

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

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Research Report

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EXECUTIVE SUMMARY

This report presents 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 home- and community-based services (HCBS) programs under Medicaid.

It 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

States that indicated they use a family caregiver assessment in their Medicaid HCBS waiver programs provided information about the timing of the assessment, types of questions asked of the family caregiver, how the plan for the person receiving care (care recipient) is affected, and how and when the family caregiver is connected to services and supports. Findings include:

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 care recipients 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 caregivers* about their own health and well-being, and any services or support 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 states met our minimum criteria for having a family caregiver assessment.

Another seven states are considered “assessment light.” These states include a few questions directed to family caregivers, but do not adequately address health or well-being, feelings of stress, or their support needs. Of the states that do not currently have a family caregiver assessment, three states are planning to include it in their HCBS assessment process in the future. Two states have implementation set for 2013, while the other state’s implementation date is undetermined.

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, the process affects the individualized care plan for the care recipient. In all of these states, the assessment is used to help connect family caregivers 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.

Policy Recommendations

Previous studies have shown that assessing and addressing family caregivers' needs helps to maintain their health and sustain their ability to provide care, and prevent or postpone more costly nursing home placement of the care recipients. Nearly a decade ago, consensus was reached by a group of nationally recognized health and long-term services and supports (LTSS) experts about principles and guidelines for effective family caregiver assessment in practice settings.

Recently, the federal Commission on Long-Term Care called for the Centers for Medicare & Medicaid Services (CMS) to require assessment of family caregivers' needs and inclusion of the identified family caregiver needs in care recipients' care plans that are dependent on family caregivers.

This project yielded the following recommendations:

1. Family caregiver assessment should be a part of all assessment tools for Medicaid HCBS waiver programs, including comprehensive assessments developed at federal and state levels, to establish responsive person- and family-centered service plans. Funding to conduct family caregiver assessment would improve assessment processes by providing additional time for program staff to follow up on needs identified by family caregivers. CMS should provide guidance to states on "promising practices" in developing and administering family caregiver assessment tools.
2. When a family caregiver assessment is conducted, family caregivers must be directly asked about their (a) own health and well-being, (b) level 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, including those designed 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 on the family caregiver. States in the Balancing Incentive Payment Program (BIPP), which will be developing standardized assessment tools, should also add questions directed to family caregivers.
8. If states assign their assessments for publicly funded programs to managed care companies, the assessment tools and data should be publicly available.

Conclusion

Family caregiver assessment is an important component of a person- and family-centered care planning process for HCBS. Providing high-quality care for the care recipient often requires an understanding of the family caregiver's situation.

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 caregiver—as part of client assessment for HCBS.

INTRODUCTION

Family caregivers are the foundation of the country's long-term services and supports (LTSS) system. More than 90 percent of older people receiving care in the community rely on unpaid family care, either alone or in combination with paid help. Even among those who receive publicly or privately funded LTSS, 72 percent of all older adults and 79 percent of those with the most severe disabilities also have a family caregiver.¹

Family caregivers arrange, coordinate, and provide assistance with the tasks of daily living. In addition, a recent national study found that 46 percent of family caregivers are performing complex medical and nursing tasks at home in addition to assisting with activities of daily living for people with chronic, physical, and cognitive conditions.²

In 2009, an estimated 42.1 million family caregivers in the United States provided about 40.3 billion hours of unpaid care to adults with limitations in daily activities. The estimated economic value of their unpaid contributions was \$450 billion in 2009—more than total Medicaid spending for all populations that year.³

Family members and friends who take on the caregiving role for people with complex, chronic, or disabling conditions and functional limitations—such as those caring for loved ones with Alzheimer's disease—are themselves vulnerable and at risk of emotional, physical, and financial strain. The strain, if unrelieved by services and supports for the family caregiver, may lead to premature, unnecessary, and more costly nursing home placement, and greater health and financial burdens for the family caregiver.

Medicaid is the nation's primary public payer for LTSS. Each state develops its own criteria and procedures for its Medicaid program, including assessment processes for HCBS waiver programs designed to meet the needs of people who prefer to get their LTSS in their homes or communities.⁴ Although Medicaid requires states to have an assessment process to determine a person's eligibility for HCBS waiver services, there is no requirement to assess the needs of the person's family caregiver, even if the plan of care depends on the family member providing LTSS in the home.

The AARP Public Policy Institute, in collaboration with the Family Caregiver Alliance, is exploring this issue because previous work in how health and social service professionals can better support family caregivers uncovered a startling fact. That is,

¹ A. Houser, M. J. Gibson, and D.L. Redfoot, *Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community: Data from the National Long-Term Care Survey* (Washington, DC: AARP Public Policy Institute, September 2010).

² S. Reinhard, S., C. Levine, and S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* (Washington, DC: AARP; New York, NY: United Hospital Fund, October 2012). Funded by The John A. Hartford Foundation.

³ L. Feinberg, S. C. Reinhard, A. Houser, and R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* (Washington, DC: AARP Public Policy Institute, June 2011).

⁴ S. M. Tucker and M. E. Kelley, *Functional Assessment Processes for Medicaid Personal Care Services* (Long Beach, CA: The SCAN Foundation, Spring 2011).

some states that claim to include a family caregiver assessment as part of their procedure for determining the needs of people seeking Medicaid support for HCBS do not actually do so. They think they do, but actually do not.⁵

Based on this surprise finding, this study was conducted to survey all 50 states to examine how well the needs of family caregivers are assessed when states evaluate the needs of older people and adults with disabilities who qualify for Medicaid HCBS 1915(c) and 1115 waiver programs. The report explains the importance of assessing the needs of family caregivers, and highlights findings from the survey—describing the family caregiver questions asked in Medicaid HCBS assessment tools, and explaining how those states that assess caregiver needs use the assessment information.

A description of the research methodology is included in Appendix A. The report also highlights three states (**Massachusetts**, **Minnesota**, and **Washington**) as examples of “promising practices” in family caregiver assessment in Appendix B.

Family caregiver assessment may occur in many settings and during transitions in care across settings (including in the home, in hospitals, and in nursing homes).⁶ The focus of this report, however, is home and community settings—to highlight the importance of assessing family caregivers at risk of burnout in state Medicaid waiver programs.

The states were surveyed between July and December 2012. Those states that indicated they use a family caregiver assessment in their Medicaid HCBS waiver programs provided information about the timing of the assessment, how the care recipient’s plan of care is affected, and how and when the family caregiver is connected to services and supports. Forty-six states plus the District of Columbia responded to the survey, a 92 percent response rate. Interviews with key informants were conducted in 13 states.

⁵ This finding arose from a pilot project of Aging and Disability Resource Centers’ (ADRCs) assessment processes for Medicaid HCBS waiver services, funded by The John A. Hartford Foundation. See C. Woodcock, A. Tripp, B. Holt, and E. Reaves, *New Jersey Care Partner Support Pilot Program: Final Report* (Baltimore, MD: The Hilltop Institute, University of Maryland, March 2012).

⁶ M. J. Gibson, K. Kelly, and A. K. Kaplan, *Family Caregiving and Transitional Care: A Critical Review* (San Francisco, CA: Family Caregiver Alliance, September 2012).

Case Example: What *Should* Happen

Mrs. Graham, an 88-year-old widow, has been living independently in her studio apartment in subsidized senior housing for many years. She relies exclusively on her Social Security income. She is overweight, has diabetes, and suffers from severe osteoarthritis. She finds it hard to walk, but neighbors help her get to the on-site senior center for one hot meal a day and to visit with friends. Sandy, her 62-year-old daughter, is divorced and works part time. She visits her mother daily to check in on her health, monitor her medications and diet, shop, and take her to doctors' appointments. After all of these years, she sometimes jokes that her health isn't as good as her mother's.

Mrs. Graham's grandchildren are all almost as concerned about their mother's health as their grandmother's. They have finally convinced Mrs. Graham to apply for Medicaid HCBS waiver services. A nurse care manager comes to Mrs. Graham's house to conduct an assessment of her health status and her needs for assistance with daily tasks. Sandy, as the family caregiver, is subsequently interviewed about what tasks she does to help her mother and how well prepared she feels to carry out these tasks. Sandy is also asked how she is doing, and about her own stress and strain levels, her support and service needs, her goals, and her ability to continue providing care.

The answers from both the client and family member are taken into account when developing the care plan for the client. This process helps to ensure that Mrs. Graham receives the care she needs, and that Sandy receives referrals to family caregiver services in the community to provide the support she needs to continue providing care for her mother at home.

