

# Recognition of Family Caregivers in Managed Long-Term Services and Supports: State Progress



**2020 HCBS Conference**  
**December 9, 2020 | 1:30 – 2:30 PM**

# Housekeeping

- All participants on mute
- Meeting is being recorded
- Participants can submit questions, comments and feedback by:
  - Chat box
- For any technical issues, please email:
  - Jillian Salmon at [JSalmon@advancingstates.org](mailto:JSalmon@advancingstates.org).

# Overview and Introductions

# Agenda

- Introductions and Overview
- PPI's Focus on Family Caregiving and MLTSS
- Overview of Family Caregivers
  - Who they are, what they do, costs they face
- Why MLTSS Matters to Family Caregivers
- Study Methodology
- Key Findings
- Recommendations and Takeaways
- Q&A

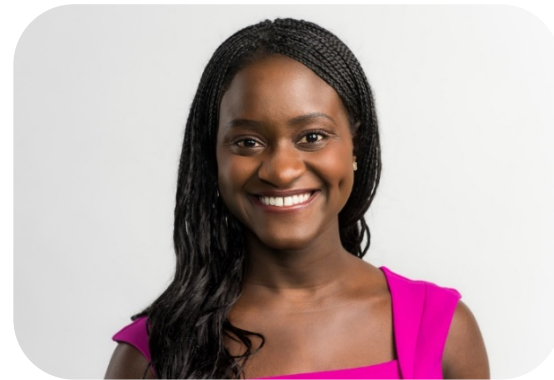


# Speakers



**Lynn Friss Feinberg, MSW**

*Senior Strategic Policy Advisor  
AARP Public Policy Institute*



**Edem Hado, MPH**

*Policy Research Senior Analyst  
AARP Public Policy Institute*



**Jessica Kasten, MA**

*Research Director  
IBM Watson Health*



**Elizabeth Lewis, MS, LCPC**

*Senior Research Leader  
IBM Watson Health*

# About Us

**AARP Public Policy Institute (PPI)** develops policy solutions designed to significantly improve economic security, health care, and quality of life for older Americans. Founded in 1985, we inform and stimulate public debate on the issues we face as we age. Our nationally recognized experts analyze a wide range of issues, and we convene public and private sector decision-makers to consider innovative policy solutions.

**IBM Watson Health** is committed to building smarter health ecosystems. This means simpler processes, better care, faster breakthroughs, and improved experiences for people around the world. We have the essential capabilities necessary to help our clients drive their digital transformations: deep industry expertise, data and analytics, and actionable insights—underpinned by security and trust.

# Tell Us About Yourself

**1. Are you currently a family caregiver?**

- a) Yes
- b) No

**2. Which statement best describes your caregiving experience?**

- a) I was providing care **before** the coronavirus pandemic, and I still am now.
- b) I began caregiving **after** the coronavirus pandemic, and I still am now.
- c) I am not providing care now, but I have provided care in the past.
- d) I have never been a caregiver.
- e) None of the above.

