needed to assess the accuracy and timeliness of this data.

## Innovation Spotlight: Workforce Data Contract Requirements in Tennessee

Tennessee's contracts with MCOs require that contracted organizations (1) track and trend every time a member does not receive initial or ongoing LTSS due to inadequate provider capacity; (2) identify systemic issues; (3) implement remediation and quality-improvement activities.

As a result, **Elevance Health** has developed data-oversight capabilities to comply with contractual agreements, using EVV to track data and gaps at the provider, county, and aggregate levels. Elevance Health also has designated staff who monitor workforce data and respond to identified care gaps in real time, even before EVV data is available.

## Wages and Compensation

With median hourly wages for DCWs ranging from \$8.76 in Louisiana to \$17.45 in Massachusetts, low wages and compensation are major factors driving the direct-care workforce shortage.<sup>12</sup> These wages result in 44% of DCWs living in or near poverty, and many advocates have long been pushing to raise wages to ensure workers earn a living wage, improve quality of care for individuals with LTSS needs, and attract more workers to this growing industry.<sup>13</sup>

---

<sup>12</sup> Robertson, C., Sawo, M., & Cooper, D. (2022; June 2). All States Must Set Higher Wage Benchmarks for Home Health Care Workers. Economic Policy Institute. <https://www.epi.org/publication/state-home-health-care-wages/>

<sup>13</sup> Snyder, R., & Espinoza, R. (2022; March 21). America's Direct Care Workers Provide Crucial Support... But Do They Receive It? John A. Hartford Foundation. <https://www.johnahartford.org/blog/view/americas-direct-care-workers-provide-crucial-support-but-do-they-receive-it>



This issue was recently highlighted in the Medicaid Access proposed rule, which included provisions around DCW payment adequacy and wage reporting.<sup>14</sup> While many agreed during our focus groups that wages for DCWs should be increased, there were concerns that, in the absence of wage increases from state legislatures, the 80% wage pass-through proposal would not resolve the underlying challenges driving workforce shortages (e.g., ensuring a livable wage, limited worker pipeline) and would disproportionately harm smaller providers. Interviewees were unable to identify any state-by-state estimates of appropriate wages for this workforce, and stakeholders held differing views on the appropriate standard of comparison for wages, whether wages in competing industries, livable wages that account for costs of living, or another benchmark altogether. Improved reporting of DCW wages and benefits will help to provide a baseline understanding for considering these important questions and to inform policy decisions that ensure sufficient payments are provided to DCWs.

Currently, health plans, providers, and states are accessing data on wages and compensation through the following sources:

- Payroll software;
- Provider cost reports;
- National Core Indicators–Intellectual and Developmental Disabilities (NCI–IDD) State of the Workforce Survey; and
- National Core Indicators–Aging and Disabilities (NCI–AD) State of the Workforce Survey.

While providers can pinpoint wages and compensation for DCWs through payroll software, according to our interviews, coordinated and standardized efforts to track, trend, and report these data remain limited. One provider shared that it tracks DCWs’ average hourly rates but not their full benefit packages.

---

<sup>14</sup> Federal Register. Medicaid Program; Ensuring Access to Medicaid Services. 88 FR 27960. (2023; May 3). <https://www.govinfo.gov/content/pkg/FR-2023-05-03/pdf/2023-08959.pdf>

Some states are also gathering data on wages and compensation through cost reports. For example, New York collects and reviews cost reports filed by providers to assess the following measures: total wages spent, highest vs. lowest wages for workers, overtime hours paid, value of benefits, and more.<sup>15</sup>

Moreover, some states have been electing to collect these data through the administration of surveys to provider agencies. In 2021, 29 states participated in the annual NCI-IDD State of the Workforce Survey to collect comprehensive data from provider agencies on DCWs who support adults with intellectual and developmental disabilities (IDD),<sup>16</sup> and five states participated in a pilot to test the NCI-AD State of the Workforce survey

## National Core Indicators (NCI) Surveys

NCI is a national collaborative effort between three nonprofit organizations to partner with state agencies to better measure and track the performance of their services for older adults and people with disabilities. NCI leads two main initiatives: NCI-AD aims to improve services for older adults and people with physical disabilities and NCI-IDD aims to improve services for people with intellectual and developmental disabilities.