Key Terms and Definitions

Who is a family caregiver? In this study, we define family caregiver as “a relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance to an older person or adult with a chronic or disabling condition. These individuals may live with or separately from the person receiving services. Caregivers may provide emotional or financial support, as well as hands-on help with different tasks.”⁷

Who is the care recipient? The care recipient is the older person or adult with disability who receives assistance with daily living tasks. In this report, we use the terms “care recipient,” “client,” “beneficiary,” and “consumer” interchangeably to describe the recipient of Medicaid HCBS.

What is person- and family-centered care? Person- and family-centered care (PFCC) is an orientation to the delivery of health care and supportive services that addresses an individual’s needs, goals, preferences, cultural traditions, family situation, and values. PFCC can improve care and quality of life through its focus on how care is delivered from the perspective of the older adult and, when appropriate, his or her family. PFCC both recognizes and supports family caregivers.⁸

What are family caregiver services and supports? Family caregiver services and supports include information about managing chronic conditions and available services, assistance in gaining access to services and supports, education and training on direct care skills, and respite care (to provide temporary relief from caregiving tasks). Support services may also include counseling, short-term therapy groups to increase coping skills, family meetings, in-person and online support groups, and assistive technologies.

What are home- and community-based services (HCBS)? HCBS support community living and the delay or prevention of admission to an institution by people with disabilities. They can include personal care (help with activities of daily living, such as bathing or dressing), transportation, assistance with managing medications and money, adult day services, homemaker services, home modifications, and assistive technologies. HCBS also include family caregiver services and supports.

How are HCBS provided to older people and adults with physical disabilities in the Medicaid program? The Medicaid 1915(c) HCBS waiver program is one of the primary means through which Medicaid participants receive personal care and other HCBS. HCBS are also being provided through 1115 waivers in some states, and under other Medicaid HCBS options.

HCBS waivers through 1915(c) of the Social Security Act permit the secretary of the Department of Health and Human Services to waive certain Medicaid provisions to allow services to be delivered in community rather than institutional settings and are used in almost all states. Section 1115 demonstration waivers permit states to test new or existing ways to deliver and pay for program coverage, such as using managed care for LTSS.⁹ This paper focuses on these two ways of providing HCBS to older people and adults with physical disabilities.

What is the HCBS assessment? Medicaid beneficiaries must meet medical and “functional” eligibility criteria as well as financial criteria. Eligible individuals applying for Medicaid-funded HCBS waiver services must demonstrate the need for a “level of care” that would meet the state’s Medicaid eligibility requirement for services in an institutional setting.¹⁰ The information gathered during the assessment process is used to determine the Medicaid beneficiary’s support needs and develop a service plan to address the identified needs.^{11,12}

What is a standardized assessment tool? This is a tool, sometimes known as a “uniform,” “comprehensive,” or “common” assessment tool, that is used in a fair and consistent manner throughout a state to ensure that services are equitably delivered.^{13,14} It is designed to determine eligibility for Medicaid-funded LTSS, identify service and support needs, and to establish care plans to address identified needs.

How is family caregiver assessment defined? A family caregiver assessment asks questions of the family caregiver. It does not ask questions of the client about the caregiver. Experts have defined family caregiver assessment “as 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 meeting the needs of the care recipient.”^{15,16} It should approach issues from the family caregiver’s perspective and culture, determine what types of assistance may be needed in order to maintain the caregiver’s health and well-being, and develop a care plan for the caregiver that includes this assistance.¹⁷ Based on a family caregiver assessment, action is taken to address identified needs to better support both the family caregiver and the client.

⁷ S. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Raising Expectations: State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Caregivers* (Washington, DC: AARP Public Policy Institute, September 2011).

⁸ L. Feinberg, *Moving Toward Person and Family Centered Care* (Washington, DC: AARP Public Policy Institute, March 2012).

⁹ Medicaid.gov, “Home and Community Based Services.” Accessed at <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>.

¹⁰ Ibid.

¹¹ M. E. Kelley and S. M. Tucker, *Elements of a Functional Assessment for Medicaid Personal Care Services* (Washington, DC: The SCAN Foundation, Spring 2011).

¹² S. M. Tucker and M.E. Kelley, *Functional Assessment Processes for Medicaid Personal Care Services*, The SCAN Foundation CLASS Technical Assistance Brief Series (Washington, DC: The SCAN Foundation, Spring 2011).

¹³ A standardized assessment tool does not necessarily mean that the same tool is used to assess all beneficiaries receiving LTSS; it could mean that the same types of questions are asked of all Medicaid beneficiaries.

- ¹⁴ C. Ingram, A. Lind, and B. Ensslin, *Uniform Assessment Practices in Medicaid Managed Long-Term Services and Supports Programs* (Hamilton, NJ: Center for Health Care Strategies, Inc., August 2013).
- ¹⁵ Family Caregiver Alliance, *Caregiver Assessment: Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference, Vol. I* (San Francisco, CA: Family Caregiver Alliance, 2006).
- ¹⁶ L. Feinberg and A. Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations* (Washington, DC: AARP Public Policy Institute, June 2012).
- ¹⁷ L. F. Feinberg, K. Wolkwitz, and C. Goldstein, *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support* (Washington, DC: AARP Public Policy Institute, March, 2006).

BACKGROUND

Support for family caregivers, including assessing and addressing their needs, was recognized as one of five key dimensions in a high-performing state LTSS system.¹⁸ In addition, almost a decade ago (in 2005), consensus was reached by a group of nationally recognized health and LTSS experts about principles and guidelines for effective family caregiver assessment in practice, including timeliness, care planning, service referral, and follow-up.¹⁹

Over the past three decades, numerous studies have documented that family caregiving can compromise caregivers' mental and physical health, their professional careers, and their future economic security.^{20,21,22} Assessing and addressing family caregivers' needs helps to maintain their health and sustain their ability to provide care, and prevent or postpone more costly nursing home placement of the care recipients.²³

Achieving quality of care for the care recipient often depends on augmenting the care recipient's HCBS care plan by also assessing and addressing the family caregiver's needs. Yet, assessments of family caregivers' needs are often overlooked because, according to Medicaid policy, the legal beneficiary of LTSS services is an individual, not a family.²⁴

This is not surprising because Medicaid HCBS waiver programs are meant to supplement, but not replace, supports provided by the care recipient's family or friends.²⁵ In current practice, the care recipient's assessment and plan of care typically describe the family supports that complement the waiver services, but do not assess or address the family caregiver's own support needs directly. Research shows, however, that family caregivers provide approximately 50 to 80 hours of help with everyday living tasks per

¹⁸ S. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Raising Expectations: State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Caregivers* (Washington, DC: AARP Public Policy Institute, September 2011).

¹⁹ Family Caregiver Alliance, *Caregiver Assessment: Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference, Vol. I* (San Francisco, CA: Family Caregiver Alliance, April 2006).

²⁰ S. Zarit, "Assessment of Family Caregivers: A Research Perspective," in *Caregiver Assessment: Voices and Views from the Field, Vol. II* (San Francisco, CA: Family Caregiver Alliance, April 2006).

²¹ N. Guberman, "Assessment of Family Caregivers: A Practice Perspective," in *Caregiver Assessment: Voices and Views from the Field, Vol. II* (San Francisco, CA: Family Caregiver Alliance, April 2006).

²² R. Schulz and P. Sherwood, "Physical and Mental Effects of Caregiving," *American Journal of Nursing* 108, no. 9 (2008): 23–27.

²³ L. Feinberg and A. Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations* (Washington, DC: AARP Public Policy Institute, June 2012).

²⁴ J. Feder and C. Levine, "Explaining the paradox of long-term care policy," in *The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers*, ed. C. Levine and T.H. Murray (Baltimore, MD: The Johns Hopkins University Press, 2004).

²⁵ L. Sands, H. Xu, J. Thomas, S. Paul, et al., "Volume of Home and Community Based Services and Time to Nursing Home Placement," *Medicare & Medicaid Research Review* 2, no. 3 (2012). Accessed at <http://dx.doi.org/10.5600/mmrr.002.03.a03>.

week, depending on the care recipient's functional level,²⁶ and may experience their own physical health problems and emotional strain from the care they provide.²⁷

Family caregiver assessment is a tool for assessing and addressing the needs of family caregivers. It is especially important to identify at-risk family caregivers before they burn out or compromise their own physical and mental health. Family caregiver assessment is also a means of recognizing family caregivers as partners of professionals in providing health care and LTSS. For years, experts have placed family caregiver assessment at the top of agendas for caregiver practice, research, and advocacy. In its absence, family caregivers typically remain invisible. If acknowledged at all, they are commonly seen as a “resource” by busy health and social work professionals, not as individuals with their own unique strengths and needs.

