

HCBS Sustainability Summit Technical Supplement

Table of Contents

The ARPA HCBS TA Collective	2
Organizations Supporting the TA Collective.....	5
Description of the HCBS Sustainability Summit	7
HCBS Sustainability Summit Attendees	9
HCBS Sustainability Summit Agenda.....	11
HCBS Sustainability Summit Discussion Framework for Future Policy Changes to Achieve a High-Performing HCBS System	14
ARPA HCBS Sustainability Summit Discussion – Challenges Identified	16
Uniqueness of HCBS (or Why is HCBS Different?)	27

The ARPA HCBS TA Collective

Recognizing that states needed to move quickly to take full advantage of this huge infusion of new federal dollars, a collection of foundations—The John A. Hartford Foundation, the SCAN Foundation, the Care and Respect with Equity for All (CARE) Fund, the Milbank Memorial Fund, the Peterson Center for Health Care and Arnold Ventures—came together to fund the American Rescue Plan Act (ARPA) Home and Community-Based Services (HCBS) Technical Assistance Collective (the TA Collective). The ongoing participation in all phases of the ARPA HCBS TA Collective’s work by the John A. Hartford Foundation, the SCAN Foundation and the Milbank Memorial Fund was exceptionally important.

The TA Collective is comprised of HCBS policy experts including Brian Burwell, and staff from ADvancing States, Halperin Health Policy Solutions, the National Association of State Directors of Developmental Disabilities Services, and Riverstone Health Advisors. The TA Collective’s mission is to support states in achieving the objectives included in their ARPA HCBS Spending Plans to expand, enhance, and strengthen their HCBS systems by March 31, 2025.

Members of the ARPA HCBS TA Collective know the states and how HCBS services are operationalized at the ground level; understand the detailed and complex language of HCBS which leads to provision of ‘nuts and bolts’ TA craved by states; offer a range of experience spanning Federal, state, and consulting arenas; are HCBS experts that have high credibility with Medicaid agencies and CMS; and work collaboratively to provide support across multiple initiatives.

The ARPA HCBS project – which operated from October 2021 through March 2024 – includes five areas of focus that each address a critical component of the short-term success and long-term sustainability of ARPA HCBS funding initiatives.

- State Technical Assistance;
- State Affinity Groups;
- An ARPA HCBS Issue Brief;
- Hosting an HCBS Sustainability Summit; and
- A comprehensive report on the successes and challenges of implementing ARPA HCBS Spending Plan Initiatives.

State Technical Assistance – Part 1

Beginning in October 2021, twelve states received intensive and short-term help from the TA Collective to support development of a state-specific comprehensive Project Management Plan. This plan meticulously delineated all pertinent initiatives, outlined key tasks for implementation, and identified the responsible parties involved. The sustained need for ongoing direct TA underscores the complexity and evolving nature of the challenges these states face, emphasizing the importance of tailored support to navigate and successfully execute their initiatives. The ongoing assistance seeks to ensure a strategic and effective approach in addressing the multifaceted aspects of project management and implementation within these states.

State Affinity Groups

In March, 2022, the TA Collective created two Affinity Groups (AGs), which shared their challenges and experiences in two focus areas as determined state interest: (1) Enabling technology to support HCBS; and (2) Initiatives to raise wages and create career development opportunities for Direct Care Workers. Both AGs held six sessions during the spring of 2022 to share experiences, highlight best practices, listen to guest speakers, and

seek common solutions to overcome barriers to implementation. In addition to the states receiving targeted TA, an additional 27 states participated in these AGs, which highlighted best practices and identified common barriers states were experiencing during ARPA implementation. These efforts – which concluded in June 2022 - indicated that states needed help with implementation, not just planning. Following these affinity groups, the TA Collective produced two focused papers. The first paper detailed insights from the HCBS Workforce Shortages Affinity Group, highlighting state efforts to increase worker compensation and training. The second paper outlined discussions from the Enabling Technology Affinity Group, showcasing innovative state strategies for incorporating technology into HCBS programs.

State Technical Assistance – Part 2

Even with approximately four months of TA on project planning, the states’ need for direct TA remained high. The TA Collective was able to provide direct ARPA HCBS project implementation TA to five states during calendar year 2023; this technical assistance addressed diverse initiatives within the ARPA HCBS Spending Plans of these states. They included modernizing state case management systems; creating new Medicaid service packages for at-risk foster children; developing ARPA HCBS sustainability plans; implementing an Independent Support Living Pilot for individuals at-risk of needing Medicaid LTSS services and supporting Aging and Disability Resource Center modernization. These states collectively aimed to enhance and modernize their HCBS systems, recognizing the need for external assistance to navigate complexities, improve efficiency, and ensure the successful implementation of their initiatives. The TA Collective played a pivotal role in facilitating their progress and addressing specific needs across these diverse initiatives.

ARPA HCBS Issue Brief

The TA Collective focused their research and writing on assessing the states’ evaluation activities of their ARPA HCBS initiatives. Beginning with a state survey in February 2023, the TA Collective used those responses to identify states actively involved in, or planning for, evaluation activities and invited the states to participate in one of three focus groups. At ADvancing States’ spring membership meeting, the TA Collective convened 14 influential leaders from nine states occupying pivotal roles in ARPA HCBS implementation and evaluation to extract additional context and details about their approach to ARPA HCBS initiative evaluations. An issue brief summarizing these findings was released in January 2024, and highlighted the value and importance of evaluating innovations, pilots, and untested initiatives. It also shared observations and recommendations about the evaluation of ARPA initiatives, targeted at both states that have begun, and states yet to plan for, evaluation.

HCBS Sustainability Summit

Sustainability is the primary issue facing states because of the short-term Federal investment in HCBS under ARPA. States are acutely aware that investments made during the spending period that states intend to sustain will require an alternative funding stream. The TA Collective set out to address this major policy issue by holding a first-of-its-kind one-day HCBS Sustainability Summit in October 2023. This event convened thought leaders from all facets of the HCBS community, including individuals with lived experience, provider organizations, advocacy groups, and state and federal officials. The Summit’s aim was to raise awareness and devise legislative strategies to keep HCBS budgets at this higher level, through federal and/or state funding.

ARPA HCBS Implementation Report

Finally, the forthcoming ARPA HCBS Implementation report will serve as the conclusion of the TA Collective's work. This reports aim is to compare states' initial proposals with their actual implementation under the HCBS Spending Plans. Through analysis of the 2021 ADvancing States report and an online survey across all 50 states

and the District of Columbia, the TA Collective will track how states pursued their initiatives—whether as planned, extended, modified, or unexplored. The report will identify successful HCBS implementations, challenges faced, and highlight key themes and takeaways that could inform future investments in HCBS programs around the nation.

Organizations Supporting the TA Collective

Between October 2021 and March 2024, a variety of foundations and other philanthropic entities provided funding to make the TA Collective a reality. They recognized the significant challenge that states were facing: to implement innovative initiatives to enhance, expand and strengthen HCBS systems while simultaneously addressing the impact of the public health emergency on those systems. They also recognized the expertise that the members of the TA Collective brought to the table to support states' effective implementation of their ARPA HCBS initiatives.

The John A. Hartford Foundation, the SCAN Foundation and the Milbank Memorial Fund invested funds in all three rounds of ARPA HCBS technical assistance provided by the TA Collective. The Peterson Center for Healthcare, Arnold Ventures and the Care for all with Respect and Equity (CARE) Fund provided funding for rounds one, two and three, respectively. The TA Collective is most grateful for this support.