NCI supports states in administering various surveys to assess the experiences and outcomes of individuals receiving publicly funded services and the quality of services provided.

The NCI-AD Adult Consumer Survey and NCI-IDD In-Person Survey involve interviews with participants and cover a wide range of measures relating to access, care coordination, safety, etc. NCI-IDD also surveys family members of participants to better understand their experiences.

---

<sup>15</sup> Home Care Cost Report Instructions. New York State Department of Health. [https://www.health.ny.gov/facilities/long\\_term\\_care/reimbursement/hccr/docs/instructions.pdf](https://www.health.ny.gov/facilities/long_term_care/reimbursement/hccr/docs/instructions.pdf)

<sup>16</sup> 2021 State of the Workforce Survey Report. National Core Indicators—Intellectual and Developmental Disabilities. (2021). <https://idd.nationalcoreindicators.org/wp-content/uploads/2023/02/2021StateoftheWorkforceReport-20230209.pdf>

among agencies employing DCWs within the aging and disabilities sector.<sup>17</sup>

These surveys capture valuable information on wages and benefits for DCWs, among other variables. However, the data collected are de-identified, reported in aggregate at the state level, and released after a time lag, which limits health plans' and providers' ability to respond in real time. Moreover, participation is voluntary for states and provider agencies, and responses are kept anonymous in order to encourage provider participation, limiting researchers' and other stakeholders' ability to study the impact of DCW wages and compensation on consumer experiences and outcomes.

### **Innovation Spotlight:** **NCI-AD State of the Workforce Survey Pilot**

In 2022, Colorado, Indiana, Missouri, Washington, and Wisconsin participated in a pilot testing the NCI-AD State of the Workforce Survey. This online survey was administered to provider agencies employing DCWs within the aging and disabilities sector and aimed to capture information about wages, benefits, and turnover of DCWs.

Respondents shared that the survey informed them of new strategies related to DCW recruitment and retention, and some felt the survey provided a comprehensive view of the challenges faced by DCWs and providers. The pilot also revealed opportunities for improvement in survey administration, including the need for additional support for states to determine the total eligible provider population and obtain contact information, additional support for providers to complete the survey, improved communications to increase provider awareness of the survey, and a shorter survey tool with greater clarity.

---

<sup>17</sup> NCI-AD State of the Workforce 2021 Pilot Report. (2021). National Core Indicators—Aging and Disabilities. [https://nci-ad.org/upload/files/V2\\_ACCESSIBLE\\_NCI\\_SoTW-2021.pdf](https://nci-ad.org/upload/files/V2_ACCESSIBLE_NCI_SoTW-2021.pdf)

## Stability

The direct-care workforce sees high turnover rates—estimated to range between 40 and 60%—in part due to low wages and poor job quality stemming from the intensive nature of the work and limited benefits, supervisory support, and career-advancement opportunities.<sup>18</sup> Monitoring measures of stability is essential to better understanding the capacity of the direct-care workforce and developing tailored solutions. While there is no nationally standardized system to collect data on measures such as turnover and retention, stakeholders are currently collecting this data through the following means:

- Provider-specific internal databases and payroll software;
- Exit interviews; and
- NCI-AD and NCI-IDD State of the Workforce Surveys or other state-administered surveys.

To support their internal business operations, providers are conducting exit interviews and internally tracking retention rates using their internal databases and payroll software to assess the stability of the direct-care workforce. One provider shared that it conducts exit interviews with staff to better understand their reason(s) for departure and completes this process with 80% of workers who leave. Another provider measures retention and attrition rates at different timestamps (e.g., 30-day, 60-day, 180-day) across different roles to better understand stability and turnover within the organization.