In contrast to viewing family caregiver assessment as a way to determine the hours of care family caregivers are “willing and able” to provide, we view it as a way to determine how to meet the family caregiver's own needs for support. This distinction parallels the mixed meanings of “family support,” which is variously used to mean (a) support of the care recipient by the family caregiver, and (b) support of the family caregiver. It also reflects the dual perspectives of “family caregiver as provider” and “family caregiver as client.”^{28,29}

States have the latitude to determine the components of the client assessment within the guidelines provided by the Centers for Medicare & Medicaid Services (CMS). As a result, client assessments in Medicaid HCBS waiver programs vary from state to state, or among multiple Medicaid waiver programs within states. Those states that conduct an assessment of family caregiver needs under their Medicaid HCBS program are doing so voluntarily.

Public Policies for Family Caregiver Assessment

Nearly a decade ago, some policy makers began calling for family caregiver assessments to be a mandatory part of the client assessment process for Medicaid HCBS waivers, and to add family caregiver supports to the range of services offered and managed under the waiver programs.³⁰

²⁶ M. P. LaPlante, C. Harrington, and T. Kang, “Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home,” *Health Services Research* 37, no. 2 (2002): 397-415.

²⁷ L. Feinberg, S. C. Reinhard, A. Houser, and R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* (Washington, DC: AARP Public Policy Institute, June 2011).

²⁸ S. Reinhard, S., C. Levine, and S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* (Washington, DC: AARP; New York, NY: United Hospital Fund, October 2012). Funded by The John A. Hartford Foundation.

²⁹ S. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Raising Expectations: State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Caregivers* (Washington, DC: AARP Public Policy Institute, September 2011).

³⁰ B. Vladack, “You can’t get there from here: Dimensions of caregiving and dementias of policymaking,” in *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*, ed. C. Levine (New York, NY: United Hospital Fund, 2004).

Recently, the federal Commission on Long-Term Care called for CMS to require assessment of family caregivers' needs and inclusion of the identified caregiver needs in care recipients' care plans (or hospital discharge plans) that are dependent on family caregivers.³¹

Some states have moved forward in including assessment of family caregiver needs as part of HCBS and other federally-funded or state-funded family caregiver support programs.³² A recent example of changing policies at the state level is Rhode Island's passage of the Family Caregivers Support Act of 2013 as part of the state's Medicaid LTSS reform efforts (see Appendix C). The new law³³ requires a family caregiver assessment if the plan of care for the Medicaid recipient involves a family caregiver. A plan of care would be developed to take into account the needs of both the care recipient and the family caregiver.

Some CMS initiatives established under the Patient Protection and Affordable Care Act (ACA) seek to encourage greater use of HCBS as a proportion of LTSS spending, and recognize the importance of considering family caregiver needs as part of the client assessment process. The Balancing Incentive Payments Program (BIPP), for example, requires states to use a standard assessment instrument in order to participate in the program. States have the option to assess family caregiver needs as part of the BIPP assessment process.

In its guidance to states on BIPP, CMS recommends that family caregiver needs be considered as part of best practices, recognizing that "families and/or caregivers often have needs outside the needs specific to the individual eligible for services. These needs are typically connected to caregiver stress, a need for information and referral, support groups and/or respite care. An assessment process that incorporates components tied to caregiver needs will result in a more well-rounded assessment of the service and support needs of the whole family."³⁴

States also have options for providing Medicaid services to support family caregivers after their needs are assessed and included in a plan of care. In Medicaid HCBS waiver programs, respite can be provided in the family home while the caregiver is away for a few hours or overnight. Some states permit respite to be provided outside the home, such as adult day care programs, or other programs in designated respite care facilities.³⁵

³¹ Commission on Long-Term Care, *Report to the Congress* (Washington, DC: Commission on Long-Term Care, September 30, 2013). Accessed at <http://www.ltccommission.senate.gov/Commission%20on%20Long-Term%20Care-%20Final%20Report%209-26-13.pdf>.

³² S. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Raising Expectations: State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Caregivers* (Washington, DC: AARP Public Policy Institute, September 2011).

³³ Rhode Island Public Law No. 2013-469, enacted July 16, 2013.

³⁴ E. Kako, et al., *The Balancing Incentive Program: Implementation Manual* (San Francisco, CA: Mission Analytics Group, October 2011). Accessed at http://hsd.aphsa.org/Home/doc/Balancing_Incentive_Program_Manual.pdf.

³⁵ J. O'Keeffe, P. Saucier, B. Jackson, et al., *Understanding Medicaid Home and Community Services: A Primer, 2010 Edition* (Washington, DC: U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Office of the Assistant Director for Planning and Evaluation, October 2010). Accessed at <http://aspe.hhs.gov/daltcp/reports/2010/primer10.htm>.

Family caregiver education and training may also be authorized as a distinct service in HCBS waiver programs. Such services include paying health care or social service professionals to come into the home to train family members on how to perform specific tasks or how to use equipment properly, or paying for family caregivers to attend special training classes. Under 1915(c) waivers, “states may provide training to caregivers to the extent it is necessary to enable the participant to be cared for outside of an institution.”^{36,37}

Family caregiving resources to which Medicaid staff can make referrals are also available in all states through the Older Americans Act’s Title III-E National Family Caregiver Support Program, administered through the Area Agencies on Aging. A few state-funded programs also provide resources for family caregivers. There are also community programs that operate outside of those funding streams that provide family caregiver support services.

³⁶ Ibid.

³⁷ Centers for Medicare and Medicaid Services (CMS), *CMS’ Legal Authority to Support Caregivers* (Washington, DC: CMS, 2007). Accessed at <http://www.cms.gov/Outreach-and-Education/Outreach/Partnerships/downloads/CMSCaregivers91907.pdf>.

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, and that the concept of assessing a family caregiver’s own needs is not well understood in many Medicaid HCBS programs. While we had assumed that a family caregiver assessment must include talking with the family caregiver, that was not the case in many of the state responses and state tools collected in this study.

Some state officials view family caregiver assessment as simply asking care recipients whether they have a family member involved in their care, and how many hours of care that family member provides. Availability of family or friends to provide care reduces Medicaid HCBS for beneficiaries because HCBS are intended, in part, to help fill gaps when different levels of family or other natural supports are unavailable or insufficient to meet the beneficiary’s needs.

In this traditional approach, questions about the extent of family support are typically directed to the care recipient only. Family caregivers, however, often have their own needs for services and supports to help them meet the many demands of their role, and help avert physical and emotional strain and financial burden.

Because there was not a common understanding of what constitutes a family caregiver assessment, we found that we needed to explicitly define the term. For purposes of this study, the criteria used to define family caregiver assessment were: at a minimum, the family caregiver assessment ***must ask questions of family caregivers*** to (a) *assess their health and well-being*, (b) *determine their levels of stress and feelings of being overwhelmed*, and (c) *determine any service and support needs they may have*.

