The Future of HCBS: A Report from the HCBS Sustainability Summit

APRIL 2024

ADVANCING STATES

ARPA HCBS
Technical Assistance Collective

The **ARPA HCBS Technical Assistance Collective** is made up of four organizations with deep expertise in HCBS systems: ADvancing States, Halperin Health Polcy Solutions, the National Association of State Directors of Developmental Disability Services (NASDDDS), Riverstone Health Advisors, as well as Brian Burwell. 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.

ADvancing States represents the nation's 56 state and territorial agencies on aging and disabilities and supports visionary state leadership, the advancement of state systems innovation and the articulation of national policies that support long-term services and supports for older adults and individuals with disabilities.

Halperin Health Policy Solutions is an independent consulting firm that provides state and federal government agencies, non-profits, and provider organizations with direct assistance related to healthcare and long-term services and supports (LTSS) access and coverage issues for lower-income older adults and persons with disabilities.

NASDDDS assists member state agencies in building person-centered and culturally and linguistically appropriate systems of services and supports for people with intellectual and developmental disabilities and their families.

Riverstone Health Advisors consults to state and federal agencies, health plans, vendors, and providers as they strive for success in government healthcare programs, including Medicaid home and community based services (HCBS) and other Medicaid long-term services and supports (LTSS) programs, Medicaid managed care, and Veterans' healthcare, among other programs.

Brian Burwell is an independent contractor and nationally recognized expert on HCBS policies and programs. He served as a Commissioner on the Medicaid and CHIP Payment and Access Commission for six years. His career has been focused on Medicaid policy for older persons and persons with significant disabilities.

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Acknowledgments

ADvancing States and our partners with the ARPA HCBS Technical Assistance Collective (TA Collective) are proud to release a report from the HCBS Sustainability Summit. Through the generous support of the John A. Hartford Foundation, The Care and Respect with Equity for All (CARE) Fund, The SCAN Foundation, and the Milbank Memorial Fund, the TA Collective brought together 18 HCBS thought leaders — comprised of state officials, HCBS advocacy leaders, people with lived experience and their caregivers — for a day-long meeting to discuss the challenges facing the HCBS system and approaches to building on the successes of the ARPA HCBS initiatives. The Summit attendees identified key principles for HCBS investment as well as specific strategies that Congress, the federal government and states could implement. We are grateful to these foundations for their support in making the Summit possible.

We thank the Summit attendees as well as our Summit facilitator, Penny Thompson, for sharing their perspectives and expertise.

- 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
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- Kevin Prindiville — Executive Director, Justice in Aging

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- 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
- Emily Stewart — Executive Director, Community Catalyst
- Haeyoung Yoon — Senior Director of Policy and Advocacy, National Domestic Workers Alliance

The HCBS system is facing more challenges than ever before. Our hope is that this report — and the strategies contained therein — can serve as a roadmap for future direction and investments in our HCBS system.

Sincerely,

Martha A Roherty

Martha Roherty, Executive Director
ADvancing States

Executive Summary

In October 2023, the American Rescue Plan Act (ARPA) Home and Community-Based Services (HCBS) Technical Assistance Collective hosted a Sustainability Summit with HCBS thought leaders, including individuals with lived experience, to discuss how to sustain the commitment to and investment in HCBS that were central to the states' ARPA HCBS spending initiatives.

While ARPA was a much-needed response to the COVID-19 Public Health Emergency (PHE), it created a truly unique opportunity for states to make strategic investments that both addressed the short-term urgent needs exacerbated by the PHE and assisted in state efforts to shore up those areas longer term. These investments have affirmed the need for long-term, sustainable approaches to ensure that HCBS is available to all individuals who need them.

Congress passed a law called the American Rescue Plan Act, also called ARPA. This law gave states additional money for home and community-based services. Several organizations came together the provide technical assistance to states on this effort. This group is called the ARPA Technical Assistance (TA) Collective.

The money from ARPA allowed states to make important improvements to HCBS and allowed states to try new ways of providing services.

In October 2023, the ARPA TA Collective hosted a meeting, called a summit, to hear from national experts on how to continue progress on improving HCBS.

The Summit attendees identified some important considerations:

- The LTSS system must honor the choice of most Americans to live in their homes.
- People with lived experience must have a voice in efforts around HCBS.
- Operating HCBS must be made simpler and more understandable for all partners in the system.
- HCBS must be available to all, regardless of how people communicate, their backgrounds and their cultures.
- Congress, CMS and states must create a space for new ideas and sharing across the country.

The Summit attendees also had a list of detailed changes, both short and longer term, that will help improve HCBS for people who need them.

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 long-term services and supports 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.** The institutional bias within Medicaid poses an ongoing challenge to the true realization of HCBS as a viable option for all.

Summit attendees offered an abundance of thoughtful considerations for improving, expanding, and enhancing HCBS, focused on the broader systems changes necessary for advancing HCBS. The ARPA HCBS Technical Assistance Collective rounded out these strategies both with more detail and with some thoughts of their own.

This paper outlines the most impactful strategies around HCBS and provides a comprehensive list of all immediate and discrete strategies, as well as those aimed at systemic reform.

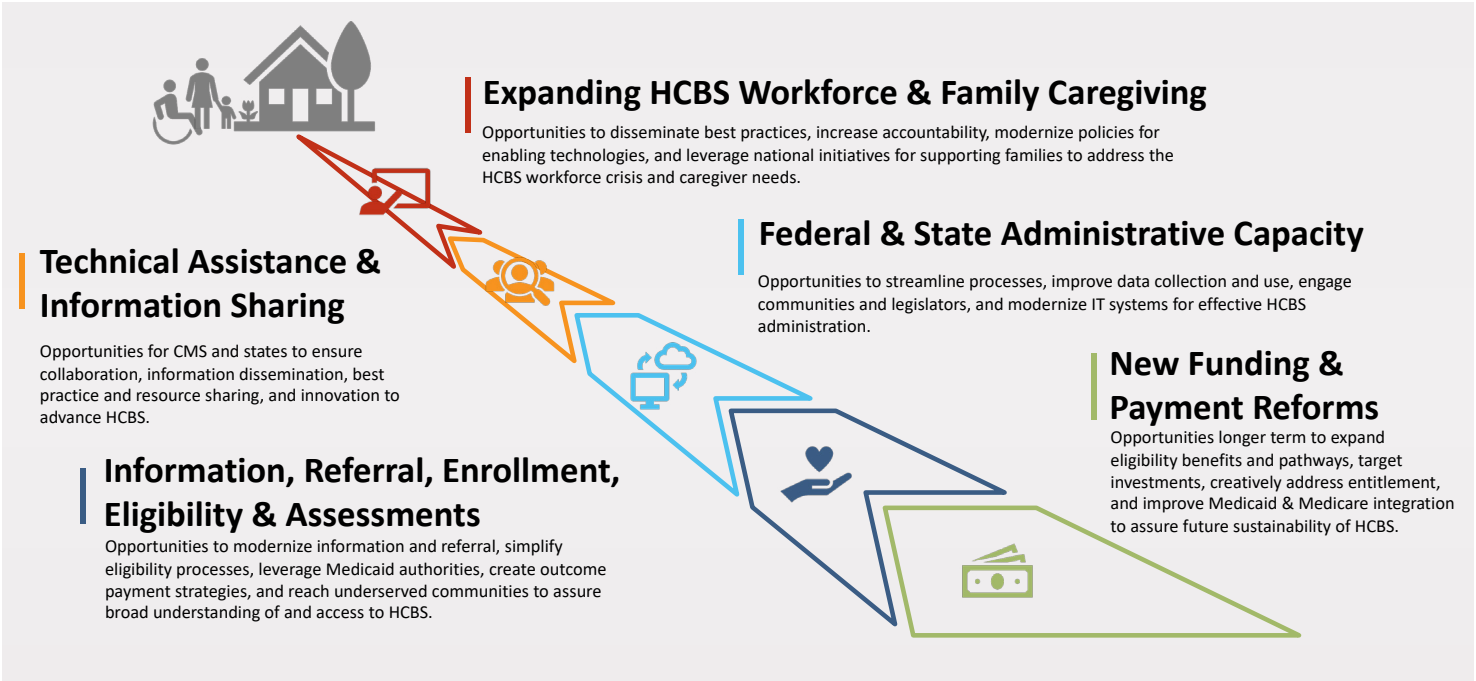
Summit attendees offered an abundance of thoughtful considerations for improving, expanding, and enhancing HCBS, focused on the broader systems changes necessary for advancing HCBS.