Some states are administering the aforementioned NCI-AD and NCI-IDD State of the Workforce Surveys to collect and report data on DCW turnover, retention, and vacancy rates and length of employment, while others have collaborated with academic institutions and MCOs to develop and administer their own surveys. As noted previously, Wisconsin is using ARPA funds to administer the NCI-AD and

---

<sup>18</sup> Strengthening the Direct Care Workforce. (2023; March 10). National Conference of State Legislatures. <https://www.ncsl.org/health/strengthening-the-direct-care-workforce>

NCI–IDD State of the Workforce Surveys and Arizona is using funds to develop a bidirectional database with workforce metrics including stability.<sup>19,20</sup>

**Innovation Spotlight:**  
**Employment and Community First CHOICES**  
**Workforce QuILTSS Initiative Survey**

As part of a statewide workforce initiative, **TennCare** collaborated with the Institute on Community Integration at the University of Minnesota and MCOs to develop and administer the Employment and Community First CHOICES QuILTSS Workforce Initiative Survey. The online survey was administered annually from 2018 to 2020 and aimed to gather comprehensive workforce data (e.g., wages, turnover, retention, vacancy, length of employment) from provider agencies serving people with disabilities.

Data gathered from the surveys informed discussions about ways to find and retain DCWs and enhance access to services for people with LTSS needs.

## Consumer Experiences

Direct-care workforce shortages and instability often delay provision of necessary services and supports, reduce quality of care, and limit individuals' ability to remain in home- and community-based settings, all of which may negatively impact

---

<sup>19</sup> American Rescue Plan Act: Medicaid HCBS Direct Care Workforce Reform and Analysis. Wisconsin Department of Health Services. (Last revised October 4, 2023.)

<https://www.dhs.wisconsin.gov/arpa/hcbs-directcareworkforce.htm>

<sup>20</sup> Arizona Health Care Cost Containment System (AHCCCS) Spending Plan for Implementation of the American Rescue Plan Act of 2021, Section 9817. (2022; January 19). [https://azahcccs.gov/AHCCCS/Downloads/Initiatives/ARPA/AHCCCS\\_ARPA\\_HCBS\\_SpendingPlan.pdf?time=1696626235809](https://azahcccs.gov/AHCCCS/Downloads/Initiatives/ARPA/AHCCCS_ARPA_HCBS_SpendingPlan.pdf?time=1696626235809)

consumer experiences and outcomes.<sup>21</sup> However, efforts to better understand the impact of DCW availability, wages, and stability on consumer experiences and outcomes are impeded by the inadequacy of existing workforce data and inability to link different data sources. Currently, health plans, providers, and states are capturing data on the experiences and outcomes of individuals who receive LTSS through the following sources:

- Member satisfaction surveys administered by plans and providers;
- Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home and Community-Based Services Survey; and
- NCI–AD and NCI–IDD surveys (e.g., NCI–AD Adult Consumer Survey, NCI–IDD In-Person Survey, NCI–IDD Family Surveys)

Health plans and providers are largely administering their own surveys to assess member/client satisfaction and experiences, and there is no set of standardized measures. One provider shared that it gathers net promoter scores from clients, while another provider stated that it conducts routine client satisfaction surveys. One plan conducts routine member satisfaction surveys and correlates survey data with access data to compare supports needed against supports received.

Nationally, CMS designed the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services Survey (HCBS CAHPS) for voluntary use by state Medicaid programs to assess the experiences of adult Medicaid enrollees who receive LTSS from state HCBS programs.<sup>22</sup> According to AARP’s 2023 LTSS Scorecard, only 10 states received full credit for fielding the HCBS CAHPS survey for one or more HCBS program in 2020, 2021, 2022, and/or 2023.<sup>23</sup>

---

<sup>21</sup> Strengthening the Direct Care Workforce. Administration for Community Living. (2023; September 7). <https://acl.gov/programs/direct-care-workforce>

<sup>22</sup> CAHPS Home and Community-Based Services Survey. (2023). Agency for Healthcare Research and Quality, Rockville, MD. <https://www.ahrq.gov/cahps/surveys-guidance/hcbs/index.html>

<sup>23</sup> Reinhard, S., Harrell, R., Blakeway Amero, C., Flinn, B., Houser, A. Lingamfelter, P., Choula, R., Caldera, S., Hado, E., & Alexis, J. (2023; September, 28). *Innovation and Opportunity: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers, 2023 Edition*. Washington, DC: AARP Public Policy Institute. <https://doi.org/10.26419/ppi.00203.001>

States can also partner with NCI-AD and NCI-IDD to administer surveys to understand the experiences of older adults and people with disabilities who receive services from state agencies. (See **Table 2** below for reporting metrics related to workforce and gaps in care in the NCI-AD In-Person Survey).

