

CONCLUSIONS AND ISSUES FOR THE FUTURE

This study illuminates the large role states play in the nation's support of family caregivers. The wide-ranging study profiled the experience of all 50 states and the District of Columbia in providing publicly funded support services to caregivers of older people and younger adults with disabilities since the passage of the NFCSP. Designed to take a broad focus, the study examined policy choices and state approaches to caregiver support through state agencies responsible for the administration of the NFCSP, Aged/Disabled Medicaid waiver programs, and state-funded programs that have either a caregiver-specific focus or include a family caregiving component in their service package.

Conclusions

This report of caregiver support services in the U.S. revealed the following:

While there is increasing availability of publicly funded caregiver support services, there is also great unevenness in services and service options for family caregivers across the states and within states.

In this study, state program administrators identified the lack of resources to meet the range of caregiver needs in general, and limited respite care options in particular, as the top unmet needs of caregivers in the states.

All states now provide some explicit caregiver support services as a result of the passage of the NFCSP in 2000. Yet, similar to HCBS in general, the availability of caregiver support services varies greatly across the U.S.

due to differences in philosophy, program eligibility criteria, funding and approaches to program design and administration of services. For example, although respite care is the service strategy most commonly offered to help caregivers, and is available in all 50 states, our findings suggest that the goal of respite (i.e., whether it is targeted toward the care receiver or viewed as a service to sustain the family caregiver), its definitions, and the amount of respite assistance available to family members varies substantially from state to state and programs within states.

In this study, state program administrators identified the lack of resources to meet the range of caregiver needs in general, and limited respite care options in particular, as the top unmet needs of caregivers in the states. At a practical level, such service gaps and variations pose challenges for caregivers by limiting choices for needed support services that may not be available where they live. Service inequities may also place more pressure on already strained caregiving families and compromise the ability to care for a loved one.

The NFCSP is emerging as a key program to enhance the scope of caregiver support services and is fueling innovation in the states, but is inadequately funded.

In this study, the NFCSP was found to expand the range and scope of services to caregivers of older people in states where caregiver support

services existed before the establishment of the NFCSP. In other states, the NFCSP now serves as an important resource for the provision of services not available previously. In addition to respite care, caregiver education and training, care management and family consultation, individual and/or family counseling and support groups are offered by the majority of the states to some degree under the NFCSP.

The NFCSP also appears to be speeding the adoption of consumer direction in explicit family caregiving programs. However, the modest level of NFCSP funding leaves gaps in caregiver support services and also results in substantial variation in service availability across the states. When compared to Aged/Disabled Medicaid waiver funds spent on respite care alone, the NFCSP funding appears even more limited.

While there is great variation among states and programs within states in their approach to caregiver assessment, there is broad recognition of the value of uniformly assessing caregiver needs and the importance of training and technical assistance in this area.

Only five states that use a uniform assessment tool for all HCBS

programs for older people and adults with disabilities were found to include

a family caregiving component as part of systematic assessment practice. The majority of state-funded and Medicaid waiver programs in this study assess only the person with disabilities, not the needs and situation of the family caregiver. Yet, systematic assessment of the caregiver's

needs as distinct from, but related to the needs of the care receiver, is central to systems change and to improving policy and practice in HCBS. Indeed, identifying and meeting the specific needs of family caregivers is often a deciding factor in determining whether an individual can remain at home or must turn to more costly nursing home care. Without uniform, aggregated assessment information on the caregiver, it is difficult to measure the impact of services on family caregivers and to assure quality of care for frail elders and adults with disabilities.

Systematic assessment of the caregiver's needs as distinct from, but related to the needs of the care receiver, is central to systems change and to improving policy and practice in HCBS.

States have mixed views on approaches to systems development, the importance of caregiver support services within home and community-based care, and integrating family caregiving programs into HCBS.

On the one hand, state program administrators in this study often had different perspectives on these issues and, more frequently than not, respondents within a state lacked agreement. On the other hand, during the time of this survey, states were facing an economic downturn while they were attempting to develop plans to rebalance long-term care by expanding HCBS options. In addition, the advent of the NFCSP created a paradigm shift with its new mandate to explicitly provide services to family caregivers of older people. Recognizing the legitimate needs of family caregivers as a "consumer" or "client population" has been found to be a relatively new concept for many states (Feinberg et al., 2002). Therefore, it is not surprising that in a time of major organizational and systems

change, there may be different levels of understanding and perspectives of how states can and should accomplish the policy goal of reforming long-term care by expanding HCBS.

