

Systems Development

"I think that this is the most important program that the aging network has done in the last 20 years in terms of crossing boundaries and starting to think of older people in terms of their families and those who support them. We are moving toward supporting families as opposed to making people fit into categorical age criteria, and recognizing that older people are part of larger family systems. If we are successful... it will change the way that we deliver social services. This is working to break down some of the silos that we talk about. We are becoming more responsive as a result of supporting caregivers."

--NFCSP respondent

State System of Home and Community-Based Services (HCBS)

In the absence of a national, cohesive long-term care system, states have developed their own systems, primarily funded by Medicaid and state general revenues. Currently, a key policy goal in most states is reforming long-term care by expanding HCBS (Weiner et al., 2002). States face growing needs for long-term care services and supports due to an aging population, consumer preference for HCBS and constrained federal and state resources. Many states seek to develop more responsive community systems of long-term care, including family caregiver supports.

State approaches to systems development in HCBS and family care vary greatly due to differing administrative structures, funding sources and levels, program eligibility requirements, service definitions and distinct services, and other factors. For example, a respondent in this study (an administrator of a state-funded program) notes a major challenge: *"Differences in the definition of ADLs and IADLs from one funding stream to the next [NFCSP and Medicaid waiver, primarily]. This creates an organizational barrier because it leads to staff inconsistencies and not being able to translate the same assessment information from two different tools."*

States also differ in the degree to which they integrate their family caregiver support programs into other HCBS programs, and state officials' views about this issue vary, too (Feinberg & Newman, in press). The NFCSP may be helping states to advance their system development efforts. One study respondent, for example, tells of collaboration between the Medicaid waiver administration and the family caregiver support program to educate waiver service staff about the needs of the state's family caregivers.

Program administrators within a state often have differing views about the level of integration of their states' HCBS system for the elderly and adults with physical disabilities.

In this study, we asked state program administrators to choose one statement that best characterizes the level of integration of their state's HCBS system for the elderly and adults with physical disabilities. We gave them three choices:

- ♦ integrated through intake, assessment, care planning and data collection
- ♦ part of a larger program, but separate assessment and data collection

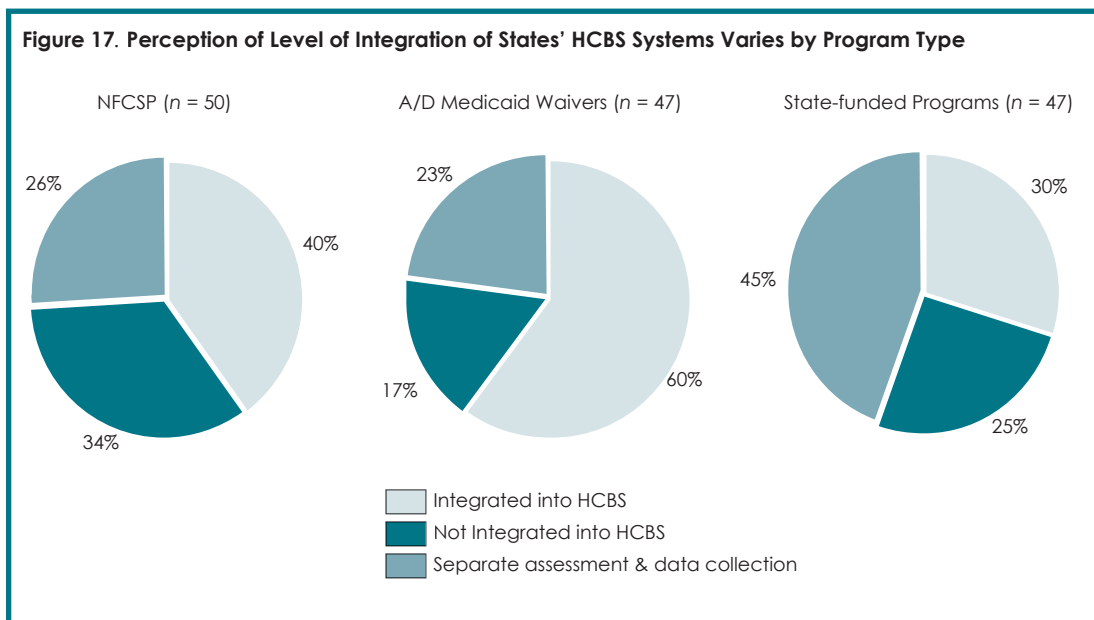
- ♦ not integrated into the state’s home and community-based service system.