Twenty-three states received full credit in the LTSS Scorecard for participating in the NCI-AD project and fielding a survey for one or more LTSS programs in the state.<sup>24</sup> Forty-eight states, plus the District of Columbia, participate in the NCI-IDD project.<sup>25</sup>

## CAHPS Home- and Community-Based Services Survey

The HCBS CAHPS Survey was developed by the Agency for Healthcare Research and Quality and designed to assess the experiences of adult Medicaid enrollees who receive LTSS from state HCBS programs. It consists of 69 core items that ask enrollees about their experiences with getting needed services, communication with providers, personal safety, community inclusion, and more.

Relevant survey topics include:

- Staff come to work on time
- Staff work as long as they are supposed to
- Someone tells you if staff cannot come
- Unmet need measures (e.g., sufficient staff to help with activities of daily living (ADLs), instrumental activities of daily living (IADLs), etc.)

**Source:** CAHPS Home- and Community-Based Services Survey 1.0.

<https://www.medicaid.gov/sites/default/files/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-english.pdf>

---

<sup>24</sup> Ibid.

<sup>25</sup> NCI-IDD Participating States. <https://idd.nationalcoreindicators.org/how-it-works/participating-states/>

**Table 2. NCI–AD In-Person Survey: Sample Reporting Metrics Related to Workforce<sup>26</sup>**

Domain	Sample Reporting Metrics Related to Workforce
Everyday Living	<ul style="list-style-type: none"> <li>▪ % of people who have adequate support for everyday activities</li> <li>▪ % of people who have adequate support for self-care</li> </ul>
Safety	<ul style="list-style-type: none"> <li>▪ % of people who feel safe around their support staff</li> </ul>
Satisfaction	<ul style="list-style-type: none"> <li>▪ % of people whose services help them live the life they want</li> <li>▪ % of people whose paid support staff do things the way they want them done</li> <li>▪ % of people whose paid support staff change too often</li> </ul>
Service Coordination	<ul style="list-style-type: none"> <li>▪ % of people who have a backup plan if their paid support staff don't show up</li> <li>▪ % of people whose services meet their needs and goals</li> <li>▪ % of people whose paid support staff come and leave when they are supposed to</li> </ul>
Self-direction	<ul style="list-style-type: none"> <li>▪ % of people who can choose what services they receive</li> <li>▪ % of people who can choose when they receive services</li> <li>▪ % of people reported to be using a self-directed supports option</li> <li>▪ % of people who can choose their paid support staff</li> </ul>

While HCBS CAHPS, NCI–IDD, and NCI–AD surveys are all voluntary for states to administer, CMS proposed in the Medicaid Access proposed rule to introduce new requirements around collecting and reporting quality measures for LTSS from its

---

<sup>26</sup> National Core Indicators—Aging and Disabilities. 2021-22 NCI-AD Adult Consumer Survey National Report. Human Services Research Institute and ADvancing States. [https://nci-ad.org/upload/reports/2021-22\\_NCI-AD\\_Adult\\_Consumer\\_Survey\\_Part\\_1.pdf](https://nci-ad.org/upload/reports/2021-22_NCI-AD_Adult_Consumer_Survey_Part_1.pdf)



recommended measure set.<sup>27</sup> The measure set, which was released in July 2022, includes measures derived from HCBS CAHPS, NCI-IDD, and NCI-AD.<sup>28</sup> If finalized, this rule will result in more states administering these standard consumer experience surveys.

However, NCI data is typically reported at the state level; our interviews suggested that some states share with their plan partners survey data on their members, but this varies by state.<sup>29</sup> This makes it challenging to connect consumer experience data with specific providers and workforce metrics.

Furthermore, neither NCI-IDD/NCI-AD nor HCBS CAHPS includes specific questions tying gaps in care to the worker shortage, to the extent that the consumer can report on this. Both surveys could benefit from inclusion of a new question on whether the individual experienced a gap in care due to paid support staff not showing up. With regard to self-direction, NCI could also consider adding a question to capture individuals who are unable to hire support staff under self-direction, which would partly reflect workforce capacity as well.

