Many individuals with CRPS or other disabilities may find they need assistance with tasks of daily living—such as meal preparation, bathing, dressing, mobility, shopping, or transportation. Some people may have friends or family willing and able to take on caregiver roles while others lack social supports who can fulfill their needs or any social supports at all. Some may feel uncomfortable asking for or accepting offered help even if their loved ones are willing to help them if the loved one isn't compensated in exchange for their labor or if the disabled person feels too much like a "burden." Others may be aware of facility care homes offering varying levels of assistance that they would qualify for due to their need, but are uncomfortable with consenting due to not wanting to leave their own homes or other adjacent personal reasons.

For all these scenarios, there are Personal Care Programs—or 1915 waivers—offered through state Medicaid that will pay an in-home aide or assistant to help the disabled person with tasks of daily living for a certain number of hours per month based on a state assessment of the person's level of need. These hours are assigned to the disabled person to be dispersed as they desire, whether to one aide or split between several. The aide(s) can be from professional staffing agencies or connection centers meant to help pair clients with nurses or certified aides that will meet your medical needs and personal preferences or they can often be family or "close as family" friends given a waiver to continue the caregiving they have already been providing but receive some compensation for their time and labor, though in some states spouses and parents of minor children are excluded from qualifying due to the expectation that they will care for their disabled dependents without compensation.

Exposition

The Personal Care program is operated under Home and Community Based Services (HCBS) through shared funding from the federal government's HHS and state governments. For people with care needs high enough that they would otherwise qualify for long-term care in a care home facility, HCBS offers the Personal Care waiver program to help keep people in their own homes and communities; this generally has better physical and mental health and personal comfort outcomes for the individuals and is considerably cheaper for the government than facility-based care. These are specifically called 1915 waivers and there are a few different subtypes; the most relevant three for the CRPS community are likely to be: 1915(c) which allows states to offer services like case management, home health aides, personal care, day programs, and respite care, as long as it does not cost more than it would for the person to be institutionalized, 1915(i) which are aimed at low-income individuals (below 150% FPL) who do not need to live in facilities, and 1915(j) which is aimed at self-directed personal assistance, offering patients a more active role in choosing their carers and directing care.

We're going to walk through what the in-home assessment for how hours are assigned may broadly look like, though there may be some variation between states. However, before we dive into that, there are two major points I want to bring to your attention about HCBS, and they are both money-related.

First, HCBS’ personal care program is a long-term facility care alternative; this means it is subject to Medicaid’s clawback or estate recovery. After the patient dies, Medicaid will attempt to seek reimbursement from remaining assets for the costs the government paid on long-term care. There are various exemptions for surviving spouses and children living in the recently deceased’s home, and different ages (often 55 to 65) when estate recovery usually starts applying to care provided. However, some states have estate recovery start accruing at any age if long-term care services are utilized, which can be particularly of note for younger, disabled individuals. Some assets can be protected from estate recovery, such as through MAPT, but those ways should be carefully explored and enacted if the asset is worth protecting. Medicaid Estate Recovery: Rules, Limits & Variations by State — MedicaidLongTermCare.org

Second, with the federal government making steep budget cuts, particularly to HHS, the HCBS department is receiving a fraction of its past funding in 2026, and Medicaid is also slated for deep cuts. During the COVID era and its following recovery, HCBS received an influx of funding improve and expand services offered by the program and to recruit and retain more in-home care workers, since 86% of long-term services and support users received HCBS in 2021 with that number expected to increase as the populace continues to age.[1] In 2013, which was the first year that in-home care overtook institutionalized care, the HCBS budget was $56B.[2] By 2020, HCBS’s budget was $125B.[3] In 2021 and 2022, it was $115B and $130B, respectively.[4] In 2026, the powers that be are providing HCBS a federal budget of $410m,[5] or 0.003% of $130B, according to the currently leaked budget proposal, though I will update this with official numbers once the bill is finalized.

