Toward a Shared Definition of Home and Community-Based Services

Final Report of the HCBS Definition Project

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This public report explains the purpose, process, and key learnings of this Consensus Project to describe and define HCBS.

Funded by The SCAN Foundation. The SCAN Foundation envisions a society where everyone can access and afford the care and supports they need to age well at home and in their communities. Working alongside partners to generate evidence, elevate lived experience, shift narratives, and build public will, our work helps to advance policies that strengthen the systems and infrastructure that make this future possible.

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I. Introduction

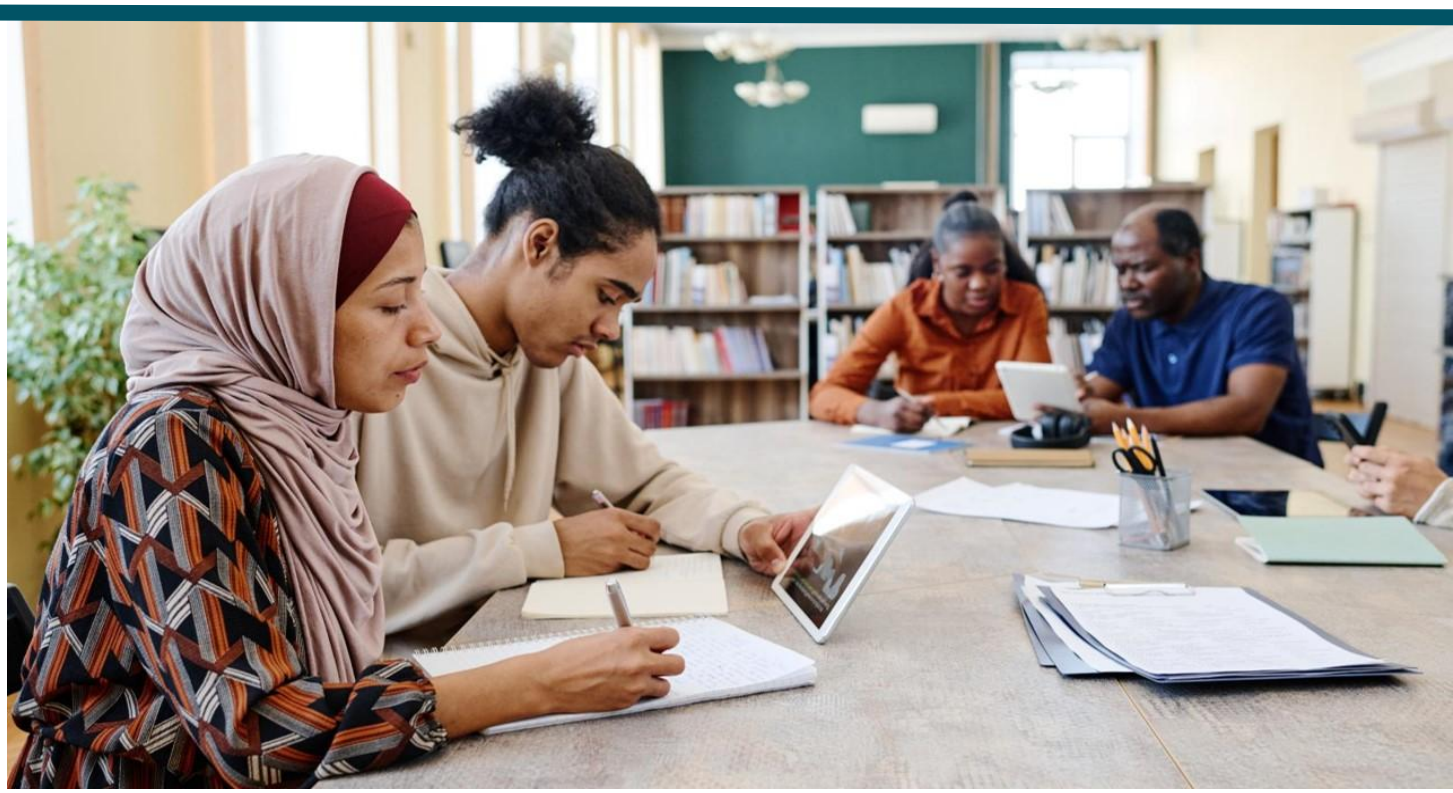
Home and community-based services are central to the ability of millions of people with disabilities, older adults, and their families to live, work, learn, and participate in their communities. Yet the term home and community-based services, or HCBS, does not have one consistently used definition.