# PPI's Focus on Family Caregiving and MLTSS



# AARP Public Policy Institute Focus

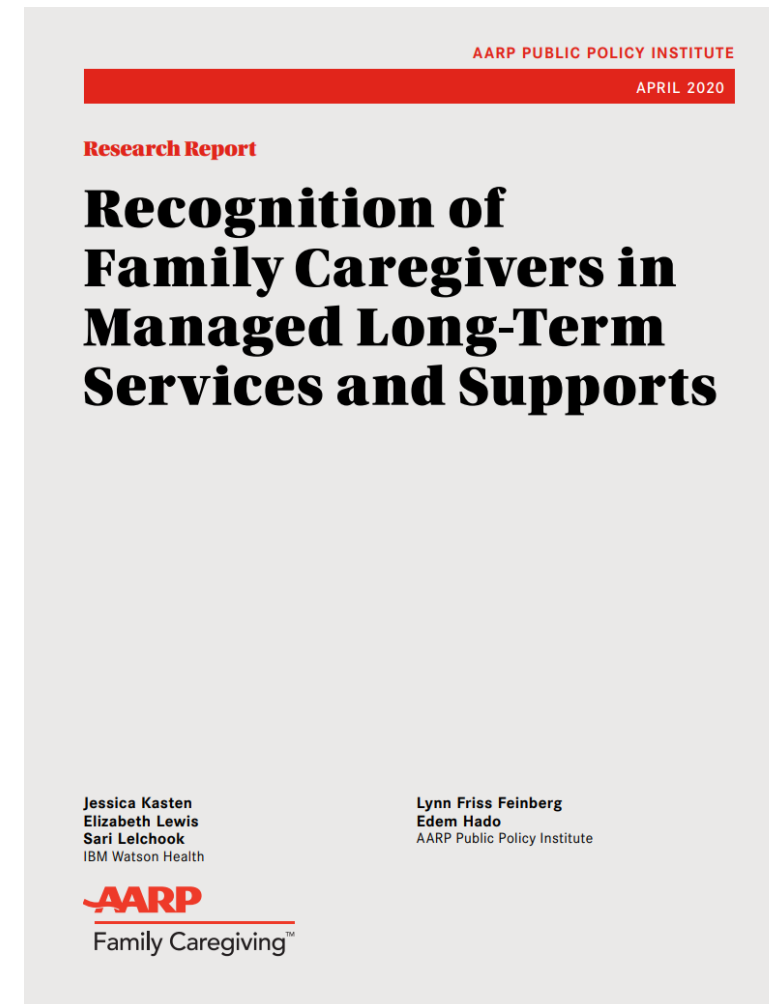
- **Surveys**
- **Research Reports**
  - Care Coordination in Managed Long-Term Services and Supports, 2015
  - Family Caregivers and Managed Long-Term Services and Supports, 2016
  - Emerging Innovations in Managed Long-Term Services and Supports for Family Caregivers, 2017
- **Roundtables**
- **Learning Collaborative**
  - Discussions with key stakeholders on promising practices in MLTSS

*Decade of research and dialogue on family caregivers and MLTSS*

# Our New Research Report

## *Recognition of Family Caregivers in Managed Long-Term Services and Supports*

[www.aarp.org/family-caregivers-in-mltss](http://www.aarp.org/family-caregivers-in-mltss)



# Why We Did This Study

- Nearly half the states have transitioned their Medicaid LTSS delivery systems to managed care, known as managed LTSS (MLTSS)
- States with MLTSS programs are now more aware of the importance of understanding and addressing caregiving issues—because family members play a key role for those with health and functional needs
- Managed care plans can lead the way towards **person- and family-centered care**

# Overview of Family Caregivers

# Family Caregiver *Broad Definition*

Any relative, partner, friend, or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic, disabling, or serious health condition.



