

## Other Issues

*"Supporting family caregivers is family-friendly state policy."  
--Medicaid waiver respondent*

As state administrators work to strengthen and enhance services in the home and community, they face complex issues. We asked respondents for their opinions about key policy and programmatic issues for caregiver support and long-term care in their state. What do they see as unmet needs for caregivers? What are their views about training and technical assistance to better meet the needs of family and informal caregivers? What are their major challenges, what have they learned about providing caregiver support services and what would they recommend to other states pursuing similar goals? What new legislation has been enacted in the states to support caregiving families?

### Top Unmet Needs of Caregivers

**State program administrators see the lack of resources to meet caregiver needs in general and limited respite care options as the top unmet needs of family caregivers in the states.**

When we asked respondents this open-ended question, "What would you say is the major unmet need of family caregivers in your state?" we received many different answers, but definite themes emerge. As Figure 21 shows, about half of all respondents in the states identify as unmet needs the overall lack of resources for a range of caregiver services (e.g., services for working caregivers, culturally appropriate services, family counseling) and the limitation in respite options. Although a minority of respondents identify other unmet needs in the top five, their concerns reveal the challenges officials are facing in the states as they implement caregiver support programs: lack of public awareness about caregiver issues and programs, shortage of workers to provide help to caregivers, and access to services in rural areas.

**Figure 21. Top Five Unmet Needs of Caregivers in the States**

	Program responses*	
	n	%**
Lack of resources to provide a range of services	69	50%
Limited respite care/options	66	47%
Lack of public awareness about caregiver issues/programs	38	27%
Shortage of providers (workforce)	23	17%
Limited access to services in rural areas	13	9%

Note. \*N=139. \*\*Percentages are based on total number of responses.

### Program Support Needs: Training and Technical Assistance

**About half the state programs offer training for staff who work with family caregivers.**

Well-trained staff can reduce the stress of the family caregiver (Levine, 2004). As shown in Table 6, 69 programs or about half (47%) of programs surveyed provide training for staff who work with family caregivers. Another six programs (4%) say they are developing training on caregiving topics.

- ♦ The top five training areas are:
  - caregiver assessment (60%)
  - best practices in service delivery (54%)

- data collection and reporting (50%)
  - outreach and public awareness (47%)
  - caregiver intake issues (47%)
- ♦ NFCSP respondents (61%) are, not surprisingly, more likely than state-funded (40%) or Medicaid waiver programs (39%) to provide caregiver-related training to program staff.

**Three of the top five current training topics match those training and technical assistance areas almost all respondents say would benefit staff: best practices in service delivery, outreach/public awareness and caregiver assessment.**

Figure 22. Top Five Identified Technical Assistance & Training Areas for Staff Who Work with Family Caregivers*	% Responding "Strongly Agree" or "Agree" **
Best practices in service delivery	99%
Culturally/ethnically appropriate services	97%
Program evaluation/outcome measures	96%
Outreach/public awareness	92%
Caregiver assessment issues	91%

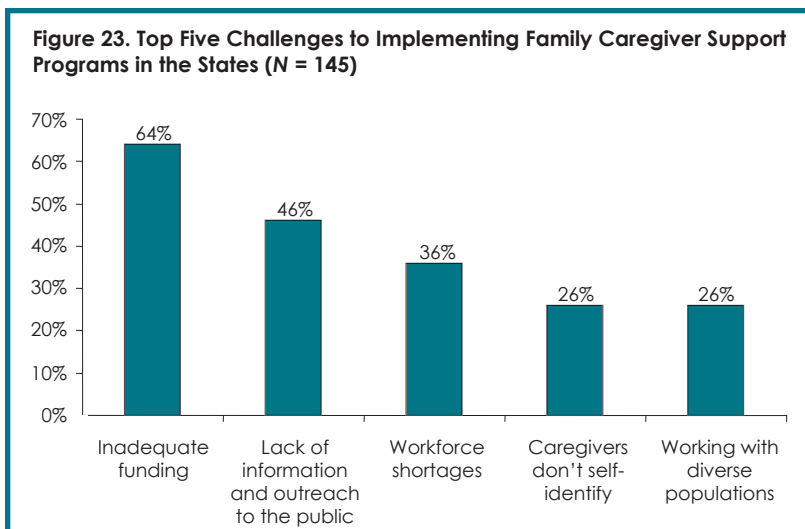
Note. \*N = 139. \*\*Percentages are based on total number of responses.