Most Impactful Strategies

The paper describes all the many strategies that came from the Summit attendees and the ARPA HCBS TA Collective. Figure 1 is a high-level depiction of short- and long-term opportunities for Congress, the Centers for Medicare & Medicaid Services (CMS), the Administration for Community Living (ACL), and states to take aim at creating HCBS reforms necessary to ensure the growth and sustainability of these critical services. These strategies are guided by several overarching principles that emerged from the Summit:

- Our nation's LTSS system must prioritize the preference of most people in the U.S. to live in HCBS settings.
- People with lived experience must have a voice in efforts around HCBS.
- HCBS must be the first option offered to individuals, and the system must have capacity to serve all individuals who choose it.

Figure 1. HCBS Sustainability Strategies



- Operating HCBS must be made simpler and more understandable for all partners in the system.
- HCBS must be available to all, regardless of how they communicate, their backgrounds, and their cultures.
- Congress, CMS and states must create a space for new ideas and sharing across the country.

Figure 1 depicts the five critical areas where action and/or investment is necessary to build a sustainable HCBS system.

The body of the paper expands upon Figure 1 to provide detailed, key strategies suggested for the short-term where statutory authority exists, as well as key strategies requiring amendment to statutory authority. Each strategy identifies the applicable accountable entity(ies). Additionally, longer term systemic reforms are outlined as identified as part of the Summit outcomes.

While these strategies provide discrete actions to effectuate change, the Summit attendees resoundingly call for national leadership to establish a "north star" for the HCBS system, a shared vision that makes HCBS a healthcare priority and builds a sustainable HCBS system that has capacity to meet growing needs.

I. Introduction

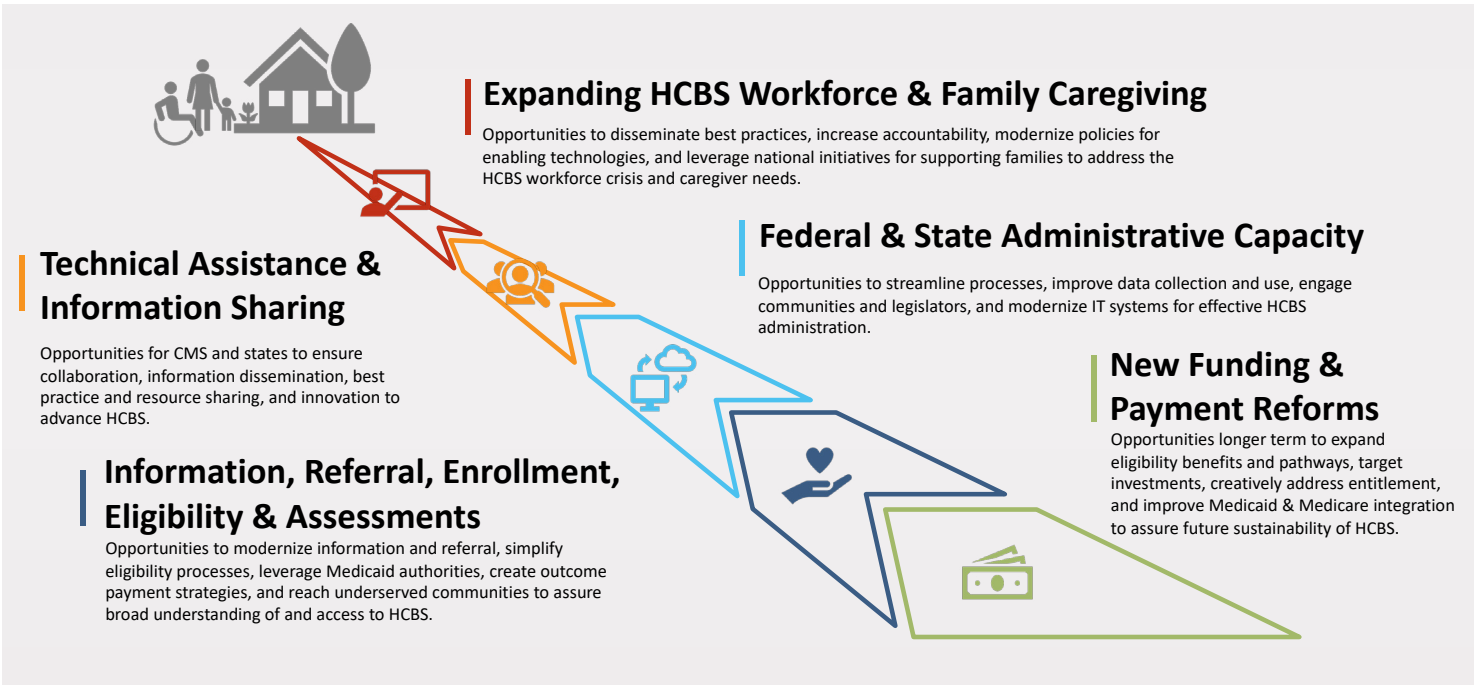
Our nation does not have sufficient existing capacity to fully support all people who currently need long-term services and supports (LTSS), much less those people who will need LTSS in the future. Individuals with disabilities and individuals who are aging and who need LTSS overwhelmingly want to live at home, not in an institution.[1] With this understanding, in 2021 — as part of the country's response to the COVID-19 Public Health Emergency (PHE) — Congress made a short-term, but very significant, investment of approximately $37B in our nation's Medicaid home- and community-based services (HCBS) LTSS system.[2] The American Rescue Plan Act (ARPA) included temporary enhanced funding to state Medicaid programs, which states have used to enhance and expand their HCBS programs. States have only until March 31, 2025, to utilize these resources. Meanwhile, demand for HCBS continues to grow, while the institutional bias of Medicaid persists.

The country is at a critical juncture as a nation. There are challenging questions to face and respond to about the future of our nation's LTSS system. Because Medicaid is the primary public payer for LTSS, questions about Medicaid HCBS programs are at the heart of the public policy debate about the future of LTSS as well as the statutory structures within Medicaid that continue to favor institutional options for LTSS.

For these reasons, on October 11, 2023, the ARPA HCBS Technical Assistance Collective (TA Collective) convened eighteen of our nation's leading Medicaid HCBS experts from a variety of sectors to participate in the HCBS Sustainability Summit. This first-of-its-kind convening of experts, including individuals with lived experience, aimed to enumerate some of the most significant challenges to Medicaid HCBS programs and to discuss possible paths forward to capitalize on ARPA HCBS investments and help assure the short- and long-term sustainability of our nation's Medicaid HCBS delivery systems. The HCBS Sustainability Summit — and the larger work of the TA Collective — was made possible by significant investments from a collection of foundations.

This report includes the potential solutions identified by the Summit attendees to meaningfully reform the HCBS system to help assure short- and long-term sustainability. The potential solutions fell into five distinct categories, depicted in Figure 1. The first four groups represent strategies that are achievable within existing statutory authority. The fifth set of potential solutions requires longer glidepath enabled by new or amended state or federal authority.

