

Eligibility and Assessment

"The aging network now recognizes the family caregiver as a valued consumer in need of support services in their own right. Other HCBS programs don't yet share this philosophy."

--Medicaid waiver respondent

Eligibility criteria determine who will have access to caregiver support, further define service priorities, and vary by source of program funding. Most HCBS programs focus solely on the functional limitations of frail elders or persons with disabilities. The programs usually do not address the "family unit" together as the client system, the range of informal caregivers' needs or the complexity of caregiving responsibilities (Feinberg et al., 2002; Levine, C., Reinhard, S., Feinberg, L. F., Albert, S., & Hart, A., 2004).

State officials generally define family caregiving programs as those that specifically serve families who are providing care to a relative. Although states vary, they typically do not consider programs targeted to serve an older person or younger adult with disabilities as caregiver support programs, even if they provide important and often significant benefits to families.

Who Is the Program Client?

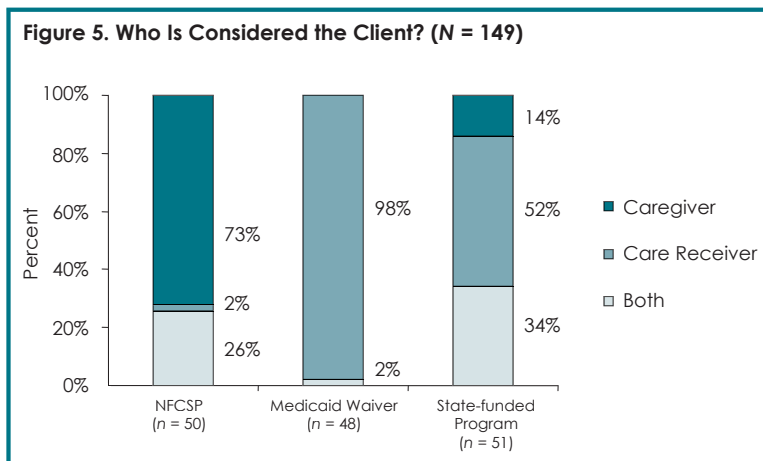
Client designation varies by funding source, with half of the programs in this survey recognizing either the family or informal caregiver as the primary client (30%), or both the person with disability and the caregiver as the client population (21%).

A program's client designation impacts eligibility and shapes how program services are configured and delivered. As shown in Table 1 and Figure 5, the three types of programs examined in this study (i.e., NFCSP, Medicaid waiver and state-funded) differ considerably in whom they see to be program clients.

- Across all three types of programs, half the respondents (74 or 50%) say they consider the person with disease/disability (i.e., the care receiver) the client.
- All but one of the Medicaid HCBS waiver programs (48 out of 49) identified the individual with disability as the client, as did more than half of state-funded programs (52%) and one state NFCSP (Virginia).

Among programs focused on the care receiver, a sizeable proportion (44%) cannot say whether or not their clients have a family caregiver because they do not collect these data.

We found that the family or informal caregiver is the primary client in nearly one-third (30%) of the programs studied (44 programs in 38 states and the District of



Columbia). "I think we 'get' it now," says one state NFCSP administrator, "but that was one of the biggest challenges and one of the lessons learned. The focus [of the program] is the caregiver, the client is the caregiver, and the recipient is the caregiver too. That is quite a switch from how we think, especially in the HCBS world."