About The John A. Hartford Foundation

The John A. Hartford Foundation, based in New York City, is a private, nonpartisan, national philanthropy dedicated to improving the care of older adults. The leader in the field of aging and health, the Foundation has three priority areas: creating age-friendly health systems, supporting family caregivers, and improving serious illness and end-of-life care. For more information, visit <http://www.johnahartford.org/> and follow [@johnahartford](#).

About The SCAN Foundation

The SCAN Foundation is an independent public charity dedicated to creating a society where older adults can access health and supportive services of their choosing to meet their needs. Our mission is to advance a coordinated and easily navigated system of high-quality services for older adults that preserve dignity and independence. Learn more at <https://www.thescanfoundation.org/> and [@TheSCANFndtn](#).

About the Milbank Memorial Fund

The [Milbank Memorial Fund](#) is a nonpartisan foundation that aims to improve population health by connecting leaders with the best available evidence and experience. It does this work by:

- Identifying, informing, and inspiring current and future state health policy leaders to enhance their effectiveness
- Convening state health policy decision makers on issues they identify as important to population health, particularly in areas related to primary care, aging, and sustainable health care costs
- Publishing high-quality, evidence-based publications and *The Milbank Quarterly*, a peer-reviewed journal of population health and health policy

About the Peterson Center on Healthcare

Established by the Peter G. Peterson Foundation in 2014, the [Peterson Center on Healthcare](#) is a non-profit organization dedicated to making higher quality, more affordable healthcare a reality for all Americans. The organization is working to transform U.S. healthcare into a high-performance system by finding innovative

solutions that improve quality and lower costs, and accelerating their adoption on a national scale, collaborating with stakeholders across the healthcare system, and engaging in grant-making, partnerships, and research.

About Arnold Ventures

[Arnold Ventures](#) is a philanthropy dedicated to tackling some of the most pressing problems in the United States. Driven by a mission to maximize opportunity and minimize injustice, it invests in sustainable change, building it from the ground up based on research, deep thinking, and a strong foundation of evidence. We drive public conversation, craft policy, and inspire action through education and advocacy. Arnold Ventures is headquartered in Houston, with offices in Washington, D.C., and New York City.

About the Care for All with Respect and Equity (CARE) Fund

The CARE Fund brings diverse funders together to invest in movement building for universal publicly supported care infrastructures that will fuel economies, improve the wellbeing of kids and families, create millions of good jobs, promote equity, and enable people with disabilities and older adults to live independently with safety and dignity. Learn more at <https://www.carefund.org/>.

Description of the HCBS Sustainability Summit

The Sustainability Summit was a small assembly of HCBS thought leaders, representing government and non-government entities, held in Denver, Colorado on October 11, 2023. The Summit was an unprecedented gathering of our nation's leading HCBS policy experts, advocates, and individuals with lived experience convened to have a candid and wide-ranging discussion of the strengths and weaknesses of the current HCBS system, the impacts of the ARPA HCBS Funding Initiative on improving the system, ideas and suggestions for maintaining the momentum created by the ARPA initiative after the funding period ends in March 2025, and to create a vision for building a strong and sustainable HCBS system over the longer term.

The Summit was, to a large degree, spurred by the imminent cessation of enhanced HCBS funding made available under ARPA, but the purpose of the Summit extended far beyond this focus. The Summit aim was to have a candid and wide-ranging discussion of the strengths and weaknesses of the current HCBS system, the impacts of the ARPA HCBS Funding Initiative on improving the system, the ideas and suggestions for maintaining the momentum created by the ARPA initiative, and to create a vision for building a strong and sustainable HCBS system over the longer term.

The HCBS policy expertise and the HCBS program management experience of the attendees at the Sustainability Summit was unparalleled and groundbreaking. The objective was not to develop a set of specific policy options for the future of Medicaid-funded HCBS services, but rather to create an environment in which the attendees could have an open and candid discussion about the status of the current HCBS system and what is needed to meet the demands of a fast-growing population of people who will need HCBS services over the next 30 years.

Twenty individuals were invited to participate in the Summit—ten from state governments responsible for administering HCBS programs and implementing the ARPA initiative, and ten from outside state government representing different constituencies of persons receiving HCBS services. The size of the Summit was kept intentionally small to promote a more informal atmosphere, and all attendees were assured that their input would not be attributed in the published report. Two of the invitees had to cancel at the last minute, one due to a health issue, the other two due to a work conflict, so on October 11, 2023, 17 persons were present at the Summit. The funders and members of the TA Collective also attended the Summit but were specifically requested not to join the discussion. One of the invitees who was unable to attend later participated in a one-on-one interview to provide additional input into the discussion.

The TA Collective conducted several activities to help prepare invitees for the Summit. These activities included:

- Providing a list of all 20 invitees along with the invitation letter so that all invitees were aware of other invitees.
- Emailing a first draft of the Summit agenda to invitees in early September 2023.
- Conducting a mid-September webinar providing an overview of the ARPA HCBS Funding Initiative and technical detail on how the Summit was being funded and administered. The webinar was conducted primarily for invitees outside of state government who were not involved in the day-to-day administration of the program. After the webinar, a brief survey was

sent to all invitees asking for feedback on the draft agenda and what they wanted to get out of the Summit.

- Conducting a pre-meeting conference call with all invitees at the end of September which gave them an opportunity to ask any questions they may have about the Summit.
- Approximately one week in advance of the Summit, sending a final agenda, an Executive Summary of the research paper on Efforts to Evaluate the Impact of ARPA HCBS Investments, and a draft of the Discussion Framework to all invitees.

HCBS Sustainability Summit Attendees

Name	Title and Affiliation
Max Barrows	Outreach Director, Green Mountain Self Advocates
Susan DeMarois	Director, California Department on Aging
Robert Espinoza	Executive Vice President of Policy, PHI
Lee Grossman	Medicaid Director, Wyoming
Julie Foster Hagan	Assistant Secretary, Louisiana Office for Citizens with Developmental Disabilities
Valerie Huhn	Director, Missouri Department on Mental Health
Patti Killingsworth	Vice-President, LTSS Strategy, CareBridge
Jennifer Kucera	Self Advocate, Ohio
Olietunja Mann	Norwill Healthcare Services, LLC
Maria Mann	Norwill Healthcare Services, LLC
Liz Matney	Medicaid Director, Iowa
Ursel McElroy	Director, Ohio Department on Aging
Kate McEvoy	Executive Director, National Association of Medicaid Directors
Kevin Prindiville	Executive Director, Justice in Aging
Michelle Probert	Medicaid Director, Maine
Bea Rector	Assistant Secretary, Washington Aging and Long-Term Support Administration
Susan Reinhard	Senior Vice President and Director, AARP Public Policy Institute
Bonnie Silva	Director, Colorado Office of Community Living

Name	Title and Affiliation
Emily Stewart	Executive Director, Community Catalyst
Haeyoung Yoon	Senior Director of Policy and Advocacy, National Domestic Workers Alliance