Figure 1. HCBS Sustainability Strategies



The balance of this paper is organized into four sections:

- **Why Is HCBS Unique?** — This section highlights some of the most important — and often misunderstood or overlooked — characteristics of our nation's HCBS system. Understanding these unique characteristics is essential to understanding the how's and why's of system reform.
- **HCBS Sustainability: Considerations and Potential Solutions for the Future** — Summit attendees urge swift action on implementing potential solutions. This section expands upon Figure 1 to provide detailed, key strategies suggested for the short-term where statutory authority exists, as well as key strategies requiring amendment to statutory authority.
- **Longer Term Systemic Reforms to the HCBS System** — Summit attendees also assert that bigger, bolder, and broader reforms are imperative. This section outlines their ideas for transformative change.
- **Conclusion** — This section synthesizes the rich ideas outlined in the report and re-emphasizes that reform of the national HCBS system must be approached with urgency.

A technical supplement to this report provides more information about the TA Collective; our funders; the foundational work to plan and host the Summit; the purpose and structure of the summit; and the unique characteristics of HCBS, as well as a detailed and comprehensive discussion of the Summit attendees' perspectives on the challenges that need to be addressed.

II. Why is HCBS Unique?

HCBS are unique within Medicaid. These services became available for state use in the early 1980s to serve as an alternative to care in a hospital, nursing facility, or intermediate care facility for individuals with intellectual and developmental disabilities. With the premise of these services predicated on the alternative to institutionalization, their utilization by states has required arduous administrative procedures to demonstrate that, but for these services, people will be in institutions and the cost of these services would not exceed those of facility-based care. This framework is anachronistic and perpetuates a fundamental institutional bias within the Medicaid program while simultaneously taxing stretched state resources needed to administer these programs.

HCBS is not a monolith. It is an intricate constellation of a wide array of services and supports designed to assist individuals to live and thrive in their communities. Despite their flexibility and ingenuity — in the face of the administrative hurdles — HCBS is frequently misunderstood. The complex clinical and financial eligibility processes make it opaque to many individuals and their families, and the creativity of both the services and service delivery models contribute to misperceptions of its efficacy by policy makers and oversight agencies.

HCBS are optional Medicaid benefits, so state funding for and design of HCBS programs is variable among and even within states. Access to HCBS is highly dependent on state resources, with the limited levers of service scope, eligibility and rates available to assist states in managing the outlays needed to support this essential program. Furthermore, Medicaid coverage of HCBS is frequently mistaken for Medicare, contributing to general confusion about our nation's LTSS system.

The Summit attendees agree that better understanding of HCBS programs among the public and by policymakers is necessary, and that administrative streamlining and flexibilities, as well as supports to HCBS providers, are essential. HCBS is unique for the following reasons.

- Medicaid is the only significant public payer for HCBS. Even though Medicare does not cover community-based LTSS, HCBS is frequently thought of as a Medicare-provided benefit.
- States must still make anachronistic assertions to offer HCBS instead of institutional benefits.
- HCBS is a highly diverse set of services, meeting the varied needs of many different target populations. Supports may span a lifetime for some individuals while providing key short-term services as needed for others.
- Because Medicaid is the primary payer that covers HCBS, many HCBS providers rely on Medicaid as their only source of revenue.
- HCBS enjoys widespread and bipartisan support in executive and legislative branches; however, because of the very unique and tailored services it provides, HCBS often garners a perception of being more susceptible to fraud, waste, and abuse than other services.
- Unlike most other services covered by Medicare, Medicaid and private health insurers, HCBS are non-clinical. They are focused on quality of life rather than medical necessity.
- Unlike home health care or hospital-at-home, HCBS are not simply about delivering services and supports in the home; rather, they are about enabling people to choose where they live and, if they wish, to remain active or become involved in their communities.

- A substantial proportion of HCBS providers — in contrast to institutional LTSS providers and many home health agencies — are small provider organizations that have limited administrative capacity and do not have the means or opportunity to achieve not-for-profit status.
- Understanding the lived experience of advocates and participants is especially important as it relates to HCBS program design and policy making.
- Each state operates numerous HCBS programs, and those may be administered across multiple state agencies. Creating further fissures in the HCBS delivery system is inconsistent implementation of HCBS at local levels from county to county.
- HCBS financing is different from other Medicaid services and is unlike other Medicaid services because it requires unique federal authorities.
- HCBS programs had the opportunity to waive many of the federal requirements under the PHE to assure LTSS access for waiver participants, because waiver participants were among those most affected by COVID-19 in the US.
- The public universally knows about the existence and purpose of nursing homes but, by contrast, knows very little about the existence and availability of HCBS.

III. ARPA HCBS Sustainability: Considerations and Potential Solutions for the Future

The ARPA HCBS Sustainability Summit was a solutions-based discussion. Ideas, considerations, and recommendations were welcome. Consensus was not sought or required. This section reflects an aggregation of the potential solutions identified by and suggestions made by one or more Summit attendees.

The Collective observed that the Summit attendees nearly unanimously acknowledged that the momentum, spirit, commitment, and philosophy of the ARPA HCBS undertaking must be sustained and leveraged. To achieve this, there must be assurances that 1) lessons learned from ARPA HCBS initiatives are not lost; 2) accomplishments are maintained; 3) the increased attention to doing better and more, enlivened by the ARPA HCBS opportunity, must be fostered and continued; and 4) further improvements in expanding, improving, and enhancing access to HCBS must be achieved.

Figure 2 provides a snapshot of the 29 strategies discussed and offered by the Summit attendees.

The potential solutions are next framed according to focus areas and are mapped to two key categories:

1) Actions that are achievable within existing statutory authority [Tables 1.A through 4.D]; and
2) Longer-term strategies that call for new or amended authority in statute [Tables 5.A through 5.G].

Each potential solution includes a descriptor and key considerations, along with the identification of the accountable entity(ies). While this paper identifies accountable entity(ies), state and/or federal legislators or private sector entities could undertake or advance progress towards many of these potential solutions.

Figure 2. Sustainability Summit Strategies

Short-term Strategies with Existing Statutory Authority	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
1. EXPANDING CAPACITY OF THE HCBS WORKFORCE AND SUPPORTING FAMILY CAREGIVERS				
Build upon the existing ACL investments to enhance the Direct Care Workforce Strategies Center elevating and disseminating best practices and evidence-based approaches for improving recruitment and retention efforts		✓	✓	✓
Increase accountability in how rate increases are being spent by providers		✓		✓
Modernize coverage policy and foster dissemination of new and/or improved technologies to support individuals receiving HCBS and their paid and unpaid supporters and caregivers, including access to everyday technology		✓		✓
Leverage several national initiatives (RAISE, Supporting Families Community of Practice) to amplify and disseminate best practices on supporting families, recognizing the need for supports and training for family and informal caregivers with eye toward identifying and addressing the needs of caregivers		✓	✓	
2. TECHNICAL ASSISTANCE (TA) AND INFORMATION SHARING				
Sponsor and facilitate multi-state collaboratives for states to develop, test and implement new HCBS initiatives in a knowledge-sharing environment		✓		
Establish a center of excellence on key HCBS program areas		✓		
Leverage the HCBS Clearinghouse and other national dissemination strategies to share HCBS program and policy information		✓		✓

Continues.

Short-term Strategies with Existing Statutory Authority	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
2. TECHNICAL ASSISTANCE (TA) AND INFORMATION SHARING *(Continued)*				
Develop and fund a national HCBS innovation and strategies Technical Assistance (TA) Center, increasing CMS resources to expand TA to states in developing and managing HCBS programs		✓		
Conduct a national evaluation of the impacts of Appendix K flexibilities and the ARPA HCBS innovations to inform future policy development		✓		
3. ENHANCED FEDERAL AND STATE ADMINISTRATIVE CAPACITY				
Undertake concerted efforts at the federal level to simplify HCBS application processes and operational activities to ensure streamlined and effective administration of HCBS programs, strategically stretching key federal and state resources		✓		
Establish a continuous improvement process, enabling the rapid deployment and solidification of key learnings and improvements from national initiatives, including ARPA, Appendix K, and other projects		✓		
Partner with states and adequately fund improved data collection and analysis capabilities, enabling the routinization of ongoing program evaluation, continuous quality improvement and the full transparency of LTSS spending and impact		✓		
Initiate and leverage intentional, meaningful, and ongoing community and legislative engagement around HCBS		✓		✓
Fund a Modernizing HCBS IT Systems TA Center, supporting state Medicaid and operating agencies to modernize state Information technology, care manager/support coordinator, incident management, and decision-making tools and systems		✓		✓

Continues.