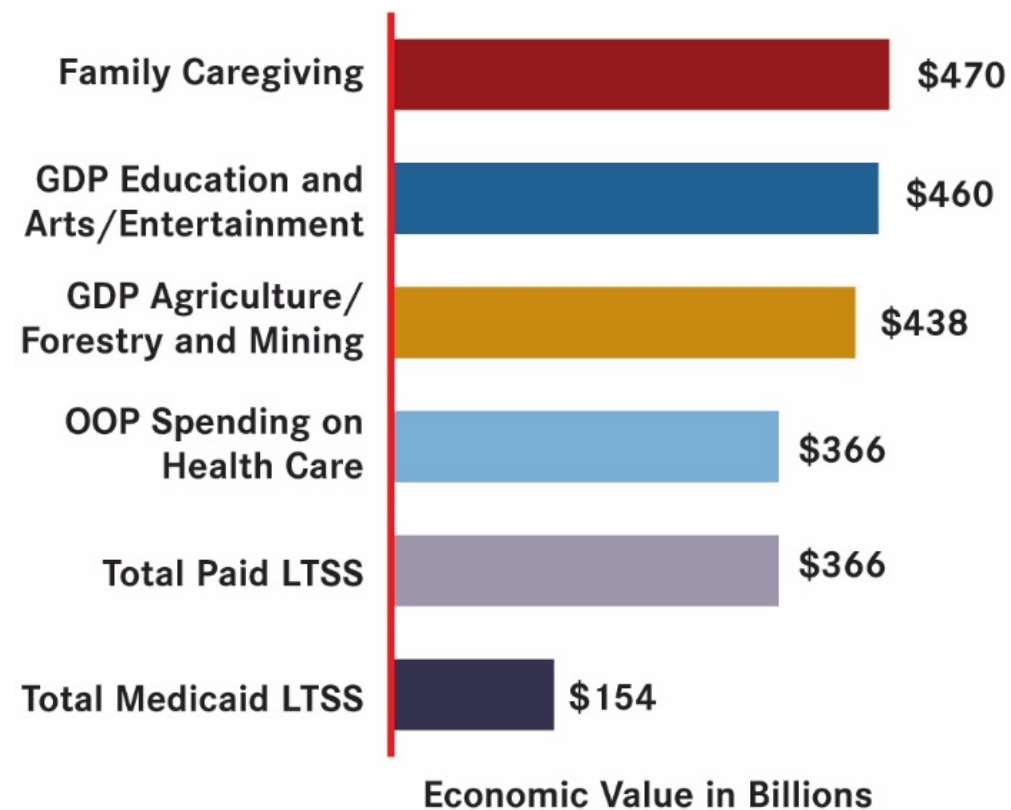
# Valuing the Invaluable

- In 2017, about **41 million** family caregivers in the U.S. provided an estimated **34 billion hours** of care to an adult with limitations in daily activities.
- The estimated economic value of their unpaid contributions was about **\$470 billion**.



Source: Reinhard, Feinberg, Houser, Choula, and Evans (2019). *Valuing the Invaluable: 2019 Update, Charting a Path Forward*, Washington, DC: AARP Public Policy Institute.

# How much is \$470 Billion?



\$470 Billion = \$1,450 for **every person** in the U.S.  
  
(325 million people in 2017)

# Today's Family Caregivers

- Family caregiving cuts across gender, age, and race/ethnicity
  - 61% are women; 39% are men
  - Nearly 1 in 3 (29%) is a Millennial (23%) or Gen Z (6%)
  - 1 in 5 (19%) is age 65+
  - 39% represent multicultural communities
- 1 in 10 (11%) is a student
- 29% have provided care for 5+ years
- More than 1 in 4 (26%) care for someone with dementia
- Nearly half (46%) provide care for someone age 75+
- 61% are employed



Source: National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*



# What Do Family Caregivers Do?



# Caregivers are Vulnerable and At-Risk Themselves

Family caregiving comes at substantial costs to the caregivers themselves

- Physical health risks
- Financial impacts
- Emotional strain/mental health problems
- Social isolation
- Workplace issues; lost career opportunities
- Retirement insecurity



# Few Family Caregivers have Conversations with Health Care or Social Services Providers

- Only 29% say a doctor, nurse or social worker ever asked about what was needed to care for their relative/close friend
- Much fewer (13%) say a health or social service provider has asked what they need to care for themselves.
  - Down from 16% in 2015



Source: National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*.

# Caregiver Support Services Make a Difference

- Evidence suggest that when family caregivers are adequately assessed for unmet needs and provided targeted supportive services
  - It helps maintain their own health and well-being
  - Sustains their ability to provide care
  - Prevents or delays more costly nursing home placement



Source: National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America*, Washington, DC: National Academies Press, 2016.

# Why MLTSS Matters to Family Caregiving

# Medicaid and Long-Term Services and Supports



- Medicaid is the nation's largest public health insurance program for people with low-incomes
- Medicaid also serves as the primary source of public funding for long-term services and supports (LTSS)
- 14 million adults of all ages needed LTSS in 2018 as a result of long-term illnesses, disabling conditions, or frailty

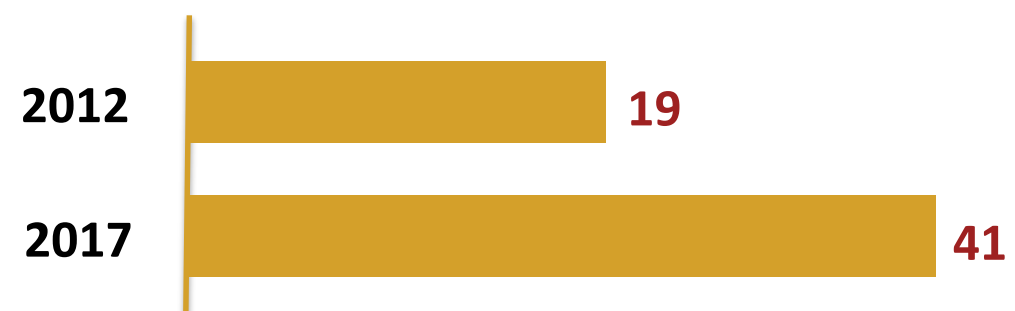
Source: Hado, and Komisar (2019). *Long-Term Services and Supports*. Washington, DC: AARP Public Policy Institute.