HCBS Sustainability Summit Agenda

**Hilton Denver City Center
Penrose Ballroom
Wednesday, October 10**

Time	Activity
7:30 - 8:30 a.m.	<p>Breakfast</p> <p><i>Location: Outside Penrose Ballroom</i></p>
8:30 – 9:00 a.m.	<p>Setting the Stage - Penny Thompson (facilitator)</p> <p>Penny will review the agenda and Summit Agreements as well as outline the desired outcomes from the Summit.</p>
9:00 – 9:45 a.m.	<p>State Progress in Evaluating the Outcomes of ARPA HCBS Investments – Anne Jacobs and Alissa Halperin</p> <p>Anne and Alissa will present the results of the Collective’s white paper ‘Impact of ARPA Investments’. Attendees will discuss how research and evaluation activities are critical to identifying successes and failures of ARPA initiatives, and how that information can be used to inform future HCBS investments.</p>
9:45 – 10:00 a.m.	<p>Break</p>
10:00 – 11:15 a.m.	<p>Implementation of the ARPA Initiative: The Perspective from States - Susan DeMarois, California; Julie Foster Hagen, Louisiana; Lee Grossman, Wyoming</p> <p>Susan, Julie and Lee will briefly share their individual experience with ARPA implementation, the obstacles they faced in achieving the objectives laid out in their HCBS spending plans, and how they are strategically approaching the end date of ARPA funding in March 2025.</p>
11:15 – 12:15 p.m.	<p>Sustaining ARPA Investments after March 2025 - Penny Thompson</p> <p>Sustainability means moving forward through planful continuation or non-continuation of ARPA HCBS investments or learnings for purposes of enhancing, expanding, or strengthening HCBS Programs. This can include:</p>

Time	Activity
	<ul style="list-style-type: none"> retaining learned into a knowledge library for future program and policy development; incorporating lessons learned into programs or policies; continuing initiatives temporarily; continuing initiatives permanently; or modifying initiatives before permanent continuation. <p>Factors which impact the sustainability of ARPA investments over the short-term include but are not limited to:</p> <ul style="list-style-type: none"> The current fiscal and political environment in states Stakeholder input and influence on state decisions The impact of Federal requirements (fiscal, administrative, maintenance of effort) State and provider capacity The need for ongoing administrative flexibility Availability of information about the success of current initiatives
12:15 – 1:00 p.m.	<p>Buffet Lunch</p> <p><i>Location: Independence Room</i></p>
1:00 – 2:45 p.m.	<p>Sustainability: Building on the ARPA HCBS Foundation - Penny Thompson</p> <p>Using the Discussion Framework as a guide, we will get the perspective of attendees regarding the continuing investments and HBCS policy changes that are most needed to sustain the ARPA HCBS initiative over the longer term. This includes priority setting, as well as specific policy options for future considerations.</p>
2:45 – 3:00 p.m.	<p>Snack Break</p>
3:00 – 4:00 p.m.	<p>Sustainability: Building on the ARPA HCBS Foundation (cont.)</p>
4:00 – 4:30 p.m.	<p>Considerations for the Final Report – Penny Thompson</p> <ul style="list-style-type: none"> How can we best synthesize the work of the Sustainability Summit into a Final Report that has maximum influence? How specific should the Final Report be in terms of the legislative, regulatory, and/or administrative changes which warrant serious consideration? Should certain considerations be prioritized? Should the Final Report lay out a vision for longer-term goals?

Time	Activity
	<ul style="list-style-type: none">• Are there other communication channels we should pursue to disseminate findings and considerations?
4:30 – 5:00 p.m.	<p>Final Report Production and Closing Comments – Penny Thompson</p> <p>We will discuss a timeline for completion of the final report, including making an advanced copy of the executive summary of the report available to the summit attendees for their information.</p>
5:00 p.m.	<p>Close of Summit</p>

HCBS Sustainability Summit Discussion Framework for Future Policy Changes to Achieve a High-Performing HCBS System

Area of Focus	Illustrative Examples
<p>New or Expanded Sources of Funding for HCBS Services and Payment Reforms</p>	<ul style="list-style-type: none"> • Enhance Federal funding mechanisms • Expand benefits eligible for federal matching funds • Create new sources of support for people at-risk of needing HCBS • Incorporate lessons learned from the ARPA HCBS Initiative into new funding initiatives • Develop and implement more outcomes-based payment systems for HCBS services
<p>Expanding the Capacity of the Caregiver Workforce</p>	<ul style="list-style-type: none"> • Increase wages for direct care workers • Improve recruiting and retention policies for direct care workers • Increase supports for unpaid caregivers, including training • Adopt new technologies to support HCBS participants and their caregivers
<p>Access, Enrollment and Eligibility Systems</p>	<ul style="list-style-type: none"> • Expand awareness about availability and access points to HCBS • Facilitate application and enrollment processes for Medicaid HCBS • Take advantage of existing authorities to expand Medicaid eligibility for HCBS applicants • Better meet individuals' needs through improved assessment processes
<p>Participant and Community Engagement</p>	<ul style="list-style-type: none"> • Be more transparent when developing in the HCBS policies • Engage participants and community members in program design decisions • Expand use of HCBS outcome measures which elicit direct input from consumers regarding their experience with HCBS services

Area of Focus	Illustrative Examples
<p>Increased integration with non- Medicaid Services and Supports</p>	<ul style="list-style-type: none"> • Increased funding for affordable housing specifically for HCBS recipients • Supplemental funding to subsidize room and board costs for Medicaid program participants living in community settings • Accelerate development of integrated Medicare/Medicaid models
<p>Enhanced State and Federal Administrative Capacity</p>	<ul style="list-style-type: none"> • Targeted funding to expand state and federal staff capacity for HCBS administration and oversight • Simplify HCBS waiver application and review processes • Create new flexibilities for states to pilot new programs and initiatives • Mainstream Appendix K authorities (i.e., emergency federal waivers) • Conduct comprehensive review of CMS oversight of HCBS services • Develop recommendations to Congress for simplifying HCBS operations • Expand technical assistance to states for managing HCBS programs
<p>Knowledge Development and Technical Assistance</p>	<ul style="list-style-type: none"> • Support a national evaluation of the impacts of the ARPA HCBS Initiative to inform future policy development • Conduct case studies of successful ARPA HCBS initiatives • Support a national Technical Assistance Center that states could draw upon for technical assistance and best practice dissemination • Support multi-state collaboratives in which states could develop and implement new HCBS initiatives in a knowledge-sharing environment
<p>Modernize HCBS IT Infrastructure</p>	<ul style="list-style-type: none"> • Identify best practices and update case management systems to support effective management of HCBS services • Enhance knowledge sharing across states in information technology (IT) procurement development and implementation • Support states in the development of specifications for new procurements

ARPA HCBS Sustainability Summit Discussion – Challenges Identified

Summit attendees identified a plethora of challenges to HCBS Sustainability during the Summit. In this document, we offer a full and detailed discussion of the challenges raised.

A. Unlocking Innovation

Summary of the Challenge: Notwithstanding the innovation that occurred in states as they implemented ARPA HCBS initiatives, structural and policy changes are needed to sustain and expand innovation in the HCBS space.

The ARPA infusion of dollars into HCBS provided an historic opportunity to try bold, new approaches to supporting people in their homes and communities. While work has been done nationally to highlight ideas and methods for improving HCBS and establishing more flexible policy, the current structure of Medicaid, and HCBS in particular, often serves as a barrier to modernization. It is not lost on today's LTSS thought leaders that even though ARPA created an incubator for different models, very little of the learning and growth achieved can be sustained without structural and policy modifications that pave the way to unlocking innovation. This theme of unlocking innovation is thread throughout the challenge topic areas. Innovative thinking and problem solving are critical to successfully improving, expanding, and enhancing HCBS programs but, this requires information sharing and collaboration, a strong direct care workforce, administrative flexibilities and capacities, and more.