---

<sup>27</sup> Federal Register. Medicaid Program; Ensuring Access to Medicaid Services. 88 FR 27960. (2023; May 3). <https://www.govinfo.gov/content/pkg/FR-2023-05-03/pdf/2023-08959.pdf>

<sup>28</sup> State Medicaid Director Letter # 22-003 RE: Home and Community-Based Services Quality Measure Set. (2022; July 21). <https://www.medicaid.gov/sites/default/files/2022-07/smd22003.pdf>

<sup>29</sup> Comparison of NCI-AD Adult Consumer Survey and HCBS CAHPS Survey. [https://nci-ad.org/images/uploads/FINAL\\_NCI-AD\\_and\\_HCBS\\_CAHPS\\_Comparison\\_2021.pdf](https://nci-ad.org/images/uploads/FINAL_NCI-AD_and_HCBS_CAHPS_Comparison_2021.pdf)

**Innovation Spotlight:**  
**ASPE Data Set Linking NCI-IDD Data to  
Other State Data**

The Office of the Assistant Secretary for Planning and Evaluation's **Office of Behavioral Health, Disability, and Aging Policy** is piloting the creation of a publicly accessible, de-identified dataset that links the following data sources: NCI-IDD In-Person Survey, Supports Intensity Scale, Medicaid claims, and other relevant state-level data sources. This effort will enable the linking of NCI data with individual level clinical data and can provide a framework for future linking of NCI workforce-related data to individual-level claims.

For information on the pilot, please visit: <https://aspe.hhs.gov/dataset-intellectual-developmental-disabilities-linking-data-enhance-person-centered-outcomes>

## **Summary of Current Data Sources on Workforce Dimensions**

**Table 3** outlines the various data sources referenced above that are already being used and could be further leveraged to measure and monitor the adequacy of the direct-care workforce. The table outlines the lowest level of granularity, and the opportunities and challenges that exist for each data source.

**Table 3. Opportunities and Challenges by Data Source**

Type of Data	Data Source	Lowest Level of Granularity	Opportunities	Challenges/Limitations
Administrative and Claims Data	EVV	Individual consumer	<ul style="list-style-type: none"> <li>▪ EVV has potential to provide rich data that allows for tracking availability of workers, delays in initiating services and supports, and percentage of authorized services provided</li> <li>▪ Some states require reason codes for missed-shift reporting</li> </ul>	<ul style="list-style-type: none"> <li>▪ Depends on status of state’s EVV infrastructure and specific reporting requirements/system design</li> <li>▪ Real-time availability of data varies</li> <li>▪ Missed-shift data can be noisy due to frequent modifications to shifts</li> </ul>
	Provider payroll software	N/A (applies to individual worker)	<ul style="list-style-type: none"> <li>▪ Contains data that allows for tracking of wages, retention, attrition, turnover among workers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Data collection not standardized and reporting not required in most states</li> <li>▪ Designed and used to support provider business operations rather than reporting or evaluation</li> </ul>
	Payer and	Individual	<ul style="list-style-type: none"> <li>▪ Some plans are tracking</li> </ul>	<ul style="list-style-type: none"> <li>▪ Data collection not</li> </ul>

	provider authorization and scheduling systems	consumer	<p>care gaps, percentage of referrals fulfilled, etc.</p> <ul style="list-style-type: none"> <li>Some providers tracking referral-acceptance rates</li> </ul>	<p>standardized and reporting not required in most states</p> <ul style="list-style-type: none"> <li>Data metrics collected often depends on whether the provider is engaged in value-based purchasing (VBP) arrangements</li> </ul>
Provider Survey Data	NCI-IDD State of the Workforce survey	State (publicly available); providers are anonymized	<ul style="list-style-type: none"> <li>Surveys service-provider agencies for people with intellectual and/or developmental disabilities and captures information about wages, benefits, and turnover of direct-care workers</li> <li>28 states, plus the District of Columbia, participate</li> </ul>	<ul style="list-style-type: none"> <li>Data aggregated by state and released 1-2 years later</li> <li>Voluntary participation and anonymized data to encourage provider participation limits ability to connect workforce data to individual consumer data on unmet need</li> </ul>
	NCI-AD State of the Workforce survey	State; providers are anonymized	<ul style="list-style-type: none"> <li>In 2023, 5 states participated in a pilot to test the survey among agencies employing direct-care workers within the aging and disabilities</li> </ul>	<ul style="list-style-type: none"> <li>Limited reach—recently piloted in 5 states</li> <li>Data not yet publicly available—the next version of the survey and methodology will build on</li> </ul>