The SCAN Foundation funded Human Services Research Institute (HSRI) to lead a national process to identify the essential elements of HCBS and develop a practical consensus definition. The project, which was guided by an Advisory Group, examined how HCBS is currently described; gathered perspectives from people who receive, provide, administer, study, and advocate for these supports; and convened a national consensus panel to reach agreement on a definition.

This report describes the project, what was learned, how the consensus definition developed, and how the definition may be used in policy development, legislative drafting, and advocacy. The definition is intended to apply across all ages and disability populations and is not limited to Medicaid or any other single payer or program.

Project at a Glance

229 Definitions	15 Interviews	3 Advisory Group meetings	3 Consensus Rounds
Identified from more than 7,500 search results	With people who use, provide, manage, study, or advocate for supports	Used to review findings and shape key questions	Each combined advance review, discussion, and revision



II. Why a Shared Definition Matters

HCBS is a familiar term in aging and disability policy, but it does not always mean the same thing to everyone. Sometimes it refers only to services funded through a specific Medicaid waiver. In other cases, it describes a much broader range of supports that help people live at home and take part in community life. These differences make it harder to align policy, compare programs, measure results, and explain available supports clearly.

"There needs to be a shared starting point. If we are serious about community living, we must start by agreeing on what we are talking about."[1]

— Theo Braddy, Executive Director, National Council on Independent living

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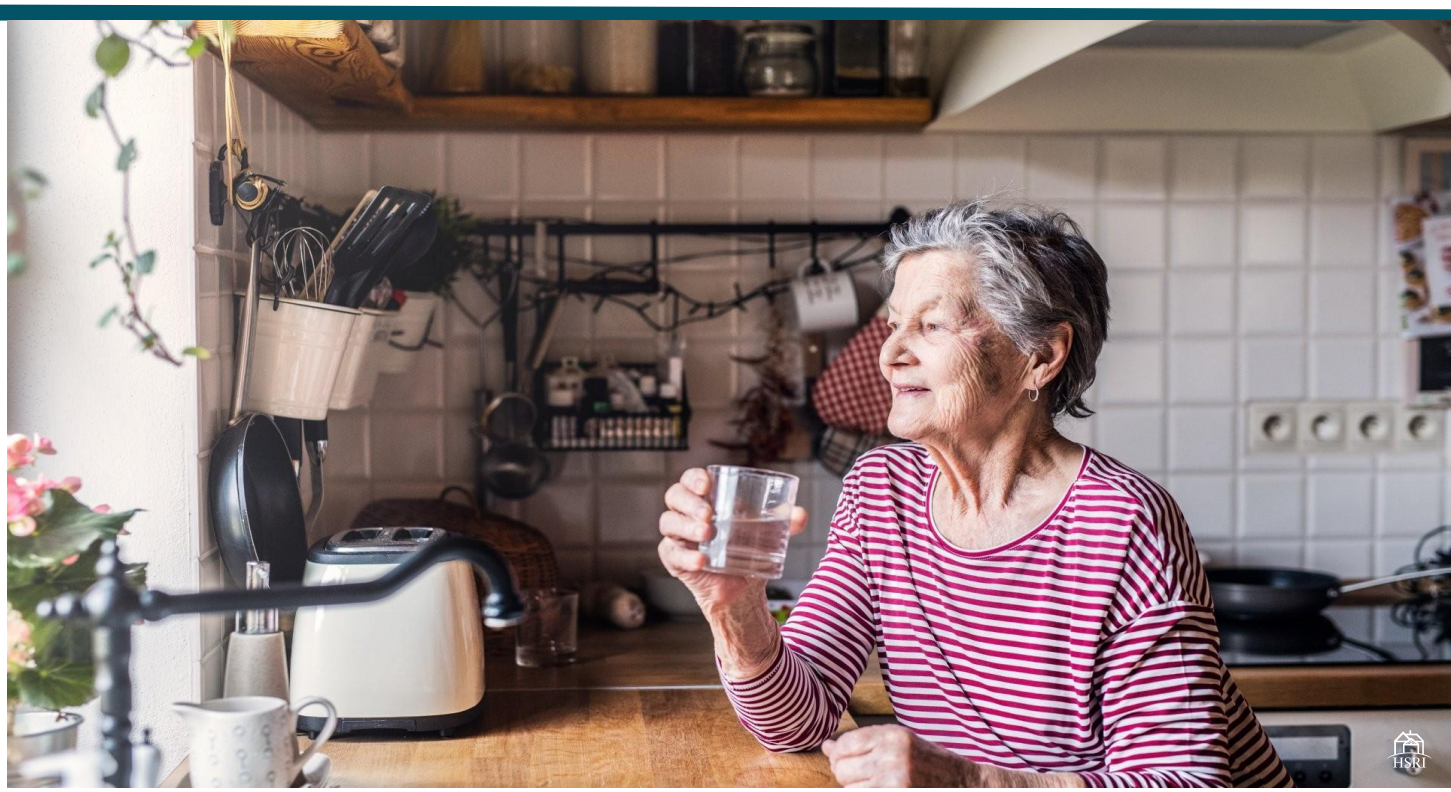
[1] A Message from Theo Braddy: We Cannot Fix What We Refuse to Define - National Council on Independent Living