# States are Increasingly Using Medicaid Managed Care to Deliver LTSS

Number of States with MLTSS Programs



Total Number of MLTSS Programs



- State Medicaid agencies are leveraging their contacts with health plans to
  - improve the coordination of acute care and LTSS
  - better control and predict Medicaid spending on LTSS
  - provide more person-centered assessment and service delivery

Source: Lewis et al. *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update*.

# Family Caregivers Play a Critical Role in Care Coordination and Care Planning

- Family caregivers and other unpaid caregivers help members stay at home and in the community
- Support for family caregivers is a fundamental component of a high-performing LTSS system
  - AARP State LTSS Scorecard, [www.longtermscorecard.org](http://www.longtermscorecard.org)





# States can use Managed Care Contracts to Advance Person- and Family-Centered Care

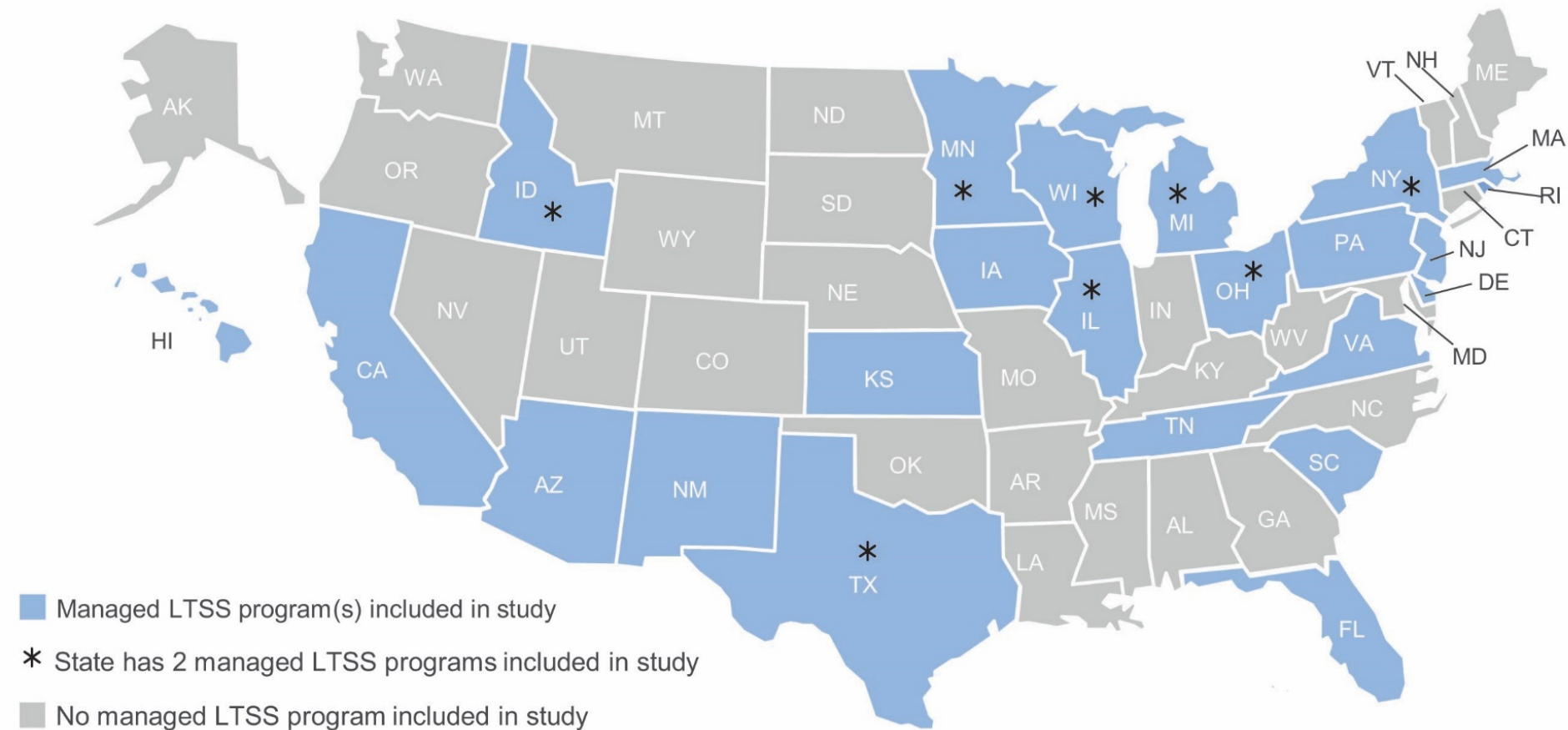
- A number of states have adopted promising innovations in managed care plans to support family caregivers, when the plan's member depends on them for care
- States can take additional steps to design services and supports around the needs and goals of members and their family caregivers



