IMPROVING DATA ON THE WORKFORCE DELIVERING HOME AND COMMUNITY-BASED SERVICES

A Joint Issue Brief by:

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Introduction

On April 18, 2023, President Biden signed *Executive Order 14095: Increasing Access to High-Quality Care and Supporting Caregivers*, which laid out a number of key actions, including increasing support for the paid and unpaid workforces who provide care and assistance to people with disabilities and older adults. The Executive Order charged the Secretary of Labor (DOL) and the Secretary of Health and Human Services (HHS),

> *"In consultation with relevant agencies and external experts and organizations, to jointly conduct a review to identify gaps in knowledge about the home- and community-based workforce serving people with disabilities and older adults; identify and evaluate existing data sources; and identify opportunities to expand analyses, supplement data, or launch new efforts to provide important data on the home- and community-based care workforce and ensure equity for people with disabilities and older adults."*[1]

In response, HHS and DOL established the Home and Community-Based Services (HCBS) Federal Opportunities Regarding Workforce and Research Data (HCBS FORWARD) workgroup (***Appendix A***). Over the past year, this workgroup met to identify key policy questions on this workforce to establish data priorities, analyzed existing data sources on this workforce, and identified ways to fill critical gaps in knowledge. This effort was driven by a focus on policy: what data we need to support the workforce, meet the growing demand for these workers, improve access to high-quality services, and track the impacts of policy changes over time. The external input gathered from people with disabilities, older adults, and their families; HCBS workers, including those providing self-directed care; unions; disability, aging, and labor advocacy and provider organizations; state leaders; and researchers was essential to informing this work. The new solutions that have emerged are bold, alongside opportunities to add onto and maximize existing data.

The brief provides background information on HCBS and the work of the HCBS FORWARD workgroup and summarizes the workgroup's recommendations to federal and state agencies, non-profit organizations, and research institutions to improve data infrastructure and information on the HCBS workforce. Implementing these recommendations will bolster the data infrastructure needed to answer key questions about the HCBS workforce and drive data-informed policy decisions to improve the quality of and access to HCBS for the millions of Americans who are receiving or need these services.

Background

Home and Community-Based Services

HCBS programs provide opportunities for older adults and children and adults with disabilities to receive services in their own homes and communities rather than in institutions.[2] HCBS can include a combination of medical and non-medical services, such as case management, homemaker, personal care, adult day health, habilitation (both day and residential), and respite care services. HCBS programs serve a variety of population groups of focus, such as older adults as well as children and adults with intellectual or developmental disabilities, physical disabilities,

mental health/substance use disorders, and complex medical needs. The HCBS FORWARD workgroup group focused on the most common types of workers providing services in the home and community -- personal care aides, home health aides (and some nursing assistants), and direct support professionals.

One in five adults, including 27% of adults 65 and older, say they are currently receiving ongoing home care support with everyday activities from either a family member (19%), a friend (11%), or paid nurses or aides (5%).[3] Most people rely on family and friends for informal care.[4] Among paid HCBS, the majority are financed by Medicaid (57%),[5] followed by other public sources, including the Older Americans Act, Medicare Advantage, the Veterans Health Administration, and state/local funding; private long-term care insurance; or out-of-pocket payments made by individuals receiving services or their families.[6,7]

In order to meet the requirements of the Executive Order, the HCBS FORWARD workgroup focused on the paid HCBS workforce who fill a critical gap, notably for individuals with limited caregiving networks or with more complex support needs.[8] These paid workers are disproportionately women, persons of color, and immigrants with little or no formal education beyond high school.[9] While exact job titles and definitions can vary, the general jobs of focus for the working group included:

- **Personal Care Aides (PCAs)** assist with essential daily tasks in homes and a variety of other settings and may help individuals engage in work or community life. PCAs are often hired through a home care agency or directly by consumers; and constitute one of the largest occupations in the country with the most projected job growth over the next decade.[10,11]
- **Home Health Aides (HHAs)** (and some Nursing Assistants) assist with essential daily tasks, including for short-term care, to manage a medical condition or to rehabilitate following an acute illness. HHAs work in homes, assisted living, and other non-institutional settings; are often hired through a licensed home health agency; and constitute one of the largest and fastest growing occupations in the country.[11,12]
- **Direct Support Professionals (DSPs, also called habilitation or rehabilitation aides)** specialize in supporting individuals with intellectual and developmental disabilities (IDD), substance use disorders, and serious mental illness in living in and participating in their communities with their family and peers, including through employment. The majority of DSPs work in in-home services, supported living arrangements, and small staff-supported community residences. DSPs often help connect individuals to jobs, volunteer opportunities, friends, religious groups, and civic life, and may assist individuals with daily living tasks (if needed), and the implementation of therapeutic programs.[13]