Short-term Strategies with Existing Statutory Authority	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
4. INFORMATION AND REFERRAL, ENROLLMENT, ELIGIBILITY, AND ASSESSMENTS				
Modernize and centralize information and referral systems in states and expand awareness among the general population about Medicaid and the availability and access points to apply for HCBS		✓		✓
Work continually to simplify and facilitate Medicaid processes for both financial and clinical eligibility for HCBS		✓		✓
Ensure that states have access to resources and information on the full array of authorities to expand access/eligibility for HCBS programs		✓		
Continue to refine assessment processes to ensure meaningful person-centered planning processes that accurately reflect individual needs		✓		✓
Develop and implement more outcome-based payment systems for HCBS		✓		✓
Engage with key sister state agencies and legislatures to ensure a full understanding of HCBS across populations, including opportunities for self-direction				✓
Expand the availability of self-directed services, with appropriate supports to ensure equitable access across all HCBS populations				✓
Undertake an effort to understand the availability of HCBS across all socioeconomic and racial and cultural groups and initiate targeted outreach efforts for underserved communities		✓		✓

Continues.

Short-term Strategies with Existing Statutory Authority	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
5. NEW OR EXPANDED SOURCES OF FUNDING FOR HCBS AND PAYMENT REFORMS				
Expand the benefits eligible for federal matching funds (e.g., support for housing and other social determinants of health, considering the needs of the individuals and their family and support network)	✓			
Create new sources of support and eligibility pathways for individuals at-risk for Medicaid and for needing HCBS	✓			
Commit to targeted investments and/or enhanced Federal financial participation (FFP) to support the strengthening of the workforce necessary to support a robust HCBS system of support, based upon an analysis of the investments through the ARPA spending plans aimed specifically at Direct Care Worker (DCW)/Direct Support Professional (DSP) compensation and benefits	✓			
Pursue efforts to create an entitlement for HCBS with requisite support to ensure a smooth transition and sufficient resources	✓			
Develop career pathways for new legal immigrants to be immediately enrolled in a Direct Care Workforce (DCW) training program and then placed in a DCW provider agency to mitigate the critical shortage issues facing HCBS programs	✓			
Require more holistic coordination of Medicaid and Medicare services and supports, as well as other public benefit programs, which enable individuals to remain in HCBS settings	✓	✓		
Implement new state demonstrations to integrate Medicaid and non-Medicaid services managed and operated by a single state agency		✓		✓

1. *Expanding Capacity of the HCBS Workforce and Supporting Family Caregivers*

Access to in-home supports is a critical component of community living for individuals using HCBS. The lack of a direct care workforce to support demand for services as well as the lack of support for unpaid caregivers has combined to create a crisis of sizable proportion. Strong federal and state policies to support both workforces are needed to sustain community living. All Summit attendees concurred that the HCBS system needs more direct support professionals (also called DCWs/DSPs), and they recognized that multi-faceted approaches, including the expanding the use of enabling technology, are needed to address today's workforce challenges.

Tables 1.A through 1.D list the potential solutions identified.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 1.A. Build upon existing ACL investments to enhance the DCW Strategies Center by elevating and disseminating best practices and evidence-based approaches for improving recruitment and retention efforts.		✓	✓	✓

Summit attendees acknowledged that compensation increases for DCWs/DSPs 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. CMS could partner with and build on ACL's DCW Strategies Center to support and advise states in their design, implementation, and evaluation of recruitment and retention approaches. While areas of focus should include the impact of wages and bonuses on recruitment and retention, study should extend further to consider more creative approaches to impact recruitment and retention. For example, evaluation aims should include, but not be limited to, self-direction and expansion of paying family and other informal caregivers who provide care. When carefully designed, these approaches can offer improved individual choice and control while simultaneously addressing workforce challenges. For all focus areas, the best practices dissemination should include educating state legislators about the types of strategies and their impacts. CMS and ACL also should develop multi-state collaboratives to build DCW capacity, fund demonstrations to develop new and innovative approaches for building the DCW, underwrite small business loans to individuals and small organizations want to start up a new DCW agency, and provide technical assistance to states on DCW capacity building.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 1.B. Increase accountability in how rate increases are being spent by providers.		✓		✓

CMS should establish a toolkit that states can use to collect reliable, timely and complete data regarding HCBS providers' costs. Likewise, CMS should develop clear, unambiguous model definitions that providers can use when reporting about DCW/DSP wages and benefits. CMS's work should be built on best practices and learnings from states, particularly from wage increases and bonuses implemented as part of states' ARPA spending plans. States should, in turn, implement reporting requirements that will enable them to understand their HCBS providers' spending on DCWs/DSPs, as well as hierarchical corrective actions that will enable them to hold HCBS providers accountable for both reporting and meeting spending requirements. CMS's proposed Access Rule contemplates a "minimum loss ratio" for HCBS providers' spending on the DCW. If the final rule includes this requirement or one like it, states will need such tools and models in short order. Despite states and states' legislatures having made significant investments to increase provider payment rates and to make one-time bonus or hazard payments, we, as a nation, do not yet have clear evidence that the HCBS delivery system is any better off from those investments. The 2022 National Core Indicators® Intellectual and Developmental Disabilities State of the Workforce Survey®(NCI SoTW) report[3] revealed a dollar-and-a-half increase in median hourly wages relative to 2021 wages across the 24 states that participated in the survey, with some states seeing increases of more than 15 percent. These may be early signs of positive changes. States should invest in ongoing data collection and analysis to understand the persistence of these wage increases and benefits and the degree to which provider rate increases impact DCW/DSP wages and benefits.

	Accountable Entity			
	Congress	***CMS***	***ACL***	***State Medicaid and/or HCBS Operating Agencies***
Table 1.C. Modernize coverage policy and foster dissemination of new and/or improved technologies to support individuals receiving HCBS and their paid and unpaid supporters and caregivers, including access to everyday technology.		✓		✓

CMS must update its HCBS taxonomy of services to reflect recent and ongoing innovations in enabling technologies. At the same time, CMS must update its waiver application review criteria and coverage policies to enable states to readily, creatively, and affordably deploy enabling technologies as a means to support and supplement paid and unpaid workers and to empower participants. In turn, states should explore creative solutions to deploy new and improved technologies, as well as everyday technologies such as mobile phones, to support waiver participants and their paid and unpaid caregivers. Both CMS and states should consider not only non-traditional services, but also consider creative approaches to covering such services under their waivers. For example, in some cases, it might make sense to cover a new technology as part of a quality improvement intervention to address waiver health and welfare assurances. CMS also should consider ways to foster more rapid dissemination of enabling technologies and policies covering them. Some of this work could be achieved through a clearinghouse model, like that described above under Table 1.C, whereby states could share and seek information about new technologies and new coverage approaches. In addition, CMS or ACL could establish a grant program designed to fund states as they develop their enabling technology infrastructure, such as toolkits for case managers' use, model "smart" homes and technology libraries, and advisory services that could be accessible to waiver participants.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 1.D. Leverage several national initiatives (RAISE, Supporting Families Community of Practice) to amplify and disseminate best practices on supporting families, recognizing the need for supports and training for family, informal supports, and unpaid caregivers with eye toward identifying and addressing the needs of caregivers.		✓	✓	

The total annual economic value of unpaid family caregiver work was recently estimated at over $600 billion, significantly exceeding the value of paid caregiving.[4] CMS should gather information about best practices for supporting families, informal supports and unpaid caregivers. Families, informal supports and unpaid caregivers are the backbone of the country's LTSS system. When those individuals are no longer available, the demands on the paid workforce increase, and, in many cases, the flexibility and/or quality of the individual's supports may be at risk of decreasing. Thus, identifying and deploying best practices in caregiver supports is an essential part of the workforce development solution. Support for family, informal supports and unpaid caregivers might include training, help accessing available community services or resources for their own health, housing, or other health related social needs. In other words, these supports should consider caregivers as people, not just as caregivers.

