

Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home- and Community-Based Service Waiver Programs

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- ✓ **Family caregiver assessment is an important component of a person- and family-centered care planning process for home- and community-based services (HCBS). This In Brief summarizes findings from a 50-state survey examining how well the needs of family caregivers are assessed when states evaluate the needs of older people and adults with disabilities who qualify for HCBS programs under Medicaid.**
- ✓ **This report is the first detailed analysis of family caregiver assessment tools and processes in use by the states in Medicaid HCBS 1915(c) and 1115 waiver programs. Forty-six states plus the District of Columbia responded to the initial survey, a 92 percent response rate. Interviews with key informants were conducted in 13 states.**
- ✓ **Family support is often essential for helping older people and adults with disabilities continue to live at home and in the community. Yet the work of family caregivers can be demanding—physically, emotionally, and financially. If caregiver needs are not assessed and addressed, their own health and well-being may be at risk, which may in turn lead to burnout—jeopardizing their ability to continue providing care in the community.**

Key Findings

The concept of assessing a family caregiver’s own needs is not well understood in many Medicaid HCBS programs.

We found that the term “family caregiver assessment” has mixed meanings among HCBS state officials.

Some view family caregiver assessment as simply asking the client (“care recipient”) whether they have a family member involved in their care and how many hours of care that family member provides. Only a minority of states viewed family caregiver assessment to mean that questions are asked *of the caregiver* about their own health and well-being, and any services or supports they may need to be better prepared for their caregiving role.

Only about 30 percent of states include any family caregiver assessments in their Medicaid HCBS waiver programs.

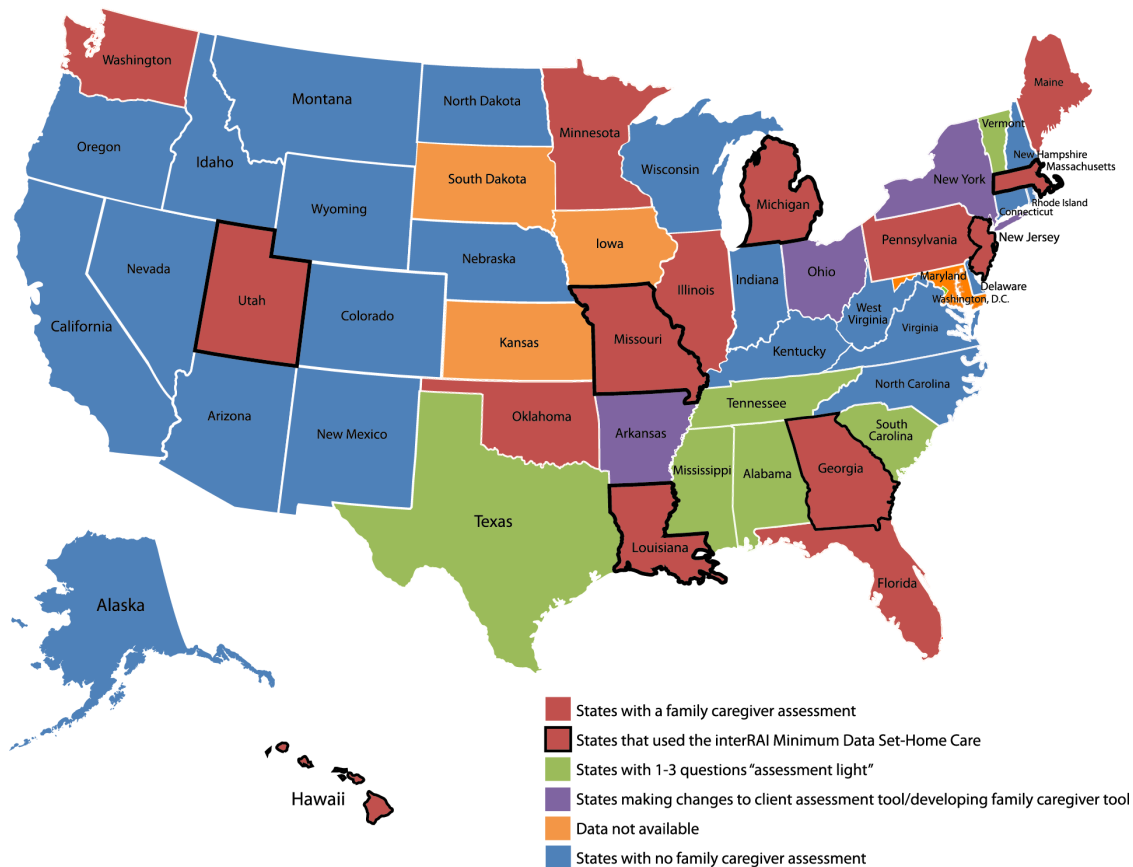
We found that less than half of all states (21 states and the District of Columbia) have any questions directed to family caregivers in their client assessment tools for Medicaid HCBS waiver programs and only 15 met our minimum criteria for having a family caregiver assessment.