At the start of the project, the team and Advisory Group members agreed that the definition should:

- support policy development, legislative drafting, and advocacy;
- be payer-neutral—not tied to Medicaid or any one program;
- be relevant across all ages and disability groups and to people with functional support needs;
- be practical in real policy settings, while remaining clear to a broad audience; and
- be forward-looking and grounded in choice, autonomy, self-direction, dignity, and community participation.

Team members also agreed to use the term “HCBS” for the present, recognizing that it was common in current policy and payment language. However, there was recognition that others, including people using HCBS, may use different terms to describe the services and supports they receive.



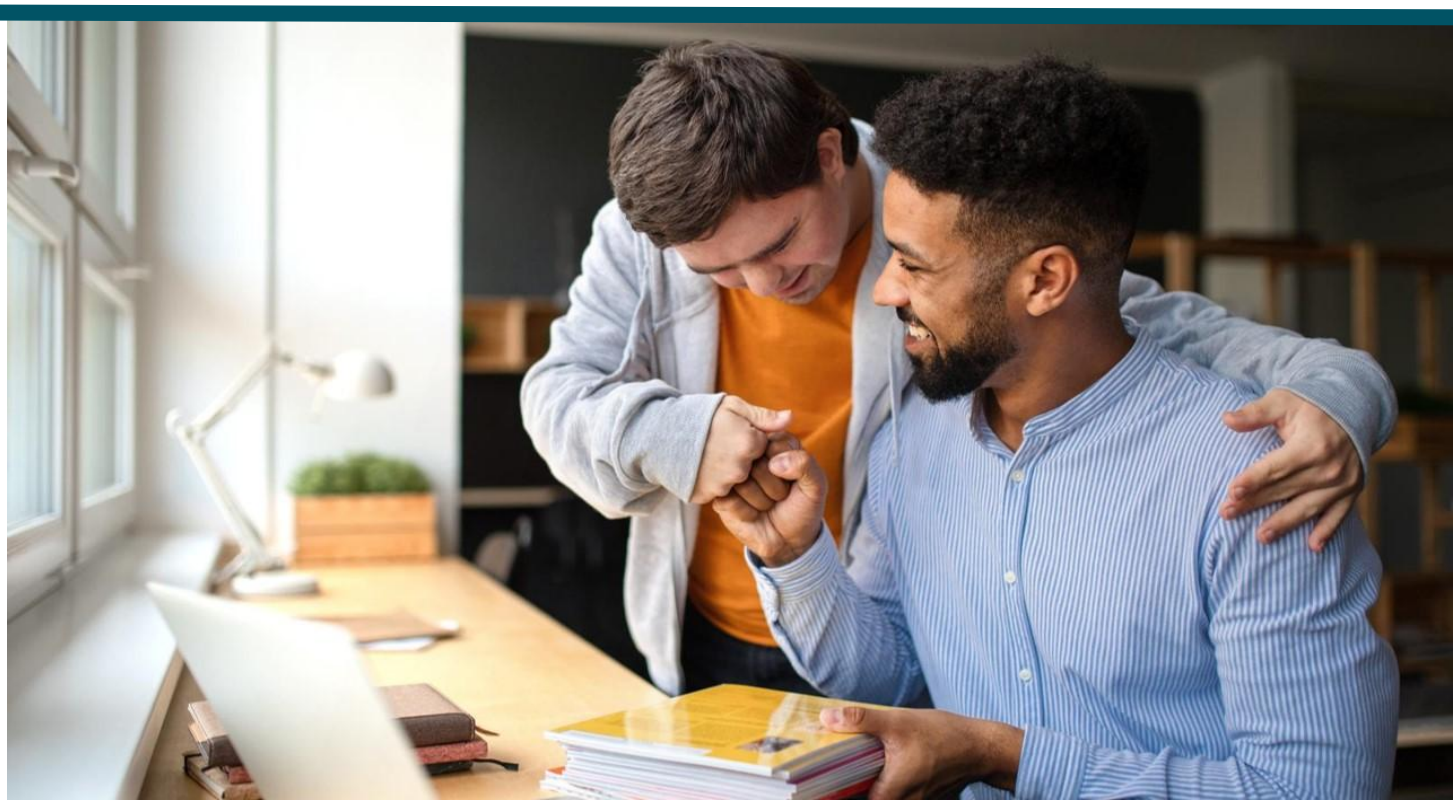
III. How the Project Worked

The project began with research and listening, then moved into a structured consensus process. Each step helped narrow the questions and improve the definition. Project activities included:

- **Limited field survey**: A brief survey gathered early input from administrators, advocates, providers, and others in the HCBS field about what the definition should include and how it might be used.
- **Environmental scan**: HSRI reviewed research, government and advocacy materials, provider resources, and definitions used across programs and policy settings. The team also looked at related quality frameworks to identify commonly valued outcomes.
- **Key informant interviews**: Fifteen interviews gathered more detailed perspectives from people who use, provide, manage, study, or advocate for services. Participants brought experience from aging, disability, behavioral health, veterans' services, chronic illness, brain injury, and family support.
- **National Advisory Group**: A national group with experience in policy, advocacy, research, service delivery, and using services met three times. Members helped the project team understand the findings from the environmental scan and key informant interviews, and to decide which questions the Consensus Panel needed to address.
