Caregiver Assessment within Medicaid HCBS Waiver Programs Across the States

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Overview

- What we mean by *Caregiver Assessment*
- Why we did the study
  - Family caregivers need greater recognition and support
  - Importance of caregiver assessment in policy and practice
- Describe fundamental principles for assessing family caregiver needs
What We Mean by

*Caregiver Assessment*
What is Caregiver Assessment?

• **Caregiver Assessment:**
  - Refers to a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver— as well as the caregiver’s ability to contribute to the needs of the care recipient.

  - Means that questions are asked directly to the caregiver, not questions asked of the care recipient about the caregiver.
Why We Did the Study
Family Caregiving

• Backbone of LTSS system

• Helps delay or prevent institutionalization

• Support for family caregivers is a key component of a high-performing LTSS system
  - AARP *State LTSS Scorecard*
  - [http://www.longtermscorecard.org](http://www.longtermscorecard.org)
Family Caregiving

• More than 42 million family caregivers

• Typical caregiver: 49 year-old woman

• Some 6 in 10 caregivers also have paid jobs
  – ¾ have worked while caregiving

• Nearly half (46%) perform medical/nursing tasks
  – AARP & UHF, *Home Alone: Family Caregivers Providing Complex Care*

• Value of family caregiving estimated at more than $450 billion annually
How Much is $450 Billion?

**Family Caregiving is as big as Medicare and Medicaid**

- Total Medicare: $509 billion
- Family Caregiving: $450 billion
- Total Medicaid: $361 billion
- Total Formal LTSS: $203 billion

AARP Public Policy Institute, 2009 data
Caregivers Are a Vulnerable and an At-Risk Group Themselves

- Caregivers can experience enormous stress from their responsibilities
  - Physical demands
  - Financial burdens
  - Workplace issues from juggling caregiving & work
  - Loss of employment income
    - retirement insecurity
  - Emotional strain/mental health problems
  - Social Isolation
Caregivers Are a Vulnerable and an At-Risk Group Themselves

• The stress on family caregivers can lead to negative consequences:
  – Impede the caregiver’s ability to continue providing care
  – Lead to higher costs for health care and LTSS for the care recipient
  – Affect quality of care and quality of life for both the care recipient and family members.

• Demographic trends are expected to decrease availability of family caregivers
  – More reliance on fewer family caregivers as the Baby Boomers age
Caregiver Support Ratio

You Take Care of Mom, But Who Will Take Care of You?

Family caregivers provide the majority of long-term services and supports (LTSS). But the supply of family caregivers is unlikely to keep pace with future demand. The Caregiver Support Ratio is defined as the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 and older—those most likely to need LTSS. The caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

In 2010, the caregiver support ratio was more than 7 potential caregivers for every person in the high-risk years of 80-plus.

In 2030, the ratio is projected to decline sharply to 4 to 1; and it is expected to further fall to less than 3 to 1 in 2050.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

Family Caregiving

- Family caregiving is on the public policy agenda

- As LTSS shifts from nursing homes to HCBS, reliance on family caregivers grow

- Caregiver assessment is an essential next step
  - The needs of family members are assessed and addressed so they can continue in their caregiving role without being overburdened
    - AARP State LTSS Scorecard
Medicaid

• Medicaid is the major funder of LTSS

• States are “rebalancing” Medicaid LTSS away from institutional care and towards HCBS
  – What most people and their families prefer

• This is accomplished largely through Medicaid waivers—enabling the care recipient to remain in their homes, often with reliance on family caregivers.
Medicaid

- Under Medicaid, the client is the older person or adult with disabilities, not the family caregiver.

- HCBS are typically viewed as services and supports to help fill in the gaps when family care is insufficient.
  - To supplement, but not replace, family care.

- Medicaid identifies the care recipient’s support networks, but not the family caregiver’s needs for information, education, and supportive services.

- Family caregivers need greater recognition and support in Medicaid waiver programs.
New Medicaid LTSS Policies at the State Level

• Rhode Island’s *Family Caregiver Support Act of 2013*
  – Part of the state’s Medicaid LTSS reform efforts
  – Requires a caregiver assessment if the plan of care for the Medicaid beneficiary involves a family caregiver
  – A plan of care will be developed to address the needs of the care recipient and the family caregiver.
Moving Toward Person- and Family-Centered Care

• Practitioners must consider not only how the family caregiver can help the care recipient, but also what support the family needs
  – Person- and family-centered perspective

• Supporting the caregiver improves support for the care recipient
This AARP PPI study, conducted by the Family Caregiver Alliance, is first to examine whether Medicaid HCBS programs include a caregiver assessment with questions directed at the caregiver.