2. Technical Assistance and Information Sharing

There was broad agreement that information sharing and technical assistance (TA) around substantive innovations and approaches to operations would be beneficial for states.

Tables 2.A through 2.E list the potential solutions suggested.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 2.A. Sponsor and facilitate multi-state collaboratives for states to develop, test and implement new HCBS initiatives in a knowledge-sharing environment.		✓		

Knowledge sharing across states typically happens through state associations or, sometimes, on an ad hoc basis. Knowledge sharing is a challenge not only for states — it is also a challenge for many state-based advocates. This recommendation suggests that CMS provide guidance, advice, and expertise to support states in areas where similar initiatives are being pursued by multiple states (e.g., workforce initiatives). Additionally, there is a real need for cross-sector HCBS systems planning and coordination — Medicaid, I/DD, aging agencies all coming together — to alleviate duplication of efforts while also creating forward momentum. Fostering information-sharing among states and among state agencies should be systematized and a key part of an efficient expansion of HCBS best practice ideas.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 2.B. Establish a Center for Excellence on Key HCBS Program Areas.		✓		

CMS could partner with and build on ACL's DCW Strategies Center to support and advise states in their design, implementation, and evaluation of workforce-related initiatives. This approach would enable states to circumvent procurement rules that, for many states, hampered their engagement of experts and supplements to state staff, particularly during planning and the initial months of the spending period. States could quickly gain expertise, learn about successful demonstrations in other sectors or other states, share information and tools through learning collaboratives, etc.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 2.C. Leverage national dissemination strategies, including the HCBS Clearinghouse, to share HCBS program and policy information.		✓		✓

The HCBS system would benefit from a significant investment in CMS infrastructure and resources to support the implementation of HCBS initiatives. CMS should devote more time and resources to supporting states in this work. ADvancing States currently operates a national HCBS Clearinghouse to share some HCBS program and policy information but relies on contributions from HCBS experts. This Clearinghouse — and others like it — could be expanded with additional funding.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 2.D. Develop and fund a national HCBS Innovation and Strategies TA Center, increasing CMS resources to expand TA to states in developing and managing HCBS programs.		✓		

This recommendation focuses on the provision of guidance, advice, and expertise to support states in areas where similar initiatives are being pursued by many states, such as self-direction and HCBS workforce initiatives. An HCBS Innovation and Strategies TA center could provide consulting and staff-extension to states which struggle with human resource capacity. The goal for this TA center could be to hold small regional conferences, disseminate lessons learned and best practices, and be available for states to draw upon for TA for new HCBS initiatives. It also could conduct case studies of state ARPA HCBS initiatives that were successful in achieving their objectives for improving HCBS system capacity. While there are existing avenues for HCBS TA, they may or may not be suitable. This TA center should have the capacity to respond to TA requests upon short notice and with limited barriers to states, so that there is immediate assistance to support states with meeting urgent implementation timelines.

Table 2.E. Conduct a national evaluation of the impacts of Appendix K flexibilities and the ARPA HCBS funding initiative innovations to inform future policy development.

There is great opportunity in funding a contractor to complete a comprehensive review of Appendix K waivers used by states during the PHE by:

- Conducting stakeholder interviews with a significant number of states regarding the successes and failures of Appendix K waivers, and
- Developing recommendations to Congress on Appendix K changes that should be folded into ongoing HCBS policy.

Such a national evaluation should be designed to demonstrate which efforts were impactful, how success was achieved, and the degree to which it was sustained post-PHE. A full-scale evaluation enables the amplification of successes as well as the avoidance of efforts that did not demonstrate the desired outcomes.

3. Enhanced Federal and State Administrative Capacity

Multiple Summit attendees noted that an infusion of time-limited investments, like ARPA, alone are not sufficient. There must be process and rule changes to support and facilitate innovation with investments in our nation's HCBS delivery system. Furthermore, states need more and improved flexibilities from CMS, as well as internal flexibility to pivot and modify endeavors as they are implemented.

Tables 3.A through 3.E list the potential solutions suggested.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 3.A. Undertake concerted efforts at the federal level to simplify HCBS application processes and operational activities to ensure streamlined and effective administration of HCBS programs, strategically stretching key federal and state resources.		✓		

There was strong concurrence that the existing structure of Medicaid HCBS imposes administrative hurdles that stifle innovation because they divert limited state and federal resources that could be brought to bear on modernizing the HCBS system. For example, Summit attendees noted that 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. Attendees strongly encourage CMS to take action that will result in streamlined and effective administration of HCBS. Summit attendees suggest a first step is for CMS to conduct a comprehensive review of statute, regulation, policy, and processes with the aim of identifying ways to eliminate, streamline or template components of the HCBS waiver application and review process. There are opportunities to target new funding that will expand state and federal HCBS staff capacity and create new flexibilities for states to pilot additional programs and initiatives. Simplifying approvals for changes to HCBS operations would facilitate states expanding waiver populations, adding new benefits to waiver programs, changing the definition of current benefits, modifying HCBS provider payments, and changing HCBS quality oversight processes. Lastly, the Summit attendees concur there are efficiencies in mainstreaming flexibilities that are consistently permitted under HCBS waiver authorities.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 3.B. Establish a continuous improvement process, enabling the rapid deployment and solidification of key learnings and improvements from national initiatives, including ARPA, Appendix K, and other projects.		✓		

There is a longstanding challenge for state agencies to make room for creativity in HCBS due to inadequate human capacity capital to manage just the basic federal administrative requirements for delivering HCBS. Vastly different program requirements, operations, and oversight across the various HCBS Medicaid authorities add to complications for states who can only keep up with meeting federal

expectations let alone explore innovation. CMS should use the findings from the national evaluation of Appendix K flexibilities and ARPA HCBS innovative initiatives (suggested in 1.E above) to modify existing HCBS authorities and rules to improve the HCBS programs available to states, including streamlining the waiver application, reporting requirements, and oversight processes. Federal partners can further reduce the burden on states by aligning their issuance of federal guidance with state legislative timelines, paving the way for state governments to take policy and financing action in response to new federal requirements.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 3.C. Partner with states and adequately fund improved data collection and analysis capabilities, enabling the routinization of ongoing program evaluation, continuous quality improvement and the full transparency of LTSS spending and impact.		✓		✓

In many cases, HCBS 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. There is still much to learn from the ARPA HCBS initiatives themselves and about how to structure future investments of federal and state dollars in our nation's HCBS delivery system. CMS and State Medicaid Agencies must ensure there is baseline data and ongoing data collection and analysis so that the influence of HCBS and HCBS investments can be measured and evaluated, which must be a requisite component of HCBS program operations going forward. The proposed Access Rule establishes a uniform set of HCBS quality measures, which will aid in evaluating HCBS programs on a national level. Standardizing data collection for both institutional and HCBS programs may allow for more comparable data analysis. This is important and time-consuming work, and many states do not have resources to build this capacity. Assistance from CMS could help address the deficits in data analytic capacity at state agencies by providing financing, guidance to states, and policy standardization.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 3.D. Initiate and leverage intentional, meaningful, and ongoing community and legislative engagement around HCBS.		✓		✓