- **Consensus Panel**: A national panel used a three-round modified Delphi process to arrive at a consensus definition. Almost all of the National Advisory Group members participated plus

additional invited members. This panel comprised researchers, advocates, providers, policy makers, people using services and family members, to reflect a range of experience and perspectives. Members reviewed each draft definition, responded independently through online surveys and voting, discussed areas of agreement and disagreement, tested the definition with sample user personas, and refined the language.

- **Final report and supporting materials**: HSRI prepared the final definition and related materials to help people understand how to use it in policy, advocacy, and research.



IV. Why HCBS is so Closely Associated with Medicaid

Community-based services and supports did not begin with Medicaid. Families, disability organizations, aging organizations, state and local agencies, and other programs supported people in their homes and communities before the term HCBS became widely used. The disability rights and independent living movements also challenged the assumption that people who needed substantial assistance should live in institutions or other segregated settings.

However, “home and community-based services” became established as a formal policy term largely through Medicaid. When Medicaid was created in 1965, the program included strong and explicit pathways for paying for institutional care. States generally had much less authority and flexibility to use Medicaid funds for services provided in a person’s home or community. This contributed to Medicaid’s institutional bias: public financing was often more readily available when a person entered an institution than when the person sought support to remain at home.

In 1981, Congress created the Medicaid Section 1915(c) waiver authority. It enabled states, with federal approval, to provide specified home and community-based services to people who would otherwise meet the requirements for institutional care. This was a major policy change. It helped

states expand community alternatives and made HCBS an increasingly important part of Medicaid long-term services and supports.