According to the U.S. Bureau of Labor Statistics (BLS), the number of PCAs, HHAs, and nursing assistants more than doubled between 2000 and 2022 from approximately 2.4 to 5.1 million, and demand for these workers is expected to continue to grow to more than 5.9 million jobs in the next decade as the United States population ages and more people seek services in home and community-based settings.[14,15] HHAs and PCAs are projected to experience the largest increase in new jobs of any occupation between 2022 and 2032. Projected to gain

804,600 jobs, this occupation is expected to account for approximately one of every six new jobs, and by 2032, will represent the largest occupation in the economy.[16]

Many of these workers left their jobs during the COVID-19 pandemic, increasing the shortage of workers to meet demand, and underscoring the importance of this workforce in maintaining the health and well-being of older adults and people with disabilities.[17,18,19] Despite the high, and increasing, demand for these workers and the important services they perform for individuals, families, and society, these jobs are persistently poor quality, often with part-time hours and unpredictable scheduling, wages lower than other comparable entry-level jobs, limited access to training, few benefits, and high rates of injury.[20] As a result, job turnover is high, recruitment and retention are challenging for both families and service providers, and people often cannot get the care they need.[20]

Policy Priorities and Data Infrastructure Needs

Having access to skilled professionals is essential to helping a person with a disability or older adult live independently and be fully integrated in the community rather than in a nursing home or other institution. High-quality HCBS depend on the availability of a well-trained, stable workforce. To that end, policymakers and providers are looking for ways to increase the pipeline of workers and improve job quality and retention to meet the growing demand for HCBS. It is widely recognized that increasing wages and benefits, providing opportunities for professional training and advancement, and improving occupational safety are important steps towards improving the quality of these jobs and obtaining better recruitment and retention outcomes. However, progress has been slow due to the challenges of raising and sustaining higher wages, and expanding benefits and opportunities for direct care workers, in a context where prices are already challenging for families to afford.[20]

National data on the HCBS workforce do exist and are regularly used by researchers, advocates, and government agencies interested in better understanding the direct care workforce. Data collected by BLS, and the U.S. Census Bureau often contain information about workers' occupations, which is used to calculate estimates and statistics on employment, wages, demographics, anticipated job growth, and a number of other job-related datapoints on HCBS workers - some of which are cited in this brief. However, the existing data are imperfect and often lack the necessary level of detail to best inform evidence-based policy decisions and identify factors associated with high-quality HCBS.[21] This is due to a number of different and often interrelated factors, including insufficient sample sizes for detailed estimates or analyses, coding challenges that can make identifying specific direct care jobs difficult or impossible, and a lack of data collection on many factors relevant to this workforce. While most of the data gaps identified by the workgroup are not unique to the HCBS workforce, the importance of these workers to the United States economy combined with increasing demand for services and persistent job quality, recruitment, and retention challenges in the sector make additional data collection crucial.

The last national direct care workforce surveys were focused on the nursing assistant and HHA segments of the direct care workforce in 2004 and 2007, respectively, and have not been replicated or expanded to other parts of the HCBS workforce.[22,23] Specifically, more information is needed on such factors as workforce characteristics, job characteristics and work

environments, experiences with clients, training, recruitment and retention, wages, availability, access and use of employer-sponsored benefits, eligibility for and use of public assistance benefits, job satisfaction, and outcomes for both consumers and workers in order to effectively plan and evaluate policy decisions.

States are in the early stages of developing the data infrastructure needed to quantify direct care work, assess workforce stability, and begin to build an evidence base.[24] Funding from Section 9817 of the American Rescue Plan Act (ARP) of 2021[25] have allowed some states to invest in direct care workforce infrastructure needs, including the development of worker surveys. However, ARP funds have largely been used by states to plan for or implement changes in payment policies, such as increasing Medicaid payments to HCBS workers, implementing monetary incentives, or funding training initiatives and opportunities for career ladders.[26] Even when states collect data on this workforce, differences in data collection methods and nomenclature have hampered comparisons across occupations and settings.[26] Available data are often insufficient to understand and address gaps, to inform policies to support HCBS workers, and/or to measure the impacts of policies over time.[26] Strengthening data infrastructure on the HCBS workforce is critically important to understanding their needs, to improving workforce planning efforts and informing policies to support HCBS workers, to following trends and evaluating the impact of policy changes over time, and for allowing policymakers and others to have useful data to understand future challenges.