CMS and states, as partners in HCBS delivery, must consistently embrace and welcome robust and regular community engagement, discussion, and collaboration with participants, family caregivers, legislators, providers, advocates, and direct care workers. This is about more than federal or state requirements; it is about culture change. Provision of training and TA to advocacy organizations could help to facilitate this culture change and assure that community members are better positioned to advocate for their involvement and for policies that community members want. 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.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 3.E. Fund a Modernizing HCBS Information Technology (IT) Systems TA Center, supporting state Medicaid and operating agencies to modernize state IT, care manager/support coordinator, program integrity systems, incident management, and decision-making tools and systems.		✓		✓

Significant opportunity exists to position HCBS for the future by supporting states to develop HCBS infrastructure to improve program operations and oversight. A key method for bringing about such change is a TA center for modernizing HCBS IT systems. This type of TA center would work with individual states, or groups of states, to: (1) develop detailed system requirements for new HCBS IT systems; (2) provide support to states in developing advance planning documents (APDs) to CMS and negotiating approvals of APDs; (3) support states with the development of HCBS IT procurements and the evaluation of vendor proposals; (4) support states with the implementation of new HCBS IT systems into their ongoing HCBS operations; and (5) support states with ongoing contract management issues with vendors during the contract period of performance. To address unsubstantiated claims of widespread fraud among HCBS providers, the TA center should give priority to the development of new IT technologies which ensure that HCBS claims are being paid only for services rendered under approved HCBS care plans. Additionally, the TA center should support the development of new technologies which can effectively audit services paid for under self-directed care models.

The TA center also would serve as a clearinghouse and information hub for products and resources regarding HCBS IT modernization efforts, supporting the pollination of new technologies and best practice among and across states. The Summit attendees call for CMS to take a leadership position with states in this space, leveraging intra-agency collaboration among CMS divisions to gather the right type of expertise to support both HCBS and IT aspects of modernization and fund such a TA center to support states with their HCBS IT Systems work.

4. *Information and Referral, Enrollment, Eligibility, and Assessments*

Access to HCBS starts with a strong information and referral system that assesses need and directs individuals accordingly. Upon entering the Medicaid LTSS door, eligibility should be simplified as much as possible. Additionally, determining need and building a person-centered plan of care should minimize the burden on the individual and remain focused on their goals and outcomes. Summit attendees stressed that improvements are necessary to educate and outreach to those who could benefit from HCBS but, also that reforms are necessary to enrollment, eligibility, and assessment rules and processes to appropriately serve all who need and want HCBS in the way they need and want them.

They suggest the potential solutions listed in Tables 4.A through 4.H.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 4.A. Modernize and centralize information and referral systems in states and expand awareness among the general population about Medicaid and the availability and access points to apply for HCBS.		✓		✓

Too often, individuals needing supports in their home are not aware of their options until they (or a loved one) are in need. This often results in inequitable access to those critical services. Moreover, most Americans believe that Medicare will cover in-home care when it is needed; it does not. Information and referral systems and Aging and Disability Resource Centers are one of the few places where individuals can go to learn about LTSS services, but they are woefully underfunded and disjointed, operating with obsolete technology, lack of access to new communications modalities (chat bots, interactive voice response systems, etc.), and coverage that varies dramatically across states and even within states. Processes for drawing down Medicaid administrative match for information and referral systems are cumbersome and require strong relationships among state and local parties. Recognition of the interrelatedness of Medicaid and pre-Medicaid systems is lacking. States should collaborate across human services agencies to modernize and develop more robust and comprehensive, centralized information and referral systems and access points for HCBS. To do that, states will need additional funding, as well as TA (like that described in 2.E above) for this modernization as well as for expanding outreach and education about Medicaid and the availability of HCBS.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 4.B. Work continually to simplify and facilitate Medicaid processes for both financial and clinical eligibility for HCBS.		✓		✓

While Medicaid application systems for those determined eligible based on income only have recently been integrated and streamlined, those that qualify based on disability face significant barriers in both understanding the multiple steps required and receiving assistance in the most appropriate manner. Financial and functional/clinical eligibility processes and systems are disjointed and decentralized in many states. Allocating resources to in-person or technology-enhanced application assistance is challenging for state agencies with multiple priorities. CMS and states need to partner intentionally to reduce barriers to HCBS eligibility.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 4.C. Ensure that states have access to resources and information on the full array of authorities to expand access/eligibility for HCBS programs.		✓		

By leveraging the State Medicaid Director (SMD) Letter 21-004[5], states can take advantage of existing authorities to expand Medicaid HCBS eligibility and enable more individuals to access HCBS. TA, including recommended approaches from CMS and support in data analysis and cost modeling for the expansion(s) states are considering, will better position states to take advantage of these opportunities, as states may not have the expertise to identify or execute needed action steps.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 4.D. Continue to refine assessment processes to ensure meaningful person-centered planning that accurately reflects individual needs.		✓		✓

Improving assessment processes to better identify participants' needs, preferences, goals, and wishes is essential to informing a person-centered service plan that is led by the individual and results in services and supports that best meet their needs and the desired outcomes. Aligning functional eligibility assessment tools and person-centered planning processes will eliminate the need for participants to give their most personal information to multiple individuals multiple times. Both immediate and longer-term TA from CMS on implementing compliant and appropriate person-centered planning processes is a must.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 4.E. Develop and implement more outcome-based payment systems for HCBS.		✓		✓

As a first step, there must be a philosophical agreement that HCBS should be structured to support people not just to survive in their own home or community-based setting but, instead to thrive in the life they lead in that home or community-based setting. Payment methodologies today focus on how many hours of which services are provided. By developing and implementing a more outcome-based payment system for HCBS, we can shift the reimbursement focus to a more person-centered one that focuses on progress towards outcomes instead of simply how many units of service were delivered. For example, one state has developed a value-based payment model for supported employment whereby the supported employment provider receives a lump sum payment after the individual achieves each of a series of employment milestones. Some states have begun to pay for reporting, as a means of capturing HCBS delivery system data that was not previously available. These states anticipate evolving to incentive payments based on process and outcome measures when the necessary data is available. CMS could play a critical role in collecting these innovative practices and supporting broad dissemination.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 4.F. Engage with key sister state agencies and legislatures to ensure a full understanding of HCBS across populations, including opportunities for self-direction.				✓

Not all lawmakers and policymakers fully understand HCBS, what it is, what payor sources cover it, and how individuals access it. Nor do individuals who could benefit from HCBS or their loved ones. Self-direction programs are not well understood by state staff, much less by participants and legislators. Significant and ongoing engagement should be undertaken to ensure a broad understanding of HCBS, what it includes, its role and value, how to obtain it, and how to pay for it. State engagement of key sister state agencies and legislatures to ensure a full understanding of HCBS across populations, including opportunities for self-direction, would be of great benefit to individuals who need HCBS.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 4.G. Expand the availability of self-directed services, with appropriate supports to ensure equitable access across all HCBS populations.		✓		✓

Section 2402(a) of the Affordable Care Act requires the Secretary to ensure all states receiving federal funds — among other things — develop service systems that maximize independence and self-direction for individuals using HCBS. Many states have encouraged individual choice of self-directed care models, in which eligible HCBS participants choose their own caregivers, including family and friends. Self-direction is noted by many as part of the HCBS workforce solution. 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. Furthermore, today's HCBS program designs often disincentivize reliance on self-direction. Moreover, not all populations have access to self-directed options; states should work to make it available to all populations along with support brokers and other assistance that maximize the potential of self-direction. CMS should facilitate states' expansion efforts by providing resources (e.g., a self-direction toolkit and enhanced funding), exploring ways to reduce barriers (e.g., ways to reduce the added burden on case managers), and institute more robust oversight of agency with choice models to assure the participant has true choice and control.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 4.H. Undertake an effort to understand the availability of HCBS across all socioeconomic and racial and cultural groups and initiate targeted outreach efforts for underserved communities.		✓		✓

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 do not have a complete handle on the inequities within their systems and potentially resulting from their processes. Without this information, inequities cannot be remediated. An affirmative commitment to study the availability and accessibility of HCBS across all socioeconomic, racial, and cultural groups is critical and acting upon the study findings with systemic and policy changes as well as outreach to underserved communities is imperative.