Additional Medicaid authorities, demonstrations, court decisions, regulations, and federal initiatives subsequently expanded access to services in community settings. These included establishing a standard definition of HCBS supports current and future efforts to sustain the community living imperative laid out through the Olmstead decision, Money Follows the Person, and newer Medicaid state plan and self-directed service options. Together, these developments reinforced HCBS as a Medicaid term of art or a term with specific meanings tied to eligibility rules, statutory authorities, covered services, settings, and federal requirements.

For many policymakers, administrators, researchers, providers, and advocates, HCBS is still understood primarily through a Medicaid lens. Definitions may focus on specific waiver services, contrast HCBS with Medicaid-funded institutional care, or describe only services that are reimbursable under a specific authority.

Medicaid remains the nation's largest and most important public payer of long-term services and supports, and Medicaid policy is therefore essential to any discussion of HCBS. At the same time, people may receive similar supports to stay in their communities through other programs such as the Older Americans Act, state or local funding, veterans' programs, private insurance, personal resources, or unpaid family and community support. A definition intended to guide broader policy and advocacy must recognize the Medicaid origins of the term without treating Medicaid's program boundaries as the boundaries of HCBS itself.

This history helps explain both the value and the difficulty of developing a shared definition. The project needed to produce a definition that is informed by the long Medicaid history of HCBS and is sufficiently broad to describe the purpose and essential characteristics of home and community-based supports across payers, programs, populations, and stages of life.

V. Initial Findings

A. Early Survey Input

The early survey showed strong interest in a shared definition. It also highlighted a central challenge: the definition needed to be clear without becoming so detailed that it left out people, services, or new approaches. Respondents emphasized everyday life in the community, cautioned against a Medicaid-only view, asked the project to consider less clear-cut situations such as assisted living, and wanted language that would work for different audiences.

B. Environmental Scan

The environmental scan identified 229 definitions from more than 7,500 search results from a 20 year-period. These definitions came from researchers, government agencies, advocacy organizations, providers, educational organizations, and other groups. Some were a single sentence. Others described in detail who uses HCBS, what supports are included, what HCBS is meant to accomplish, how services are funded, where they are provided, or how they differ from institutional care.

Several patterns were clear:

- Nearly half of the definitions referred to aging in place or living or remaining in the community as a central purpose.
- About one-quarter referred to independence; community engagement or inclusion appeared less often.
- Personal care and support with activities of daily living were the most commonly named services, while about one-third of definitions provided no service examples.
- Older adults and people with disabilities were the most commonly named populations, but nearly one-quarter of definitions named no population.
- Definitions were almost evenly divided on whether they explicitly contrasted HCBS with institutions.

This scan was not fully comprehensive. However, the HSRI team collected enough definitions to reach the point where the findings were consistent. This created confidence that the scan reflected a broad sense of how the term is used.

There was not one definition that clearly dominated the field. Instead, definitions often reflected the program, payer, population, or policy purpose of the organization using the term. This finding showed why the project first needed to be clear about how the new definition would be used.

C. Interviews

The 15 interview participants brought a wide range of perspectives. The participants included people who use services, family caregivers, advocates, administrators, providers, and researchers. Their comments moved the discussion beyond a list of programs and services and toward the purpose of HCBS. Themes included:

- **Specificity and inclusion**: More detail can make a definition easier to apply, but it can also leave out a person, service, or new model. A very broad definition protects flexibility but may be too vague for legislation or program decisions.
- **Purpose before a service list**: Interviewees generally wanted the definition to explain what HCBS should make possible—choice, control, participation, dignity, and a whole life—not simply list services.
- **Institutions and community**: Many people understood HCBS as an alternative to institutional care. At the same time, they wanted the definition to describe community life in positive terms, not only by what HCBS is not.
- **Paid and unpaid support**: Interviewees generally distinguished formal HCBS from unpaid help provided by family and friends. They also stressed that unpaid caregivers are essential and may need support themselves.

