
Managed Long-Term Services and Supports & Family Caregivers

Tues, September 1, 2015
2:30 – 3:45 p.m.

Wendy Fox-Grage, moderator
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**Public Policy
Institute**

Why Support for Family Caregivers Matters

MLTSS & Family Caregivers

2015 National HCBS Conference

September 1, 2015

Lynn Friss Feinberg, MSW



- Family caregiving is one of the least appreciated but most important issues the U.S. faces as our population ages.



- Chronic illness and disability affects the family as well as the individual.



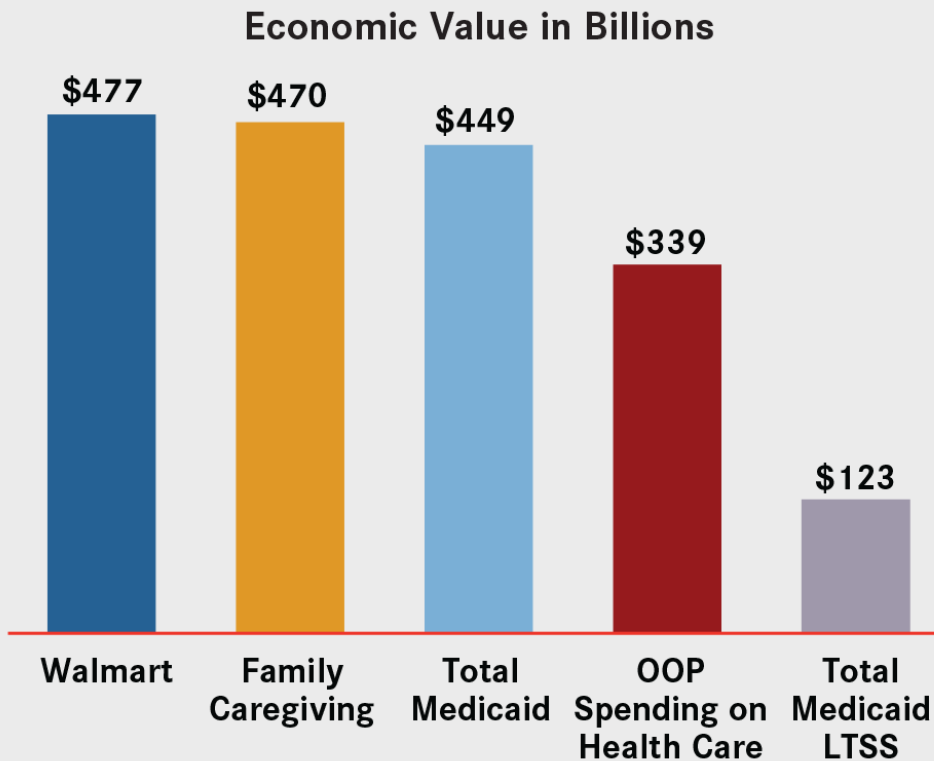
Family Caregiving

- An estimated 40 million family caregivers provide about 37 billion hours of care
 - Only 1 in 3 (32%) receive paid help
- Most (60%) also have paid jobs
- Nearly half (46%) perform medical/nursing tasks
- Economic value of family caregiving estimated at \$470 billion in 2013



How Much Is \$470 Billion?

The economic value of family caregiving is as big as the world's largest company, and bigger than Medicaid and out-of-pocket (OOP) spending on health care.



Caregivers are Vulnerable and At-Risk Themselves

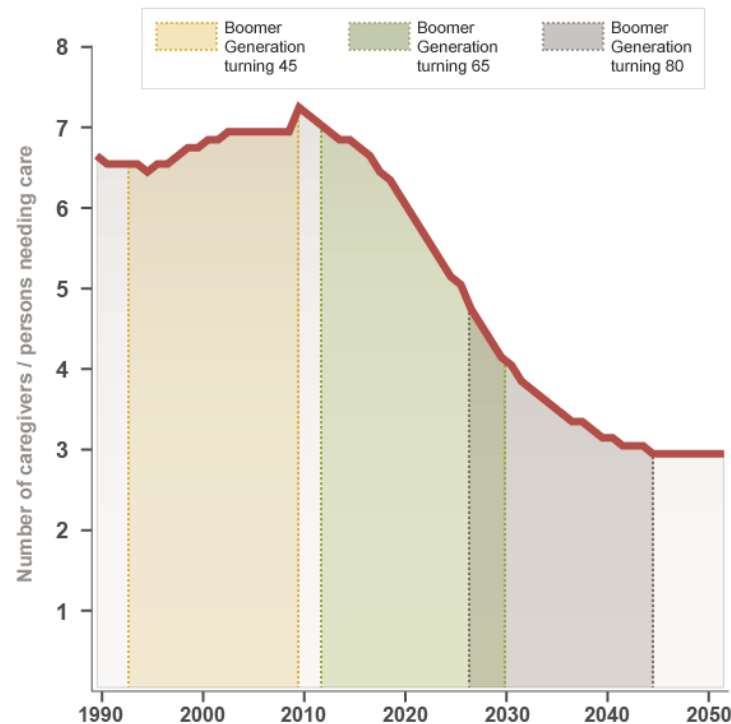
- Family caregivers can experience enormous stress from their responsibilities
 - Physical demands
 - Financial burdens
 - Workplace issues from juggling caregiving & work
 - Loss of employment income & benefits
 - Retirement insecurity
 - Emotional strain/mental health problems
 - Social isolation

