JULY 2026

Key Informant Report

HCBS Definition Project

Plain Language Summary

Human Services Research Institute, known as HSRI, worked on a project with The SCAN Foundation to create a shared definition of “home- and community-based services.” These are also called HCBS. HSRI talked with 15 people as part of this work. Some of these people used HCBS. Talking with people who use HCBS is important to create a shared definition. These 15 people came from different backgrounds and different parts of the country. They were offered payment for talking with HSRI. Most of the people liked the idea of creating a shared definition of HCBS.

The people HSRI talked to were:

- Older adults or people with disabilities
- Caregivers
- People who help run HCBS programs
- Advocates
- Researchers

The project team asked people how they define HCBS.

HSRI learned that most people knew the term “home- and community-based services.” Some people were confused about what it meant. HSRI learned that people have seen different ways of defining HCBS. Sometimes this can cause problems. People don’t always realize they are talking about the same thing. People also said that HCBS is a big idea. Sometimes having different ways of talking about HCBS can make it easier to understand.

People gave many different examples of services provided in the community. These were things like:

- Help with everyday activities at home, such as getting dressed or making meals.
- Help with doing things in the community, like working at a job.

They told HSRI that services people get in an institution or a hospital are not part of HCBS. Many people said the goal of HCBS is to help people live in their own homes and be part of their communities. They said that HCBS can make people's lives better, healthier, and with fewer changes they don't want. HCBS can help people have choices and spend time with other people. They also said it was important to ask people using HCBS to learn if their services were good.

HSRI learned that a shared definition could help more people understand what HCBS is. This includes people who write laws. People said it is important that the definition is broad. Many people said that HCBS should look different for each person. Each person has different needs. They did not want people with different disabilities or important services to be left out of the definition. People also said that a shared definition should explain what HCBS is for. A shared definition should also explain how HCBS can change people's lives. It is important to have a definition that is respectful and easy to understand.

HSRI brought together a group of people to help create the shared HCBS definition. This group is called a consensus panel. The consensus panel used the information people shared about how to define HCBS.

1. Purpose

To inform developing a consensus home- and community-based services (HCBS) definition, HSRI conducted key informant interviews. The goal was to gather insight from individuals representing a range of perspectives, including people who use services. The interviews explored how HCBS is defined, including variations in existing definitions, what the key elements of HCBS are, and HCBS purpose and outcomes. Key informant interviews, along with the environmental scan and results from a small survey of experts and interested parties, collectively support the work of a consensus panel. In particular, the interviews validate and expand on environmental scan and survey themes, bring in lived experience, identify nuances, and highlight specific issues for the panel's consideration.

2. Methodology

HSRI developed a semi-structured interview guide which included informed consent language. The guide was submitted to the HSRI Institutional Review Board for review and approval.

Key informants were identified by HSRI, with assistance from The SCAN Foundation, the Public Policy Lab, and a veteran-serving organization who received recruitment materials. Recruitment emails describing the purpose of the project and the interviews were sent to a subset of potential interviewees identified as priorities by HSRI and The SCAN Foundation. HSRI scheduled interviews with those who expressed an interest in participating.

The interviews were conducted using Zoom or Microsoft Teams and lasted on average between 45 to 60 minutes. Prior to starting the interview, an HSRI team member read a standard informed consent script. Conversations were audio-recorded, transcribed using AI-based software, and checked by team members for quality assurance. After the interviews, participants received a thank-

you email. Participants were offered a $40 gift card in appreciation of their time, although not all participants chose to receive one. Team members entered information from the transcripts into an Excel file for qualitative analysis, and themes were identified using AI and by staff who reviewed the Excel file. Following individual review, HSRI team members met to discuss and reach consensus on major themes.

3. Findings

a. Background Information on Informants

HSRI completed in-depth interviews with 15 total key informants who brought varying and sometimes multiple perspectives to the conversations. Table1 shows interviewees' roles; people could represent more than one role.

Table 1. Key Informant Interviewee Roles

Role	Count
Older adult/Person with a Disability/Service User	8
Researcher	2
Caregiver	4
Advocate/self-advocate	6
Provider or State Association Leadership	4
Program administration	1
Veteran	1

Interviewees represented a variety of disability populations, including older adults, children with complex health care needs, veterans with disabilities, people with behavioral health conditions, people with brain injuries, people with physical disabilities, people with chronic conditions, and people with developmental disabilities. Several also had informal caregiving experience. Interviewees spanned multiple age groups, self-reported race, and geographic locations.