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

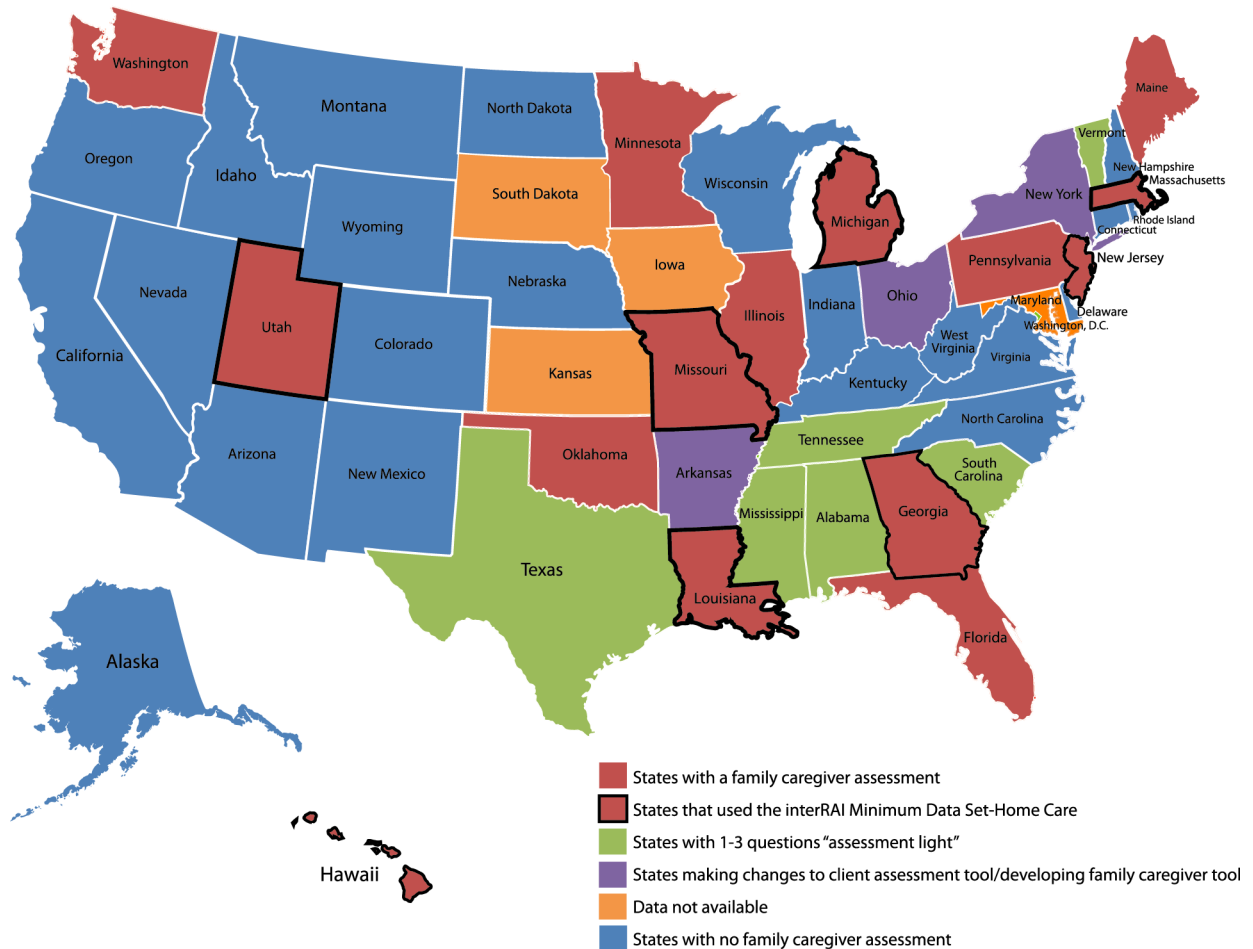
At the end of 2012, 15 states included family caregiver assessment as part of their Medicaid HCBS client assessment tools. Seven of these states used state-specific tools that met our criteria (FL, IL, ME, MN, OK, PA, and WA). The other eight states (GA, HI, LA, MA, MI, MO, NJ, and UT) used the interRAI Minimum Data Set-Home Care (MDS-HC). The interRAI MDS-HC instrument contains some elements of a family caregiver assessment. More states reported plans to adopt this instrument in 2013 as part of BIPP.³⁸

Another seven states (AL, DC, MS, SC, TN, TX, and VT) include one to three questions that are directed to family caregivers and ask about their health or well-being, but are not sufficiently comprehensive to be considered a family caregiver assessment based on our criteria.

³⁸ Three additional states (IN, IA, and MD) are reported to have adopted or be adopting the interRAI HC for use with older people and/or adults with physical disabilities as part of their work plans for the BIPP Program. See the Balancing Incentive Program, *Summary of States' Core Standardized Assessment (CSA) Instruments*, (Washington, DC: CMS, September 2013). Accessed at http://www.balancingincentiveprogram.org/sites/default/files/CSA_State_Summary_Draft_2013_09_19.pdf.

Three additional states (AR, NY, and OH) plan to implement new tools in 2013 that will assess family caregiver needs, in addition to assessment of the care recipient's need for services and supports to determine eligibility for HCBS waiver programs (Figure 1).

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.

Most states that assess family caregiver needs in their Medicaid waiver programs 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. However, states varied in the other uses they made of family caregiving data, the timing of assessments, and training of the assessors.

While 15 states met our criteria for having a family caregiver assessment, we have information on the uses of the assessment data, the timing of assessment, and training of assessors for only 10 states.³⁹ In 9 of the 10 states, the family caregiver assessment affects the care plan for the care recipient. In all 10 states, the family caregiver assessment is used to connect family caregivers to needed services and supports provided by state-funded and federally-funded family caregiver support services or local programs in the community (Table 1).

Table 1
Process of Family Caregiver Assessment: Uses of Data

	FL	GA	HI	IL	LA	ME	MA	MI	MN	MO	NJ	OK	PA	WA	UT
					NA	NA				NA	NA				NA
Affect Care Plan for Care Recipient	X	X	X				X	X	X			X	X	X	
Connect Caregivers to Services & Supports	X	X	X	X			X	X	X			X	X	X	
State Uses Assessment Data to:														X	
Manage workloads	X		X						X			NA	X	X	
Determine timelines of assessments/reassessments	X		X					X	X			NA	X	X	
Quantify hours authorized	X		X						X			NA	X	X	
Set individual client budgets	X		X					X	X			NA	X	X	
Create management reports	X						X	X	X			NA	X	X	
CMS waiver quality assurance reports	X							X	X			NA	X	X	
Develop programs to support/benefit caregivers	X						X		X			NA	X		
Determine client outcomes and identify risks	X		X				X		X			NA	X	X	

NA = Not available.

Note: Data for MN are current as of the end of 2012. MN is redesigning its family caregiver assessment process as part of its new MnCHOICES program, to be implemented in 2013. See case study in Appendix B.

The timing of a family caregiver assessment is important because it should be incorporated into the client's care plan. In 7 of the 10 states for which we have survey responses, the family caregiver assessment occurs during the first client assessment to determine eligibility for the Medicaid HCBS 1915(c) program. In the other 3 states, the family caregiver assessment occurs after the client assessment has been completed, at the initial contact for services for the client or at no preset time. In all 10 of the states, the family caregiver assessment becomes part of the client's file (Table 2).

³⁹ We do not have information on caregiver assessment processes for LA, ME, MO, NJ, or UT.

Table 2
Process of Family Caregiver Assessment: Timing

	FL	GA	HI	IL	LA	ME	MA	MI	MN	MO	NJ	OK	PA	WA	UT
					NA	NA				NA	NA				NA
Timing of Assessment															
First time assessment of care plan to determine eligibility		X	X	X			X					X	X	X	
When an assessment is complete	X														
At initial contact for services/enrollment								X							
Varies									X						
Assessment makes it into client file	X	X	X	X			X	X	X			X	X	X	

NA = Not applicable.

Note: Data for MN are current as of the end of 2012. MN is redesigning its family caregiver assessment process as part of its new MnCHOICES program, to be implemented in 2013.

Assessor training on how to conduct the assessment and develop the care plan is important as it standardizes the process and helps to ensure equity. Such training can ensure that the assessors have the information necessary to connect family caregivers to the most appropriate supports or services specific to the particular caregiving situation. Training is provided in all 10 states to those conducting a family caregiver assessment, through in-person training, online modules, and the use of reading material (Table 3).

Table 3
Process of Family Caregiver Assessment: Training

	FL	GA	HI	IL	LA	ME	MA	MI	MN	MO	NJ	OK	PA	WA	UT
Has Assessment Manual	X	X	X	X*	X	X	X	X	X	X	X	X	X	X	X
Training Provided to Assessors					NA	NA				NA	NA				NA
Online			X						X					X	
In person	X	X	X	X			X	X	X				X	X	
Reading material			X				X	X				X		X	

* Instructions but no formal manual.

NA = Not applicable.

Note: Data for MN are current as of the end of 2012. MN is redesigning its family caregiver assessment process as part of its new MnCHOICES program.

What Family Caregiver Questions Are Asked in Assessment Tools?

In the 15 states that assess family caregiver needs, we identified 20 assessment domains grouped into 7 categories.^{40,41} We found that the states vary in the range and type of questions asked of family members about their caregiving situation. However, the majority

⁴⁰ Family Caregiver Alliance, *Caregiver Assessment: Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference, Vol. I* (San Francisco, CA: Family Caregiver Alliance, 2006).

⁴¹ Family Caregiver Alliance, *Caregiver Assessment: Voices and Views from the Field, Report from a National Consensus Development Conference, Vol. II* (San Francisco, CA: Family Caregiver Alliance, 2006).

of the questions are framed in a multiple-choice format following a typical rating scale, with options ranging from “strongly agree” to “strongly disagree” (see Table 4).