Policymakers are also looking for ways to improve the quality of HCBS. Expanded data infrastructure is central to evaluating whether increasing wages and benefits will address challenges facing this workforce, and ultimately improve care quality. Similarly, data are needed to examine how training requirements impact entry, advancement, and mobility within this workforce, as well as skills development, quality of care, and access to increased wages and benefits. Improvements in data quality will help bridge knowledge gaps and improve our current understanding of the skills and training required, the duties performed, personal and work environment characteristics, organizational commitment and job satisfaction, job quality enhancements, aspects of organizational and management practices, training, career development, and worker-supervisor relations. Finally, given that the majority of these workers are women of color, and many are immigrants with limited educational backgrounds, these jobs have implications for equity and economic opportunities for these populations. Gathering demographic data and other worker characteristics will help policymakers understand equity implications of policy changes that affect this workforce.

The HCBS FORWARD Workgroup

HHS and DOL established the HCBS FORWARD workgroup in May 2023 and convened this group of agency representatives monthly thereafter (***Appendix A***). The workgroup prioritized select populations of paid HCBS workers, including home care workers (such as PCA, HHAs, and some certified nursing assistants), and DSPs. The workgroup chose to focus on these populations of workers because the majority of HCBS involve support with personal care,[5] the fastest growing HCBS occupations are PCAs and HHAs,[14] and the COVID-19 pandemic exacerbated HCBS workforce shortages and intensified the need to recruit and retain paid home

care workers and DSPs.[17] The workgroup also prioritized quantitative data collection needs, but recognized that qualitative data adds value to understanding the workforce as well.

Throughout the year, the HCBS FORWARD workgroup identified key knowledge priorities, reviewed existing data sources, and recommended ways to fill critical gaps in knowledge. The workgroup solicited input from external groups (***Appendix B***) and prepared a data source information resource (not shown) that builds on a prior U.S. Government Accountability Office (GAO) report that examined federal and state data available on the paid direct care workforce.[21] This resource allowed the HCBS FORWARD workgroup to efficiently review and compare federal data sources. We also held supplemental enrichment sessions with in-depth focus on special topics related to our work (***Appendix C***).

Data Priorities and Knowledge Gaps

To lead the work, HCBS FORWARD workgroup members identified key policy research questions about this workforce, which were organized into select domains: wages, benefits, training, satisfaction, employment/workforce characteristics, and health and well-being, and the link between workforce investments and characteristics and outcomes for both consumers and workers. The questions in each domain served as the basis for identifying data priorities and knowledge gaps. For example, some of the questions considered related to benefits included:

- How many HCBS workers have access to paid sick leave?
- How many HCBS workers are offered mileage reimbursement or travel pay?
- Are HCBS workers offered enough hours to qualify for employer-sponsored health insurance?
- Are HCBS workers offered employer-sponsored retirement benefits?
- Does the availability of employer benefits increase HCBS workforce retention rates?

A summary of domains considered is identified in ***Appendix D***.

Current Data Collection Efforts

To identify limitations and where better data are needed on the HCBS workforce, the workgroup systematically reviewed available federal data sources, including government data sets collected and published by BLS and the U.S Census Bureau, administrative data, federal initiatives with data collection components, relevant reports, and prior research. The workgroup considered the ability of each data source to address variables of interest by domain (***Appendix D***); and documented populations sampled, data collection frequency, sampling and data collection methodologies, geographic areas surveyed, and limitations of data collection in a data source information resource (not shown).

The results of this review revealed that federal data on HCBS workers are insufficient to address many of the most pressing research and policy questions. There are no national data sources related to many of factors of interest on the HCBS workforce identified by the workgroup, and existing public data sources were found to be limiting in one way or another.[27] For example, while there are data on public assistance benefit receipt and occupations available in the Survey of Income and Program Participation (SIPP), the sample size is too small to be broken down by

each of the direct care occupations of interest separately. Similarly, the BLS Occupational Employment and Wage Statistics program provides national estimates on the size and wages of the HCBS workforce, but these data are insufficient for measuring the stability of the workforce or its capacity to meet rising demand.