- **Language and tone**: Participants repeatedly said that the words mattered. Many preferred "support" to more clinical language, and they wanted the final definition to be understandable to people beyond specialized policy audiences.

D. The Advisory Group's Role

The Advisory Group helped the project team make sense of the research and decide which issues the Consensus Panel should concentrate on. Members met three times between September 2025 and February 2026 to review findings, respond to emerging themes, and advise on the project's direction. The Advisory Group supported a payer-neutral HCBS definition and emphasized that the wording should follow from the definition's intended use. Members also identified issues that needed careful discussion: how HCBS differs from institutional models, the role of unpaid caregiving, the boundaries of the definition, and the balance between being specific and remaining flexible.

The Advisory Group did not write the definition. Its role was to sharpen the questions for the Consensus Panel. The initial research and Advisory Group discussions gave the panel a strong starting point without deciding the answers in advance. Almost all Advisory Group members continued onto the Consensus Panel, where they took part in the same structured process as the additional panelists.

VI. Building Consensus

HSRI and The SCAN Foundation brought together a Consensus Panel that expanded the Advisory Group and represented the many people and systems connected to HCBS. Panelists brought experience in aging, disability, behavioral health, veterans' services, policy, administration, research, advocacy, service delivery, and using services.

A. How the Consensus Process Worked

The panel used a modified Delphi process. In practice, this meant that panelists reviewed the draft definition language on their own, discussed it together, and then reviewed a revised version in the next round. Before each meeting, HSRI sent the current draft, a summary of earlier findings and decisions, background materials, and a short online survey. The survey was hosted in Menti. This approach gave each panelist time to consider the language independently and provide ratings and comments before the group discussion.

HSRI summarized the online responses before each meeting so the group could spend its time on the issues that needed the most discussion. Anonymous online voting made it easier for panelists to give candid feedback and helped the team see where there was agreement. During the meetings, panelists asked questions, clarified different interpretations, and worked through disagreements.

Materials and draft language were written in plain language. Facilitators also paused to explain technical ideas or unclear terms whenever needed.

HSRI also scheduled optional pre-meetings before each round. These sessions gave panelists a chance to ask questions about the materials or processes and get technical help. Three panelists attended the first session. No panelists joined the later optional sessions, but HSRI staff remained available at the scheduled times and throughout the process to answer questions.

After each meeting, the project team combined the advance survey results with the discussion notes, recorded why changes were made, and prepared the next version of the definition. Panelists could then see how the language had changed and review the definition again as a whole.

B. The Three Rounds

- **Round 1**: Building the structure (March 2026): Panelists reviewed the starter definition and discussed who should be included, which services should be named, whether duration mattered, what “home and community” meant, whether providers needed to be described, and how to address institutions. This round identified the main parts of the definition and the questions that still needed work.
- **Round 2**: Testing the boundaries (April 2026): Panelists reviewed Version 2 and tested it with personas representing different ages, support needs, settings, services, time periods, and goals. The personas made the language more concrete and showed where the definition worked well or created uncertainty, for example, for behavioral health, health-related supports, family support, employment, and short-term needs.
- **Round 3**: Reaching agreement (May 2026): Panelists reviewed Version 3, discussed the remaining concerns, refined the wording, and decided what explanatory materials should accompany the definition. The panel reached consensus on the main definition and agreed that a preamble and companion materials were needed to add detail and context without making the definition too long.

VII. Final Consensus Definition

Preamble: Intended Use of the Definition

This definition is for policy development, legislative drafting, and advocacy efforts. It is intended to be payer-neutral (not tied to Medicaid or any one program), relevant across populations who have needs for functional supports — this includes all ages and disability groups — and practical and usable in real policy settings.

The definition is intentionally grounded in the values of choice, autonomy, and self-direction, recognizing that while people experience "home" in many ways, policy must clearly distinguish community-based supports from models that replicate institutional control.

Consensus Definition of HCBS

Home and community-based services (HCBS) are a range of supports provided to people in their homes and local communities.

HCBS assist people of all ages who need help to live or remain at home and engage in community life. HCBS may be short-term, long-term, or intermittent. They help people to exercise their right to have choice and control over their lives, including where and with whom they live and their day-to-day activities, including work, school, or other meaningful ways they engage in their community.