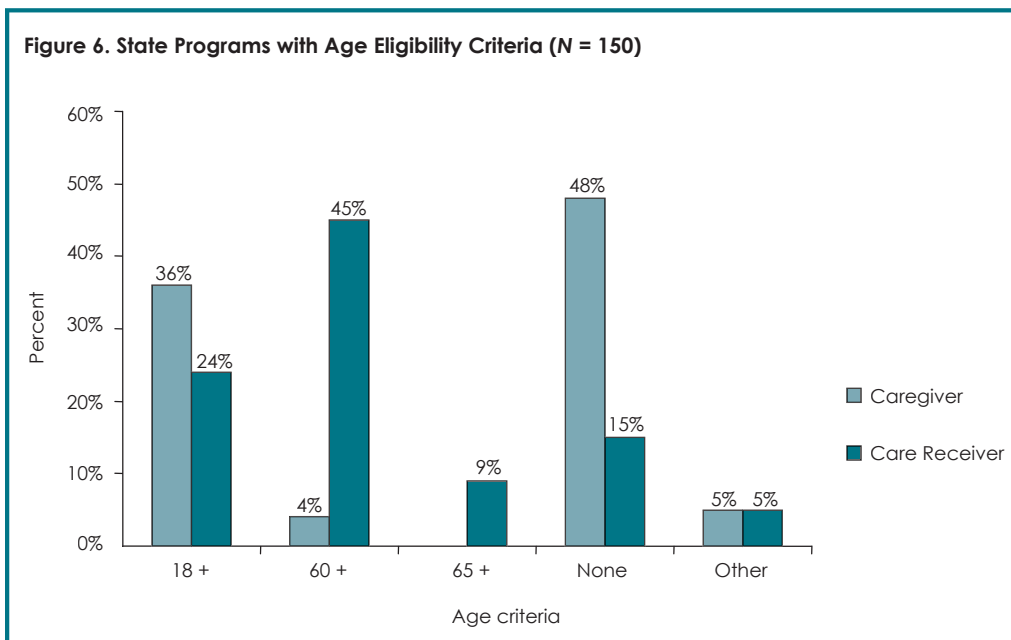
- ♦ NFCSPs make up the great majority of programs (37 out of 44; 84%) designating the caregiver as primary client. They have an explicit requirement under the OAA to serve caregivers of older people. Nevertheless, a sizeable number of NFCSPs (those in 13 states¹⁸) view both the family caregiver and the person with disease/disability as the primary client group.
- ♦ Only a few state-funded programs (seven in six states¹⁹) identify the family caregiver as their primary client. These programs typically have explicit state mandates to serve family and informal caregivers.

Overall, 31 programs in 23 states (21%) including New Hampshire's Medicaid waiver program and 17 of the 50 state-funded programs in this study, take a more "family centered" approach to service eligibility and consider *both* the person with a disability (i.e., the care receiver) and the caregiver to be clients.

Eligibility Criteria

The programs in this study serve a range of disease/disability groups. Eligible populations most commonly include persons 60 years and older with physical disabilities (79%) and/or persons 60+ with Alzheimer's

disease or a related cognitive impairment (73%). Younger adults (i.e., age 18-64) with physical disabilities are eligible for more than one-third (38%) of the programs, generally Medicaid HCBS waiver (52%) or state-funded (49%) programs. State-funded programs in only nine states²⁰ focus solely on persons with dementia.



¹⁸ Arizona, Connecticut, Florida, Hawaii, Idaho, Missouri, Montana, New Mexico, Nevada, New York, Pennsylvania, Rhode Island, Texas.

¹⁹ California (Caregiver Resource Centers); Nevada (Community-Based Caregiving Training); Oklahoma (Respite Resource Network); Oregon (Lifespan Respite Care); Virginia (Caregiver Grant Program); and Washington (Family Caregiver Support Program; Respite Care Services).

²⁰ Alaska, California, Florida, Kentucky, Maine, New Jersey, Ohio, Pennsylvania, Texas.

Programs use a range of criteria, including age, functional status and/or income to determine eligible populations, with most state-administered programs focused on care-receiver characteristics.

Age: As shown in Figure 6 the vast majority of programs have age eligibility criteria for care receivers (85%) and fewer have age criteria for the caregiver (52%). Not surprisingly, given the OAA mandate, NFCSPs were the most likely of all program types to serve caregivers of persons age 60 and older.

- ♦ The most common age requirement for care receivers are age 60+ (68 programs; 45%) and age 18+ (36 programs; 24%).
- ♦ The most common age requirement for caregivers is 18+ (53 programs; 36%); just a few programs require the caregiver to be age 60 or older (6 programs, 4%).

Functional Status: Most programs use some type of criteria related to the functional status or diagnostic category of the care receiver to determine program eligibility. As shown in Table 2, functional eligibility requirements vary by source of funding and type of service.

The most common functional requirements for eligibility are based on the status of the care receiver:

- ♦ nursing home eligible (50 programs²¹, 33%)
- ♦ limitations in two ADLs (33 programs, 22%)
- ♦ diagnosed with Alzheimer’s disease or a related cognitive impairment (28 programs, 19%)
- ♦ a few programs (16, 11%) report no functional status requirements.

Income: Like functional status and age, states vary widely in financial eligibility requirements depending on funding source and type of service provided. Most publicly funded programs restrict the income eligibility of the care receiver to target those most in need.