Much of the data that are available cannot be disaggregated by state, making it difficult to understand how Medicaid and other state-level policies impact this workforce. Existing national data typically do not include how the services provided by HCBS workers are funded. As a result, very little is known about if or how workers who provide services to families and consumers through private pay differ from workers providing government-funded services, or how those working under self-direction models differ from those providing more traditional, agency-driven HCBS.[28] Further, data are needed to better understand emerging trends such as leveraging technologies that support efficiency and effectiveness in home care; and quantifying linkages between workforce investments and quality outcomes.

External Input into the Development of Recommendations

The HCBS FORWARD workgroup solicited input from members of the public on domain topics of interest and data needs and identified available and relevant state and local data sources. Workgroup leadership held a listening session at ADvancing States' *Home and Community-Based Services Conference* in Baltimore, Maryland, on August 29, 2023. External input was provided by people with disabilities, older adults, and their families; HCBS workers, including those providing self-directed care; unions, disability, aging, and labor advocacy and provider organizations; state leaders; and researchers. Commentors identified the need to share forthcoming state and union-based workforce data reports; ensure quality around the source of workforce survey data; recognize the potential difference in the availability of benefits within an organization and worker access and use of benefits; and consider the limitations of analysis across states given variation in rate setting methodology, workforce definitions, and certification requirements. External input is summarized in ***Appendix B***.

Recommendations for Improving Data on the HCBS Workforce

The HCBS FORWARD workgroup found that new HCBS workforce data collections and trend data are needed to provide national estimates of workforce characteristics, job characteristics and the work environment, experiences with clients, training, recruitment and retention, wages, access and use of employer-sponsored benefits, eligibility for use of public assistance benefits, and job satisfaction. Understanding these characteristics as well as the interaction between these characteristics, workforce investments, and quality of care is essential to effectively planning and evaluating policies to improve care for older adults and people with disabilities in home and community-based settings, and to address critical worker shortages and improve HCBS workforce job quality. The workgroup also identified opportunities to expand analyses, supplement existing data, and launch new efforts to provide important data on the HCBS workforce. Based on this review, the HCBS FORWARD workgroup identified five recommendations that, if implemented, will significantly improve data and information on this workforce.

National Data Collection

Recommendation 1: Establish and regularly field a nationally representative survey of the HCBS workforce

There is currently no nationally representative survey that specifically samples the HCBS direct care workforce. Ensuring that there is an adequate supply of HCBS workers is essential to ensuring that older adults and people with disabilities can live in their homes in the community. Based on input received from external groups and the HCBS FORWARD workgroup, a new national survey of the HCBS workforce should collect data on:

- workforce characteristics,
- job characteristics and the work environment,
- experiences with clients,
- training,
- recruitment and retention,
- wages,
- access and use of employer-sponsored benefits,
- eligibility and use of public assistance benefits,
- job satisfaction, and
- outcomes for both consumers and workers.

The national data collection should be replicated every 3-5 years in order to evaluate the impact of policy changes, follow trends over time, and have timely data to understand future challenges. Because HCBS policy is often set at the state level, an ideal national survey would also offer the opportunity to ensure a sufficient sample size for state comparisons to better understand the unique characteristics of the workforce and the impact of state policies.

Filling this major gap in data, however, will require a substantial new effort and is likely to require a phased approach as well as a significant ongoing source of funding. Since 2012, the National Center for Health Statistics (NCHS) has conducted the National Post-Acute and Long-term Care Study (NPALS) to monitor trends in the supply, characteristics, and use of the major sectors of paid, regulated long-term services and supports (LTSS) including residential care, adult day services, home health, nursing home, hospice, inpatient rehabilitation, and long-term care hospitals. While this is an essential source of information on LTSS providers including some HCBS sectors (adult day services centers and residential care communities), the NPALS does not include other providers who provide HCBS, such as home care.