Caregivers are Vulnerable and At-Risk 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 produce a care gap
 - More reliance on fewer family members as boomers age

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

Caregiver Support Ratio



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.

Moving Toward Person- and Family-Centered Care

- Support for family caregivers is a key component of a high-performing LTSS system
 - AARP State LTSS Scorecard, www.longtermscorecard.org
- 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*
- Viewing family not just as “resources” but as “clients”

- Time to raise the visibility and support for caregiving families to keep them from burning out.



Thank you

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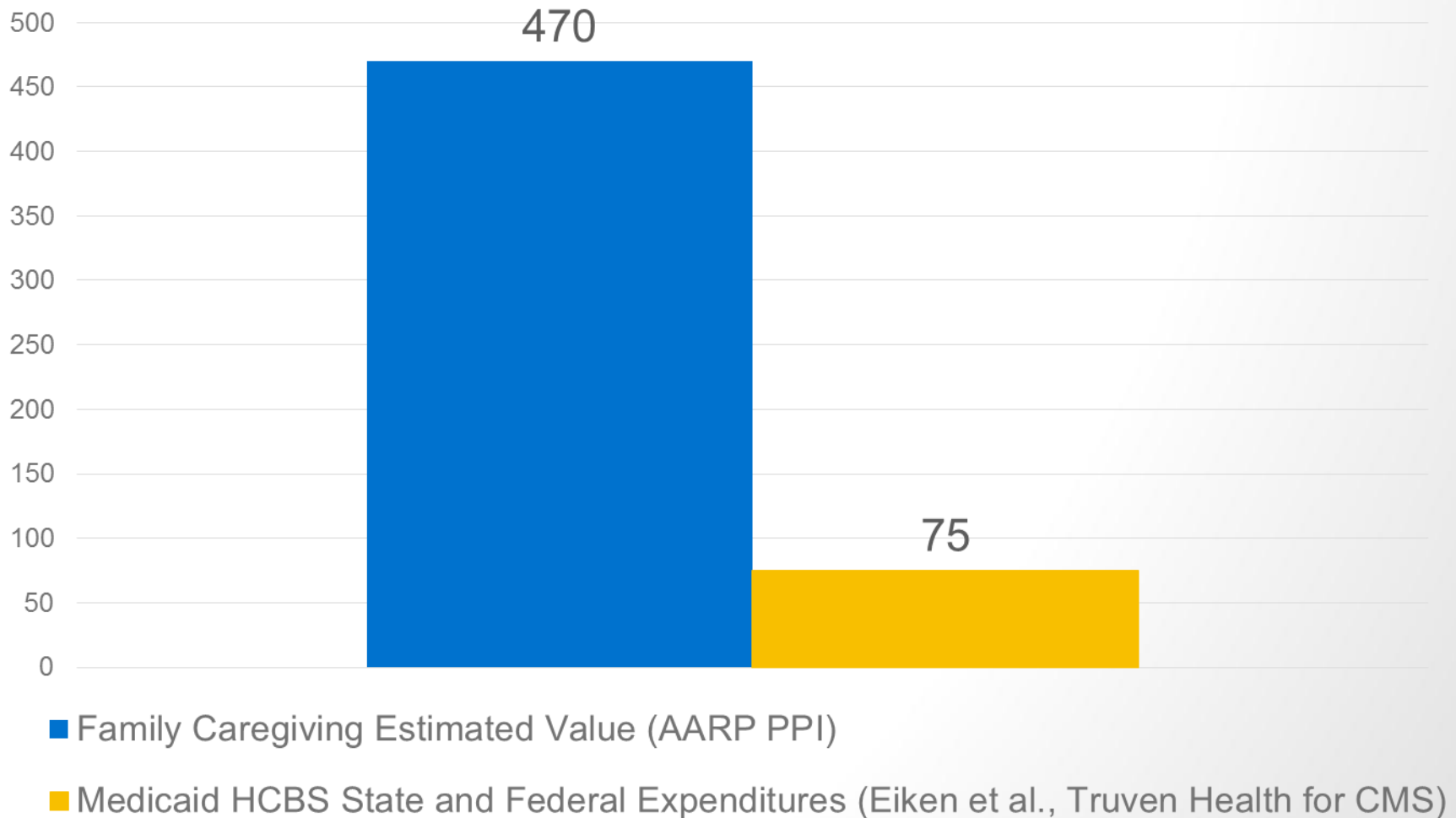
MLTSS and Family Caregivers