- ♦ A total of 61 of 146 (42%) programs responding report no income requirements for their program. These are the NFCSPs (79%) and state-funded programs (21%).
- ♦ Programs with financial requirements typically look at the care receiver’s income and/or assets. Although amounts allowed vary widely, SSI-eligibility is the most common.

Assessment

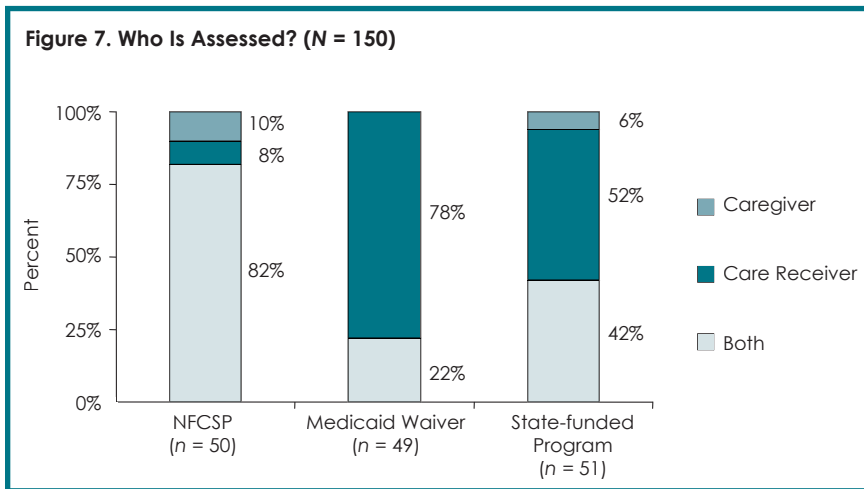
Less than half of the programs in this study uniformly assess caregiver needs.

Caregiver assessments may establish eligibility for explicit caregiver programs or for support services from broader HCBS programs. Few state programs uniformly assess the family caregiver’s well-being and his or her own service needs, even though understanding the role, multiple stressors and particular situation of the family caregiver is viewed as essential to

²¹90% of the Aged/Disabled Medicaid waiver programs.

any care plan developed for the care receiver (Baxter, 2000; Feinberg, 2004; Gaugler, Kane, & Langlois, 2000). "Caregivers need a formalized assessment system," advocated one Medicaid waiver respondent. "They need a tool that asks them what they need, that is unified and formalized and can be used across the health care continuum."

As shown in Table 3, about half of the state administrators (49%, 74 programs) say they assess needs, in some way, of both the older adult or person with disabilities and the family caregiver. This approach to dual assessment is much more common among the NFCSPs (82%), compared to Medicaid waiver (22%) or state-funded programs (42%) (see Figure 7).



Medicaid waiver and state-funded programs most commonly assess only the person with disease or disability (in 78% of waiver and 52% of state-funded programs). In all, 68 programs (45%), including four NFCSPs (Iowa, Louisiana, New Hampshire and Virginia), report they assess only the person with disease or disability.

Eight²² programs (5%) in seven states and the District of Columbia assess only the family caregiver's needs.

Despite the variation among programs in their assessment

targets, there is broad recognition of the value of uniformity in program assessment instruments. The more established the program, the more likely it is to use a uniform tool. Among all 150 programs surveyed, the majority (69%; 104 programs) use a statewide, uniform assessment tool in their program, rather than instruments that differ from one locality to another. Moreover, programs with a uniform assessment process often include the family caregiver's situation in their assessment.

- ♦ Almost all Medicaid waivers (94%) report using a uniform tool, as compared to state-funded programs (64%) and the NFCSPs (51%).
- ♦ More than two-thirds (68%; 71 programs) of the 104 programs with a uniform assessment tool say they assess the family caregiver's needs and situation, too.

Still, fewer than half (47%) of all state administrators in this survey say their state program uniformly assesses the family caregiver's needs and situation in addition to the care receiver. The programs that most typically utilize a uniform assessment process for the care receiver but do not conduct a caregiver assessment are the Medicaid HCBS waivers (44%). "We don't have caregiver issues built into the assessment process," comments one Medicaid waiver respondent. "This would be a whole new way of thinking about support and services."

²² NFCSPs in Alaska, District of Columbia, Maine, Minnesota, and North Dakota; state-funded programs in California (Caregiver Resource Centers); Nevada (Community-Based Caregiving Training); and Oklahoma (Oklahoma Respite Resource Network).

As shown in Figures 8 and 9, client designation appears to influence assessment policies. Programs that are “caregiver-specific” or view both the care receiver and the family caregiver as their clients, generally assess both members of the dyad to better understand the care situation.