- Supported by:
  - AARP Foundation
  - The John A. Hartford Foundation
  - U.S. Administration for Community Living, Administration on Aging

http://www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf
Fundamental Principles for Caregiver Assessment

1. Because family caregivers are a core part of health care and long-term care, it is important to recognize, respect, assess, and address their needs.

2. Caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.

3. The caregiver assessment should result in a plan of care (developed collaboratively with the caregiver) that indicates the provision of services and intended measurable outcomes.
4. Caregiver assessment should be multidimensional in approach and periodically updated.

5. Caregiver assessment should reflect culturally competent practice.

6. Effective caregiver assessment requires assessors to have specialized knowledge and skills.
   - Understanding of the caregiving process and its impacts
   - Benefits and elements of an effective caregiver assessment

7. Government and other third-party payers should recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities.
Conclusion

- Consistent approaches to assessing caregiver needs will:
  - Help practitioners better understand and address family needs and capabilities
  - Enable caregivers to access needed supportive services and training
  - Assume optimal outcomes for the care recipient
  - Provide solid information to policymakers and program administrators to improve service delivery.
Thank you

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Caregiver Assessment Within Medicaid Waivers Across the States
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Project Partners

• An AARP Public Policy Institute project with support from The John A. Hartford Foundation and the Administration on Aging/Administration for Community Living

• National Center on Caregiving, Family Caregiver Alliance conducting the study
Project Goals

• Create a national inventory of functional assessment instruments that include caregiver assessment within Medicaid Home and Community-Based Services (HCBS) and Personal Care Services (PCS) for adults.

• Identify the assessment process for HCBS/PCS as a key opportunity to assess the caregiving situation as well as the needs, resources, and strengths of a family caregiver.

• Focus on identifying key components and best practices in the inclusion of family caregivers within the functional assessment process.
Background

- Support for family caregiving, including caregiver assessment, is increasingly being recognized as a key dimension in a high-performing state long term services and support (LTSS) system.
- Assessing and addressing caregivers’ needs helps to maintain their health and sustain their ability to provide care, and prevent or postpone nursing home placement of the care recipients.
Background

- Caregiver assessment may occur in many settings and during transitions in care across settings, including in the home, in health care settings.
- The focus of this study was community settings, focusing on caregiver assessment in state HCBS programs under Medicaid 1915(c) or 1115 demonstration waivers.
Current Functional Assessment Process

- All states conduct medical and functional assessments of the needs of applicants for waiver services
- However, there is great variability in assessments across states or among Medicaid LTSS services
- States that conduct a caregiver assessment, do so voluntarily
- Interest is growing in establishing uniform assessments
What is HCBS functional assessment?

• Medicaid beneficiaries must meet medical and functional eligibility criteria as well as financial criteria.

• States use functional assessments in order to determine the need for and level of personal care and other HCBS services.

• Such assessments are also a key opportunity to assess the caregiving situation and the needs, resources, and strengths of a family caregiver.
Who is a Family Caregiver

- 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
How has caregiver assessment been defined?

• “A systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the ability of the caregiver to contribute to (meeting) the needs of the care recipient”

• It should approach issues from the 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 that includes this assistance
Methods

• Qualitative and quantitative components
• 50 states plus District of Columbia are included in this study.
• Purposive sample: Contacts/key informants were state employees knowledgeable about their state’s Medicaid HCBS1915(c) waiver and 1115 waiver services
• All contacts were e-mailed and asked:
  – To provide a copy of the states’ functional assessment tool, manual, and any related documents
  – If their state uses a caregiver assessment, and if so, to provide a copy of that as well
  – Complete a short survey
Methods: Quantitative Survey

- Type and number of aged and disabled waivers,
- Whether the state is consumer directed and offers the optional PCS benefit,
- Use of managed care
- Use of uniform assessment tools throughout the state.
- The central focus, however, was on two questions:
  - Does the state use a caregiver assessment
  - Does the state have an assessment manual for their functional/caregiver assessment
Methods: Qualitative