Table 4
Family Caregiver Assessment Domains

	FL	GA	IL	ME	MA	MN	OK	PA	WA	inter RAI* only
Context										
Demographic information	X	X	X	X	X	X	X	X	X	
Relationship to care recipient	X	X	X	X	X	X	X	X		X
Family/living situation					X			X	X	
Employment	X		X			X	X	X		
Care duration	X					X	X	X	X	
Caregiver’s finances								X		
Care frequency			X	X	X	X	X			X
Out-of-pocket caregiving expenses								X		
Types of Care Work										
Areas of caregiving work					X	X	X			
Caregiver’s Values and Preferences										
Willingness to provide care		X						X		
Health and Well-being of Caregiver										
Physical health	X	X	X		X	X	X	X		
Mental health/stress	X	X	X	X	X	X	X	X	X	X
Consequences of Caregiving										
Caregiving’s effect on life of caregiver	X	X	X		X	X	X	X		X
Strain								X		
Mistreatment of client due to strain								X		
Employment’s effect on caregiving		X	X					X	X	
Skills/Abilities/Knowledge to Provide Care Recipient with Needed Care										
Ability/barriers to continue caring for client	X	X	X	X			X	X	X	X
Resources that Caregiver Could Choose to Use										
Back-up support for care recipient/other caregivers	X	X		X	X	X	X			X
Services or support needs	X		X		X	X	X	X	X	
Use of support/services			X					X	X	

*States that use the interRAI HC only have been coded consistently on the assumption that they all use the questions/sections pertinent to family caregivers. These states are: HI, LA, MI, MO, NJ, and UT.

Two states (GA, MA) use the interRAI plus another family caregiver assessment.

Seven states use state-specific tools.

Demographic Data

Demographic information about the family caregiver typically includes gender, age, kinship, marital status, race and ethnicity, whether they live with or near the client, and employment status. Almost all states (14) ask about kinship, while six ask about the family caregiver’s employment situation, and two ask if the family caregiver was financially dependent on the client. Pennsylvania was the only state to ask about any potential out-of-pocket expenses incurred as a result of caregiving.

Eleven states ask about the frequency of care (hours per week) provided by the family caregiver, but only four also ask about the duration of caregiving (total length of time), which may be more closely linked to potential burnout and the need for supportive services. Only two states (MN and OK) ask the family caregiver about both the frequency and duration of care.

Types of Care Work

Fourteen states inquire about the type of help the family caregiver gives to the client, such as assistance with activities of daily living (ADLs), and instrumental activities of daily living (IADLs). Six states specify the ADLs and IADLs performed; Massachusetts lists each ADL and IADL separately to gather information about who is performing each individual task to determine what level of care the family caregiver is providing. The other states group the ADLs and IADLs together when asking if the family caregiver performs those tasks.

Pennsylvania asks whether the family caregiver performed “health care” and “medical care” tasks, and Minnesota asks about technology needs. No states ask about difficulties with, or training needs for, managing multiple medications, using medical equipment, or handling care coordination for the client across acute care and LTSS.

The Family Caregiver’s Values and Preferences

Only three states ask about the family caregiver’s willingness to provide care; that is, whether they wished to continue providing care. Massachusetts, for example, asks: “Does the caregiver wish to continue her/his caregiving role?” We found no questions that address cultural preferences, attitudes toward filial obligations (a sense of duty to care for parents), or the family caregiver’s goals for care.

Health and Well-being of the Family Caregiver

The need to identify at-risk family caregivers is a fundamental component of assessing caregiver needs. Capturing information about the family caregiver’s physical health, mental health, and levels of stress is particularly crucial as these are often the primary areas where the family caregiver needs support to prevent burnout. Research also suggests that highly stressful family caregiving is associated with increased mortality among some family caregivers.⁴²

All 15 states include questions about the family caregiver’s emotional and mental health or stress levels. For example, Illinois asks the family member: “Overall how stressed do you feel in caring for this person?” Florida, Georgia, and Oklahoma ask the family caregiver: “Is your emotional well-being better, the same, or worse since you began caregiving?” Massachusetts asks: “How does the family caregiver rate her/his emotional health at the present time?”

While all states list a decline in the family caregiver’s mental and physical health as a potential barrier to continued family care, only about one-half of the 15 states include

⁴² See R. Schulz and S.R. Beach, “Caregiving as a risk factor for mortality: The caregiver health effects study,” *Journal of the American Medical Association*, 282, no. 23 (1999): 2215–2219; and M. Perkins et al., “Caregiving strain and all-cause mortality: Evidence from the REGARDS study,” *Journal of Gerontology Series B: Psychological and Social Sciences*, 68, no. 4 (2013): 504–512.

specific questions that ask family caregivers about their physical health and whether their physical health interferes with caregiving duties.

Consequences of Family Caregiving

Eight states ask about caregiving's effect on the life of the family caregiver, both positive and negative, with questions framed in different ways. Louisiana asks two complementary questions: "I find caring gives me: A great deal of satisfaction, some satisfaction, no satisfaction"; and "I find caring creates: No major difficulties, some difficulty, major difficulties." Minnesota asks: "Do you have difficulty getting a good night's sleep three or more times a week?" Minnesota also asks the family member the open-ended question: "What activities do you enjoy doing? Are there any activities that you enjoy doing that you would like to do more frequently? Is there anything needed to support or help you do these activities?"

Pennsylvania includes items such as: "Health suffered due to involvement with consumer"; "Social life suffered due to caring for consumer"; and "Uncomfortable having friends over due to caring for consumer." Family caregivers can choose their answer from a scale ranging from "never" to "always." Three states ask a question to gauge whether family caregiving affects the family caregiver's employment. For example, Pennsylvania asks the question: "How has your caregiving and social life and/or employment affected each other?" Washington lists "employment is negatively impacted" as an optional answer when asking if there are any barriers to continued family caregiving.

Skill, Ability, and Knowledge to Provide Care Recipient with Needed Care

In particular, questions regarding the skills, abilities, and knowledge of family caregivers can help to identify those tasks that are most problematic and stressful for the family caregiver. This information, in turn, can lead to targeted referral to appropriate consumer materials, one-on-one training, or referral to educational events or supportive services in the community.

Five states ask about training needs. Typical items in this area include: "Does not have the necessary training or skills"; "Need training or services"; and "Lacks knowledge or skills." Washington asks if there are barriers to continued caregiving and provides eight possible answers, including: "Does not have necessary training/skills"; and "Caregiving is too difficult." Oklahoma asks specifically what type of training family caregivers might need to be better prepared for handling their caregiving tasks with an open-ended question: "Do you need training or services?"

Resources That the Family Caregiver Could Choose to Use

The main outcome of the assessment process is to connect the family caregiver to appropriate services and supports. Seven states ask family caregivers directly about their service or support needs. Minnesota asks: "Are you willing to be contacted by a community organization that can give you more information or assistance with caregiving?" Massachusetts asks: "What are the caregiver's immediate needs/concerns that prompted this assessment?" There are 13 answers to choose from, and the family caregiver may choose all that apply. Examples include: "balancing work and caregiving

responsibilities”; “dealing with the caregiver’s own health”; “financial strain/constraints”; “managing the care recipient’s medications”; “accessing services for the care recipient”; and “understanding and managing the care recipient’s health needs and/or behavior.”

Only three states ask about family caregivers’ use of services and support. Illinois provides a table with a list of services and the options: “has service”; “needs service”; “service provider”; and “date of referral.” Washington asks: “Are you currently using any caregiver support service(s)?” There are six options to choose from, and family caregivers are also asked how often they have used those services. Nine states ask whether there is back-up support for the family caregiver. The question is most often posed as: “If you were unable to continue providing care, who would?” Massachusetts ends its family caregiver assessment with the question: “Was a caregiver action plan developed after the assessment was completed?”

Cross-state Instruments: The interRAI MDS-HC

The interRAI MDS-HC instrument contains some elements of a family caregiver assessment, but it does not have an intentional focus on family caregivers’ needs for advice, support, and services in a structured way. The “Social Support” section of the tool is designed to determine the amount of help and capacity of the informal system to provide support for the care recipient, and whether they can continue in their roles as helpers. Like the other assessment instruments in this study, it does not go beyond ADLs and IADLs to determine other complex, health-related activities a family caregiver may perform (such as wound care). It also does not address the level of care coordination activities undertaken by a family caregiver on behalf of the care recipient.