In only 21 states do all program administrators within the state agree on this issue.

- ♦ More than four in 10 (43%) or 62 programs (in 33 states and the District of Columbia) report that their state’s HCBS system is integrated through intake, assessment, care planning and data collection.
 - In 14 states²⁹ all program respondents within the state agree on the level of integration.
- ♦ Nearly one-third (31%) of state administrators for 45 programs (in 21 states) say they are part of a larger program, but have separate assessment and data collection.
 - In three states (Florida, New Jersey and Pennsylvania) all respondents within the these states are in agreement on this issue.
- ♦ About one in four (26%) respondents for 37 programs (in 23 states) characterize their program as not integrated into the state’s HCBS system.
 - In four states (Kentucky, Massachusetts, New York and Rhode Island) the program respondents within these states are in agreement on this issue.

As shown in Figure 17, the perception of level of integration varies by type of program.

- ♦ Medicaid waiver respondents are the most likely to view their state’s HCBS system as integrated (60% Medicaid waivers, 40% NFCSPs, 30% state-funded programs).



²⁹Arizona, Delaware, Iowa, Indiana, Kansas, Maine, Minnesota, Mississippi, North Dakota, New Hampshire, South Dakota, Washington, West Virginia, Wisconsin.

- State-funded program respondents are the most likely to view their programs as part of a larger program, but with separate assessment tools and data collection requirements (45% state-funded, 26% NFCSPs, 23% Medicaid waivers).
- The NFCSPs are the most likely of the three program types to view their program as not integrated into their state's HCBS system (34% NFCSPs, 25% state-funded, 17% Medicaid waiver programs).

About one-fourth of the states use a uniform assessment tool for all HCBS programs for the elderly and adults with disabilities; family caregiving is a component in just five states' uniform assessments.

A uniform assessment tool and protocol for all HCBS programs is one method that states utilize to develop support systems that are more responsive to consumer needs and preferences and to coordinate eligibility and care across various state programs that serve frail elders, adults with physical disabilities and their family caregivers. As discussed in earlier findings (see Eligibility and Assessment section), we asked state program administrators if their specific program uses a uniform assessment tool. We also asked administrators whether their state has a uniform assessment tool for *all* its HCBS programs for the elderly and adults with physical disabilities, and if the state does, whether this tool includes a family caregiving component.

- A total of 60 programs (41%) in 30 states and the District of Columbia report a uniform assessment tool for all HCBS programs in their state.
- Of these, only half (31 of 60 programs) in 17 states indicate their state's tool includes a caregiving component.

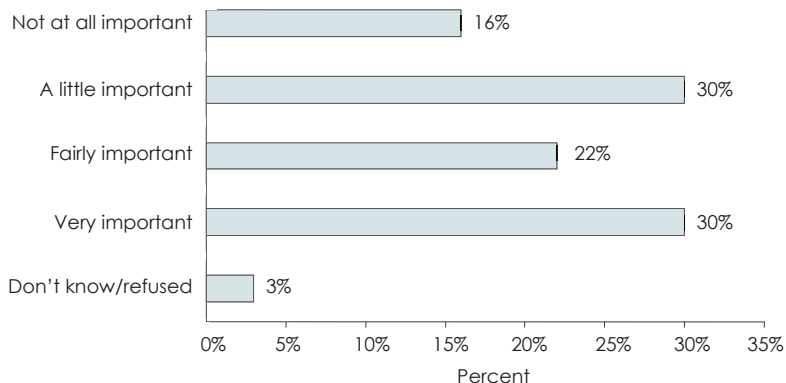
Not surprisingly, given that administrators in the majority of states have differing perceptions about the level of integration they see in their state's HCBS system, there is also a general lack of agreement among state program administrators about the adoption of a uniform HCBS assessment tool in their state.

- In just 12 states³⁰ do all program administrators within the state agree that a uniform assessment tool is used for all HCBS programs for the elderly and adults with disabilities.
- Of those 12 states, respondents in only five (Delaware, Louisiana, Minnesota, South Dakota and Washington) report their state's tool includes a caregiving component.