• We conducted interviews with key informants in 10 states with more developed caregiver assessments

• Questions about:
  – Development of tool and how long it has been in use
  – Assessment process
  – Analysis and application of the data
  – Challenges and best practices
State Assessment Information Obtained

- All states, plus DC were contacted; 92% response rate (4 states were not responsive)
- Received complete functional assessment tools from 41 states
- Five states reported using an 1115 waiver,
- Remaining states use a 1915(c) waiver.
- 37 states offer the optional personal care services state plan benefit.
Key Findings

• There is not a common understanding of what constitutes caregiver assessment among state officials

• Some states viewed caregiver assessment as asking the care recipient whether or not they had someone to assist them

• This lead to the stating the criteria used to define caregiver assessment as: first must ask the questions of the family caregiver at a minimum to:
  • (1) Assess their health and well-being
  • (2) determine their level of stress and feelings of being overwhelmed
  • (3) determine any service and support needs they may
Key Findings

• About 30% of states include family caregiver assessments that met our criteria – 15 states

• Seven of the states used state-specific tools (FL, IL, ME, MN, OK, PA, WA)

• Eight states used the interRAI Minimum Data Set – Home Care (GA, HI, LA, MA, MI, MO, NJ, UT)

• Three states indicated that they intended to include caregiver questions within the next 1-2 years

• As a note, another seven states (AL, DC, MS, SC, TN, TX, VT) include one to three questions that are directed to the caregiver but are not comprehensive
Key Findings

- The majority of states with caregiver assessments use the information collected to develop a service plan and in connecting families to services and support
  - In 9 states the caregiver assessment affects the care plan; all 10 states refer to community services and supports
  - 7 states conduct the caregiver assessment at the first functional assessment process;
  - All states provide assessor training

Note: data in this section collected on 10 states (out of 15 identified) key informant interviews
What Caregiver Questions are Asked?

• Reviewed specific questions; categorized them under the seven domains of assessment questions (National Consensus Development Conference on Caregiver Assessment, 2005)

• Context: 14 asked kinship; 6 about employment; 2 about if family caregiver was financially dependent on care recipient; 11 about frequency of care; 4 about duration of care; 2 about frequency and duration

• Health and Functional Status of Care Recipient (types of care work): 14 asked about assistance with ADL’s and IADL’s; 6 about specific tasks performed; 1 asked about “health care” and “medical tasks”
What Caregiver Questions Are Asked?

- **Caregiver Values and Preferences**: 3 states asked about the caregiver’s willingness to provide care; no questions about cultural preferences, goals of care.
- **Health and Well-Being**: 15 states asked about the caregiver’s emotional health and stress levels; 6 states asked about physical health.
- **Consequences of Caregiving**: 8 states asked about the positive and negative effects of caregiving.
- **Skills/Abilities/Knowledge**: 5 states ask about training needs.
- **Resources**: 7 states ask about service needs; 3 ask about service use.
Policy Recommendations

• Caregiver assessment should be included in all functional assessment tools for Medicaid HCBS waiver programs.

• Caregiver assessment should be directed to the family caregiver and include basic demographics and care demands/impacts/needs:
  – Kinship, frequency and duration of care, employment, age
  – Skills/abilities/knowledge to provide needed assistance
  – Well-being of the family caregiver(s)
  – Consequences of providing care
  – Resources for the family
Policy Recommendations

- The interRAI MDS-HC should be expanded to include a broader assessment directed to family caregivers.
- The service plan should address the needs raised during the assessment to achieve a person and family-centered service plan.
- The caregiver assessment should be part of the Medicaid HCBS client record and e-records if available.
Policy Recommendations

• Funding should be increased for the National Family Caregivers Support Program (Title IIIE, OAA)

• States should include caregiver assessment in the Medicaid managed care and for dual-eligible managed care programs

• All assessment tools and data should be publicly available
• **Report also includes:**
  - Best Practice section that provides an overview of three states: Washington, Minnesota, Massachusetts
  - Tables that display caregiver assessment questions for specific states, uses of the data, timing of the assessments, training for assessors

Report to be published late 2013 by AARP, Public Policy Institute
• “If support is given to the caregiver, the caregiver is stronger and more resilient, and that equates to better care and quality of life for the older adults.”
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