5. New or Expanded Sources of Funding for HCBS and Payment Reforms

Summit attendees agreed it is imperative that there be new and expanded sources of funding for HCBS and that existing payment structures need considerable reform. HCBS are a fundamental part of LTSS programs, and they need to be funded in a more permanent way. Tables 5.A through 5.G list the proposed solutions identified.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 5.A. Expand the benefits eligible for federal matching funds (e.g., support for housing and other social determinants of health, considering the needs of the individuals and their family and support network).	✓			

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 obtaining HCBS. Despite the scarcity of data regarding disparities, Summit attendees recognized an observable pattern in access to HCBS. When individuals can own a home, live with family members, or have other allowable resources that enable them to cover their housing costs, they readily choose HCBS. When individuals do not have similar resources and options, they often are forced to choose an institutional setting such as a nursing facility and then remain stuck there because housing options are not available to support transition back to an HCBS setting. Expanding Medicaid coverage to allow state HCBS programs to cover housing costs and the cost of meeting other health related social needs is good policy and would place access to HCBS and access to nursing home care on a more level playing field. The recent ACL-funded Housing and Services Resource Center provides an opportunity to identify strategies to address this very issue, making it possible for people to live stably, affordably, and successfully in their communities.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 5.B. Create new sources of support and eligibility pathways for individuals at-risk for Medicaid and for needing HCBS.	✓			

States lack sufficient authority and flexibility to serve those at risk of being or becoming eligible for nursing home level of care. The growing demand for Medicaid LTSS is unsustainable without investments in 'upstream' coverage options that can delay or even prevent full Medicaid eligibility. States have used section 1115 authority to leverage federal funds to serve individuals at-risk of needing institutional care, as well as state funded programs. However, this is a piecemeal approach. Summit 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.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 5.C. Commit to targeted investments and/or enhanced FFP to support the strengthening of the workforce necessary to support a robust HCBS system of support, based upon an analysis of the investments through the ARPA spending plans aimed specifically at direct service professionals' compensation and benefits.	✓			

Summit attendees felt strongly about capitalizing on the lessons learned from the ARPA investments. Coupled with the facts regarding the DCW crisis, there is an opportunity to undertake a detailed analysis specific to the ARPA investments intended to address workforce compensation and benefits. There is value in understanding the successes and missed opportunities brought about by the one-time payments and incentives states brought to bear. Comparatively, even more telling may be an analysis of those states that retained those investments beyond the ARPA spending period. These two prongs of post-ARPA evaluation are an opportunity to inform future, strategic investments with thoughtful implementation timelines to strengthen the direct care workforce as a pivotal and necessary component of a robust HCBS system. As noted in Table 4.B, states will need to build new data collection and analysis capabilities, so they can make informed decisions about future targeted investments.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 5.D. Pursue efforts to create an entitlement for HCBS with requisite support to ensure a smooth transition and sufficient resources.	✓			

The most pivotal payment policy reform mentioned by many Summit attendees is that HCBS should be an entitlement under Medicaid to match individual and family preference for HCBS. They were careful to note that making HCBS a Medicaid mandatory benefit along with an entitlement for nursing facility services runs the risk of bankrupting states' Medicaid programs without accompanying levers to contract expensive institutional services. Such a move to create an HCBS entitlement must ensure a consistent philosophy of 'community-first' prioritized over facility-based options at the federal, state, and local levels.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 5.E. Develop career pathways for new legal immigrants to be immediately enrolled in a DCW training program and then placed in a DCW provider agency to mitigate the critical shortage issues facing HCBS programs.	✓	✓	✓	

Despite findings in the recently published 2022 NCI SoTW[6] showing an increase in direct service professional median hourly wage and a decrease in the turnover ratios nationally, the data are still alarming regarding the effects of an ongoing workforce crisis. There simply are not enough DCWs/DSPs to provide needed LTSS to those currently enrolled let alone those projected to need services. We also know that there are serious issues regarding equity within the direct care workforce. Today, most direct care workers are women, people of color and immigrants, with immigrants constituting 32% of the home care workforce and 26% of the residential care aide workforce compared to 17% of the U.S. labor force.[7] Summit attendees see legal immigrants desiring to work as a pipeline for meeting the critical DCW need. In fact, restricting the immigration of individuals interested in and willing to deliver HCBS is counterproductive. The Summit discussion highlighted the opportunity to create career pathways for legal immigrants to join the DCW. This consideration calls for CMS and ACL to develop and deliver to states and Congress an analysis of existing avenues via which immigrants can be enrolled in DCW training programs and jobs under today's laws, as well as new avenues that could be made available through Congressional action.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 5.F. Require more holistic coordination of Medicaid and Medicare services and supports, as well as other public benefit programs, which enable individuals to remain in HCBS settings.	✓	✓		

In most states, more than a majority of HCBS participants are dual eligibles — that is, eligible for both Medicaid benefits as well as Medicare. Navigating a system where health care services are delivered in one system, and HCBS in another is extremely challenging. CMS and private funders have made investments in supporting states to better integrate care delivered under these two disparate systems. However, an integrated care experience is not the case for most dual eligibles. Efforts by Congress and CMS can require improved coordination of Medicaid and non-Medicaid supports, thus promoting the opportunity for more individuals to remain in their homes and communities with holistic services,

including HCBS. In the minds of the Summit participants, there is an urgency to accelerate the development of integrated Medicaid and Medicare models. This includes capacity building at the state level to bolster the knowledge and understanding of state Medicaid agency staff about Medicare and its impacts on Medicaid services. Additionally, efforts along these lines must include information and support for individuals and families to navigate the complexities of dual eligibility. Finally, there must be a mechanism for savings from averted Medicare spending to accrue to Medicaid for its efforts.

	Accountable Entity			
	Congress	*CMS*	*ACL*	*State Medicaid and/or HCBS Operating Agencies*
Table 5.G. Implement new state demonstrations to integrate Medicaid and non-Medicaid services managed and operated by a single State agency.		✓		✓

The siloed nature of public benefit programs, including Medicaid, the Older Americans Act programs, Supplemental Nutrition Assistance Program (SNAP), Low Income Home Energy Assistance Program (LIHEAP) and Section 811 housing vouchers, leads to confusion and frustration for individuals trying to access those programs as well as significant administrative burden and potential duplication of effort in states. The braiding and blending of multiple federal fund sources could lead to significant improvement in both access to services for individuals as well as more efficient state operations. Agencies across the U.S Department of Health and Human Services and other relevant federal agencies could come together to effectuate innovations in public benefit program delivery.

IV. Longer Term Systemic Reforms to the HCBS System

This paper's potential solutions have, thus far, focused on more immediate actions that accountable entities can take now to improve the HCBS system. Summit attendees urge swift action on implementing those potential solutions. Bigger, bolder, and broader reforms, however, are equally imperative. The nation needs to take a long view and set its sights on transformative change.

At the Summit, this process was often referred to as "creating a north star." The development of such a bold vision would serve as motivation for all stakeholders in the HCBS system to aim for a common destination. All voices — including the voices of those who have lived experience — need to be reflected in the establishment of the north star because a shared vision means everyone's vision.