We asked respondents to share their views about the benefit to their staff of technical assistance and training on 11 specified topics. Figure 22 shows the five areas where state program administrators see the most likely benefit. Interestingly, two of the top three areas for technical assistance are *not* among the topics that actual training programs most often address: culturally/ethnically appropriate services and program evaluation/outcome measures.

### Top Challenges, Lessons Learned and Recommendations

**States identify inadequate funding as the main challenge to implementing caregiver support services.**

In telephone follow-up interviews we asked program respondents this question, "What are the three main challenges to implementing family caregiver support services in your state?" The majority of program respondents (64%) report "inadequate funding." As Figure 23 shows, many of the other recurring themes match the officials' views on unmet caregiver needs:



- ♦ **Lack of information and outreach to the public.** Nearly half (46%) feel that many families who might benefit from their services do not know where to go for help. More outreach is needed to educate families about caregiving needs and available services.
- ♦ **Workforce shortages.** More than one in three (36%) respondents face a shortage of qualified service providers (e.g., social workers) or direct care workers (e.g., nurses aides). Low wages and turnover are often cited as a big part of this challenge.

- **Caregivers don't self-identify.** One in four (26%) respondents say it is often difficult to provide services when many caregivers don't identify with the term "family caregiver." Rather, family members view themselves as the husband, wife or daughter and may not recognize their own support needs or that programs could assist them in the care of their loved one. Increased public awareness campaigns can help alleviate this challenge.
- **Working with diverse populations.** One in four (26%) cite the challenge of providing targeted services to support ethnically diverse caregivers and meeting the needs of working, long-distance and other caregivers with particular care concerns.

Among just the NFCSP respondents specifically, one in four (25%) note the challenge of the "paradigm shift" in serving a new constituency, family members and friends, along with supporting the older person, the traditional client in the long-term care system.

***The major lesson learned by the states in providing family caregiver support is 'one size does not fit all'—so increase the choices that families have.***

We asked in our follow-up interviews with state program administrators, "What is the major lesson you've learned in providing family caregiver support services?" (see Figure 24). Among the many lessons that they share, the one that comes up most often is maximizing flexibility and choice for families. "Support is different for each family – there's there's no one size fits all for families," one Medicaid waiver respondent puts it. "Sometimes the support is more for the caregiver themselves than for the care receiver."

Figure 24. Major Lessons Learned by State Programs in Providing Family Caregiver Support Services	Program responses*	
	n	%**
Maximize flexibility and choice for families	47	33%
Allow caregivers to tell you what they need	37	26%
Provide a range of support services to meet caregiver needs	25	18%
Focus on consumer education and outreach to general public	22	16%
Caregivers don't self-identify	14	10%

Note. \*N=141. \*\*Percentages are based on total number of responses.

Other lessons that multiple respondents report are that it is important to focus on consumer education and outreach to the general public and that caregivers often need help to self-identify with the term "caregiver." One NFCSP respondent explains, "No one knows the stress and need (emotional, mental, and physical) of caregivers. Once you start talking about it people understand, but until you start that dialogue they can't conceptualize the need."

***To strengthen caregiving programs, state officials recommend more innovation in program design to provide a broader array of services, better coordination and integration of caregiver support into HCBS, and more local collaboration.***

When asked what recommendations they would make to other states that are implementing caregiver programs, respondents have many suggestions. As Figure 25 shows, the top recommendations are these:

- ♦ **Ensure innovative programs and a flexible array of caregiver support services to meet the diverse needs of families and the individuals for whom they care.** Respondents emphasize the importance of finding new ways for delivering services (e.g., through enhanced use of technology and on-line support groups, or providing mobile respite in rural areas) as well as the importance of flexibility to caregivers, especially for those who may be hard to reach (e.g., rural, working and long-distance caregivers).
- ♦ **Coordinate and integrate caregiver support into HCBS.** Respondents call attention to the fragmented nature of long-term care services and stress the need to integrate caregiver support into the HCBS system, making the delivery of caregiver services an everyday practice in family-centered home and community-based care. *"Don't look at caregiver programs in a silo,"* recommends one NFCSP respondent. *"Integrate caregiver support into other HCBS programs."*
- ♦ **Collaborate with local stakeholders.** Respondents suggest collaboration with local consumer groups to build consensus, develop programs and deliver services. One state-funded respondent notes, *"Tapping into community resources is a key element to a successful program."*

	Program responses*	
	n	%**
Ensure innovative programs and a flexible array of caregiver support to meet the diverse needs of families	57	40%
Coordinate and integrate caregiver support into HCBS	42	29%
Collaborate with local consumer groups/ agencies to build consensus, develop programs, and provide services	32	22%
Maximize family and consumer involvement in service planning and delivery	28	19%
Conduct strategic planning/needs assessment prior to program implementation	27	19%
Promote consumer-directed models of care	26	18%

Note. \*N=144. \*\*Percentages are based on total number of responses.

