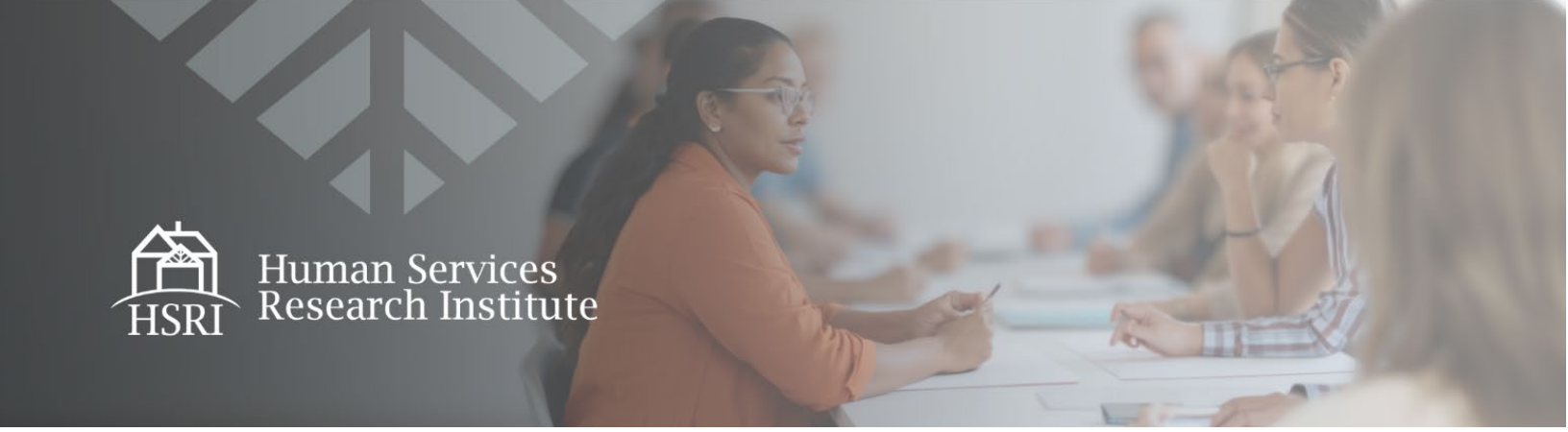

JULY 2026

What We Learned: Foundational Research

HCBS Definition Project

About the HCBS Definition Project

The SCAN Foundation contracted with Human Services Research Institute (HSRI) to help develop a consensus definition of "home- and community-based services," or HCBS, that is not tied to any payer, and that can support policymaking and advocacy to increase access to services. A Consensus Panel of experts played a key role in shaping this definition.

Prior to convening a consensus panel for the project, HSRI conducted foundational research to:

- Understand how HCBS were currently defined.
- Gather input on what a consensus definition should include and how it might be useful.
- Identify important considerations for the Consensus Panel to review.

The goal was to make good use of the panel's time and to make sure the deliberations were informed by a range of views and current usage.

What We Learned

Prior to convening the Consensus Panel, HSRI gathered information from four sources:

- A detailed Environmental Scan of how HCBS is defined across federal and state agencies, research literature, advocacy organizations, and provider groups.
- A limited survey of professionals and stakeholders.
- Fifteen in-depth interviews with people who use services, provide services, study services, or advocate in this space (key informants).
- A national Advisory Group.

This document summarizes these activities. The findings were not intended to limit, but rather help frame, the issues the Consensus Panel considered.

Advisory Group Input

This project was guided by a national Advisory Group of individuals with deep experience in policy, advocacy, research, and service delivery across aging and disability systems. The Advisory Group met three times between September 2025 and February 2026 to review findings, react to emerging themes, and provide strategic input.

The Advisory Group:

- Endorsed the goal of a definition not tied to any particular payer's HCBS definition.
- Surfaced areas that may require careful handling, including
  - How HCBS contrasts with institutional support settings
  - Unpaid caregiving
  - The balance between being very specific about what is included and wanting to remain flexible so that HCBS can be as person-centered as possible.
- Emphasized that the intended use of the definition matters.

The Advisory Group did not draft a definition. Instead, they helped sharpen the questions that moved forward to the Consensus Panel. Almost all members of the Advisory Group agreed to continue their work on the project as members of the Consensus Panel.

WHY: What Is HCBS Meant to Do?

Overall, we found general agreement about what is the main purpose of HCBS.

- In the Environmental Scan, even though the wording varied, many definitions pointed to the same underlying idea: *HCBS exists to help people live outside institutions and take part in everyday community life*.
- Survey respondents most often said that purpose and outcomes are essential parts of a definition, or how HCBS should be described.
- In interviews, people described what HCBS is supposed to make possible.
  - "*I think the purpose of HCBS is to keep people with disabilities and older adults … out of institutions, out of nursing homes, and in the communities that they love.*"
  - "*The purpose of the services… [is] to give people with disabilities the opportunity to live the same kinds of lives as people without disabilities … having your choice … and self-determination.*"
  - Across interviews, words like *choice, control*, *participation*, and *dignity* came up repeatedly.

With broad agreement about what HCBS is meant to accomplish, Consensus Panel members discussed how clearly and directly that purpose should be reflected in the definition.

WHO: Who Is This About?