1. **Given shortages in the DCW workforce, states have used ARPA funding to support alternative and innovative care models for meeting the demand for HCBS but the shortages continue and, thus, the need for continuing the innovation is real.** Many states have encouraged consumer choice of self-directed care models, in which eligible HCBS participants choose their own caregivers, including family and friends. Appendix K waivers broadened the types of individuals, including spouses and parents of minor children, that could be paid as caregivers. These waivers have helped to meet the growing demand for services in the community. While states represented at the Summit stated that participation in self-directed care models has grown, those increases have not been sufficient to offset the decline in agency-employed caregivers.
2. **New technologies for supporting older adults and persons with disabilities in their own homes are developing rapidly and are an underutilized resource in Medicaid HCBS programs and not enough states are informed about and engaged in making these available to participants.** A number of Summit attendees felt strongly that new technologies were a highly underutilized resource for supporting HCBS recipients at home and are a key to addressing the previously outlined workforce challenges. Seeing the opportunities for business growth in the senior market and for persons with disabilities, private companies have invested heavily in developing new technologies that assist people with physical and mental conditions to live more independently. New technologies are coming onto the market with increasing frequency. However, states have neither the capacity nor the expertise to assess the potential value of these technologies for their HCBS populations. Neither are Medicaid procurement and payment structures compatible with the purchasing of these technologies in HCBS programs. Currently, Medicaid pays providers to provide services, not produce better outcomes. A few states, such as Missouri and Ohio, are seen as national leaders in employing technologies to support HCBS participants in their own homes, and knowledge transfer across states will be an important factor in building state capacity in the technology space in the coming years. A national effort to support state efforts to make greater use of technologies in HCBS programs is needed.

B. Workforce Challenges

Summary of the Challenge: All Summit attendees concurred that there is a direct care worker shortage in the HCBS system and that the direct care workforce challenge is an immense and urgent challenge to address.

1. **Building a quality and sustainable Direct Care Workforce is considered the biggest challenge facing HCBS systems.** No challenge to forming and sustaining a quality HCBS system was considered more daunting by Summit attendees than that of building a Direct Care Workforce that can meet the growing demand for HCBS services. It has been documented that there are currently not enough DCWs to serve existing HCBS users.⁶ The ARPA HCBS initiative was enacted at the beginning of the COVID pandemic—March 2021—exactly the time when the size of the Direct Care Workforce was declining even more rapidly than it had been as workers left the job market to avoid the possibility of infection, or moved in response to economic conditions to retail jobs. Thus, the capacity of the DCW at the start of ARPA funding was at an all-time low.
2. **While most states implemented sizeable increases for DCW wages and compensation with their ARPA funding, Summit attendees agreed that compensation for Medicaid-financed DCWs still fell considerably short of the private sector market for entry level jobs.** As the overall economy recovered from the COVID pandemic, wages in the private sector rose at an even greater rate, creating an even larger gap between Medicaid rates and private sector rates for entry level jobs. Many DCWs in the Medicaid market also move on to the private sector market for caregivers, working for individuals and families with higher incomes, and where wages often start at \$20.00 per hour or higher.
3. **Most states have not committed to making DCW compensation increases permanent after the ARPA infusion of federal dollars ends.** Since ARPA funding is scheduled to end in March 2025, states would need to commit to continuing and funding DCW compensation increases permanently. Most increases to DCW compensation were either implemented on a temporary basis or in the form of one-time payments.
4. **Attendees acknowledged that compensation increases for DCWs are necessary but are not by themselves sufficient for building a quality and sustainable workforce. Investments also need to be made in non-compensation factors that will increase worker satisfaction in the Medicaid market.** Many DCWs work for agencies that do not provide health insurance, paid time off, child care or transportation subsidies. All these factors – separate from direct wages – negatively impact the ability of DCWs to continue to work in this field. One national study indicates that in many states, DCWs are indeed themselves receiving Medicaid because they do not have access to private health insurance.⁷ Additionally, DCWs often feel isolated in their jobs, working one-on-one with their clients, rather than feeling part of a larger system of care where they have the opportunity for increased interaction with other workers, employers, and state government staff. Second, advocates observed the low value which society in general places on both older adults and persons with disabilities, as well as caregivers themselves. It is simply not a valued profession. It's not just about the money, it's also about dignity and respect. Third, the absence of broader career pathways, where workers can see a pathway to rising up in the workforce to higher paying jobs, was seen as another limiting factor. Fourth, more technical assistance needs to be provided to DCWs who wish to branch out on their own and start their own business, teaching them basic business skills, which would also help build capacity. There are millions of HCBS caregivers, and they need to be recognized as an important component of the overall health care workforce.
5. **States underestimated the time and effort needed to implement compensation increases, ensuring that rate increases for providers were passed through directly to Direct Care Workers.** This was partly because provider rate increases required CMS approval prior to implementation. Most states used an attestation process as the mechanism for distributing compensation increases. This process requires providers to attest in writing that providers will distribute a specified percentage of their anticipated rate increase to their DCW

employees. Although attestation forms included significant penalties for non-compliance with contractual obligations, enforcement of these obligations were usually modest. One state at the Summit said that it had hired two full time staff with finance and accounting backgrounds to detect provider compliance. States often relied on advocacy groups to monitor provider compliance, and several advocacy organizations represented at the Summit agreed that provider compliance with state and federal labor laws was part of their mission statements.

6. **Only limited research on the DCW shortage is available to the Medicaid policy community.** Much of the information about the workforce shortage is anecdotal and is derived from the daily administration of HCBS programs at the state and local level. The only state-based data collection tool – the State of the Workforce survey – is dependent on state administration of the survey tool. However, for those states that participate, extremely useful data is available including average wages, turnover and retention rates.⁸ Several states have used ARPA funding to support better research on the workforce shortage and the impact of compensation increases on reducing the gap between the demand for services and the supply of caregivers. Early results from several states suggest that compensation increases have improved retention rates, but not the recruitment of new caregivers into the Medicaid market. More academic-level research needs to be conducted on the workforce shortage, including studies that can make comparisons across states and produce data that are usable by Medicaid policymakers.
7. **Direct Care Workers can play an important role in stakeholder engagement activities.** Several states indicated that they had formed DCW advisory groups as part of their ARPA initiatives and have found them to be extremely helpful in providing feedback into how services are actually delivered at the individual level. At first, DCWs were timid in expressing their views for fears about their job security, but gradually gained confidence in their opportunity to provide feedback. ADvancing States supports Indiana’s DCW advisory board, and has found the effort to be “overly successful.” All kinds of people now want to meet with the DCW board. ADvancing States said that is important to pay DCWs for their participation in stakeholder engagement activities because travel costs can be prohibitive for many DCWs, and it conveys the message that their time and viewpoints are valued.

C. Financing

Summary of the Challenge: Medicaid as the primary payer of HCBS is a significant barrier to making HCBS available to all those who prefer to live in community.