The interRAI MDS-HC was used in eight states (GA, HI, LA, MA, MI, NJ, MO, and UT) at the end of our data collection period in 2012, and more plan to use it in the future.^{43,44} The focus of the Social Support section is on unpaid caregivers who may be a family member, friend, or neighbor.⁴⁵ It includes a brief series of questions about “informal helpers” to determine whether they assist with ADLs or IADLs, the number of hours of help provided, and to clarify their relationship to the care recipient. These questions are directed to the care recipient and, if available, the family caregiver.

There is another brief series (three questions) to determine family caregiver distress and ability to continue care. These questions are directed to the family caregiver and separately to the care recipient. For example, the family caregiver or care recipient may indicate the caregiver is unable to continue in caring activities for such reasons as a decline in the caregiver’s health, living at a distance from the care recipient, or competing work and caregiving responsibilities of the family caregiver.

⁴³ These states are IN, IA, and MD. See the Balancing Incentive Program, *Summary of States’ Core Standardized Assessment (CSA) Instruments*, (Washington, DC: CMS, September 2013). Accessed at http://www.balancingincentiveprogram.org/sites/default/files/CSA_State_Summary_Draft_2013_09_19.pdf.

⁴⁴ According to interRAI Fellow Mary James, two other states (NY and SD) are using a variant of the HC called the Community Health Assessment (CHA), with trigger algorithms that lead to a functional supplement or a mental health supplement.

⁴⁵ J. N. Morris, B.E. Fries, R. Bernadei, et al., *interRAI Home Care (HC) Assessment Form and User’s Manual, Version 9.1* (Washington, DC: interRAI, 2009).

Some states (GA and MA) use the interRAI as a trigger to conduct a more robust family caregiver assessment, typically within the federal and state-funded family caregiver support programs.

POLICY RECOMMENDATIONS

The many ways in which HCBS can be expanded under ACA provide opportunities for stakeholders, at both the federal and state levels, to move beyond general statements about family caregivers as partners in care to specific actions and programs. A small number of states have already moved in this direction. Their experience is especially valuable in determining the level of effort required by states to implement clear procedures and protocols for conducting family caregiver assessments and for addressing the needs identified during the assessment process. A common theme from states that assess family caregiver needs is the value placed on the natural supports provided by family and friends that extend the ability of the care recipient to remain in the community and in the setting of their choice.

We offer eight recommendations that emerged from this study.

1. ***Family caregiver assessment should be a part of all assessment tools for Medicaid HCBS waiver programs, including comprehensive assessments developed at federal and state levels, to establish responsive person- and family-centered service plans.***
Funding to conduct family caregiver assessments would improve assessment processes by providing additional time for program staff to follow up on needs identified by family caregivers. CMS should provide guidance to states on promising practices in developing and administering family caregiver assessment tools.
2. ***When a family caregiver assessment is conducted, the questions must be directly asked of the family caregiver and should address the following categories:***
 - Context and background: gender, age, relationship, length of time providing assistance, number of hours per week or month, other care demands (children, other relatives or friends), employment, and whether the family caregiver lives with the HCBS client
 - Skills, abilities, and knowledge to provide needed assistance: the range of assistance provided and whether the family caregiver feels confident and competent in providing assistance with ADLs, IADLs, medical and nursing tasks, and care coordination across acute care and LTSS
 - Well-being of the family caregiver: self-rated health, depression screen, health conditions
 - Consequences of providing care: stress or burden screen, work strain
 - Resources that the family caregiver could choose to use: social support networks, direct care skills training, short-term counseling, support groups, and other caregiver resources and services such as respite

One gap area for instrument development is the assessment of capability and competency related to medical and nursing tasks currently being performed by the family caregiver, such as wound care or preparation of special diets. While the

majority of Medicaid HCBS assessments ask about medical conditions and health care needs of the client, there is no indication in the assessment tools of who may be currently performing those complex care tasks in the home. If the family caregiver is identified as performing these complex tasks, training should be provided to the family caregiver to address the family member's needs and capabilities.

3. ***The interRAI Minimum Data Set-Home Care (MDS-HC) instrument should be expanded to include additional questions directed specifically to family caregivers in order to assess their service and support needs.***

Our study found that the interRAI assessment tool is in use across eight states, includes available user manuals, and is being implemented in additional states in 2013.

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.***

This recommendation may increase the need for additional Medicaid HCBS staff training about: (1) family caregiver concerns; (2) matching assessment results with available state or federal programs or local or regional resources available; and (3) referral to or provision of consumer information materials on key family caregiving topics.

Often the services for family caregivers are distinct from those for the care recipient. Internal processes should be developed for seamless, direct referrals to federal and state programs and local services to ensure ease of access for family caregivers.

5. ***The family caregiver assessment should be part of the Medicaid HCBS client record and coded for electronic records if available.***

Including the information from the family caregiver assessment would provide a full picture of all of the supports available to an individual using HCBS. If electronic records are used, elements of the family caregiver assessment may be used in other state or federal programs for direct caregiver support services, eliminating the need for duplicate assessments for family caregivers.

6. ***Funding should be preserved and increased for caregiver support services under the Older Americans Act's National Family Caregiver Support Program (NFCSP).***

The NFCSP is the most consistent source of funding for family caregiver support services in the community. One of the main outcomes of a family caregiver assessment process is linking family caregivers to supportive services. For the past five years, the appropriation for the NFCSP has remained fixed at approximately \$154 million per year. Appropriations for this program should keep pace with the increase in the numbers of family caregivers and demand for services, and should develop a uniform family caregiver assessment for recommended use across the states. In addition, protocols should be implemented to ensure

improved communication and coordination between HCBS and NFCSP programs at the state and local levels for seamless referrals of family caregivers.

7. ***States should examine their assessment tools for people in Medicaid HCBS managed care programs and for those eligible for both Medicaid and Medicare, adding a component to assess family caregiver needs whenever the client's care plan depends upon the family caregiver.***

States in the Balancing Incentive Payment Program (BIPP), which will be developing standardized assessment tools, should also add questions directed to family caregivers.

8. ***If states assign their assessments for publicly funded programs to managed care companies, the assessment tools and data should be publicly available.***

If public funding is used for delivery of HCBS, then the client and family caregiver assessment instruments should be available as part of generally accepted principles regarding transparency of operations.

CONCLUSION

Family caregiver assessment is an important component of a person- and family-centered care planning process for HCBS that increases the engagement of both the care recipient and the family. Providing high-quality care for the care recipient often requires an understanding of the family caregiver's situation.

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

One of the most notable findings of this project is the mixed meaning of family caregiver assessment depending upon the perspective of stakeholders. Many state respondents in this study interpreted it as a means of determining whether a family caregiver was available to help meet the care recipient's needs for support, and the number of hours a family caregiver spends assisting the care recipient. In contrast, we view family caregiver assessment as a way to determine how to meet family caregivers' own needs for support to enable them to continue in their caregiving role.

Although a plan of care frequently rests upon the ability of the family caregiver to continue providing support, the family caregiver's own needs for support are often not assessed or addressed. Viewing family caregivers as legitimate program clients is a relatively new concept for many state and local public agencies and programs, and represents a paradigm shift.⁴⁶

Both state and federal leadership is needed to elevate the importance of assessing and addressing family caregiver needs in public programs that depend upon 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, this is the opportune time to add family caregiver questions as part of client assessment for HCBS.

⁴⁶ L. Feinberg and S. Newman, "Consumer Direction and Family Caregiving: Results from a National Survey," in *State Policy in Practice: Community Living Exchange* (Washington, DC: Rutgers Center for State Policy and Washington, DC: National Academy for State Health Policy, 2005).

APPENDIX A: METHODOLOGY

Between July and December 2012, the National Center on Caregiving at Family Caregiver Alliance (FCA) conducted a survey of all 50 states plus the District of Columbia for the AARP Public Policy Institute on assessing family caregiver needs in Medicaid HCBS programs. The study consisted of two components: (1) a 50-state survey, and (2) in-depth key informant interviews.

State administrators from both state Medicaid agencies and the state aging and disability agencies completed a short survey including questions about the number and type of Medicaid HCBS 1915(c) aged and disabled waivers,⁴⁷ whether a family caregiver assessment was administered as part of the client assessment process, and background information on the state's LTSS system. State administrators were also asked to provide a copy of their client assessment tool for Medicaid eligibility, the family caregiver assessment (when available), and any user manuals for the assessment processes.^{48,49} Forty-six states and the District of Columbia responded.⁵⁰

States that indicated they use a family caregiver assessment in their Medicaid HCBS waivers were then asked to complete an additional short survey about the timing of the family caregiver assessment, how the client's care plan is affected by the assessment of family caregiver needs, and how and when the family caregiver is connected to services and supports.