Among service recipients and caregivers, HCBS funding sources used for HCBS included private pay or private insurance, state-funded services, Medicaid, and Medicare. Researchers, advocates and program administrators were primarily engaged with Medicaid and other federally funded programs, such as the Older American's Act and Veterans Administration.

b. Current HCBS Definitions

Most interviewees reported knowing and/or using the term "home- and community-based services," although there was some confusion among services users about what this meant. It was noted that this term is most commonly used in policy and professional language, less so in everyday conversations. How people defined HCBS was often tied to Medicaid definitions of the term. Some people also reported using publicly available research reports, the Older Americans Act, and Olmstead to define HCBS. Context could be important when using a definition. One respondent explained, "it depends who I'm talking to."

Interviewees also confirmed there was variability in how HCBS is defined, across states, programs, and systems, or by population. Variation could also be linked to funding structures and who is paying for services. "Whether we're talking about the VA as well as OAA services, or whether we're only talking about OA … I think [a clear definition of HCBS] is necessary, because the resources from which all those services come from is so different."

There were mixed opinions as to whether the current variability is problematic, with a few interviewees stressing the need for flexibility or a balance between consistency and adaptability. One interviewee commented that without a common definition people don't see themselves as part of the "same fight."

Key Informant Voices

"Usually when I'm defining HCBS, I'm defining it to people who want to take it away. So, I always talk about … people's health outcomes being better."

"I think [HCBS] benefit[s] people by giving them not only a happy, healthy outcome, but it also helps you … to be able to want to be in this world and help to make it a better place."

"I think the purpose of HCBS is to keep people with disabilities (including children) and older adults … out of institutions, out of nursing homes, and in the communities that they love, with the families that they love, however that's defined."

"In my opinion, they should ask me what I want, what I need, [and] what I don't need."

c. Community Services and Supports

Interviewees were asked what they thought "community services and supports" included and what would fall outside of this term. Service examples from across all the interviews were consistent with those found in the environmental scan, including assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL), personal care, community integration, transition supports, case management, transportation, employment supports, assistive technology, environmental modifications, and behavioral health services, among others. Some underscored that HCBS are very broad and specific to what each person needs. In terms of what is not HCBS, interviewees listed institutional services, services outside of formal programs or those that are not paid services, and general community supports, like senior centers or public recreation facilities.

Regarding the purpose of HCBS, and consistent with the environmental scan results, several interviewees listed enabling people to live in the community or stay in their home, and/or community integration. Avoiding or reducing institutionalization was mentioned by several interviewees. Other purposes included improving quality of life, normalizing disability, preventing social isolation and supporting self-determination. "The purpose of the services, I think, [is] to give people with disabilities the opportunity to live the same kinds of lives as people without disabilities. It's not just living in the community but living in the community and having your choice."

The desired HCBS outcomes described by interviewees were generally related to the purpose but often broader than just where people lived to encompass quality of life, autonomy, social participation, and health and safety. Specific examples included friendships and community connections, happiness, feeling involved or connected to the community, less precarity, sustainability, being healthy, and feeling good about oneself. Several people noted that outcomes were specific to the person. For example: "I view the whole goal is to provide support to individuals so they can live their lives as they wish, however they define a good life. The outcome has to be in the context of that—did these services support the person in living their life?"

HSRI asked interviewees how, based on their experience, community services and supports were currently monitored to ensure system quality, and how, ideally, they should be monitored. Identifying how HCBS quality should be defined and assessed can support an inductive understanding of HCBS components and purpose. Interviewees mentioned experience-of-care surveys, regulations, licensure, visits, and quality reviews as some examples of current quality monitoring approaches, along with tracking community tenure and emergency department visits. "Ideal" quality monitoring responses most often included asking participants and reflected a person-centered lens. Noted one interviewee, "Are you looking at the things that are most easily discernible, that are objectively measured, that you can get at in a review easily?—[because those are] not

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"In a world where we had a really good consensus definition that felt inclusive to everyone and had full support from impacted communities, I think it would be helpful from a policy lens … [to have] an understanding when you're using that term … of [the] specific services you're talking about—beyond just the supports that are being delivered to that person, but the funding mechanisms [and] the structures that they're connected to. So, when you are making a policy decision, it's very clear about who you're impacting and in what ways."