1. **The HCBS service system lacks a reliable and dedicated source of funding.** Since HCBS are primarily funded through Medicaid waiver programs, state budgets for HCBS expand or contract subject to annual budget decisions made by state governments and their legislators. Although all states cover HCBS to some extent, it is not a mandatory Medicaid benefit, meaning that people who meet the eligibility criteria for services do not have a legal entitlement to the services they need. Most states manage the costs of HCBS programs through caps on the number of individuals who can be served under each independent waiver program, and most states maintain waiting lists for people who are otherwise eligible to need services. As one person at the Summit with lived experience stated: “My close friends and I live in constant fear that the services we need in our everyday lives to live independently are going to be drastically reduced or terminated entirely.”
2. **The financing of the ARPA HCBS funding initiative had two major drawbacks which curtailed the ability of states to implement systemic reforms to the HCBS system.**
 - a. The first drawback Summit attendees noted was the *one-time* nature of the funding. While the amount of the funding under ARPA was significant, states had no guarantee that additional funding would be available for the HCBS service system after ARPA funding ends in 2025. Thus, legislatures were averse to taking on budgetary commitments for system reforms that would increase state

expenditures after ARPA funds are depleted. For example, many did not make long-term commitments to wage increases for Direct Care Workers. Also, additional staff capacity to help implement the ARPA Funding Initiative were generally hired on a contract basis, with no commitment to continued staffing resources over the longer term.

- b. The second drawback was the *time constraint placed on the expenditure of ARPA funds*. Given the deadlines imposed on states by CMS in regard to the submission of their HCBS Spending Plans, several states said that the development of their Spending Plans was a hurried process and, in some cases, led to poor decisions about how the ARPA funding was going to be used. Moreover, extensive delays in the implementation of ARPA initiatives, as described elsewhere in this report, only served to further shorten the time period states had to complete their ARPA initiatives and meet their objectives. These delays put even greater pressure on states to make spending decisions quickly, and get money out the door. Several states commented that if they had to do it over again, they would do things entirely differently. One recommendation that came out of the Summit was that if Congress enacts another ARPA-like initiative, more time needs to be allowed for the planning phase of the program.
3. **Skepticism was expressed about maintaining Medicaid as the sole and primary source of funding for the HCBS system.** Virtually all HCBS are funded through the financing structure of the Medicaid program. Skepticism was expressed by some Summit attendees about whether Medicaid was the right financing structure for the kinds of systemic reforms that are needed to build a strong and sustainable HCBS system. Furthermore, doubts were expressed about whether Medicaid budgets could withstand the kind of budget growth that must accompany the building of such a system. Others stated that HCBS needs to be accepted as an important component of the nation’s overall health care system, and that providers ought to be able to draw upon multiple funding sources, like other health care providers.
4. **In discussing the financing of future HCBS policy changes, attendees used two frames of reference, the first being policy changes that could be enacted in the immediate future, and the second being the financing of a systemic reform effort for the long term.** Policy changes that could be made over the short term are addressed in detail in Section V. Many suggestions were made. Summit attendees recognized the additional flexibilities afforded to them during the Public Health Emergency (PHE) and raised concerns about their ability to implement changes in the near term as the PHE comes to an end and those flexibilities are no longer available. Likewise, Summit attendees also conveyed a lack of national perspective and understanding about ARPA HCBS spending plan initiative effectiveness. Without that knowledge, they are not positioned to benefit from the lessons learned through ARPA when they plan for the short- and long-term future of HCBS.
5. **There was strong support for some “big thinking” to take place, along with an extensive period of stakeholder engagement, in formulating the design of a reliable and dedicated financing source for HCBS.** Clearly, this kind of big thinking did not take place in drafting the legislative language for the ARPA HCBS Funding Initiative. The attendees at the Summit did not have an extended discussion on the identification of a funding source, or where the resources for a systemic reform effort would come from. That conversation was left for future gatherings of HCBS policy experts, perhaps with more fiscal expertise. The Summit was acknowledged as, perhaps, a first step in several conversations that will take place in the design of a strong and sustainable HCBS system to address the dramatic demographic challenges that lie ahead. However, the urgency to begin those conversations immediately was voiced loudly and clearly.

D. Access & Eligibility

Summary of the Challenge: While ARPA provided an influx of funds to improve, expand, and enhance HCBS, systemic barriers to access and eligibility still limit who can access HCBS, when, how, and where. The summit

attendees agree that the comparative ease of accessing nursing facility services versus HCBS is an inherent obstacle to creating a better HCBS system.

- 1. The nursing home bias negatively impacts participants' ability to access and become eligible for HCBS.** Attendees felt strongly that it is past time for the playing field to be leveled so that it is as easy for participants to access HCBS as to access nursing home care, but also so that it is as streamlined for states to implement and operate HCBS programs as it is to provide nursing home care. While the nursing home bias within the Medicaid program design as it relates to individuals and participants is a longstanding concern that still needs to be remedied, Summit attendees flagged the ongoing state operations' obstacles embedded in this bias. To provide most HCBS, states must seek approval from CMS for any substantive effort to improve, enhance, or increase HCBS access or service provision. By contrast, nursing homes are governed by statute, regulation, and conditions of participation in Medicare and Medicaid and, as long as state efforts to improve or enhance service delivery within nursing homes is not preempted by those federal rules, states need not ask CMS permission to undertake those efforts. Attendees were insistent that it was time to remove the systemic bias to participant access to HCBS but also to remove the bias that impedes state access to providing HCBS.
- 2. States lack sufficient authority and flexibility to wholly serve those at risk of being or becoming eligible for nursing home level of care.** Attendees highlighted a need for increased availability of preventive HCBS for at-risk individuals. Summit attendees agreed that the HCBS system needs increased authority for and flexibility to use Medicaid dollars to serve individuals before their needs rise to the level of nursing home need.
- 3. Eligibility rule flexibilities, including those suggested in recent guidance from CMS (SMD Letter 21-004), are appealing, but states struggle to know how to take advantage of this opportunity.** Summit attendees noted that states need robust technical assistance from CMS to explore, understand possibilities, select, and implement eligibility changes to expand access to HCBS. Summit attendees agreed that federal, systemwide eligibility changes need to be considered. Specifically, attendees noted that the more universal eligibility process or rule flexibilities should be made at the federal statutory, regulatory, and policy level. For example, attendees speculated on the effectiveness of presumptive eligibility for HCBS being incorporated into federal law and implemented by CMS, instead of each state having to separately navigate how to create and operationalize the concept. While CMS templates for adopting these eligibility flexibilities would be helpful, a broader change in the HCBS policy framework is preferable.
- 4. Even eligible individuals struggle to access the HCBS they need.** Between the workforce challenges outlined above, and other challenges individuals may encounter in obtaining specific services in their area, using technology and/or paid family caregivers is not broadly available or mainstreamed. Providers are often not equipped for creative solutioning or, if they are, they may be unable to swiftly implement new strategies or service delivery models.
- 5. Systemic disparities in access are not universally identified or remedied.** There is not enough information being collected or evaluated to understand what disparities in access and eligibility different populations face. States don't have a complete handle on the inequities within their systems and potentially resulting from their processes. Without this information, inequities cannot be remediated.
- 6. Access to housing is one of the greatest challenges to access to HCBS.** The lack of available affordable and accessible housing and the inability of state HCBS programs to support participants by subsidizing housing costs is one of the greatest challenges to access to HCBS. Attendees felt strongly that too many individuals enter nursing homes because they lack housing. Despite the lack of data about disparities, Summit attendees recognized an observable pattern in access to HCBS: HCBS is most easily accessible to those who own a home, can live with family members, or have other allowable resources that enable them to cover their housing costs. Individuals without those resources often are forced to choose an institutional setting such as a nursing facility.

E. Administrative Capacity & Cross Sector Collaboration

Summary of the challenge: While ARPA provided the single largest infusion of resources in HCBS since its inception, the limited nature of the initiative spotlighted the need for a more sustained approach. The infrastructure of the HCBS service system is untenable in its current state. The summit attendees are in firm agreement that this is linked to both administrative capacity – at state and federal levels – and cross sector collaboration. There is an urgent need to bolster both.

