

## Assessing Family Caregiver Needs: Policy and Practice Considerations

*Lynn Feinberg*

*Ari Houser*

AARP Public Policy Institute

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**Caregiver assessment is a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the ability of the caregiver to contribute to the needs of the care recipient. Effectively assessing and addressing caregiver needs can maintain the health and well-being of caregivers, sustain their ability to provide care, prevent or postpone nursing home placement, and produce better outcomes for the care recipient.**

Family caregivers are the backbone of the long-term services and supports (LTSS) system. Family members, partners, and close friends provide the vast majority of the care and support for loved ones with chronic care needs and functional limitations.

In 2009, family caregivers of adults with chronic or disabling conditions provided an estimated 40 billion hours of unpaid care with an estimated economic value of \$450 billion.<sup>1</sup> Even for recipients of paid services, family members play a critical role: 72 percent of older adults receiving paid LTSS also have a family caregiver.<sup>2</sup>

Although most family caregivers willingly undertake this role, an extensive body of research documents the negative physical, emotional, and financial consequences caregiving can have.<sup>3,4,5</sup>

### What Is Caregiver Assessment?

Caregiver assessment refers to a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the caregiver's ability

to contribute to the needs of the care recipient.

Caregivers who have their needs assessed often feel acknowledged, valued, and better understood by practitioners.<sup>6</sup> However, a caregiver assessment is not an end in itself. According to one expert on caregiving, "It's a tool to help identify the many roles a particular caregiver plays, the challenges she or he faces, gaps in knowledge and skills, and the kinds of help that will be both useful and acceptable to this caregiver and to the older adult receiving care."<sup>7</sup>

Providing quality care for the care recipient often requires an understanding of the family caregiver's situation and needs. However, these needs are frequently not identified or addressed in the recipient's care plan.

While some public programs conduct a "caregiver assessment," these are often limited to determining the willingness and ability of the family caregiver to provide care, and give little or no consideration to the caregiver's own health and well-being. Currently, when service providers or care managers refer caregivers to services and

supports, they often do so with little systematic knowledge about which services are most likely to benefit the family caregiver at that point in time.<sup>8</sup>

An effective caregiver assessment—conducted by a health care or social service professional—should approach care issues from the caregiver’s viewpoint and culture. An important component of the assessment process for family caregivers is to have someone to talk to about their circumstances and the needs of the care recipient. Research has shown that communicating with someone who understands caregiving issues and who listens to the family member’s concerns can improve outcomes.<sup>9,10</sup>

### Why Is It Important to Assess and Respond to Family Caregiver Needs?

Experts in both health care and LTSS agree on the importance of assessing caregiver needs, and have reached consensus about guiding principles and practice guidelines (see box).

Without systematic assessment of family caregiver needs, caregiving family members’ own health and well-being may be at risk, which may, in turn, jeopardize their ability to continue providing care.<sup>11</sup> Clinicians, researchers, and policy analysts are calling for expanding assessment of the individual with chronic or disabling conditions to include assessment of the family caregiver as a key component of chronic care delivery.<sup>12–20</sup>

Service interventions that include an explicit and systematic focus on assessing the needs, strengths, values, and preferences of family caregivers are important to sustain caregiving families.

When family caregivers are supported, they are better able to continue in this role, thereby reducing the cost of both public and private services. Effectively

### Fundamental Principles for Caregiver Assessment

Consensus exists among leaders in health care and in LTSS on a set of seven basic principles to guide caregiver assessment in policy and practice.<sup>21</sup>

1. Because family caregivers are a core part of health care and long-term services and supports, it is important to recognize, respect, assess, and address their needs.
2. Caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.
3. Caregiver assessment should result in a plan of care (developed collaboratively with the caregiver) that indicates the provision of services and intended measurable outcomes.
4. Caregiver assessment should be multidimensional in approach and periodically updated.
5. Caregiver assessment should reflect culturally competent practice.
6. Effective caregiver assessment requires assessors to have specialized knowledge and skills. Practitioners’ and service providers’ education and training should equip them with an understanding of the caregiving process and its impacts, as well as the benefits and elements of an effective caregiver assessment.
7. Government and other third-party payers should recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities.

supporting caregivers can reduce burdens and health risks that can impede a caregiver’s ability to provide care.

When family caregivers receive appropriate support services tailored to their specific needs—such as care consultation, education and training, counseling, support groups, and respite

care—there can be better outcomes for both the caregiver and the care recipient. Research shows that having a family caregiver can prevent unnecessary hospitalizations, and prevent or delay nursing home use among care recipients. Thus, assessing and addressing family caregivers' needs is an important component of public programs' overall approach to providing LTSS.

### Caregiver Assessment in the States

States have incorporated caregiver assessments to varying degrees in publicly funded LTSS programs (including Medicaid waivers, state plan services, aging services, and others).

The report *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* defined a high-performing LTSS system as one in which family caregiver needs are identified and addressed so that the system supports and sustains caregiving families without overstressing them.<sup>22</sup> In the dimension of support for family caregivers, a measure of the degree to which states say that they assess and respond to family caregiver needs was included as part of a composite indicator of system and legal supports for caregivers. The Scorecard provides a baseline set of indicators to evaluate LTSS system performance, and we hope to have a more robust measure of caregiver assessment for the next scorecard.

A current AARP Public Policy Institute project, in collaboration with the Family Caregiver Alliance, is conducting a comprehensive review of caregiver assessment tools, protocols, and best practices within Medicaid home and community-based services (HCBS) waiver programs. This project will increase understanding of the process for conducting a caregiver assessment, the types of questions included to assess

caregiver needs, and how assessment information is used to support family caregivers. This project will be used to enhance the caregiver assessment measures in the future (including in the Scorecard) and provide promising practices for state programs to use in addressing caregivers' needs.<sup>23</sup>

States can address identified caregiver needs by including services (such as respite, education, and training) for family caregivers' own needs as part of a person- and family-centered care plan or by referring caregivers to other supportive services. Vehicles for providing such supports to caregivers include publicly funded HCBS programs, hospital discharge planning, chronic care coordination and care transitions programs, and other new models of care under the Affordable Care Act.<sup>24</sup> However, it is often the case that such services to address caregivers' needs are not included in the care plan for the recipient of services/program participant. Adequate public funding for assessing and addressing caregivers' needs can be a barrier to implementation of effective programs.

### Conclusion

Effective and comprehensive assessment is a key step to determining appropriate support services for family caregivers, especially when the care recipient's plan of care depends upon the contributions of family members. With the movement toward person- and family-centered care, there is growing recognition of the need to expand assessment of the individual with chronic or disabling conditions to include assessment of the family. Because family support is essential to remaining in one's home and in the community, better assessment and response to caregivers' needs through the public programs that provide LTSS should be a public policy priority at both the federal and state levels.

## Endnotes

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AARP Public Policy Institute  
601 E Street, NW, Washington, DC 20049  
[www.aarp.org/ppi](http://www.aarp.org/ppi)  
202-434-3890, [ppi@aarpp.org](mailto:ppi@aarpp.org)  
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