This HCBS north star must reflect a collective vision of the goals and objectives of a systemic HCBS reform effort and be built upon the following foundational imperatives:

1. Prioritize A Sustainable National HCBS System

Even though most people express a desire to age in place, today's LTSS system reflects an institutional bias, with long-term care facilities being the settings that most payers are willing to cover and that are most available and accessible to individuals in need of LTSS. Medicaid's LTSS system includes the nation's largest and most robust HCBS system in the nation and consistently delivers a high-quality, cost-effective alternative to institutional care, yet it still suffers from institutional bias. Furthermore, the HCBS providers serving in this system are highly, if not solely, dependent on Medicaid as their source of revenue. The gaps in our LTSS system are glaring, yet we lack a national agenda to build the capacity we need and that most people want. A systemic HCBS reform effort needs support and leadership from the highest level of government to be successful. Congress and the Presidential Administration must adopt legislative and executive philosophical and policy commitments to and prioritizations of HCBS. This should include immediate statutory action to eliminate the institutional bias embedded in the Medicaid program. Institutional care and HCBS services need to be placed on a level playing field. A Congressional and Administration philosophical and policy shift should ensure that the first option offered to any person newly eligible for LTSS services is to receive services in their own home, and that a robust HCBS infrastructure exists to provide community-based care on a quick-turnaround basis once the individual's needs are identified.

Congress should assemble a national HCBS Commission to design a comprehensive, permanent national HCBS system for all individuals, regardless of income. The Commission should include representation from all sectors of the HCBS community. It should be adequately funded, staffed, and directed to design a national HCBS system, making recommendations for developing and financing an HCBS system for all people (not only for those receiving Medicaid), authorizing legislation, governance, quality, and oversight.

The National HCBS Commission should engage in an extensive stakeholder engagement strategy to advise it in creating a common vision of what a sustainable national HCBS system would look like. This strategy must elicit input from a very broad range of stakeholders engaged in the provision of HCBS services including participants, family members, local communities, direct care workers, providers, advocacy groups, the aging network, and state and local governments.

The Commission should guide the development of and be guided by the vision of the HCBS north star (discussed just above). It also should clearly lay down the specific steps that need to be achieved in reaching this shared vision for the future.

The National HCBS Commission should be charged to complete its work expeditiously, given the urgency of the HCBS crisis. Members of Congress, state legislators, and advocacy groups, having been fully engaged on the value of HCBS and need for systemic reform, will be well-prepared to take swift action upon the recommendations of the Commission.

Many attendees commented that the Sustainability Summit was a good example of how a broad representation of stakeholders in the HCBS policy arena can come together and find common ground in discussions of systems change solutions.

2. *Adopt an Agile Policy Approach that Allows Responsiveness to Address Critical and Far-Reaching Barriers to HCBS — e.g., housing and workforce.*

In the existing HCBS system, states lack the freedom and flexibility to swiftly adopt, adapt, and pivot toward creativity and full-fledged responsiveness to the needs of individuals being served. States need more agility to be able to address critical and far-reaching barriers. A nimble policy method would enable states to tackle such barriers to HCBS as meeting the needs of individuals who are at risk of needing nursing facility services, addressing housing, and building and maintaining a sustainable workforce.

States need agile policy approaches so they can serve individuals who are at risk of but have not yet reached nursing home level of care. Summit 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.

States require more agility and resources to address the affordable housing shortage for HCBS populations. A national plan for a sustainable and high-quality HCBS system must include a realistic strategy for expanding the availability of affordable housing for individuals receiving HCBS services. Many people remain on waiting lists for HCBS services simply because affordable housing options are not available to them. Room to be creative in addressing this crisis and funding housing options for individuals being served is a necessity for states.

States need more agility to build and maintain a sustainable DCW. The building of a sustainable DCW is an ongoing undertaking in all HCBS programs. DCW recruitment is an area where cross-state knowledge and sharing of best practices can be extremely helpful. The ARPA HCBS initiative showed that increasing compensation for DCWs is sorely needed, but it is not a sufficient solution. Effective recruitment and retention of DCWs involves benefits and many other non-compensation factors, most importantly the value, respect, and dignity which DCWs are afforded in choosing caregiving as a profession. Knowledge sharing among states about effective recruitment and retention models should be supported by the federal government and foundations. Changing the culture of how the public views the value of caregiving as part of our shared societal values needs to be included in recruitment and retention strategies. States require more policy agility to test and flex their best ideas for solving this crisis.

3. *Reimagine Quality*

To date, measures of HCBS performance have focused on process and mere compliance, rather than HCBS participant experience and outcomes. Past efforts to incorporate outcome measures still missed the mark. For example, one common measure used in evaluating success in the HCBS system is the number of people served in the community instead of institutions (i.e., rebalancing measures). There is no argument that this is an important data point, however, simply living in the community is not a measure of the quality of life that people experience.

In the summer of 2022, CMS released the first of its kind HCBS Quality Measure Set.[8] This represented an important step toward reimaging how we assess quality of community supports by listening to the voice of the customer. CMS and states are just beginning to formally adopt components of the measure set as part of the Money Follows the Person initiative, with the federal government signaling its intention of a broader application in HCBS writ large via language in proposed rulemaking. The Summit attendees call for HCBS quality measurement to not just ask 'what' and 'how many' but 'how effective' and 'to what degree.' This means the North Star vision must focus quality assessment and improvement on the core purpose of HCBS — supporting people to have full and productive lives in the communities in which they live. Further work on the HCBS quality framework builds on the HCBS measure set, expanding our view to how well person-centered planning and service deliver enables individuals to thrive and live an enviable life.

Conclusion

Many valuable, and in some cases difficult, lessons came from the ARPA HCBS Funding Initiative, which began in April 2021 and will end in March 2025, and occurred during the COVID-19 PHE. Yet, despite its design shortcomings — namely the constrained time for the expenditure of ARPA's time, limited funds, extended delays in the implementation process, the lack of opportunities for real stakeholder engagement, and the heavy administrative burden put on both CMS and the states — the ARPA HCBS Initiative sparked many innovative ideas for improving the HCBS system.

Summit attendees expressed much appreciation for the renewed policy focus that the ARPA Initiative placed on this critical component of the overall healthcare system — HCBS. Millions of older adults and people with disabilities receive services and supports for basic activities of daily living every day of the year from the HCBS system, so that they can live in the community with the greatest independence possible. Summit attendees also expressed appreciation for the spotlight the ARPA Initiative put on the millions of caregivers whose compassion and hard work are not given the respect and dignity they deserve.

Summit attendees expressed much appreciation for the renewed policy focus that the ARPA Initiative placed on this critical component of the overall healthcare system — HCBS.

While Summit attendees had many ideas for HCBS policy changes that could be enacted in the immediate future, they also avidly addressed the "bigger picture" of systemic reform needed at the national level. They recognized that systemic reform was a longer-range objective, and they strongly conveyed the urgency of at least beginning the process of designing a system that could meet future needs. Some overarching systems change opportunities rose clearly to the surface during the discussion. These are broad philosophical, governance, and planning ideas, considerations, and recommendations that we heard — whether it be from a few or many attendees. A large number of these systemic reform efforts require higher-level actions at the federal level, including legislative and statutory changes made by Congress. Without these systemic reforms at the national level, states will be forced to implement piecemeal solutions and our nation's HCBS system and broader LTSS system will not have sufficient capacity, will not be affordable, and, thus, will not be sustainable.

This Summit provided a unique opportunity to focus on the bigger picture of what the nation is and should be aspiring to in building a strong and sustainable HCBS system. Hope was expressed that the ARPA initiative would be a first step in an ongoing series of both incremental and systemic changes to the HCBS system. Furthermore, the desire also was expressed that the conversations that took place at the Summit would continue in other forums across the country in the immediate future.

Growing demand is going to outstrip the system's capacity — the country needs a national strategy and needs it now. The design of systemic reform in a national HCBS system must be approached with urgency. The HCBS system in its current construct is simply not sustainable for a future in which the demand for community services continues to grow rapidly. We must make haste in addressing immediate and longer term HCBS systems change. The potential solutions outlined in this paper are just the beginning, but this work must start immediately.

Endnotes

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