- Among the 44 programs (37 NFCSPs and 7 state-funded) that consider the family caregiver the client (Figure 8), eight programs (18%) assess the family or informal caregiver only and 32 (73%) assess both the caregiver and the care receiver.
- Of the 31 programs that consider both the care receiver and the family caregiver as clients (Figure 9), the great majority (81%, 25 programs) assess both family members.

Table 3, shows how the domains used to assess a family caregiver’s needs and situation vary greatly among states and programs. Figure 10 illustrates the top five areas found in uniform assessment tools used by programs to assess caregivers.

- For the NFCSPs, the top five areas of caregiver assessment are: “ability to provide care” (76%); “basic demographics” (71%); “caregiver strain” (67%); “care frequency”; and “caregiver physical health” and “caregiver depression” (57% each).
- For the Medicaid waiver programs, the top five areas of caregiver assessment are: “willingness to provide care” (92%); “ability to provide care” (88%); “care frequency” (84%); “caregiver strain” (72%); and “care duration” and “physical health” (56% each).
- For the state-funded programs, the top five areas of caregiver assessment are: “ability to provide care” (80%); “caregiver strain” (76%); “basic demographics” (64%); and “caregiver physical health”, “care frequency” and “caregiver depression” (56% each).

In their responses, state officials frequently observe that the Medicaid waiver assessment of caregivers focuses on whether or not the family caregiver is willing and available to provide care to the individual, not on the caregiver’s own particular needs and support.

Figure 8. Assessment in Programs with Family Caregiver as Main Client (n = 44)

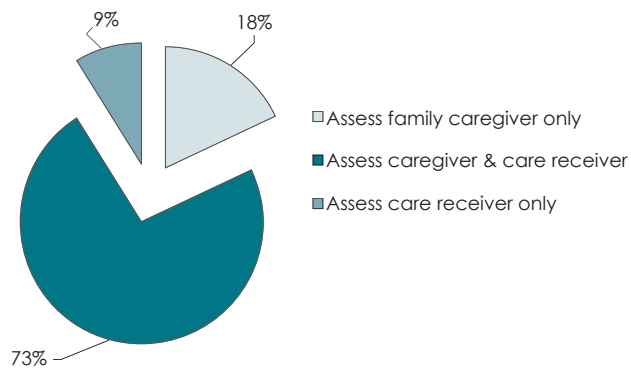


Figure 9. Assessment in Programs with Both Family Caregiver and Care Receiver as Main Client (n = 31)

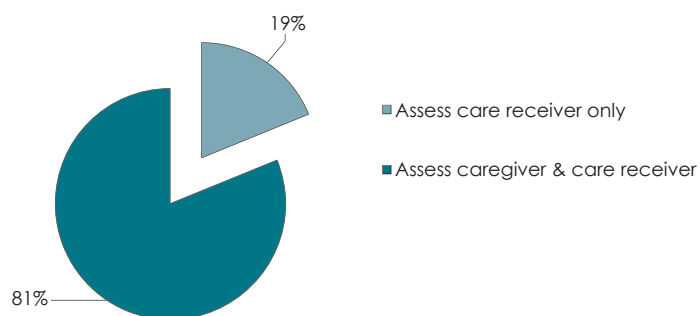
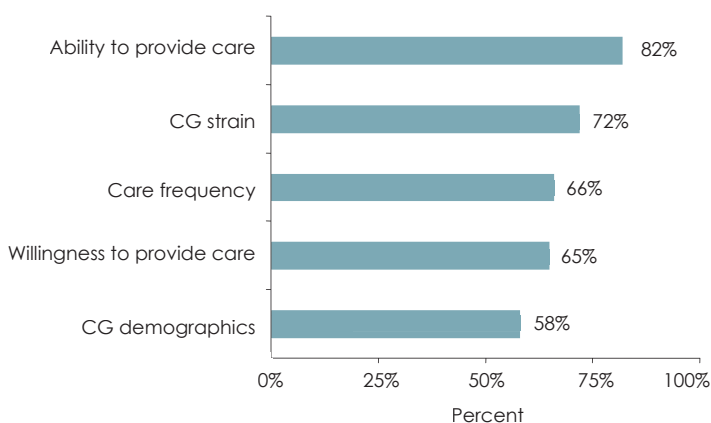


Figure 10. Caregiver Assessment: Top 5 Areas Addressed (n = 71)



Note. CG = caregiver