Several Medicaid waiver respondents from states that have uniform assessment protocols but do not assess the needs and situation of the caregiver, commented that their state does not have caregiver issues built into the assessment process. One Medicaid waiver respondent remarked: *"Sometimes we don't know who is the significant other in a client's life. A major barrier to looking at program outcomes is trying to assess how well the program is meeting the family caregiver's needs too."*

³⁰Colorado, Delaware, Indiana, Louisiana, Maine, Minnesota, Mississippi, North Dakota, Oregon, South Dakota, Washington, West Virginia.

Figure 18. States Have Mixed Views on the Importance of *Olmstead* to Caregiver Support (N = 148)



States have mixed views on the importance of *Olmstead* to caregiver support.

As a result of the *Olmstead* decision, many states have worked to develop an *Olmstead* plan and are engaged in ongoing activities to expand community services for individuals with disabilities and promote community integration. A recent analysis of state *Olmstead* plans found that some states developed specific strategies slated for implementation over a number of years; some identified

key priorities for more immediate actions; some set forth broad policy recommendations to guide future action; and others anticipated frequent plan updates and revisions in what they consider to be working documents (Fox-Grage, Folkemer, & Lewis, 2003).

Family and informal support are essential to the successful transition of those with disabilities back into the community. We asked state program administrators how important the *Olmstead* decision is in influencing the development of caregiver support services in their state. As shown in Figure 18, states have mixed views on this issue, although over half (52%) of program respondents say that *Olmstead* is “fairly” or “very” important in influencing the development of caregiver support in their state. Medicaid waiver respondents are somewhat more likely (59%) than those representing state-funded programs (53%) and the NFCSPs (46%) to report that *Olmstead* is either “fairly” or “very” important to caregiver support.

We also asked each state respondent to indicate what priority is placed on implementing an *Olmstead* plan, among all long-term care issues in their state. Nearly half (48%) report a “high” priority, one-third (33%) say “medium,” a few (6%) report “low” and two programs believe that *Olmstead* is not a priority at all. Some (12%) say they “don’t know.”

The top barriers to coordinating caregiver support programs with other HCBS programs in the states are differing eligibility requirements and service complexity and fragmentation.

We asked program administrators to identify the three most important organizational, programmatic, geographic or political barriers (other than funding) that limit or prevent coordination of the caregiver support program with other HCBS programs in their state. Eligibility issues (50%) take the lead as shown in Figure 19. One Medicaid waiver respondent identified the need to change eligibility and the service package to better support family

Figure 19. Barriers That Limit/Prevent Coordination with Other State HCBS Programs*

Barrier	Program responses**	
	n	%***
Different eligibility requirements	70	50%
Complexity and fragmentation of services	60	43%
Different client population than in other programs	55	39%
Different reporting requirements/ capabilities	37	26%
Organizational cultural differences	31	22%
Federal regulatory or statutory requirements	30	21%
Staff have too many responsibilities	29	21%
State regulatory or statutory requirements	23	16%
Lack of access to adequate computer technology and support	16	11%
Lack of knowledge of opportunities for coordination	16	11%
Low priority given to caregiver support services	14	10%
Other	9	6%

Note. *Excludes funding. **N=140.

***Percentages are based on total number of responses.

caregivers: "We must move beyond the care receiver as the focus of care," a waiver respondent explains. "No one looks at the caregiver when we look at eligibility or when they are seeking to deter institutionalization. Overall, it is the stress of the family caregiver as well as the care receiver status that puts someone in a nursing home. If we were able to look at factors outside the care receiver's status that would be helpful, and we would do a better job of truly assessing risk of institutionalization."

The next two most important barriers are complexity and fragmentation of services (43%), and different client population (i.e., informal caregivers) than in other programs (39%). No major differences were found among the three groups in this study (i.e., NFCSP, Medicaid waivers, state-funded programs).

Top Long-Term Care Issues; Caregiver Support Priority

Expanding Medicaid HCBS waivers, integrating long-term care services and implementing or expanding consumer-directed care are the top long-term care issues identified in the states.