Now HCBS and Medicaid are jointly funded by states and the federal government, so there is still the ability for states to self-fund the deficit, but the fed usually picks up between 50-75% of the bill and up to 83% in the American territories and 90% of Medicaid expansion for low-income adults,[6], [7] so that would be a steep cost to cover and many states may not be willing or able to do so or may decide to divert limited resources to other goals as funding cuts come from all avenues. My point is that there will soon be a critical funding shortage for the HCBS home care waiver programs, which will result in long or closed waitlists and likely cut care hours for people already receiving services in 2026 or maybe even sooner. If this program interests people, I strongly urge you to take the necessary steps to get an assessment or get on a waitlist NOW before the funding crisis prevents you from receiving even reduced services, and so that if more funding becomes available in the future, you will already be a program participant that can fairly easily have their hours increased or be closer to the top of the waitlist or be a prior participant with a case file that can be reopened. With all that out of the way, let’s talk about what an actual assessment may look like, so that you know what to expect.

Personal Care Programs Direct Link to Resource List Sheet for Every State

Practical Application

Before moving into the meat of the assessment that will determine the disabled person's monthly hour allotment, some personal background information will be collected, such as the person's diagnoses, medications, doctors, personal demographics, emergency contacts, and goals or plans or ways to support or specific things to know or avoid. Having a prepared list of diagnoses, medications, and providers with their names, phone numbers, and clinic addresses to give to the social worker can be helpful for them as they do the behind the scenes work after the assessment is over.

Again, the specifics of what is assessed may vary by state, but broadly expect them to include aspects like: activities of daily living (ADLs), instrumental activities of daily living (IADLs), the impact of specific moods and behaviors, cognitive performance, clinical complexity, and whether the patient qualifies for exceptional care. They may also look at informal supports (such as help from friends, roommates, school, neighbors, church groups, and other community resources), how far away you live from a full grocery store or pharmacy, whether you have on-site laundry, and your heating source.

Activities of Daily Living (ADLs) are subdivided into major categories and then rated based on the level of assistance the disabled person requires at least a certain number of times a week (e.g. weight bearing help at least three times a week), though the specific number the case manager is looking for may vary state to state; the highest level of help required over the specified threshold is the level that will be used to allocate monthly hours. There are five major levels of assistance (which again may vary slightly across states):

1. Supervision: caregiver assistance without the disabled person being touched.
2. Non-weight bearing: the caregiver touched the disabled person to help them, but did not lift or support them.
3. Weight bearing: the caregiver was leaned on or lifted or supported a part of the disabled person's body.
4. Partial help with a task: the caregiver fully helped the disabled person complete part of a task. Such as fully putting on socks and shoes as part of Dressing.
5. Total help with a task: the caregiver fully performed the task and all its components.

ADLs are rated based on both the *level* of assistance required and the *frequency* of aid required in the (often 7-14) days preceding the assessment.

Independent (scores as 0): Disabled person not assisted in any way OR received help only once or twice.

Activity did not occur / Client declined (scores as 0): the task didn't occur because the disabled person chose not to do the task or didn't accept help with the task.

Supervision Assistance (scores as 1): Disabled person was reminded, talked through the task or parts of the task, or was monitored X or more times in the X days before the assessment. The disabled person did the task without hands-on assistance.

Limited assistance (scores as 2): Disabled person received active, non-weight bearing help to complete the task or part of the task X or more times in X days before the assessment.

Extensive assistance (scores as 3): Disabled person received weight-bearing assistance during the task OR part of the task was completely performed by a caregiver X or more times in the X days before the assessment.

Total dependence (scores as 4): Disabled person is unable to do any part of this task. Entire task was performed by a caregiver every time the disabled person needed it AND it occurred X times in the X days before the assessment.

Activity did not occur / Client not able (scores as 4): Task did not occur in the X days before the assessment because the disabled person is unable to perform it even if a caregiver is available.

Activity did not occur / No provider (scores as 4): Task did not occur in the X days before the assessment because there was no caregiver available to assist the disabled person.