We then analyzed the client assessment tools for the care recipient (the older person or adult with disabilities), as well as the family caregiver assessments and any training manuals used to conduct those assessments that we obtained from state respondents. To be classified as having a family caregiver assessment, the project team used the following criteria:

At a minimum, the assessment must ask questions *directed to family caregivers* to:

1. Assess their health and well-being
2. Determine levels of stress and feelings of being overwhelmed that can lead to burnout
3. Identify any service and support needs they may have

Between September and November 2012, the project team conducted key informant interviews with state administrators in 13 states: 8 states believed to have a family caregiver assessment based on these criteria, 2 states that were "assessment light" (one to three questions directed to the family caregiver), and 3 states that did not have a family caregiver assessment as part of their Medicaid HCBS programs. These interviews were conducted to clarify questions about survey responses and to gather more in-depth information. Each interview lasted approximately 30 minutes.

⁴⁷ At the time of the survey, six states (AZ, DE, HI, RI, TN, and VT) reported using a Medicaid HCBS 1115 waiver. The rest of the states responding to the survey use a 1915(c) waiver.

⁴⁸ Forty-one states provided their client assessment tools and the accompanying user manual.

⁴⁹ Two states (NM and ND) were unable to provide their client assessment tools because they were proprietary to the managed care company administering the state's Medicaid HCBS program. In Tennessee, the project team was able to obtain the state's tool through the managed care company administering the program in that state.

⁵⁰ Four states (IA, KS, MD, and SD) did not participate in the survey.

APPENDIX B: STATE EXAMPLES OF “PROMISING PRACTICES” IN FAMILY CAREGIVER ASSESSMENT

Massachusetts

Massachusetts uses a two-step process, first using the Comprehensive Data Set (CDS), an assessment that includes, in its entirety, interRAI’s Minimum Data Set-Home Care (MDS-HC). Certain responses within the CDS screening tool are used to trigger a more robust assessment process under the Older Americans Act’s Family Caregiver Support Program (FCSP), particularly for older adults. MassHealth administers all of the state’s HCBS waivers, which are operated through sister state agencies under the umbrella of the single state agency, the Executive Office of Health and Human Services. These sister agencies or contractors conduct the client eligibility assessments for various waivers.

Background

Massachusetts has one waiver for older people, called the “Frail Elder Waiver,” under its 1915(c) HCBS Medicaid waiver program. It has multiple waivers for adults with disabilities, including a brain injury waiver. The state, through its Medicaid state plan, provides a self-directed Personal Care Attendant (PCA) program,⁵¹ and several of its 1915(c) waivers include personal care services that can be delivered by an agency for individuals who do not wish to self-direct. A voluntary managed care service delivery option is available to people 65 or older who are eligible for both Medicare and Medicaid, called Senior Care Options (SCO).

Massachusetts uses the MDS-HC as its basic assessment tool for people receiving services in its frail elder waiver, its brain injury waiver, and in the SCO program. (It is not used for the state plan PCA benefit.) A Registered Nurse (RN) conducts the initial assessment. Section G of the MDS-HC asks questions about the client’s support system and stress. Questions include whether the family caregiver (1) can continue in caring activities, due to factors such as a decline in health; (2) is not satisfied with support from family and friends; and (3) expresses feelings of distress, anger, or depression. The answers, which can come from the client or the family caregiver, can indicate a need for respite and trigger a family caregiver assessment.

The Family Caregiver Assessment and Care Planning Process

If a family caregiver assessment is triggered, a caregiver specialist under the FCSP conducts the assessment locally through Area Agency on Aging (AAA) or Aging Services Access Points throughout the state. Questions are directed at the family caregiver. They include questions about caregiver needs, strengths, areas of stress, and personal health and well-being. The FCSP staff provides caregivers counseling and information about, as well as connections to, available services and supports.

⁵¹ The Personal Care Attendant (PCA) program helps people with LTSS needs to live independently at home. The program gives each eligible consumer funds to hire a personal care attendant or direct care worker to help with activities of daily living, such as bathing or dressing. Accessed at <http://www.massresources.org/masshealth-pca.html>.

Minnesota

Minnesota includes family caregiver assessment within the state's new automated uniform assessment instrument used across state LTSS programs, including Medicaid HCBS waivers, for people of all ages and disabilities. The MnCHOICES program is administered by the Minnesota Department of Human Services.

Background

The MnCHOICES initiative is a web-based, person- and family-centered assessment and support planning application for all LTSS in Minnesota. It helps people with long-term needs make decisions about care and select support and service options.

The MnCHOICES instrument replaces the following assessment tools: (1) long-term care consultation, (2) personal care assistance, and (3) developmental disability screening. (In future phases, it will replace the private duty nursing assessment.)

Implementation begins on November 4, 2013, for new assessments, with a target date of June 2014 for all lead agencies.

The Family Caregiver Assessment and Care Planning Process

MnCHOICES includes a family caregiving domain with questions used to (1) assess the capacity of the family caregivers to provide care and support to the care recipient, and (2) identify resources to assist in the family caregiving role. Family caregivers are asked about their own health, their levels of stress related to caregiving, and any sleep difficulties.

Other questions address any issues or obstacles that make it more difficult to provide family caregiving support, and what would make the caregiving experience easier. In addition to identifying the family caregiver's needs and strengths, the module makes referrals, ranging from respite, training, coaching, and counseling to home and vehicle modification, health care, and end-of-life care. It also aids in the development of a support plan for the care recipient and family caregiver.

The family caregiving questions are triggered through the "Quality of Life" section in the MnCHOICES tool by a positive response to the question: "Is there someone who helps you at home or in the community?" If a family caregiver is identified, the certified assessor will ask the family caregiver the questions in the caregiver domain. Responses to these questions will be used by the assessor when developing the support plan together with the care recipient and their family caregiver.

MnCHOICES introduces state-certified assessors who will conduct assessments to make eligibility determinations and develop Community Support Plans (CSP) for all people assessed. The importance of the family caregiver—in regard to both the support provided and supports needed—is an essential part of the CSP. Certified assessors will be trained on the family caregiving assessment process and when to include caregiver supports in the CSP. The CSP includes assessment outcome information, including a summary of assessed needs and goals; options and choices to meet needs; referral information; and family caregiver support, if applicable.

A Coordinated Service and Support Plan is developed by a case manager when a person is in an HCBS waiver or Alternative Care program. This plan will be used by the case manager in collaboration with the care recipient and family caregiver, as appropriate, to make decisions choosing services and providers, and to implement and monitor the care plan.

Washington

Washington State uses a uniform client assessment instrument to determine functional eligibility and service and payment levels across its Medicaid HCBS waivers and state plan programs. Within the client assessment instrument, the Caregiver Status section provides an initial screening that can lead to a referral to the Family Caregiving Support Program (FCSP) for additional services.

Background

Washington uses a uniform client assessment instrument to determine client eligibility and service and payment levels for authorizing personal care services across its Medicaid HCBS waivers and state plan programs, administered by the Aging and Long-Term Support Administration (ALTS) of the Department of Social and Health Services. The Comprehensive Assessment Reporting Evaluation (CARE) tool is used for all client assessments (initial and ongoing) and includes an optional “Caregiver Status” section with questions directed to the caregiver on whether the family caregiver lives with the care recipient, length of caregiving, use of caregiver support services, level of stress, and any barriers to continued family caregiving.

The Family Caregiver Assessment and Care Planning Process

The Caregiver Status section in CARE has internal electronic links to the assessment tool used by the federal and state-funded FCSP that can identify whether an unpaid family caregiver caring for a client receiving LTSS has been served through the FCSP. In 2012, about 20 percent of the 40,000 clients who were assessed using the CARE tool and received a Medicaid HCBS service had the Caregiver Status section completed. The assessment process was triggered based on the choice of the caregiver(s) to participate and on the discretion of the case manager or social worker to initiate the Caregiver Status portion of the tool.

Through an “Exception to Policy” process, an unpaid caregiver who is caring for a person receiving Medicaid LTSS can receive a limited array of services through the FCSP, not including respite care or other services available through the waiver. The FCSP services available to those receiving Medicaid LTSS may include service information and assistance, caregiver educational programs, support groups, and referral to other community service programs.