- 1. HCBS is complex to administer and that complexity can inhibit efforts to improve sustainability of program operations and oversight.** Several attendees noted that lessons from the pandemic to expedite Appendix K approvals can be applied to normal HCBS operations. While additional human resources are needed by federal and state partners to manage growing HCBS programs, improving timelines of HCBS approvals, simplifying reporting requirements, and aligning waiver and state plan authorities can ease the pressure of current staff capacity. The discussion also pointed to opportunities to develop and enhance supporting information technology by federal partners so that states aren't compelled to create their own automated solutions for managing HCBS programs. One attendee emphasized the need for CMS to align its issuance of federal guidance with state legislative timelines, paving the way for state governmental bodies to take policy and financing action in proactive response to new or revised federal requirements. Addressing bureaucratic hurdles is paramount to assure HCBS sustainability.
- 2. All attendees agreed that lack of cross-sector collaboration is a barrier to an optimal HCBS system.** States are taking action to create multi-sector program plans, like those developed for the aging community, and to collectively problem solve the needs of individuals with complex support needs, like those occurring among partners in the I/DD, MH, criminal justice, and child and family service sectors. The summit discussion highlighted the shared agreement that the service delivery systems can no longer see individuals as having a single disability or a narrow set of support needs. Federal partners must model cross sector collaboration that designs policy and practice to promote concomitant cross sector collaboration at the state and local levels. Additionally, like many other aspects of the health and LTSS systems in this country, there was recognition by the group that access and experience may differ based on race, language, socioeconomic status, geography and other factors. Cross-sector collaboration and innovations in partnering are essential to identify and chip away at those pernicious disparities in HCBS, acknowledging the many intersections individuals using HCBS may experience.
- 3. Summit attendees were like-minded regarding the differences in how most state plan benefits, including those that are institutional and facility-based, and community-based programs are administered federally.** Overall, institutional settings, while meeting conditions of participation, have few reporting requirements or expectations to demonstrate outcomes or quality of life for particular populations served. Furthermore, other state plan services, such as state plan Personal Care, have no such reporting required at all. On the other hand, community-based programs funded through Medicaid HCBS waivers call for periodic and lengthy written program approvals and frequent data analysis and reporting. This administrative inequity is true for all HCBS authorities (1915(c), 1915(i), 1915(k), 1915(j)) but is most pronounced for the 1915(c) HCBS waiver program, which remains the dominant Medicaid authority for HCBS service delivery nationally. The HCBS waiver administrative requirements are onerous with regard to data collection and reporting and are overly focused on process and standard operating procedures, requiring data collection and reporting on items that are universally required in Medicaid. The requirements also are subject to interpretation by CMS, and that interpretation seems to change over time or even from review of one state's waiver to another state's when those waivers are under consideration at the same time.
- 4. It is unclear how CMS uses the state-submitted data on the HCBS waiver program for state-specific or national quality improvement activities.** One attendee suggested that there are methods for states to

demonstrate that HCBS programs are effective without layering the process with useless paperwork. All attendees agree that without radical changes to these practices, it constitutes a continuation of the institutional bias when operating facility-based care is easier than providing community-based supports. Attendees also acknowledged that the HCBS programs represent large, complex systems in their own right deserving of oversight, but encouraged a more meaningful quality assurance/quality improvement approach.

5. **There was strong concurrence that the existing structure of Medicaid HCBS imposes administrative hurdles that stifle innovation because they usurp key, limited state and federal resources, diverting capacity from innovation and progress.** The Summit conversation was robust regarding the need for the federal partners to set a north star for the future of HCBS and supporting individuals to have a meaningful life. People want to receive services and supports at home just as easily as they can obtain services in a nursing home or other institutional setting. A few attendees suggested obvious areas where policy flexibilities are possible without changes to statute. These opportunities include:
 - a. expedited approvals of state operational authorities,
 - b. standardized cost-reporting to assure pass-through to direct care workforce wages, and
 - c. updated policy to enhance and modernize technology coverage to enable individuals with disabilities and those who are aging to have the same access to life enabling devices and applications that are commonplace for all citizens.
 - d. There is a call to action to stop continually considering the same solutions and to lean into invention.
6. **The summit discussion highlighted that the current HCBS constructs often drive states to serve individuals only in times when they are experiencing crisis.** There is a missed opportunity to intercede early and offer support upstream to stave off crisis and the significant costs incurred. One summit attendee suggested that this could even include intervention in advance of traditional Medicaid eligibility.
7. **There is a strong belief that Federal partners also must work with states to maximize available federal resources to support the administration and quality activities of HCBS.** In order to achieve the laudable goals of workforce stabilization and enhanced quality outcomes, states need to be able to optimize their resources and fully leverage available federal contributions without administrative hurdles or ambiguity in permissibility.
8. **The summit attendees concur that strong collaboration among federal partners is a key to unlocking innovation.** There are clear signs that strong and effective collaboration is occurring among key federal agencies, but there is a cry for more. One attendee suggested the need for broader thinking at CMS about collaboration with federal counterparts at Department of Labor, Department of Education, and U.S. Citizenship and Immigration Services, recognizing that these agencies have ties to the people who receive and deliver HCBS. Such collaboration promises to leverage the strengths and responsibilities of the respective federal partners to further support the goals of HCBS. This communication is also essential among oversight agencies to ensure congruent assessment of promising practices, avoiding a fear of misaligned interpretations of statutory provisions. The importance of collaboration extends to individuals, families, advocates, and service providers. Those most directly impacted by the trajectory of HCBS *must* have a seat at the table.

F. Knowledge Sharing

Summary of the challenge: Today, there is no central repository of national best practices and related information, data, and tools. Thus, states must either use their own limited staff resources to leverage national association repositories or research best practices, build on ad hoc learnings about other states' experiences, or make their best effort to independently design HCBS programs in the absence of such knowledge sharing.

Likewise, the federal government is expending resources and imposing requirements that may no longer be justified once the experiences of states are aggregated and analyzed on a national level.