HCBS may include supports such as:

- help with everyday activities, including personal care and other services in people's homes;
- health-related and behavioral health supports;
- assistance to do things outside their home, including transportation;
- employment and other chosen day activities;
- supports for family and unpaid caregivers;
- home modifications and enabling technologies; and
- service coordination and navigation across systems, among others.

HCBS can be provided in places such as a person's home, workplace, school, and other community locations. HCBS help people to live, work, and spend time in places they choose that are part of the broader community.

How the Definition Evolved through the Consensus Process

The process to reach the definition was through multiple rounds of review, as described in the prior section. A brief summary of the progression is as follows.

How the Definition Changed

Version	Main task	Main shifts as the definition progressed
V1	Create a starting point	Referenced “medical and non-medical services and supports”, long-term needs and control over services, and included a short list of supports offered.
V2	Broaden and test	Removed technical categories and “home care”; added varied duration, control over life, employment, and settings.
V3 (beginning of third meeting)	Clarify language and boundaries	Used plainer language; removed “good life”; added school and local community; clarified caregivers; added navigation supports; and referenced institutional restrictions.
Final (end of third meeting)	Reach agreement	Moved the institutional distinction to the preamble; strengthened rights, choice, and control; refined examples; and kept the list of services and supports open-ended.

VIII. Final Reflections on this Project

The project produced a consensus definition. It also identified important considerations about how to describe HCBS and how to build agreement across different systems and perspectives.

1	The purpose of HCBS was well understood and seemed like common ground across the multiple groups HSRI connected with. Programs and service lists differ, but there was strong agreement that HCBS should help people live at home, have choice and control, and take part in community life.
2	A useful definition must be both inclusive and clear. No single sentence can name every service, population, setting, and circumstance. The final approach uses a concise definition, examples, and companion materials.
3	A payer-neutral definition creates a broader starting point. Beginning with Medicaid would have narrowed the discussion. Beginning with people's support needs and everyday lives made the definition relevant across Medicaid, aging services, veterans' programs, state-funded supports, private arrangements, and new models.

4	“Home and community” means more than where a service is delivered. A service is not community-based simply because it takes place outside a facility. Choice, control, autonomy, participation, and freedom from institutional restrictions are central to the idea.
5	HCBS may be short-term, long-term, or intermittent. Limiting HCBS to ongoing or lifelong support would leave out important uses such as post-rehabilitation supports to return to community living. The final language recognizes that people may need support in different ways and for different lengths of time.
6	Plain language helped clarify the policy ideas. Replacing technical or unclear terms pushed the panel to be more precise about support, community, meaningful activity, caregivers, and choice and control.
7	The structured process strengthened the result. Seeking advance input online gave every panelist a chance to respond independently. Meetings helped clarify different interpretations. Revisions between rounds showed how feedback was used and gave members another chance to consider the definition as a whole.

A. Implications for Policy and Practice

A shared definition can help policymakers, advocates, administrators, providers, researchers, and people who use services communicate across systems. It can support clearer policy and legislative language, create a common way to compare approaches, and help people judge whether program changes support or weaken community living. It can also strengthen discussions of quality by making the purpose and values of HCBS more explicit.

The definition will not solve workforce shortages, access gaps, inadequate funding, uneven eligibility, or quality concerns. It does give people a shared starting point for those conversations and a clearer way to explain why HCBS matters to the people and families that rely on it.

IX. Supporting Materials

The Consensus Panel recommended supporting the definition with additional materials. These materials add useful detail without making the definition too long or too restrictive. The project developed:

- a summary of the foundational research and key issues considered by the panel;
- illustrative service and support categories, intended as examples rather than a complete benefit list;
- “personas” showing how the definition applies across ages, circumstances, settings, durations, and support needs; and
- an explanation of common HCBS-related terms and how they are used across systems.

These materials are meant to help people use the definition in policy, research, advocacy, and public communication. The next step is to share the definition broadly and continue testing how it works in different policy and program settings. [HCBS Definition Project - Human Services Research Institute]

X. Acknowledgments

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