The state-funded and federally-funded FCSP utilizes the TCARE[®] (Tailored Caregiver Assessment and Referral Evaluation) system, an evidence-based process developed by Rhonda Montgomery and her colleagues at the University of Wisconsin to

better tailor support and services to an unpaid family caregiver's unique needs.⁵² All CARE and TCARE[®] assessments and client records across the Medicaid waiver and state plan programs and within the FCSP are in an electronic format, enabling the identified family caregiver and care recipient to be identified across these programs.

Most caregiver/care recipient dyads served by the FCSP do not receive Medicaid LTSS. However, family caregivers of potential Medicaid HCBS beneficiaries may be referred for additional assessment and services from the FCSP when a family caregiver is identified during intake of the care recipient for HCBS services, and if it is determined that the adult who needs LTSS is not yet eligible for, or may not be interested in, Medicaid HCBS at that time. After identification is made, an email referral form is sent directly to the FCSP program manager at the ALISA headquarters for quick review and determination of the appropriate local FCSP staff. After the referral form is forwarded, the turnaround time is 24 hours for the local FCSP staff to follow up with the family caregiver. Since the initiation of this referral system in the summer of 2011, approximately 500 referrals have been made through this process.

Once the referral is made to the appropriate Area Agency on Aging (AAA) staff for FCSP services, the family caregiver is contacted and, if willing, screened using the TCARE[®] system. Families may receive information, training, and referrals to supportive services at this level or they may move to a more comprehensive assessment process using the TCARE[®] model that can tailor a more in-depth package of family caregiver support services.

Another referral scenario is when a family caregiver, caring for a person receiving Medicaid LTSS, is identified as needing additional support during the screening process using the CARE tool. This type of family caregiver would only be eligible for a limited array of caregiver services. The state has invested in initial training of HCBS direct line staff and supervisors across programs in the following areas: (1) FCSP eligibility requirements, (2) services provided, (3) referral protocols, (4) use of assessment instruments, and (5) how to communicate with family caregivers about using supportive services.

Washington has a history of supporting family caregivers. The state has made improvements to their system in the last five years to collect data meaningful to family caregiver outcomes. Washington recently conducted an evaluation that determined that providing family caregiver support services (related to information, emotional health, and wellness) can help delay use of more expensive LTSS for the care recipient.⁵³ The ALISA staff are pursuing options to further linkages between their two assessment systems (CARE and TCARE[®]) while embedding family caregiver support within the Medicaid waiver and state plan service system.

⁵² J. Kwak, R.J.V. Montgomery, and J. Lang, "The impact of TCARE[®] on service recommendations, use, and caregiver well-being," *The Gerontologist* 51, no. 5 (2011): 704–713.

⁵³ Aging and Disability Services Administration, *Family Caregiver Support Program, A Report on the FY 2012 Expansion* (Olympia, WA: Department of Social and Health Services, January 2013). Accessed at <http://www.aasa.dshs.wa.gov/Professional/TCARE/documents/FCSP%20Expansion%20Report%20-%20January%207%202013.pdf>.

APPENDIX C: RHODE ISLAND'S FAMILY CAREGIVERS SUPPORT ACT OF 2013

Chapter 469 2013 -- H 5155 SUBSTITUTE A Enacted 07/16/13

AN ACT RELATING TO HUMAN SERVICES - FAMILY CAREGIVERS SUPPORT ACT OF 2013

Introduced By: Representatives Naughton, and E Coderre

Date Introduced: January 24, 2013

It is enacted by the General Assembly as follows:

SECTION 1. Section 40-8.10-4 of the General Laws in Chapter 40-8.10 entitled "Long-Term Care Service Reform for Medicaid Eligible Individuals" is hereby amended to read as follows:

40-8.10-4. Assessment and Coordination Unit (ACU). -- (a) The department of human services, in collaboration with the executive office of health and human services, shall implement a long-term care options counseling program to provide individuals or their representative, or both, with long-term care consultations that shall include, at a minimum, information about long-term care options, sources and methods of both public and private payment for long term care services, information on caregiver support services, including respite care, and an assessment of an individual's functional capabilities and opportunities for maximizing independence. Each individual admitted to or seeking admission to a long-term care facility, regardless of the payment source, shall be informed by the facility of the availability of the long-term care options counseling program and shall be provided with a long-term care options consultation, if he or she so requests. Each individual who applies for Medicaid long-term care services shall be provided with a long-term care consultation.

(b) Core and preventative home and community based services defined and delineated in section 40-8.10-2 shall be provided only to those individuals who meet one of the levels of care provided for in this chapter. Other long term care services authorized by the federal government, such as medication management, may also be provided to Medicaid eligible recipients who have established the requisite need as determined by the Assessment and Coordination Unit (ACU). Access to institutional and community based supports and services shall be through the Assessment and Coordination Unit (ACU). The provision of Medicaid-funded long-term care services and supports shall be based upon a comprehensive assessment that shall include, but not be limited to, an evaluation of the medical, social and environmental needs of each applicant for these services or programs. The assessment shall serve as the basis for the development and provision of an appropriate plan of care for the applicant.

(c) The ACU shall assess the financial eligibility of beneficiaries to receive long-term care services and supports in accordance with the applicable provisions of section 40-8.9-9.

(d) The ACU shall be responsible for conducting assessments; determining a level of care for applicants for medical assistance; developing service plans; pricing a service budget and developing a voucher when appropriate; making referrals to appropriate settings; maintaining a component of the unit that will provide training to and will educate consumers, discharge planners and providers; tracking utilization; monitoring outcomes; and reviewing service/care plan changes. The ACU shall provide interdisciplinary high cost case reviews and choice counseling for eligible recipients.

(e) The assessments for individuals conducted in accordance with this section shall serve as the basis for individual budgets for those medical assistance recipients eligible to receive services utilizing a self-directed delivery system.

(f) Nothing in this section shall prohibit the secretary of the executive office of health and human services, or the directors of that office's departments from utilizing community agencies or contractors when appropriate to perform assessment functions outlined in this chapter.

SECTION 2. Title 40 of the General Laws entitled "HUMAN SERVICES" is hereby amended by adding thereto the following chapter:

CHAPTER 8.11
FAMILY CAREGIVERS SUPPORT ACT OF 2013

40-8.11-1. Findings. -- (a) Family members, partners and close friends provide the vast majority of long-term services and supports.

(b) An estimated one hundred and forty-eight thousand (148,000) persons in Rhode Island are providing care at any one time to persons living in the community. The estimated value of their unpaid contributions in 2009 was one billion eight hundred eighty million dollars (\$1,880,000,000).

(c) Family or other caregivers who provide the majority of care in the home are frequently under substantial physical, psychological, and financial stress. The stress, if unrelieved by support for the caregiver, may lead to premature or unnecessary nursing home and institutional placement and health and financial burdens for the caregiver.

(d) Respite care and other community-based supportive services for the family caregiver can relieve some of the stresses faced by caregivers, maintain and strengthen the family structure, postpone or prevent institutionalization and lead to better outcomes for both the caregiver and care recipient.

(e) The percent of Rhode Islanders age sixty-five (65) years of age and older is projected to grow from fourteen percent (14%) of the state population in 2010 to twenty-one percent (21%) by 2030. As persons age, they have greater dependency needs and an increased need for long-term care services and support. Younger people with disabilities also require continued supportive long-term care services as they age.

(f) As informal caregivers and families are a vital part of the long-term care services and support system, it is an important public purpose to recognize and respect their contributions and to assess and support their needs.

40-8.11-2. Definitions. -- (a) "Caregiver assessment" is defined and 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.

(b) The term "family caregiver" is defined and refers to any relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance for, an older adult or an adult or child with chronic or disabling conditions.

40-8.11-3. Caregiver assessment requirement. -- The comprehensive assessment required in subsection 40-8.10-4(b) as part of Medicaid long-term service reform shall also include a caregiver assessment whenever the plan of care depends on a family caregiver for providing assistance with activities of daily living needs. The assessment shall be used to develop a plan of care that recognizes both needs of the care recipient and the caregiver. The assessment

shall also serve as the basis for development and provision of an appropriate plan for caregiver information, referral and support services. Information about available respite programs, caregiver training and education programs, support groups and community support services shall be included as part of the caregiver support plan. To implement the caregiver assessment, the executive office of health and human services shall adopt evidenced-based caregiver assessments and referral tools appropriate to the departments within the office that provide long-term care services and support.

SECTION 3. This act shall take effect upon passage.

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