Currently, there is no national sampling frame that could be used to identify HCBS workers. Unlike for other health professionals, there is no national certifying entity that would inform the development of a sampling frame. Some states do not license agencies that only offer aide and homemaker/chore and companion care, so in these states there is no centralized source of information on these employers or workers. Developing such a frame will require a review of state provider licensing policies and creating lists of providers, as well as thoughtful considerations about how to sample workers providing services via self-directed delivery models[29] or who work in the private market. Additionally, existing national direct care workforce survey instruments will need to be updated to capture the most relevant information on the

HCBS workforce, be tailored to different types of workers, and be cognitively tested to ensure the concepts are understandable to respondents.

HHS has taken initial steps to inform a national survey of HCBS workers. NCHS is currently fielding a pilot study of workers providing services through providers in the NPALS (nursing homes, residential care settings such as assisted living facilities, and adult day centers). In 2022, the Office of the Assistant Secretary for Planning and Evaluation and NCHS convened a group of experts to update the survey questionnaire for the pilot study. NCHS is currently testing a sampling protocol, questionnaire, and contact strategies to inform a future national direct care worker survey in the pilot. The survey is intended to be fielded in nursing homes, residential care settings, including assisted living, and adult day services centers, but could be extended to reach the HCBS sector.

Another key step towards a new national survey of the HCBS workforce will involve establishing a standard definition of DSP duties. The development of habilitation services has required a more expansive role for habilitation workers or DSPs that includes participation as a member of a planning team and implementing the person-centered plan including skill acquisition, knowledge of diagnoses and specific needs, the use of sign language/communication technology, word books or simply interpreting speech, providing trauma informed emotional support, structuring meaningful activities, coaching the person during interactions in the community, and carrying out therapeutic recommendations from Occupational Therapists, Physical Therapists, and Speech Language Pathologists. However, there is no standard definition of DSPs or the core duties that distinguish this group from other HCBS workers.

Developing a standard definition for DSPs will be a multi-stage process that will involve reviewing state policies and relevant literature and consulting with experts, DSPs, and consumers to obtain consensus on a standard definition of DSP duties that is sufficiently detailed and distinct from other HCBS workforce occupational categories. A standardized definition of DSPs may support a wide range of activities, including improved data collections, workforce development, program planning, and classification, and may ultimately also inform state Medicaid agency rate setting methods. The BLS Occupational Employment and Wage Statistics program has found that the job titles and job duties of the HCBS workforce reported by employers overlap significantly, and do not allow discrete classification of workers between occupations.

Recommendation 2: Establish and regularly field a nationally representative survey of adults with disabilities (ages 18-64) about their need for, and receipt of, services and supports

Despite being a population with many health and service needs, there is no comprehensive federal data collection on disability among adults (ages 18-64)[30] to understand the need for and receipt of assistance - whether paid or unpaid. Existing measures of functioning and need for assistance from large national surveys do not provide measures that align with eligibility criteria for programs such as Medicaid, do not ask about how people with disabilities get assistance, and do not include unmet need for assistance. Surveys sponsored by the National Institute on Aging provide a rich picture of later-life disability and cover these domains, but there is a dearth of information on people with disabilities under age 65.

A new national survey of disability services and supports, collected every 3-5 years, would fill an essential gap in understanding the need for human assistance, the type and intensity of assistance people receive, and the relationship between workforce characteristics and health and well-being outcomes for people with disabilities. This approach could fill gaps in data on the HCBS workforce by sampling people with disabilities and either asking questions about, or creating a supplement to sample, the paid providers and family members that support these adults. The supplement approach is analogous to the National Study of Caregiving supplement to the National Health and Aging Trends Study (NHATS). Like NHATS, this survey should be longitudinal to understand how care needs evolve and are met over time[31] and the impact of unmet need and to study how the impact of workforce characteristics affect the health, well-being, and independence of people with disabilities and older adults.

There are several benefits to this approach. First, it would not be linked to providers, so it could more easily capture a wider array of HCBS workers, including those who are paid privately by families or through self-directed delivery models. This approach allows a better understanding of the dynamics between paid and unpaid or informal care. It also makes it easier to link workforce characteristics with outcomes for the care recipient. Furthermore, a national survey would fill a major gap in information on working-age people with disabilities.