1. **Several attendees described that knowledge sharing across states typically happens on an ad hoc basis, even though it enables states to learn and benefit from best practices and lessons learned in other states.** One attendee noted and others agreed that the states all seem to try to be learning/implementing on their own, which is unfortunate given limited bandwidth in state agencies. Another noted that while there a lot of resources in state and federal governments homed in on HCBS, we don't know if we are spending time on the right things that are going to move the needle and, thus, could be wasting our time. Most attendees indicated that they do not have a national perspective or understanding about which spending plan initiatives have achieved the desired outcomes and which have not.
2. **Time is running out for cross-state knowledge sharing to inform states' ARPA spending plan projects.** Most attendees indicated that they do not have a national perspective about the impact of ARPA investments to date. With the end of the ARPA spending period approaching in 2025, attendees conveyed a sense of urgency so that they could invest wisely in the last 18 months of the spending period and make well-informed decisions about how and where to invest post-ARPA.
3. **Knowledge sharing is a challenge not only for states – it's also a challenge for many state-based advocates.** Some summit attendees described that opportunities for states and state-based advocates to learn from one another are limited. Without good information and resources, state advocates are not well-positioned to offer vetted and informed recommendations or to collaborate with states.
4. **State legislatures are not informed about what is and is not working across the nation, but they are generally highly interested in making informed decisions.** Summit attendees noted that state legislators are always interested in understanding what policy and program changes other states have implemented, as well as the impact of those policy and program changes. Summit attendees reflected about state legislatures' substantial influence over ARPA spending, from \how states could spend the ARPA funds to the rate at which they could use it. In some states, the availability of the funding itself was subject to legislative approval and was in question.
5. **The scale of the ARPA investments led many state Medicaid agencies to delegate spending plan project responsibilities across many teams and across state agencies, which created some duplication of effort and other inefficiencies.** One state described a decentralized but coordinated approach to make HCBS system investments. In retrospect, the state reflected that knowledge sharing and cross agency coordination alone was not as efficient as a single statewide effort.
6. **States are particularly eager for knowledge sharing for some spending plan focus areas, such as workforce development, that were common across a substantial number of states and that aim to address widespread challenges.** Without such information, states' ability to move as quickly toward a solution is hampered. Attendees noted that the state associations focused on HCBS do provide cross-state collaboration and knowledge sharing but those resources are limited. With additional funding, those activities could be bolstered to fuel more rapid and comprehensive knowledge-sharing.
7. **States spend a lot of time and resources demonstrating the projected and actual impact of HCBS waiver programs, despite a wealth of state-specific data evidencing these impacts.** For example, summit attendees discussed the fact that we have 20 years of data on the waivers demonstrating cost avoidance, as well as evidence produced by Money Follows the Person programs around intervening factors and analyses conducted by MACPAC, among others. Attendees expressed frustration that, without a centralized national clearinghouse synthesizing the state-specific information, federal entities and stakeholders are constrained in their ability to make the business case for streamlining. Attendees noted that CMS's oversight and approval processes are not the only factors at the federal level: GAO and OIG need literacy building with the data, as well. Attendees noted that these federal entities in particular seem to subscribe to myths about high rates of fraud and abuse in HCBS programs and in some cases to allow their work to be influenced by

the stigma of Medicaid and HCBS. Attendees also noted that other federal departments (e.g., Department of Labor, Department of Education) and policies (e.g., immigration policy) would benefit from a better understanding of HCBS programs and data.

8. **In many cases, data is not readily available today; where it is available, it is not standardized and, thus cannot be easily compared across states. In turn, policymakers' and program administrators' decision making must often be made without supporting data.** Comparable cross-state data are not readily available for caregivers or workforce. In the absence of such data, more than 30 states have administered the NCI-State of the Workforce™ survey. One attendee suggested that they are without a standardized workforce need formula and would like to have one to help inform states about how to allocate funding.

G. Participant & Community Engagement

Summary of the Challenge: The perspectives, experiences, and expertise of participants and members of the community are essential to successful systems design/change and program operations. Attendees expressed that systematizing processes for gathering information from all voices early, often, and throughout is not uniformly or universally done.

1. **Not all voices are included, represented, or invited.** Summit attendees raised concerns that not all participant identities are reflected in state engagement processes. They also noted that participants are multidimensional and intersectionality across traditionally categorized groups needs to be incorporated into engagement efforts. A single participant can have a disability, be a person of color, and be LGBTQIA+. Additionally, the voices, thoughts, experiences, and inputs of caregivers and direct care workers, some summit attendees stated, need to be consistently captured.
2. **Summit thought leaders call for collaboration to be grounded by the voices of people with lived experience.** CMS has an obligation to engage with states, as equal partners in the administration of the Medicaid program, on all issues related to HCBS. It is duly noted that states are required to actively seek input from services recipients in the design and operation of HCBS programs. This should be mirrored by federal HCBS partners so there is 360-degree engagement with individuals, families, advocates, and providers in the same manner at both the federal and state levels. There is resounding agreement among the summit attendees that this is an enormous opportunity to not only engage with all sectors of system stakeholders but to formalize such an approach. This sort of regular and consistent collaboration creates the opportunity to ensure people are informed, fosters a sense of trust regarding the service effects on the most intimate and personal aspects of people's lives, and promotes a give and take with a wide array of voices and perspectives. All of this results in a shared direction for HCBS where the status quo is challenged to assure that people benefiting from services and supports have a life like any other.
3. **State experts at state Departments of Education, Labor, Housing, Transportation, and more are not fully engaged in problem-solving workforce, housing, and other challenges.** While some states have been engaged in cross-agency development of multi-sector plans for aging, bringing everyone together to discuss HCBS problem-solving is not routine. As one example, attendees noted that developing a universal worker curricula or exploring ideas for providing college or high school credits with for direct care workforce coursework or in-person experience would best be considered with the involvement of state departments of education and labor. The relationships between state departments have not necessarily been developed or cultivated enough to facilitate the collaboration that would be best for the HCBS purpose needed.
4. **Lawmakers and policymakers are not fully informed about HCBS, what it is, what payor sources cover it, and how individuals access it.** State and federal lawmakers and policymakers would benefit from a more complete understanding of HCBS, attendees agreed.
5. **Individuals who could benefit from HCBS are not fully informed about HCBS, what it is, what payor sources cover it, and how to access it.** Individuals and the public need more and ongoing information about

HCBS. Too many people don't understand that it is not currently a Medicare covered service, that it is even an option, how to pay for it, and where they would start if they wanted to explore getting HCBS.

6. **Everyone needs more and ongoing engagement around how technology can be used and/or better used to support participants, providers, direct care workers, and states.** All attendees appreciated that information about available technology is constantly evolving but that too many stakeholders don't yet appreciate the value of technology and the potential for existing and future technologies to deliver remote supports and enhance independence, autonomy, and quality of life.
7. **Engagement efforts need to shift from focusing on world-view of how HCBS participants can survive to worldview of how they can thrive through HCBS.** Some attendees noted that HCBS has successfully served individuals for long enough that we know it works well. It's time, they feel, to broaden the conversation from what is important to help a participant simply get by in their HCBS setting to what will help them flourish in that setting.
8. **More time is needed for engagement and planning than the ARPA timeline provided.** Attendees universally agreed that the short timeline CMS provided for states to develop ARPA HCBS Spending Plans created challenges, one of which was the inability to engage in robust brainstorming and collaboration with stakeholders prior to submitting proposals to CMS.
9. **There is a clear need to reframe the HCBS narrative.** One attendee pointed out that stewards of the public dollar and federal advocates get nervous when there is the perception that policy change equates to less of a federal role. The summit conversation coalesced around the need to modify the message calling for policy change based on individual stories and quality of life. Another attendee gave the reminder that the general public and policymakers often bristle when they hear about 'Medicaid reform' but are more apt to listen when the conversation centers on meeting people where they are with options to remain at home rather than believing that a nursing facility is the only choice. Several attendees spoke about the data that demonstrate HCBS is an investment in financial effectiveness because people may remain at home longer and avoid more costly institutional care. There was strong concurrence that the call for change is heard best when we amplify the HCBS impact on people's lives.

H. IT Infrastructure Modernization

Summary of the challenge: Some Summit attendees asserted that HCBS information technology infrastructure limits most states' abilities to understand the needs of the individuals their HCBS programs serve, the use of services in those programs, and the opportunities for improvement.