			sector	lessons from the pilot
	Exit surveys	N/A (applies to individual worker)	<ul style="list-style-type: none"> <li>Providers can collect reason for departure</li> </ul>	<ul style="list-style-type: none"> <li>Data collection not standardized and reporting not required</li> </ul>
Consumer Survey	Surveys administered by plans or providers	Individual consumer (but often anonymized)	<ul style="list-style-type: none"> <li>Plans and providers can tailor their satisfaction surveys to capture measures related to workforce capacity</li> </ul>	<ul style="list-style-type: none"> <li>Data collection not standardized and reporting not required</li> </ul>
	NCI-IDD surveys	State (publicly available); states have individual consumer-level data and sometimes share plan-level data with plans	<ul style="list-style-type: none"> <li>Surveys individuals with intellectual and/or developmental disabilities and their family members to gather standard performance and outcome measures and includes some measures related to consumer experience of workers</li> </ul>	<ul style="list-style-type: none"> <li>Data aggregated by state and released 1-2 years later</li> <li>Currently state participation is voluntary (48 states, plus the District of Columbia, participate)</li> <li>State-level reporting limits ability of researchers to connect data to other more granular data sources on clinical outcomes or workforce (e.g., data by provider or individual consumer); however,</li> </ul>

				states could potentially do this analysis
	NCI-AD survey	State (publicly available); states have individual consumer-level data and sometimes share plan-level data with plans	<ul style="list-style-type: none"> <li>▪ Surveys older adults and individuals with physical disabilities to gather standard performance and outcome measures and includes some measures related to consumer experience of workers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Data aggregated by state and released 1-2 years later</li> <li>▪ Currently state participation is voluntary (23 states currently participate)</li> <li>▪ State-level reporting limits ability to connect data to other more granular data sources</li> </ul>
	HCBS CAHPS	Medicaid agency or MCO	<ul style="list-style-type: none"> <li>▪ Assesses the experiences of adult Medicaid enrollees who receive LTSS from state HCBS programs and includes some measures related to consumer experience of workers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Currently state participation is voluntary (10 states currently participate)</li> <li>▪ State-level reporting limits ability to connect data to other more granular data sources</li> </ul>

## Considerations for Self-Direction

In self-direction programs, the person receiving services becomes an employer, hiring, scheduling, and supervising their caregivers, and states contract with financial-management service (FMS) providers that help self-directing individuals manage their budgets and financial services. FMS providers often have some data on employees, but the quantity and quality of data largely depend on requirements within state contracts.

In general, workforce data collection and reporting in self-direction programs are limited across all five areas. However, while there are no established processes for data collection and reporting, FMS providers may have access to some data relating to wages and compensation as well as data on the experiences of individuals self-directing services.

Significant work needs to be done to understand what would be feasible and meaningful in terms of workforce data collection in self-direction programs. Some states are not yet systematically tracking FMS providers and how many workers they are paying. Building the data infrastructure necessary to track this data would also be an important next step.

## Key Takeaways and Recommendations

Based on the findings outlined above, we have identified six major takeaways and accompanying recommendations for future research, policy, and practice.

**Key Takeaway #1: There is potential in EVV to identify gaps in care due to workforce capacity issues, but much is unknown.**

### **Recommendation:**

Conduct a landscape scan of EVV systems across states, including assessing the accuracy of data, and identify best practices and recommendations for standard reporting measures, including missed-shift reporting and reason codes.

**Key Takeaway #2: The availability of data on the direct-care workforce varies significantly by state, plan, and provider (e.g., particular value-based purchasing arrangements between a specific plan and provider).**

**Recommendations:**

1. Conduct a pilot study testing the ability to link workforce data (e.g., missed-shift reporting, referral-acceptance rates) to consumer outcomes data in partnership with a plan or provider in a state with more systematic reporting.
2. Encourage states to promote plans and providers to develop more value-based purchasing agreements to drive investments and improvements in direct-care workforce and evaluate efforts.