Another seven states are “assessment light.” These states include a few questions directed to the family caregiver, but do not adequately address health or well-being, feelings of stress, and/or their support needs.

Most states that do assess family caregiver needs use the information to develop a service plan for the care recipient and to help connect family members and friends to needed services and supports.

In almost all of the states that have a family caregiver assessment, this assessment process affects the individualized care plan for the care recipient. In all of these states, the family caregiver assessment is used to help connect family members to needed services and supports provided by state-funded and federally-funded caregiver support programs, or provide a referral to local programs in the community.

Figure 1
States with a Family Caregiver Assessment



NOTE: States in purple reflect their responses to our survey. Some additional states have subsequently been reported by other sources to be adopting the interRAI HC in 2013.

Policy Recommendations

1. Family caregiver assessment should be a part of all assessment tools for Medicaid HCBS waiver programs, including comprehensive assessment tools developed at federal and state levels.
2. When a family caregiver assessment is conducted, family caregivers must be directly asked about their (a) own health and well-being, (b) levels of stress and feelings of being overwhelmed, (c) needs for training in knowledge and skills in assisting the care recipients, and (d) any additional service and support needs.
3. The interRAI Minimum Data Set Home Care (MDS-HC) is the most widely used assessment tool for Medicaid HCBS waivers across multiple states in our study. It should be expanded to include additional questions directed specifically to family caregivers in order to assess their service and support needs.
4. When a family caregiver is assessed, the care recipient's service plan should address the needs of the family caregiver raised during the assessment process to achieve a person- and family-centered service plan that best serves the person receiving Medicaid-funded HCBS services.
5. The family caregiver assessment should be part of the HCBS client record and coded for electronic records if available.
6. Funding should be preserved and increased for the National Family Caregiver Support Program (Title III-E, Older Americans Act), which provides a base of family caregiver support services in local communities.
7. States should examine assessment tools in Medicaid HCBS managed care programs and for people eligible for both Medicaid and Medicare (known as dual eligible beneficiaries). These programs should add a component that assesses family caregiver needs whenever the client's care plan depends upon the family caregiver.
8. If states assign their assessments for publicly funded programs to managed care companies, the assessment tools and data should be publicly available.

The *sine qua non* of family caregiver assessment is talking with caregivers directly to better understand their needs, problems, resources, and strengths.

Both state and federal leadership is needed to come to a common understanding of what constitutes a family caregiver assessment, and to elevate the importance of assessing and addressing family caregiver needs in public programs that depend on their unpaid services—including both Medicare and Medicaid. With many states moving toward managed care and seeking to improve care for people eligible for both Medicare and Medicaid, these are opportune times to add family caregiver questions—directed to the family caregiver—as part of functional assessment for HCBS.

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A synopsis of the AARP Public Policy Institute *Research Report*, 2013-13.
A glossary of key terms and definitions are included in the full *Research Report*.
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