

Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support

Introduction and Purpose

This In Brief summarizes the findings of the AARP Public Policy Institute Issue Paper, *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*, by Lynn Friss Feinberg, Kari Wolkwitz, and Cara Goldstein.¹ Some states incorporate caregiver support services into their programs that serve older people or adults with disabilities; in other states, caregiver support is a separate program with distinct eligibility criteria. Because many states have been increasing funding of home and community-based services (HCBS), there is strong interest among policymakers and program administrators in learning more about emerging trends and forward-looking practices in caregiver support that have the potential to bolster caregiving families and improve the quality of care for adults who receive long-term care at home.

This report highlights three emerging trends that have important implications for addressing the needs of family caregivers: caregiver assessment; consumer direction in family caregiver support services; and collaborations between the aging network and the health care system, for example, in identifying family caregivers who may be at risk for their own health problems and emotional strain associated with the caregiving role. These trends were identified from data collected for an earlier 50-state survey of 150 publicly funded programs. Eight states—Alabama, California, Georgia, Massachusetts, Minnesota, North Carolina, Pennsylvania, and Washington—were then selected for in-depth examination, including interviews with key program personnel. In addition, a literature review identified two model programs that have formed partnerships on caregiving between health care providers and area agencies on aging (AAAs).

Key Findings

Caregiver Assessment

1. One key to good outcomes in community settings is not just assessing the frail elder or adult with disabilities (i.e., the care recipient), but the family caregiver as well. The value of systematic assessment of family caregivers' needs stems, in part, from recognition of the fundamental need to sustain caregiving families and help them stay "on the job." The concept of a single, universal assessment tool for long-term care clients, including family caregivers, is gaining attention in a number of states.
2. Caregiver assessments in California, Massachusetts, Minnesota, Pennsylvania, and Washington are being used to tailor care plans and support services to meet the needs of family caregivers. These states also have been successful in using information from caregiver assessment and reassessment data to modify existing programs or develop new programs and services.

While the assessment tools vary, all include some standardized questions about basic demographics (e.g., age, employment situation), caregiver stress, burden, and health status. The structure of the assessment also may differ by state, but all programs require an in-home interview with the caregiver

¹ For the full report, see PPI Issue Paper #2006-09. March 2006.

that generally lasts between 90 minutes and three hours. Family caregivers are reassessed annually or sooner if there is a significant change in the condition or living arrangement of the care recipient. Most states have automated their assessment systems or are in the process of doing so.

Consumer Direction

3. The emergence of consumer-directed service options specifically for family caregivers is taking hold in states. These options can be particularly effective in addressing the needs of families in rural areas where fewer formal services may be available. In addition, family members often play critical roles within broader consumer-directed HCBS programs for older persons and adults with disabilities—from being paid to provide direct services to coordinating services to serving as surrogate decision-makers for persons with cognitive impairment.

4. While most states offer at least one consumer-directed service option to family caregivers, considerable variation exists among states and among programs within states in the amount of assistance provided and eligibility requirements. Most states offering consumer-directed options for caregivers include respite care (such as in-home care, adult day care, or weekend or overnight stays in a long-term care facility) and supplemental services (encompassing home modifications, yard work, chore services, and assistive devices). Amounts offered annually for respite vary, from \$500–\$1,500 in Alabama up to \$3,500 in Minnesota and \$3,600 in California.

Some states, such as Alabama and North Carolina, provide a list of approved providers and goods from which caregivers may choose; other states, such as Minnesota and Pennsylvania, allow caregivers to hire someone privately; still others, such as California and Georgia, provide both options.

Collaborations on Caregiving between the Aging Network and the Health Care System

5. Two projects—one in Maine and the other, a national project with the National Association of Area Agencies on Aging—are offering innovative ways to create partnerships on caregiving between two distinct but complementary systems: the aging network and health care providers. With federal funding from the National Family Caregiver Support Program, these projects are pursuing systems development strategies through partnerships and collaborations with health care practitioners. Many people who are providing assistance and care to family and friends do not recognize themselves as caregivers; health care practitioners can help these individuals self-identify as family caregivers and refer them to caregiver specialists in the community.

6. By proactively identifying family caregivers in primary care physician offices, rather than waiting for caregivers to seek help or continue to provide care alone, family caregiver support programs can reach caregivers before they experience any adverse effects from caregiving. This support, in turn, may delay institutionalization of those receiving care for as long as possible.

Conclusion

States play a large and growing role in financing and delivering services to support and sustain family and informal caregivers, the backbone of long-term care. These three emerging trends require changes in the way many program administrators and practitioners have traditionally performed their jobs, such as the need to adopt a more “family-centered” perspective in assessing needs and delivering services. These new approaches can help to promote an exchange of new ideas among states as they pursue the goal of strengthening HCBS and hold promise for increasing the well-being of both individual care recipient and family caregivers.