**Key Takeaway #3: While a few states are more advanced in their data collection, most states lack basic data on the direct-care workforce.**

**Recommendations:**

1. Encourage states to administer a survey to collect workforce data from providers, such as the NCI-IDD and NCI-AD State of the Workforce Surveys.
2. Encourage states to collaborate across departments of health, labor, and economic development to develop workforce data collection infrastructure and dashboards with real-time data on direct-care workers (e.g., Maine, Arizona).

**Key Takeaway #4: More information is needed on what measures would make sense in a self-direction model compared to a traditional agency model.**

**Recommendation:**

Convene FMS providers, self-direction experts, and advocates to better understand what will be feasible and meaningful in terms of data collection on the workforce within a self-direction model.



**Key Takeaway #5: Federal standard occupational classification (SOC) codes for direct-care workers are not clearly defined in the current LTSS context, limiting our ability to collect standardized data.**

**Recommendation:**

Conduct a study compiling definitions of direct-care workers across states to inform future revisions to federal SOC codes that better and more comprehensively reflect DCW competencies, settings, and populations served.

**Key Takeaway #6: More research is needed to understand and demonstrate the impacts of the direct-care workforce shortage on medical costs.**

**Recommendation:**

Conduct studies to evaluate the impacts of DCW shortages on upstream costs to payers from increased inpatient care and on downstream costs from increased acute events that could have been avoided given greater workforce capacity.

## **Conclusion**

Our focus groups, interviews, and desk research underscored that to date only limited efforts have been made to systematically collect standard data on direct-care workers and their impacts across the country. While a few states have taken proactive steps to require MLTSS health plans and LTSS providers to measure and report data related to direct-care-workforce availability, gaps, wages, and stability, most states lack basic data. As a result, our research suggests that we are currently unable to quantify the shortage of direct-care workers and assess how these workforce shortages impact individuals with LTSS needs.

Our report highlights recommendations to inform future research, policy, and practice that aim to advance efforts to improve standardized data collection and reporting, to better understand the impacts of direct-care workforce shortages, and to drive critical investments in the direct-care workforce. It is imperative for stakeholders—policymakers, states, MLTSS health plans, home-care providers—to work together to adopt more robust data collection and reporting mechanisms and ultimately address the unmet needs of the growing population of individuals needing LTSS.

## Acknowledgments

We would like to extend our sincere gratitude to the many organizations—including members of the Long-Term Quality Alliance, the National MLTSS Health Plan Association, and the MLTSS Association’s Partnership Program—who shared insights that informed this report. In particular, we gratefully acknowledge the significant contributions to the development of this report of Christina Wu and Grace Hong, LTQA 2023 G. Lawrence Atkins Policy and Research Fellow. We would also like to acknowledge Caitlin Otter, LTQA Research and Policy Intern, for her support.

## Funding Statement

The Community Living Policy Center (CLPC) is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, grant number 90TRCP0004 and 90RTCP0009. NIDILRR is a center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). This brief’s contents reflect the views of the authors and not of the National Institute on Disability, Independent Living, and Rehabilitation Research.

## How to Cite This Brief

Wu, C., Hong, G., & Kasach, M. (2024). *Measuring and monitoring the adequacy of the direct-care workforce and impacts on unmet need: Landscape scan of data sources and opportunities for future research*. Research brief. Community Living Policy Center. Brandeis University, Waltham, MA. Retrieved from <https://heller.brandeis.edu/community-living-policy/research-policy/pdfs/briefs/measuring-and-monitoring-adequacy-of-the-dcw.pdf>

## Contact Us

Email us: [CLpolicy@brandeis.edu](mailto:CLpolicy@brandeis.edu)

Find us on the web: [communitylivingpolicy.org](http://communitylivingpolicy.org)

Follow us on X: [@CLPolicy](https://twitter.com/CLPolicy)

# Appendices

## Appendix A

### List of Organizations Represented in Focus Groups and Interviews

The following organizations participated in the focus groups and interviews that were conducted to inform this exploratory study.