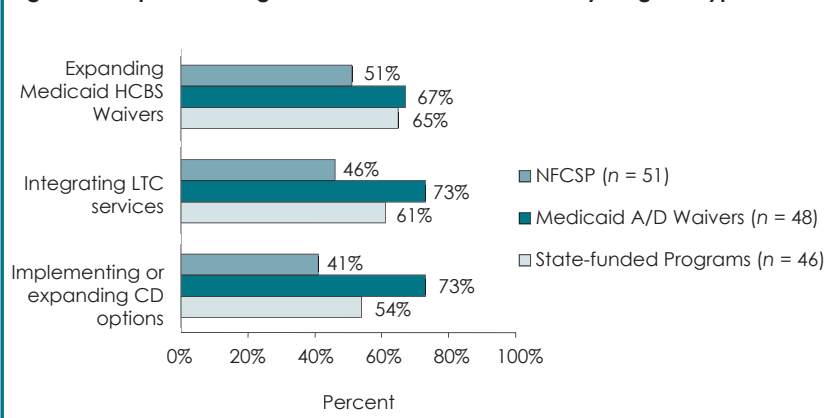
We asked state program administrators their opinion about the state's priority (high, medium, low) for 11 long-term care issues. The top priorities among respondents, include:

- expanding Medicaid HCBS waivers for the elderly and people with disabilities (61%)
- integrating long-term care services (60%)
- implementing or expanding consumer-directed options (56%).

Figure 20 shows the top long-term care priorities in the states by program type. Not surprisingly, given the economic downturn in most states at the time of this survey, lowest priority is given to expanding programs and services or creating other financial supports at the state level. Issues most frequently ranked as a low priority are:

- expansion of state-funded caregiver support programs (33%)
- expansion of state-funded home and community-based services for the elderly and adults with disabilities (32%)
- establishment of tax credits for caregiving (29%).

Figure 20. Top Three Long-Term Care Priorities in States by Program Type



Note. HCBS = home and community-based services; LTC = long-term care; CD = consumer-directed.

State program administrators have mixed views about the importance of caregiver support within home and community-based care; the majority perceive caregiver services as a medium priority.

We asked respondents to indicate what priority (high, medium, low) their state places on family caregiver support services within all of the state's home and community-based care programs. No differences emerge among program groups. Overall, program administrators view the importance of caregiver support in HCBS as follows:

- ♦ "high" priority (26%)
- ♦ "medium" priority (56%)
- ♦ "low" priority (18%)

As with other opinion questions in this survey, respondents within a state often have different views of the priority placed in their state on caregiver support. In 27 states there was no consensus. In the 23 states with consensus, we see:

- ♦ "high" priority given to caregiver support within six states (Illinois, Louisiana, Massachusetts, Montana, North Dakota and Pennsylvania)
- ♦ "medium" priority in 13 states³¹
- ♦ "low" priority in four states (Alabama, Colorado, Kansas and West Virginia).

States are beginning to establish task forces or commissions to examine family caregiver issues.

In response to the NFCSP, some states have formed task forces or commissions on family caregiving issues. Other states have established task forces or commissions to highlight the central role that family caregivers play in long-term care as states move toward more responsive and coordinated systems of care. In still other states, informal caregiving issues are being addressed as part of broader state task forces on long-term care in general or HCBS in particular.

In this study, 15 states³² report either a task force or commission on family caregiving. These entities range in scope and objective. Examples include:

- ♦ The *Connecticut LifeSpan Respite Coalition*, a grassroots coalition of individuals, is seeking to identify gaps in respite services and to coordinate existing services available to families across the lifespan.
- ♦ *Hawaii's Family Caregiver Network* is bringing together family caregivers by providing a coordinated system to disseminate information to family caregivers on a range of issues, serving as a vehicle for families to comment on and respond to caregiving needs and policies, and serving as a resource for researchers.
- ♦ The *Maryland Caregivers Support Coordinating Council*, operated through the Maryland Department of Human Resources, is working to improve support services for unpaid family caregivers in the states, including the need for additional resources for respite care.

³¹Arkansas, Arizona, Delaware, Florida, Iowa, Maryland, Minnesota, New Hampshire, Oregon, Rhode Island, South Carolina, Vermont, Wyoming.

³²Alabama, Colorado, Connecticut, Hawaii, Illinois, Indiana, Louisiana, Maryland, Michigan, North Carolina, New York, Oklahoma, Oregon, Utah, Virginia.