2015 NASUAD HCBS Conference, Washington, D.C.
September 1, 2015

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The Estimated Value of Family Caregiving and Medicaid HCBS Expenditures, 2013 (\$ Billions)



AARP Public Policy Institute Contract Study: How is Care Coordination Provided in MLTSS Programs? How are Caregivers Incorporated into the Process? (19 MLTSS Contracts)

Caregivers Asked About Their Needs

- Health and well-being?
- Level of stress?
- Training needs?
- Other supports?

Fully addressed: 1
Partly addressed: 14
Not addressed: 4

Caregiver Needs Addressed

- Service plan addresses caregiver needs

Fully addressed: 4
Partly addressed: 6
Not addressed: 9

Caregiver Contact Facilitated

- Caregivers are given care coordinator's contact info

Yes: 9
Not addressed: 10

Typical MLTSS Contract Provisions

Caregivers should be identified in the service plan.

Caregivers should be invited to participate in the service planning process with consent of the member.

Training needs of caregivers should be identified and addressed (e.g., administering medication, operating equipment, management of chronic conditions).

Information, including contact information, should be provided to caregivers.

Community resources should be identified for caregivers.

Caregiver respite and training are covered services.

Obstacles to More Consistent Approach

- Caregiver provisions have not generally been included in model contracts
- Financing of investment costs in FFS: service planning, respite, training, etc.
- Concerns about cost– uncertainty about ROI
- Focus on the covered beneficiary

MLTSS Opportunities

- Contract is a vehicle for standardizing the approach
- MCOs can recoup their investments since they are responsible for the costs of formal care when caregivers burn out
- Caregiver measures can be incorporated into value-based payment (e.g., results of caregiver survey)

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AARP Care Coordination Study:

<http://www.aarp.org/carecoordination>

STATE OF TENNESSEE

Family Caregivers in MLTSS

September 1, 2015
HCBS Conference

MLTSS in Tennessee

- Managed care demonstration implemented in 1994
- Operates under the authority of an 1115 waiver
- *Entire* Medicaid population (1.4 million) in managed care
- 3 at-risk NCQA accredited MCOs (statewide in 2015)
- Physical/behavioral health integrated beginning in 2007
- LTSS for seniors and adults w/ physical disabilities in 2010
- MLTSS program is called “*CHOICES*”
- ICF/IID and 1915(c) ID waivers carved out; populations carved in
- New proposed MLTSS program component for I/DD for 2016: *Employment and Community First CHOICES*

Family Caregivers in CHOICES

- **Critical importance recognized in initial MCO contract**
 - *“Long-term care services identified through care coordination and provided by the CONTRACTOR shall build upon and not supplant a member’s existing support system, including but not limited to informal supports provided by family and other caregivers...”*
 - Requirement to assess: *“the member’s natural supports, including care being provided by family members and/or other caregivers...and whether there is any anticipated change in the member’s need for such care or services or the availability of such care or services from the current caregiver...”*
 - As part of ongoing care coordination: *“Maintain appropriate ongoing communication with community and natural supports to monitor and support their ongoing participation in the member’s care;”*
 - Recognize as a significant change of circumstances requiring re-assessment and updates to the plan of care: *a “[c]hange of residence or primary caregiver or loss of essential social supports;”*

Supporting Family Caregivers

- Expanding the Paradigm
 - **AARP Public Policy Institute
(with Truven Health Analytics)**
 - Family Caregivers *as critical part of* needs assessment/care planning
 - Source of information/natural support
 - Family Caregivers *as a critical focus of* care needs assessment/care planning

Supporting Family Caregivers

- Expanding the Paradigm

- Federal PCP/HCBS Setting Rule (2014)

- 441.720 Independent assessment.