1199 Service Employees International Union (SEIU)	Justice in Aging
24 Hour Home Care and TEAM Public Choices	LA Care
AARP	LeadingAge
ADvancing States	Molina Healthcare
Aetna-CVS	Mom's Meals
Altarum	National Association of Direct Support Professionals (NADSP)
AmeriHealth Caritas	National Association of State Directors of Developmental Disabilities Services (NASDDDS)
ANCOR (American Network of Community Options & Resources)	National Academy for State Health Policy (NASHP)
Applied Self-Direction	National Alliance for Caregiving (NAC)
Autistic Self Advocacy Network (ASAN)	National PACE Association (NPA)
BAYADA Home Health	Netsmart Technologies
Benchmark Human Services	TCARE
CareBridge Health	TenderHeart
Caresource	The John A. Hartford Foundation

Commonwealth Care Alliance (CCA)	The SCAN Foundation
Community Catalyst	Trualta
Connect America	UPMC Community HealthChoices
Elevance Health	USAgings
GA Foods	Vesta Healthcare
Inclusa	VNS Health

## Appendix B

### Interview Guide

#### Measuring and Monitoring Access and Adequacy of the Direct-Care Workforce

**Background:** Long-Term Quality Alliance (LTQA), in collaboration with the Community Living Policy Center (CLPC) at Brandeis University and with support from the Administration for Community Living, is conducting an initial exploratory study to identify actionable solutions to work towards addressing data gaps on workforce capacity and impacts—such as unmet need—of workforce shortages on beneficiaries. The goal of this study is to **assess the current landscape of existing and potential data sources to measure and monitor access and adequacy of the direct-care workforce** through focus groups and interviews with key stakeholders, including managed LTSS health plans, providers, self-direction experts and fiscal-management intermediaries, and policy experts and advocates.

The research will culminate in a policy brief summarizing findings and outlining recommendations for potential workforce-related data sources that can be better leveraged to measure adequacy of the DCW and assess the impacts of unmet need.

#### Questions:

##### *Section 1: What measures are currently being used to monitor access and adequacy of the direct-care workforce?*

- 1) What types of data is your entity using to measure the following areas?
  - a) Availability of workers
    - Volume or number of available workers per HCBS beneficiaries or individuals with LTSS needs
  - b) Wages and compensation
  - c) Gaps in services and supports
    - Delays in initiating services and supports
    - Authorized services and supports not provided or unfulfilled (i.e., hours of personal assistance)
  - d) Stability
    - Turnover and retention rates of the workforce
  - e) Beneficiary experiences

- Satisfaction with workers, competencies, treatment
- 2) What administrative and claims data is your entity using to measure access and adequacy of the direct-care workforce?
  - a) Are there examples of data being used from Electronic Visit Verification?
- 3) What survey data is your entity using to measure access and adequacy of the direct-care workforce?
  - a) From beneficiaries? (i.e., NCI-IDD, NCI-AD, HCBS CAHPS, state-specific surveys)
  - b) From providers? (i.e., IDD Staff Stability Survey and new pilot of Aging and Disability Staff Stability Survey, data from home health providers)
- 4) What data sources exist that can be used to demonstrate the impact of the workforce shortage on beneficiaries and their health outcomes, e.g., unmet need?
- 5) Are you aware of any other data sources being used to measure access and adequacy of the direct-care workforce?

***Section 2: What measures should be developed to monitor access and a dequacy of the direct-care workforce?***

- 6) Ideally, what specifically should be measured and how, in the following areas:
  - a) Availability of workers
    - Some advocates have suggested that the Department of Labor improve classifications of direct-care workers. What should this specifically look like? How could revised classifications be used to measure and monitor access?
  - b) Wages and compensation
    - Should wages be compared to a benchmark, such as wages with direct-care workers in institutional settings or a competitive wage within other industries that compete for workers (what industries/occupations)?
  - c) Gaps in services and supports
  - d) Stability (i.e., turnover and retention)
  - e) Beneficiary experiences (i.e., satisfaction, competencies of workers, treatment)

- 7) What approaches should be used to measure and monitor access and adequacy of the direct-care workforce within self-directed programs?
- 8) How should data be disaggregated to monitor disparities for racial/ethnic minorities and other groups?
- 9) Are there other ways we should be thinking about capturing the impacts of the workforce shortage on unmet need in the system?