Overall, there was support for a definition that was not tied to a single payer or population and that was inclusive across aging and disability systems, while remaining sufficiently specific to guide policy and advocacy. However, if the language is too general, it may lose clarity.

- Definitions in the Environmental Scan often focused on broad, cross-disability groups.
    - Older adults, people with disabilities, or people with functional support needs.
    - Relatively few definitions named specific disability populations such as people with intellectual and developmental disabilities, people with behavioral health conditions, veterans, or children with complex medical needs.
    - Nearly one-quarter of definitions did not specify a population at all.
- Survey responses reflected the same pattern.
    - Different systems often define HCBS in ways that fit the population they broadly serve.
- Interviewees raised the risks of narrowing the definition too much when talking about "who" HCBS is supposed to serve.
    - "*You'd have to be careful about how you define [the] population … people interpret [disability] differently.*"
    - Some older adults who receive services may not identify as having a disability.

The panel worked to describe who HCBS is for in a way that was inclusive but still specific enough to be meaningful.

WHAT: What Counts as HCBS?

There was agreement across sources that services matter in defining HCBS.

- In the Environmental Scan, definitions spanned a wide range of services, including but not limited to:
    - Help with bathing, dressing, and daily activities
    - Transportation
    - Supported employment
    - Case management
    - Assistive technology
    - Home modifications
    - Behavioral health supports
    - Transition services
- Personal care services were mentioned most often in the Environmental Scan.
- About one-third of definitions did not include any service examples.
- Several survey respondents indicated that service types were important to include in a definition.
- Some interview participants repeatedly raised concerns about listing services.

- "*As soon as you start listing those things … you then create the possibility that something that you didn't think of might be left out*."
- "*It might be better to focus on … goals and outcomes than actually types of services*."

One question considered by the Consensus Panel was how specific the definition should be regarding services. A detailed list could create clarity, facilitate comparisons, and support legislative and policy language, but there is the risk of leaving out services that are essential HCBS for some. A broad description could protect flexibility but lack clarity.

WHERE: What Does 'Home and Community' Mean?

Another area of consideration was whether and how to define the phrase "home- and community-based." There was broad agreement that HCBS is not institutional care.

- In the Environmental Scan, about half of the definitions explicitly referenced institutions or described HCBS as an alternative to institutional care.
  - The other half used the phrase "home and community" without direct mention of institutions, suggesting the contrast with institutional care was assumed rather than stated.
  - Definitions outside federal and advocacy communities were somewhat less likely to rely on this institutional contrast.
    - Defining HCBS primarily as "non-institutional" may reflect Medicaid HCBS waivers' statutory structure rather than a fully aspirational framing that emphasizes the values of choice and self-determination.
- In interviews, many people described HCBS in contrast to nursing homes or institutions.
  - At the same time, when defining HCBS, they often focused more on daily life, participation, and control than on institutional contrast.

The Consensus Panel considered how clearly the distinction between HCBS and institutions should appear in the definition. In addition, across the Environmental Scan, survey responses, and interviews, several situations emerged that did not clearly fit inside or outside a definition of HCBS. These include assisted living, small group settings, hospice delivered in a private home, and intensive nursing support provided in the community. These types of situations sit near the boundary of the definition. These "edge cases" were explored in developing the consensus definition.

BY WHOM: Who Provides HCBS?

Whether and how to describe who provides HCBS was another area for Consensus Panel deliberation.

- Most definitions in the Environmental Scan did not describe who provides HCBS.
  - Provider types could be implicit in the type of services named (e.g., home health agencies, private duty nurses).

- In interviews, people generally distinguished formal, organized services from unpaid support provided by family or friends.
    - Most did not consider unpaid caregiving to be HCBS in a formal sense, even though they recognized its importance.
- Interviewees also raised caution about naming funders (payers), reinforcing the importance of a payer-neutral definition.
    - "*When you get into funders… you wind up erasing… folks who may need HCBS that aren't system-connected yet*."

DURATION: Is HCBS Ongoing?

- Many definitions in the Environmental Scan assumed long-term or ongoing support.
- Interview participants often described HCBS as part of supporting a person's whole life, not just short-term recovery.
- At the same time, Advisory Group members noted some individuals may use HCBS intermittently.

Language about "ongoing" or "long-term" support could help distinguish HCBS from post-acute and other types of care, but it could also leave out temporary or intermittent use.

Language and Tone

Several interview participants emphasized the importance of word choice in developing a definition. For example, one person noted: *"'Support' is a better word than "services.*" Another noted: "*The tone matters a lot.*" Some respondents also pointed out that the term "HCBS" is closely associated with Medicaid and may not feel inclusive of other systems. Based on this feedback, panel members focused on language and tone for the definition that was clear, respectful, and understandable beyond policy audiences.

Takeaways

While these initial activities did not yield a clear, common definition, they did help identify the following for Consensus Panel discussions:

- Areas of broad agreement.
- Areas that warrant careful consideration.
- Areas that require decisions about the inclusion of key definitional components.

Findings from the foundational research activities demonstrated there was shared understanding about the purpose of HCBS. They also confirmed there was concern about a definition that could exclude people or services. Further, institutional contrast is common defining HCBS, but there was variation in how directly this is expressed.

Overall, there was strong support for creating a shared definition, provided it was inclusive and usable.