# Study Methodology

# Study Approach

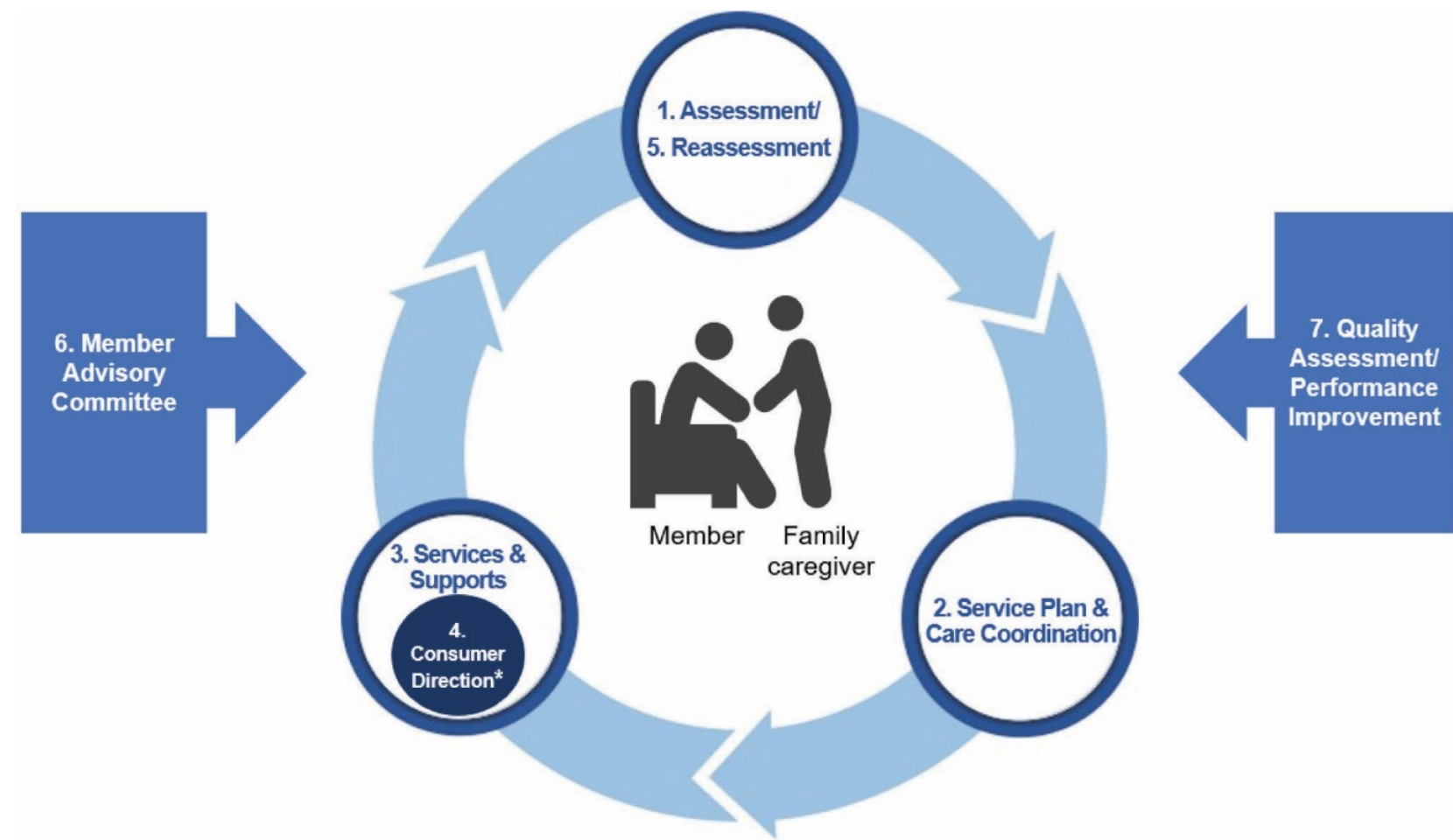
- Review of contracts for 31 Medicaid managed LTSS programs in 23 states