Our current HCBS system relies heavily on family and informal caregivers. Families need help more than ever as they struggle to balance competing demands of work, family and caregiving. Caregiver support services can help ease the burden on families, increasing confidence and competence in everyday care tasks and providing needed respite care to sustain them in their caregiving role. Without recognition of the legitimate needs of family and informal caregivers and additional investments in caregiver support services, the reforms underway in HCBS may not be as effective and meaningful to American families.

If we are serious about reducing fragmentation in home and community-based care and recognizing the legitimate needs of informal caregivers, then assessment of caregiver needs and caregiver support services should be integrated into HCBS.

If we are serious about reducing fragmentation in home and community-based care and recognizing the legitimate needs of informal caregivers, then assessment of caregiver needs and caregiver support services should be integrated into HCBS. A family-centered approach to HCBS should be considered as states continue to pursue the goal of reforming the long-term care system to strengthen integrated systems of home and community-based care.

Issues for the Future

From this study, we can identify important issues for the future. The following are five initial steps towards achieving a better caregiver support system across the nation:

- 1. Raise the funding level of the NFCSP to reduce gaps in caregiver support services and provide meaningful support to caregiving families.** The level of NFCSP funding is too low to meet the multifaceted needs of family caregivers. Increasing funds for the NFCSP will help promote systems change and ease the burdens on family caregivers. This in turn will prevent much higher Medicaid and HCBS expenditures that might be necessitated if the informal caregivers became incapacitated or unavailable (Vladack, 2004).
- 2. Improve data collection and reporting under the NFCSP and other state programs that provide caregiver support services.** As part of the development process for the NFCSP, the Administration on Aging should partner and work closely with states on uniform reporting requirements that will take effect in fiscal year 2005. Accountability is critical to the success of the NFCSP and other caregiver support programs. However, because many states do not have uniform reporting systems in use across their own HCBS programs, including those providing caregiver services, it is impossible to report at this time on caseloads and funding across all programs that provide some component of family caregiver support. Federal, state and local policymakers and program administrators must make decisions based on outcomes. Uniform data collection is essential for programs to achieve a more consistent understanding of the scope of services across the country and to ensure that federal and state funding remain viable.

3. **Strengthen and expand uniform assessment of caregiver needs in all HCBS programs that provide some component of caregiver support.** Currently, there is no consensus about how to assess family care or what should be included in a uniform caregiver assessment tool. Developing such a consensus should be a high priority (Gould, 2004). Establishing guidelines for caregiver assessment, based on an outcome-driven knowledge management system, would be a worthwhile investment to develop better data to support and drive decision making. Ultimately, consistent approaches to caregiver assessment will enable family caregivers to obtain needed support, strengthen their ability to ensure optimal outcomes and quality of care for the care receiver, remain in their caregiving role as long as appropriate, and provide solid information to policymakers and program administrators intent on improving the effectiveness and efficiency of HCBS.
4. **Conduct a national public awareness campaign on family caregiving.** Outreach to informal caregivers specifically, and to the public in general, is crucial to ensuring that families and friends access information and services early in the caregiving process, and have the supports they need to adequately sustain them in the caregiving role. In this study, lack of public awareness about caregiver issues and programs—including the notion that caregivers don't self-identify with the term "caregiver"—was a recurring theme: as a top unmet need of caregivers, as a topic for training and technical assistance, and as a challenge to implementing caregiver support services in the states.
5. **Invest in innovation, promising practices and technical assistance.** States want to know about and learn from the successes and challenges of other states' efforts to support and strengthen family and informal caregivers. State administrators of the NFCSP, Medicaid waiver and state-funded programs were particularly interested in program design to provide a broader array of services, develop consumer direction to maximize flexibility and choice for families, and to use technology with those caregivers who may be difficult to reach (e.g., rural, working and long-distance caregivers). Over 90 percent of respondents in this study viewed five topics as the top training and technical assistance areas most likely to benefit their staff: best practices in service delivery; culturally/ethnically appropriate services; program evaluation/outcome measures; outreach/public awareness; and caregiver assessment.

This first 50-state study on caregiving offers new insights into the ways states provide caregiver support services and approach family caregiving issues in the context of HCBS. As such, it provides a starting point for further examination of the policy choices and state approaches to caregiver support, as well as changes over time. We hope that this report, and subsequent papers and issue briefs emanating from this study, will help to stimulate continued development of policies and programs to support family and informal caregivers of older people and adults with disabilities.