Creating and fielding a new survey of working-age people with disabilities is a substantial undertaking and will also require a phased approach as well as a significant ongoing source of funding. Methodologists and disability experts would have to develop a sampling frame and questionnaire, as well as consider approaches to collecting information about or from the people who support the target population. The sample size would have to be large enough to represent the vast diversity of people with LTSS needs. In order to answer questions about the HCBS workforce, the survey would also need a large enough sample size to analyze the characteristics of different types of workers who aid people with disabilities. Ideally, this survey would allow for oversampling to facilitate the evaluation of policies on the workforce and population receiving assistance by states. This type of survey would create data infrastructure to drive data-informed policy decisions to improve HCBS for millions of Americans receiving these services. Notably, this type of survey could help to describe workforce shortages and impact on quality of care.

State Data Collection

Recommendation 3: Enhance consistent and systematic state data collection efforts and share evidence-informed best practices of state data collection on the HCBS workforce

To inform workforce development efforts, state data collections are needed to comprehensively measure workforce stability (attrition and vacancy rates), workforce volume (number of full and part-time workers), workforce compensation (average hourly wage and benefits), training requirements, and capacity to meet future needs. Yet many states are not collecting these and other important metrics on HCBS workers. Without this information, it is difficult to understand and address gaps, to measure the effects of policy reforms on the workforce, and to inform policies to support workers.

For example, very little is known about workers who provide services to families and consumers through private pay or self-directed services delivery models and how they may differ from those providing services through different funding sources or arrangements, yet we know that these are significant parts of the labor market.[28] When a person self-directs their services, they decide how, when, and from whom their services and supports will be delivered. Although self-directed services delivery models have become an integral component of Medicaid-covered HCBS with states reporting significant program growth in the wake of the COVID-19 pandemic,[32] these independent providers of HCBS are missed by most existing public surveys.[28]

Consumers who receive Medicaid-covered HCBS via self-directed services delivery models have available supports, including Financial Management Services (FMS) Entities of Fiscal Intermediaries to help them manage payroll and other administrative responsibilities, and Information and Assistance Services to help them develop spending plans based on their budget allocation and learn how to be an effective employer. Partnerships between states and FMS Entities, for example, may help states quantify this important labor force segment using employment records. ADvancing States, the National Association of State Directors of Developmental Disabilities Services and Applied Self-Direction have been exploring ways to collect data on self-directing program participants and the aides they recruit and employ or co-employ. Their efforts show promise but are still in the early stages.

There are opportunities for states to learn from one another and share evidence-informed practices to improve state-based workforce data collections. For example, Minnesota collects annual data on vacancies by industry occupation and region, and Texas collects data on recruitment, retention, turnover, and benefits.[8] Additionally, as part of the 2010-2014 *National Balancing Indicators Project*, the Centers for Medicare & Medicaid Services (CMS) funded Alaska, Florida, Kentucky, Maine, Massachusetts, Michigan, and Minnesota to collect data on the stability of their HCBS workforce. More recently, ADvancing States hosted an ARP learning collaborative, which identified information about direct care workforce data collection efforts in states.[33] Finally, the Direct Care Workforce Strategies Center funded by the Administration for Community Living (ACL), includes a focus on data and research and offers examples of best practices in its online resource hub.[34] Lessons learned from states that elected to use ARP funds to improve data collection on the direct care workforce are forthcoming and will be published on the online resource hub.

CMS has taken a number of steps over the last few years to increase transparency and accountability related to the direct care workforce delivering Medicaid-covered HCBS. For instance, in 2023, CMS released a Center for Medicaid and CHIP Services Informational Bulletin to encourage states to implement worker registries, which can ensure that individuals receiving Medicaid-covered HCBS have awareness of and access to qualified workers who deliver services.[35] These registries can help beneficiaries identify and employ qualified workers who meet their needs, facilitate recruitment and retention of workers in the Medicaid program to ensure an adequate supply of workers, and support state oversight activities related to program integrity, monitoring access to and quality of care for beneficiaries who receive services, and maintaining a system for communication with workers.

More recently, under the Ensuring Access to Medicaid Services final rule (CMS-2442-F) which was released in April 2024, states will be required to publish the average hourly rate paid in Medicaid fee-for-service for PCA, HHA, homemaker, and habilitation services and to establish an advisory group for interested parties to advise and consult on provider payment rates and direct compensation for HCBS workers. In addition, subject to certain exceptions and flexibilities, states generally will be required to ensure that a minimum of 80% of Medicaid payments for PCA, homemaker, and HHA services are spent on compensation for workers, and to report publicly on the percent of payments for those services, as well as habilitation services, that is spent on worker compensation. States will be required to report this data separately for self-directed services and for services that are facility-based. Among other things, the rule also improves oversight, accountability, and transparency in HCBS by requiring states to report on the number of people on HCBS waiting lists and how the states maintain their waiting lists, HCBS service delivery timeliness for certain HCBS, and a standardized set of HCBS quality measures. In combination, these requirements will substantially advance our understanding of HCBS workforce compensation, payment adequacy, access, and quality.