For example, if an adult child needs regular help Transferring (getting in or out of furniture or standing up or sitting down), they might be Supervised by their caregiving retired parent basically all the time to prevent falls. They may also receive stabilizing Non-Weight Bearing support with a hand on their arm or back several times a day and Weight Bearing support around the waist or under the arms about six times a week. In that scenario, in a state that has a three times a week threshold, the Extensive Assistance hour allocation would be used for the Transfer subcategory of ADLs.

There are seven major subcategories of ADLs and one of those—Mobility—is a three-in-one, so let’s break it down from the least to the most complex.

Eating includes getting foods and liquids from the dish or cup into your mouth or other ways such as tube feeding. It does not include meal preparation, which is accounted for under the Instrumental Activities of Daily Living (IADLs).

Dressing includes putting on, fastening, and taking off all items of clothing, including sleepwear, socks, shoes, jackets and cold weather wear, braces, prosthetics, and compression hose. Supervision here includes being reminded of weather appropriate wear.

Toileting includes help getting on or off the toilet, commode, urinal, or bedpan, wiping or cleansing after use, changing pads or briefs, and adjusting clothing, as well as catheters and colostomies. It includes assistance received even if the disabled person ended up not relieving themselves.

Transfers include help getting in or out of a bed, chair, couch, or other furniture, standing up or sitting down, or getting in or out of a wheelchair. It does not include getting in or out of a shower, tub, or car, or on or off the toilet; these are covered under other categories of

Bathing, Transportation, and Toileting.

Bed Mobility includes help received to position the disabled person while in bed or reclining on other furniture, such as turning side to side or moving down to or up from a lying position.

Personal Hygiene includes help received for grooming and hygiene needs like teeth brushing, hair combing, shaving, applying makeup, denture care, nail care, period care, and face cleansing. It can include hair care at home or at a salon, but does not include bathing or showering.

Mobility is the three-in-one subcategory, and examines three different ways people move; the undersection with the highest assistance level required will be the rating used for the Mobility subsection as a whole. **Walk in Room** includes help received to *walk* inside the disabled person's living space, whether that is a home or a facility, and includes all personal interior rooms, hallways, and sitting areas. **Locomotion IN Room** is for *wheelchair users* receiving help within their residence to move their wheelchair from place to place. **Locomotion OUTSIDE Room** is for both *wheelchair users AND people who walk* receiving help outside their immediate residence but still in the local area to get from place to place, including porches, mailboxes, yards, patios, neighbors, stairs, curbs, uneven grounds; for those in facilities or larger complexes, this includes dining areas, activity centers, front offices, and nearby outside areas. The two Locomotion undersections can be slightly confusing because one is for wheelchair users and one is for everyone, so understand the difference between the two.

For example, if a person does not use a wheelchair, requires only supervision assistance for Walk in Room, but requires Extensive Assistance for Locomotion Outside Room, the overall Mobility section's rating would be Extensive Assistance, as that is the highest score of the undersections.

The above listed ADLs are the ones that count towards the ADL score; however, there are two more that don't count towards the ADL score, but which can still reduce hours if there is informal support with one or both.

Bathing is help received with taking a full-body bath, shower, or sponge bath, including help getting in or out of the shower or tub.

Medication Management includes help received to use or take prescription medications, OTC medications, supplements, or vitamins. Reminders to take medications count towards Supervision.

Instrumental Activities of Daily Living (IADLs) are common tasks performed at home and in the community. These tasks are also rated based on *level* and *frequency* of assistance, though often over a longer period of time, such as 30 days.

Independent: Disabled person did not receive help with the task.

Assistance: Disabled person received any help with the task, including cueing, reminding, or monitoring, in the last XX days.

Total Assistance: Disabled person is a child and functioning outside of typical developmental milestones and needed the activity fully performed by others.

Activity did not occur: Activity did not occur in the last XX days before assessment.

There are five major subcategories of IADLs.

Meal Preparation includes planning meals, assembling ingredients, cooking, and setting out food and utensils. It must include cooking and actual meal preparation.

Housework includes doing dishes, dusting, making and changing beds, vacuuming, cleaning bathrooms, cleaning other rooms, taking out garbage, tidying up, laundry.