1. **State programs cannot operate efficiently and effectively because of information systems constraints.** Most Summit attendees agreed that state information systems need to be updated. One state forewent substantial enhanced match under ARPA because of challenges it encountered complying with CMS reporting requirements for claiming that enhanced match. State systems are often not interoperable. For example, they often do not connect to Health Information Exchanges. Also, administration of HCBS services is generally administered across multiple state agencies, such that each agency often contracts for and operates separate HCBS information systems that are not interoperable. This dispersion of program administration poses operational, fiscal, and political challenges when states attempt to streamline and standardize, for example, via development of a unified case management system for managing all HCBS services in a state.
2. **Technology is needed to address workforce challenges.** One attendee state is using its EVV system to run routine DSP recruitment and retention reports. This information is enabling them to evaluate whether they are seeing improvements in these areas. Also, technology used by Service Coordinators is often out of date. Service Coordinators are overwhelmed, and they are forced to operate without decision-making tools and resources that could support them in service planning.

3. **Technology is needed to monitor programs and assess outcomes.** Operational, performance, and baseline data are so critical, but we are lacking it in many areas. In some cases, we are lacking it because the data is not collected. However, in many cases, the data is housed in old information systems and, thus, is not consumable, for example, data is stored as electronic versions of PDF files. The states need to know where they are to know if they can measure whether there is meaningful progress.

Uniqueness of HCBS (or Why is HCBS Different?)

HCBS programs are unique to Medicaid. They are not well-understood by the general public or even by policymakers, and those who do understand these programs often have the misperception that fraud and waste are prevalent in HCBS programs. The programs operate under rigid requirements and, thus, are cumbersome for states to administer. Furthermore, our nation's HCBS providers are largely dependent upon Medicaid revenue, often have limited administrative capacity, and deliver services and supports that are not clinical in nature. The Summit attendees agree that HCBS programs need to be better understood by the public and by policymakers, and that opportunities for administrative streamlining and flexibilities, as well as supports to HCBS providers, need to be explored. The following unique aspects of HCBS were surfaced and discussed by attendees.

1. **Medicaid is the only payer for HCBS. Yet many smart people – including policymakers – still think Medicare covers LTSS.** The widely held misconception that Medicare pays for LTSS means that Medicaid's role in paying for HCBS is often overlooked. Policymakers do not recognize the critical role Medicaid plays, and many individuals have the false perception that they have long-term care coverage through Medicare and, thus, do not value Medicaid.
2. **Because Medicaid is the only payor that covers HCBS services, many HCBS providers rely on Medicaid as their only source of revenue. In contrast to other Medicaid providers, many HCBS providers do not have the opportunity to balance revenue streams or to make up for a loss in Medicaid streams with revenue from other payer sources.** As a result, Medicaid must be deliberate in its rate setting practices.
3. **Because Medicaid is the only payor for HCBS services, HCBS services are stigmatized, and policymakers are suspicious of fraudulent activity.** Sometimes legislatures and other external parties lose interest when Medicaid is mentioned, so they need to find other ways to talk about community-based services. There is a common perception that individuals receiving HCBS or who serve as DCWs for individuals receiving HCBS DCWs are wasteful or involved in fraudulent activity. The Government Accountability Office and the US DHHS Office of the Inspector General exhibit this bias. Some Summit attendees raised concerns about the layered and extensive documentation and administrative requirements, asking whether we are diverting enough fraud, waste and abuse to pay for this administrative burden.
4. **Unlike most other services covered by Medicare, Medicaid and private health insurers, HCBS services are non-clinical: they are focused on quality of life rather than medical necessity.** As a result, the people who work in HCBS provider agencies need to have a different set of skills than those serving in traditional healthcare settings. Direct care workers do not need a degree or clinical training. From the perspective of individuals with lived experience, DCWs can be taught everything they need to know by the individuals they serve. It's important for them to understand that the provider agencies, the participants, the states, and others are equally concerned about their well-being.
5. **Unlike home health care or hospital-at-home, HCBS is not simply about delivering services and supports in the home;** rather, it's about enabling people to choose where they live and, if they wish, to remain or become involved in their communities. Many of the services covered in HCBS waiver programs are designed with this community integration in mind.
6. **In contrast to institutional LTSS providers and many home health agencies, a substantial proportion of HCBS providers are small provider organizations that have limited administrative capacity and that do not have the means or opportunity to achieve not-for-profit status.** Also, there is no national organization that oversees or is a voice for the full range of Medicaid HCBS provider types, and only a few HCBS provider types are represented by a national association. Similar patterns are often seen at the state level. Where such organizations do exist, they are not as well-resourced as many other provider associations, and small providers often tend not to be members. HCBS providers, particularly small and start-up providers, typically

don't have a business background and may struggle to just stay afloat. Without robust provider associations, it's often hard for them to know where to go for advice and technical assistance.

7. **The HCBS delivery system is fractured and, in some states, is not consistent from county to county.** Individuals must navigate a complex, scattered system and piece together a cadre of providers and paid and unpaid caregivers to assure they have the needed services and supports. Where you live impacts what information you have and your access to HCBS programs and services. This fractured, scattered HCBS delivery system is difficult to describe to individuals and policymakers, and it is difficult to regulate and support. Moreover, states may not be able to achieve the same economies of scale in the community that they can achieve in institutional settings.
8. **HCBS is unlike other Medicaid services because it requires unique federal authorities.** To operate these waiver programs, states must comply with reporting requirements, demonstrate cost-effectiveness and prove the program design is sound and adheres to federal regulations and guidance. HCBS programs are more administratively cumbersome to operate and are less nimble than other Medicaid services. Of note, personal care services delivered under State Plan authority are subject to minimal scrutiny by CMS, whereas the very same personal care services delivered under an HCBS waiver are subject to a high degree of review and operate under more burdensome federal requirements.
9. **HCBS financing is different from other Medicaid services.** For other costly Medicaid services, states have the flexibility to use provider taxes and intergovernmental transfers to finance the state share of Medicaid. These creative financing options are not available in HCBS programs, due in part to the size and nature of the HCBS providers themselves and in part to restrictions imposed by CMS. Likewise, in contrast to hospital, nursing facility, and home health providers, no national cost reporting standard exists for HCBS providers. Some Summit attendees promoted the idea that CMS should establish a national standard HCBS provider cost report, so that DCW wages could be tracked. However, attendees additionally noted that states also likely have insufficient capacity to monitor and otherwise use HCBS cost reports, even though there is heightened stakeholder concern about the flow of Medicaid dollars to DCWs and even though such cost reporting is in alignment with CMS goals and philosophy.
10. **Medicaid policy reflects an inherent institutional bias.** As described in the two bullet points above, administration and financing of HCBS is more complex than for nursing facility services. This bias results in disparities: people who can afford rent can get community care, but for people who can't afford rent, their only option is a nursing facility.
11. **Each state operates numerous HCBS programs, and those are generally administered across multiple state agencies.** This diffuse administrative responsibility poses challenges related to financing, information systems interoperability and data sharing, provider certification and billing requirements, and much more. It is also difficult for participants to navigate the HCBS delivery system.
12. **Under the Public Health Emergency, HCBS programs had the opportunity to waive many of the federal requirements to assure LTSS access for waiver participants, because waiver participants were among those most affected by COVID in the US.** These temporary federal flexibilities reasonably demonstrated that federal reviews can be expedited and flexibilities can be extended without negatively impacting participants. Summit attendees expressed a need to explore the extension of flexibilities and opportunities for more flexibilities based on evidence accumulated by CMS during our nation's 20-plus years of administering HCBS waiver programs, as well as the Money Follows the Person demonstration.
13. **Universally, the public knows about the existence and purpose of nursing homes but, by contrast, knows very little about the existence and availability of HCBS.** Getting supported in one's own home is preferred by the majority of people yet too few understand that it is an option available to them. HCBS are uniquely underpublicized.