"I don't think [varied definitions] are at odds with each other. … For adults, I've seen it described as someone comes in the home and helps you get dressed, get in your chair, get you to work, [and] help you eat. … I've [also] seen it described as … assistance in order to contribute to society: There are disabled people receiving services so that they could go to work. It's one common definition."

necessarily the things that matter the most." Staff timeliness, health and safety, and provider check-ins, as well as transparency and data sharing, were also mentioned.

d. Consensus HCBS Definition

Interviewees generally supported developing a consensus definition, although some raised risks or considerations, especially around inclusivity. One respondent noted: "I think there's a world in which [a consensus definition] would be helpful, and that we could get to that outcome. [However] it would have to be such a consensus of the communities … that I believe that it would take a long time in a concerted effort to be as inclusive as possible of anyone who might be impacted." The main rationales cited for a consensus definition were enhancing understanding, unifying advocacy efforts, supporting payment structures, and monitoring quality and outcomes. As one person noted, "If we could define it better, and people understood it better, [people] wouldn't just think it was welfare—right?" Policymakers were cited by a few as the audience for a consensus definition.

Interviewees most commonly described goals and outcomes, and types of services and supports as the components the HCBS definition should definitely include. A few people mentioned the risk of being too specific if types of services were detailed. One respondent commented, "I think it might be better to focus on goals and outcomes than actually types of services. … You can talk about the main types of services that are frequently provided, but I think … you don't want to get too prescriptive, because you want to allow room for those unique types of services."

Interviewees were less likely to suggest including funders or population in the definitions, again raising concerns about inclusivity. Regarding funders, another respondent observed: "I think when you get into funders, as well as, like, administrators, you wind

Key Informant Voices

"So many people actually define [disability] differently. They might not include psychiatric disability, mental health, or … older adults who might not identify as disabled. … You'd have to be careful about how you define [the] population. I think it should be broad."

"As soon as you start listing those things—because these services are so person-centered—it's really difficult to catch everything … that you might need. … And by listing them, you then create the possibility that something that you didn't think of might be left out, and … now that's no longer [offered] because it was intentionally left off the list."

"You could have a very rigid definition of HCBS, where you're very prescriptive … versus something that is more descriptive and calls out examples of services, but also says … the main goal has to be to … support people where they are in their community. (HCBS) can be accessed via private pay, veterans . . . I think that there can be some looser consensus."

"I think it becomes an issue when it is portrayed or communicated as we're providing these services for these very 'sad, pitiful' populations … so let's at least give them a 'glimmer of hope' so that they have something to 'live for.' [T]he tone matters a lot."

up erasing the informal caregivers and the folks who may need HCBS that aren't system-connected yet." One interviewee with lived experience emphasized being concise and specific about cost to the individual, adding, "The word 'free' is good."

4. Discussion and Implications

The key informant interviews were a valuable supplement to the environmental scan of existing definitions. While the environmental scan provided insight on commonalities and differences among extant definitions, including common terms, services, populations, and goals, it did not address the benefits, risks, and considerations for including specific elements in a consensus definition, the value of consensus language, and how such a definition might be used. Key informants provided lived experience of navigating services, a clearer understanding of real-world boundaries, and examples of how services function together in practice. They offered ideas on HCBS goals and language and helped illustrate gaps between policy design and actual experience. The cross-cutting themes from the key informant interviews provided helpful guidance to the consensus panel deliberations. Primary among these was the tension between specificity and flexibility and the risk of excluding services, populations, and payers that are not named.

Other notable cross-cutting themes included:

- Interviewees were more likely to define HCBS by what is intended to do (purpose) than what it includes (services).
- Consideration was needed around how institutional settings were referenced to help define the boundary of what HCBS is not or what it is intended to achieve, as well as whether the definition should include informal and unpaid supports.
- Person-centeredness is a through line across what HCBS comprises, its purpose, and desired outcomes. This includes choice about living arrangement and how "home" and "community" are defined.
- There should be a "whole life" orientation when thinking about what HCBS supports.

Finally, the key informant interviews underscored the importance of thinking about the language. The term "HCBS" itself may have specific connotations with one respondent observing, "I understand why people say things like home-based services, right? Because it's more inclusive …. The connotation [of] HCBS is 'Medicaid.' And so, for people that say home-based services, it pulls in the veterans services, it pulls in OAA, it pulls in private pay." Terms and tone used in a consensus definition should include plain, person-centered, and non-stigmatizing language. One person with disability explained the word "support" was a better word than "services," because it was a synonym for "help" while "services" is associated with programs or service systems that can be intrusive, overwhelming, and hard to navigate.