Shopping includes getting food, medical necessities, and household items, as well as traveling to and from the stores and putting the items away.

Transportation includes traveling to and from health care providers and medical appointments only, as well as accompanying the disabled person to appointments if the caregiver does not use their own vehicle to take the disabled person to the appointment. (This may vary by state, but is very limited in the requirements I can see.)

Wood Supply includes using wood or pellets as the disabled person’s only source of heat.

After the ADLs and IADLs, the next two components are the Qualifying Moods and Behaviors (QMB) section and the Cognitive Performance Scale (CPS).

The **QMB** includes a Depression scoring (often with the PHQ-2/PHQ-9), whether the individual needs a mental health or therapy program, if they are easily irritable or agitated (if so, how often and is it easily altered), and if they engage in repetitive movements or pacing (if so, how often and is it easily altered).

The **CPS** involves the disabled person’s ability to communicate their needs, wants, opinions, urgent, problems, and social conversations *to the people closest to them*, whether through talking, writing, typing, signing, or in other forms. The scale is *Understood* with ideas clearly expressed, *Usually understood* with a hard time finding the right words of finishing thoughts which can make the disabled person slow to respond or need prompting to be understood, *Sometimes understood* with only being able to express basic needs like food, drink, sleep, or toilet, and *Rarely/never understood* with caregivers needing to interpret specific sounds or body language, if the disabled person can be understood at all.

The CPS also rates a disabled person’s ability to make everyday decisions. Scores are *Independent* with consistent, planned decisions that reflect the person’s lifestyle, choices, culture, and values; *Difficulty in new situations* with a planned routine and ability to make decisions in familiar situations but struggling in new situations or when faced with new tasks; *Poor decisions/ unaware of consequences* with needing reminders, cues, and supervision in planning, organizing, and correcting daily routines, who may attempt to make decisions, but do so poorly; *No/few decisions* with decision making ability severely impaired, even if reminded, and decisions rarely or never made.

Lastly, the CPS assesses short term memory in two different ways. In the first way, the disabled person is asked to remember three words and recite them at a shortly later point in the assessment; Delayed Recall is determined if one or more of the words cannot be remembered. The other way is if the disabled person has problems remembering things that happened recently in a way that is more than just common forgetfulness.

The final two components are a **Clinically Complex Key** and an **Exceptional Care Key**. These two additional Keys assess if there are qualifying conditions that need specific help (e.g. ALS, COPD, diabetes, edema, bladder or bowel incontinence, MS, pain daily, Parkinson’s, RA, ulcers, etc) or give more detail on things like qualifying treatments, appliances, nutritional fluid support, specific toileting help, or help for ventilators, dialysis, or range of motion treatments.

Closing

Hopefully this walk-through was useful, providing actionable information and perhaps alleviating some anxiety for those who get apprehensive over the unknown aspect of medical assessments, especially those done inside a person’s home. While state-specific assessments may vary across the nation, most should have similar core components as described here since the Personal Care Waiver Program is federally-backed.

The Personal Care Program can be a wonderful avenue to offer necessary support for disabled people who desire to continue living at home in their communities. For those who prefer family or friend caregivers instead of professional nurses or aides, it can offer intense psychological relief for those who feel the scales are intensely unbalanced to know that your loved one is being compensated for their time and labor, even if they were more than willing to help you for no return simply because they love you. This program can help rebalance the power dynamic inside relationships in the disabled person’s favor, providing them with more safety, opportunities, and autonomy, leaving them less vulnerable to abuse, neglect, and growing resentment. It is an excellent program for disabled clients, caregiving providers, and it saves the government money; a win all around.

Unfortunately while the next several years will likely see restrictions and cuts to this program, hopefully in the future it will be re-expanded and properly funded so that aging and disabled people can live in their homes and communities safely and with dignity for as long as possible before needing institutionalized care. I encourage anyone interested in this program to seek it out now before the funding cuts make it difficult to access.

Thanks for sticking with me, I hope you learned something, and I hope to see you next time.

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