- (a) Requirements. For each individual determined to be eligible for the **State plan HCBS benefit**, the State must provide for an independent assessment of needs, which may include the results of a standardized functional needs assessment, in order to establish a service plan. In applying the requirements of section 1915(i)(1)(F) of the Act, the State must:*

- (4) **Include in the assessment** the individual's physical, cognitive, and behavioral health care and support needs, strengths and preferences, available service and housing options, and if unpaid caregivers will be relied upon to implement any elements of the person-centered service plan, a caregiver assessment.*

Supporting Family Caregivers

- Expanding the Paradigm

- **Federal PCP/HCBS Setting Rule (2014)**

“[W]hen caregivers are being relied upon to implement the person-centered service plan, it is important that a caregiver assessment be required in order to acknowledge and support the needs of informal family caregivers. We agree that caregivers provide critical care and support that enables individuals to live in their homes and communities. When there is a caregiver involved, an assessment of the caregiver's needs is essential to facilitate the individual's linkage to needed supports.”

Supporting Family Caregivers in CHOICES

- Expanding the Paradigm in Tennessee
 - **Governor’s Task Force on Aging (2013-2014)**
 - 3 priority areas, including “Supporting Family Caregivers”
 - Increase the capacity of caregivers to make informed choices about service definitions
 - Targeted investments that lead to sustainable caregiver respite services
 - Increased awareness of the importance of employer collaboration in supporting caregivers

Family Caregivers in CHOICES

- Expanding the Paradigm in Tennessee:
Supporting Family Caregivers in CHOICES
 - **Assess the needs of family caregivers, including:**
 - (1) an overall assessment of the family member(s) and/or caregiver(s) providing services to the member to determine the willingness and ability of the family member(s) or caregiver(s) to contribute effectively to the needs of the member, including employment status and schedule, and other care-giving responsibilities
 - (2) an assessment of the caregiver's own health and well-being, including medical, behavioral, or physical limitations as it relates to the caregiver's ability to support the member
 - (3) an assessment of the caregiver's level of stress related to care-giving responsibilities and any feelings of being overwhelmed
 - (4) identification of the caregiver's needs for training in knowledge and skills in assisting the person needing care
 - (5) identification of any service and support needs to be better prepared for their care-giving role

Family Caregivers in CHOICES

- Expanding the Paradigm in Tennessee:
Supporting Family Caregivers in CHOICES
 - **Assess the needs of family caregivers**
 - Typically performed as part of the face-to-face assessment
 - at least once every 365 days as part of the annual review
 - upon a significant change in circumstances; and
 - as the care coordinator deems necessary

“[A]t each face to face visit..., the Care Coordinator shall, as part of the ongoing needs assessment, inquire about the primary caregiver’s overall well-being and ability to continue providing the level of supports outlined in the POC. If a caregiver expresses concern about his or her overall well-being and/or ability to continue providing their current level of care for the member, the Care Coordinator shall complete a full caregiver assessment and update the member’s POC and/or risk agreement, as necessary.” [Needs Assessment Protocol]

Family Caregivers in CHOICES

- **Caregiver Assessments result in:**
 - A plan to address the needs of each caregiver to maintain the health and well-being of each caregiver and sustain their ability to provide care to the member
 - Include as part of the plan of care
 - *“Caregiver training or supports identified through the caregiver assessment that are needed to support and sustain the caregiver’s ability to provide care for the member”*

Family Caregivers in CHOICES

- Implementation Challenges
 - Defining “family caregiver”
 - *“routinely involved in providing unpaid support and assistance to the member”*
 - Primary
 - Other
 - Accommodating schedules
 - Respecting privacy/confidentiality

Next Steps: Supporting Family Caregivers in Employment and Community First CHOICES

- Specific benefit group/package for individuals with I/DD living with family caregivers
 - Primary focus is children, but open to adults living with family caregivers
 - Unique benefit structure tailored to the needs of individuals and their family caregivers, based on input from family caregivers across the state, including:
 - **Respite**
 - **Supportive Home Care (SHC)**
 - **Family Caregiver Stipend in lieu of SHC**
 - Community Integration Support Services
 - Community Transportation
 - Independent Living Skills Training
 - Assistive Technology, Adaptive Equipment and Supplies
 - Minor Home Modifications
 - **Community Support Development, Organization and Navigation (includes Family-to-Family Support and Assistance)**
 - **Family Caregiver Education and Training**
 - **Conservatorship Counseling and Assistance**
 - **Health Insurance Counseling/Forms Assistance**



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THANK YOU

TennCare MCO contract available at:
<http://www.tn.gov/assets/entities/tenncare/attachments/MCOStatewideContract.pdf>