# References to Family Caregivers in Contract Elements

1. Assessment of family caregiver
2. Inclusion of family caregiver in development of service plan and coordination of care
3. Services and supports for family caregivers
4. Consumer direction that includes family caregivers
5. Reassessment triggered by loss of family caregiver
6. Inclusion of family caregivers in managed LTSS health plan member advisory committee
7. Quality of care measures or processes that involve family caregivers

# Why These Contract Elements?



\* Available in some managed LTSS programs

# State Review and Feedback

- Invited states to review and respond to validate contract review findings
- 12 of 23 states responded
- 8 of the 12 states provided supplemental information, either anecdotally or based on other policy documents

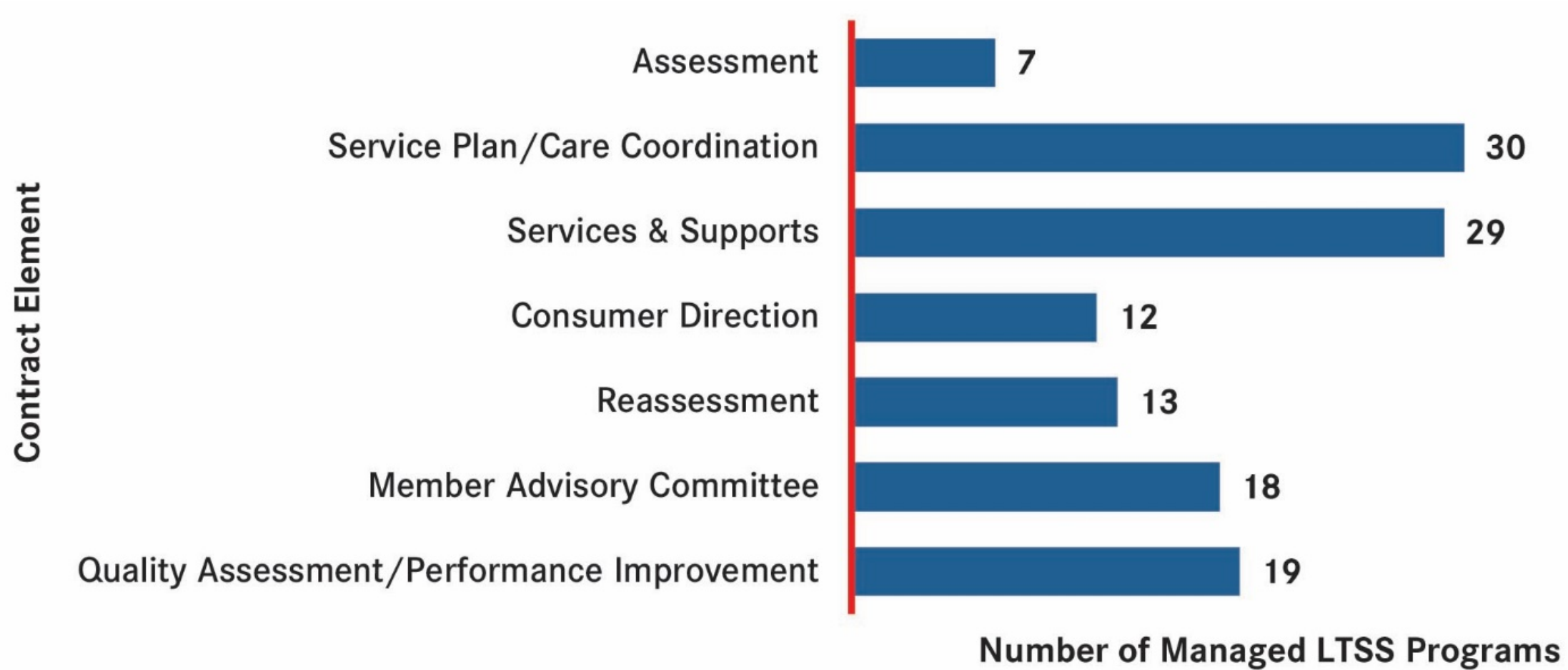
# Study Limitations

- Contract language may not convey all the ways a managed LTSS program or a health plan addresses needs of family caregivers
- Expectations for supporting family caregivers may be included in other documents (e.g., operational protocols, handbooks, etc.)