Maximize Existing Data Resources

Recommendation 4: Maximize the availability of existing federal data sources to produce additional information on the HCBS workforce

The federal statistical system produces HCBS workforce information from a variety of sources. BLS collects and publishes data on pay and benefits that are available for occupations, industries, geographic areas, and the demographic characteristics of workers, in addition to creating employment projections for many occupations including the home care workforce. The Census Bureau collects data including occupation through multiple surveys such as the American Community Survey, which produces estimates of home care workforce demographics and select job quality measures among other important dimensions. These agencies release data through a variety of means including press releases, tables, written analysis, and public use microdata files, but more could be done to broaden the exposure of the HCBS workforce data.

HHS and DOL are taking steps to make existing data on the HCBS workforce more readily available to researchers and others. ACL's Direct Care Workforce Strategies Center website serves as a centralized source for federal data on the HCBS workforce, new publications, and updates from the field. BLS will spotlight data on HHAs and PCAs by publishing summary tables and summarizing data in reports, *Spotlight on Statistics,* and *Commissioner's Corner* publications.

Recommendation 5: Maximize existing administrative data sources to provide information on the HCBS workforce

Administrative data, such as Medicaid claims data, may also be a significant resource for data on the HCBS workforce. To date, however, Medicaid claims data have not been analyzed fully to understand data on employers and workers providing HCBS. HHS is currently conducting exploratory research using the Transformed Medicaid Statistical Information System data to understand whether HCBS are provided primarily by agencies or individuals, to identify what occupations and types of agencies make up this workforce, and to assess whether Medicaid claims data can be used to identify providers claiming for HCBS. Administrative sources may

not just be a data source but may also provide foundational information for the development of a survey sampling frames, such as those discussed in Recommendations 1 and 2.

Conclusion

This report summarizes the process that an HHS-DOL workgroup used to review data on the HCBS workforce and identifies five major recommendations that, if implemented, will significantly improve data and information on this workforce. Some of these recommendations can be accomplished using existing data sources and with modest additional investments, such as publishing new analyses using existing microdata and publicizing the availability of data to inform those that may not know it exists. Others, however, especially new nationally representative surveys, would require substantial new resources.

Filling the gaps in data on the HCBS workforce cannot be accomplished by the Federal Government alone. This brief also serves as a call-to-action to states, the research community, non-profits, and private sector businesses, who all have an important role to play in building this data infrastructure.

The HCBS FORWARD workgroup focused this effort on home care workers (PCAs, HHAs and some certified nursing assistants) and DSPs. Future efforts should examine the broader HCBS workforce, including those who provide transportation, chore services, and other supports to older adults and people with disabilities.

These recommendations are only the first step. Investing in care is an investment in the future of America's families, workforce, and economy. Better data infrastructure will ensure that these investments are made wisely. More importantly, they will help ensure that older adults and children and adults with disabilities have ready access to a high-quality trained workforce that can support their goals of living independently and participating in their community; that the workforce receives family sustaining wages and benefits and is empowered to advocate for themselves and those they support; and that there is available data to ensure that these goals are being met.

Appendix A: HCBS FORWARD Federal Workgroup Participants

Participating workgroup federal partners include representatives from:

U.S. Department of Health and Human Services

- Office of the Assistant Secretary for Planning and Evaluation
- Centers for Medicare & Medicaid Services
- National Center for Health Statistics/Centers for Disease Control and Prevention
- Health Resources and Services Administration
- Administration for Community Living
- National Institute on Aging/National Institutes of Health

U.S. Department of Labor

- Office of the Secretary
- Office of the Assistant Secretary for Policy
- Office of Disability Employment Policy
- Women's Bureau
- Bureau of Labor Statistics

Appendix B: External Input

Members of the public provided input on domain topics of interest, data needs, and available and relevant state and local data sources as follows:

- Worker-Level Survey Data: It is difficult to capture the necessary individual-level worker data and employer-level data. For example: an employer reports offering benefits, but there is no specific data at the worker-level about which employees are enrolled in those benefits. Direct care worker surveys must include data collection at the individual worker-level. Without worker-level data, external groups reported using surrogate data sources including about workers from the same labor pool as the direct care workforce (e.g., retail, warehouse, service/hospitality) although training/certification requirements may be different.
- Benefits Cliffs and Plateaus: The number of hours direct care workers work is affected by income eligibility limits for public benefits (e.g., SNAP, Medicaid). Higher wages do not necessarily translate to workers working more hours or staying in the direct care workforce. Higher wages may result in some workers working fewer hours to maintain public assistance benefits.
- State Surveys, Analyses, and Reports: Some states design and conduct their own data collections and analyses on their direct care workforce (e.g., comparing wages and benefits by care setting, examining the effect of increased reimbursement rates on actual wages for workers, examining the effect of additional training/certification on worker earnings, comparing rate setting methodologies, capturing data on self-direction).
- National Core Indicators (NCI) Project: Data from the NCI Project are valuable, including worker data from the NCI Intellectual and Developmental Disabilities (IDD) State of the Workforce Survey.
- Rural/Urban Settings: Wages/earnings are affected by rural/urban differences. Some people have to travel an hour or more to work with little to no access to public transportation.
- Injuries/Mental Health: Worker retention may be affected by moral and psychological well-being, trauma/victimization, and workplace violence.
- Communication: Direct communication with workers (e.g., for survey purposes) is difficult because direct care workers are a hard-to-reach population and because communication with workers often goes through the agencies that employ them. However, direct communication with workers is essential to understanding direct care workforce needs and challenges.
- Standard Occupational Classification (SOC) Codes: Recognize the distinct types of direct care workers, including reviewing existing SOC codes and including a code for DSPs.

Appendix C: Supplemental Enrichment Sessions Held

Date: September 19, 2023
Topic: Direct Care Workforce Survey Pilot
Presenter: NCHS Federal Partners

Date: October 25, 2023
Topic: Standard Occupational Classification System
Presenter: Census Bureau, DOL Federal Partners

Date: November 30, 2023
Topic: CMS Access Rule
Presenter: CMS Federal Partners

Date: January 29, 2024
Topic: Addressing the Direct Care Workforce Shortage: A Bipartisan Call to Action
Presenter: Bipartisan Policy Center

Date: March 7, 2024
Topic: NCI State of the Workforce Surveys
Presenter: National Association of State Directors of Developmental Disabilities Services

Appendix D: Domains/Independent Variables/Comparisons

Domains:

- Wages
- Benefits
- Training
- Satisfaction
- Employment/Tenure/Turnover
- Physical Health/Occupational Injuries/Mental Health/Well-Being
- Demographics
- Quality of Care*

Independent Variables:

- Types of workers -- Personal care attendants, home health aides, certified nursing assistants, direct support professionals
- Employer characteristics
- Payors -- Medicare/Medicaid, Older American Act, Veterans Health Administration, state/local funds, private pay
- Populations served
- Types of supports provided -- Activity of Daily Living (ADL) assistance, Instrumental Activity of Daily Living (IADL) assistance, habilitation
- Classification of employees
- Unionization representation/membership

Comparisons by:

- Other similar types of jobs
- State/policy geographic area

*This foundational effort can lead to subsequent study of the HCBS workforce and quality of care using multivariate methods that involve linking data sources to existing large data sets such as the Minimum Data Set (MDS), Outcome Assessment and Information Set (OASIS), Area Resource File, and CMS quality indicators and facility-level disability level data.

Endnotes

Disclaimer: *Links and references to information from non-governmental organizations is provided for informational purposes and is not an HHS endorsement, recommendation, or preference for the non-governmental organizations*.

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30. Although some information is available on functional dependencies attributable to developmental disabilities in minor children, their measurement is more complicated than for adults because it is normal for young children to require help with personal care tasks and other daily living tasks and to gain independence in performing these tasks at different rates. Also, for many children, diagnosis of IDD does not occur until they reach school age.

31. The HCBS FORWARD workgroup acknowledges that questions about the receipt of home care services are asked in a nationally representative longitudinal survey, the SIPP, but the resulting data are not sufficient for the purposes outlined in this Issue Brief. See also, https://www.census.gov/programs-surveys/sipp.html

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