- ♦ **Maximize family and consumer involvement in service planning and delivery.** Respondents underscore the importance of recognizing families and care receivers as partners in long-term care. *"Delegate flexibility all the way down to the consumer level. It is not enough just to give it to the AAA, or to the provider,"* recommends one NFCSP respondent. Instead:
  - Listen to, assess, and take into account the caregiver's individual needs and situation.
  - Develop a vocal constituency base and have families participate in advocacy efforts to build partnerships at the community and state levels.

- ♦ **Conduct strategic planning.** Respondents recommend advance planning and a thorough needs assessments prior to program implementation. *"We did four public hearings around the state [prior to the start of the NFCSP] to hear from individuals and families to see what they needed,"* shares one NFCSP state administrator. *"This was great for us, and helped us get the input from people providing care."*

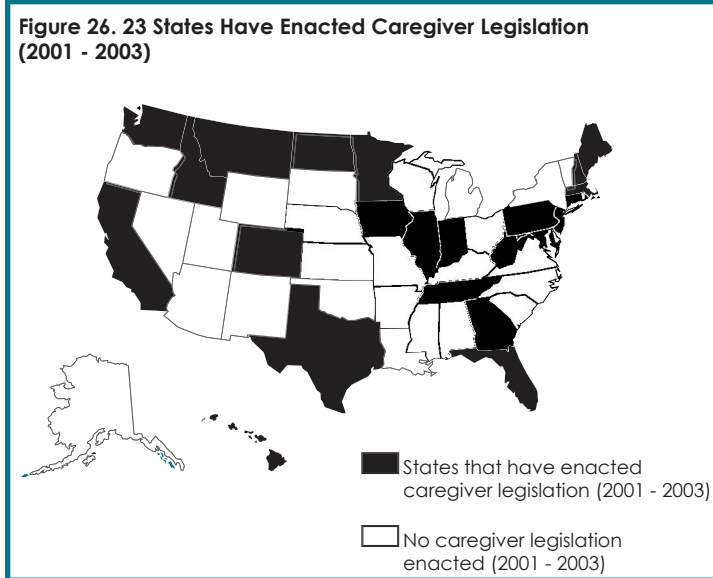
- ♦ **Promote consumer direction.** Respondents say that consumer-directed models of care allow for a more family-centered approach to support and services, including payment to families to provide care. One Medicaid waiver respondent advises, *"Make caregiver support an integral part of any type of personal care program, also allowing the families to be paid providers. Making sure families can be paid will help with funding issues, because it's built-in support for families."*

## New Legislation in the States

***State legislatures, recognizing family caregivers' important role, are enacting laws to fund caregiver support services, expand family and medical leave, and include family caregiving in state long-term care efforts.***

From 2001 through 2003, 23 states enacted legislation that was relevant to family caregiving (see Figure 26 and State Profiles).

- ♦ In 11<sup>33</sup> states, legislation funded family caregiver support programs, many enacting these changes as a direct result of the NFCSP.
- ♦ California, Hawaii and Washington enacted legislation that expanded the minimum requirements of the federally prescribed Family and Medical Leave Act (FMLA).
  - California enacted the most comprehensive paid family leave bill in the nation in 2002. It provides up to six weeks of partial wage replacement (100% employee-funded) for workers caring for a new child or seriously ill family member.
- ♦ Maryland, New Hampshire and Washington established work groups, councils or commissions to study and coordinate family caregiver support services.
- ♦ Connecticut, Hawaii and Iowa enacted legislation to ensure that family caregivers are central to long-term care programs and policies.
  - In 2001, the Connecticut legislature required state agencies to include provisions that support family caregivers in any program that assists or supports people with long-term care needs.
  - In 2001, the Hawaii legislature established support for family caregivers of adults with disabilities as a long-term goal of the state.
  - The 2003 session of the Iowa legislature added "support for caregivers" to the state's objectives for serving older individuals.



<sup>33</sup>California, Colorado, Florida, Idaho, Illinois, Indiana, Maine, Massachusetts, New Jersey, North Dakota, Pennsylvania.