# Key Findings



# Findings by Contract Element



# Family Caregiver Assessment

- **7 programs (6 states)** describe an assessment of family caregivers beyond their capacity to provide unpaid care
- **Contract language varies widely**
  - Some programs focused narrowly on the risk of caregiver burnout
  - Some provided a more comprehensive inventory of caregiver's health and well-being, level of stress, and training and other support needs

# Inclusion of Family Caregivers in Service Planning and Care Coordination

- **30 programs (22 states)** had contract language requiring that family caregivers be included in service planning and care coordination at the preference of the member

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“The contractor shall ensure the person-centered planning process includes... at minimum, the member and if appropriate the member’s legal representative, family, service providers and others directly involved in the member’s care...”

– Iowa HealthLink

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# Services and Supports for Family Caregivers

- Most common services are respite and training and consultation
- Examples of less common services:
  - Health promotion and wellness activities (multiple states)
  - Gas reimbursement for transportation to Medicaid-covered services (VA Commonwealth Coordinated Care Plus)
  - Training in how to use specialized equipment and supplies (MI MI CHOICE)
  - Hospice (AZ Long-Term Care Services)
  - Management of dementia (MA Senior Care Options)
  - Social day care (NY Managed Long-Term Care Partial Capitation)

# Consumer Direction that Includes Family Caregivers

- **12 programs (11 states)** now support consumer direction in which a spouse or other family member may be paid to provide care to the member, at the member's choice

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“Members shall have the flexibility to hire persons with whom they have a close personal relationship to serve as an Attendant Care Employee, such as neighbor, friend, or family member.”

*- Delaware Diamond State Health Plan Plus*

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# Reassessment Triggered by Loss of Family Caregiver

- **13 programs (10 states)** require a reassessment of a member affected by loss of family caregiver
- Loss defined broadly (illness, hospitalization, death, employment, or financial strain)

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“Changes in the enrollee’s condition or needs that may warrant a comprehensive re-assessment include, but may not be limited to: hospitalization, significant changes in medication, change in, or loss of, a caregiver, medical psychosocial or behavioral health crisis, excessive emergency department utilization, other major changes in the enrollee’s psychosocial, medical, behavioral condition, or major changes in caregivers or housing.”

*- Rhode Island Integrated Care Initiative*

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# Inclusion of Family Caregiver in Health Plan's Member Advisory Committee

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- **18 programs (16 states)** require health plans to include family members or caregivers

“The Contractor shall establish an Enrollee advisory committee that will provide regular feedback to the Contractor’s governing board on issues of Demonstration management and Enrollee care. The Contractor shall ensure that the Enrollee advisory committee: Is comprised of Enrollees, family members and other caregivers that reflect the diversity of the Demonstration population, including individuals with disabilities. CMS and DHCS reserve the right to review and approve Enrollee membership.”

– California Cal MediConnect

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# Quality Systems Involving Family Caregivers

- **19 programs (16 states)** require health plans to include family caregivers in quality processes

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“The Contractor shall have an ongoing quality management program for the services it furnishes to members . . . The Quality Management program shall include, but is not limited to:

- Regular, and as requested, dissemination of subcontractor and provider quality improvement information including performance measures, dashboard indicators and member outcomes to [Arizona Health Care Cost Containment System] AHCCCS and key stakeholders, including members and family members.
- Developing and maintaining mechanisms to solicit feedback and recommendations from key stakeholders, subcontractors, members, and family members to monitor service quality and to develop strategies to improve member outcomes and quality improvement activities related to the quality of care and system performance.”

– Arizona Long-Term Care Services

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# Recommendations and Takeaways

# Recommendations

- 1. State contract language for MLTSS programs should clarify that a comprehensive assessment of the member includes questions *directly asked of family caregivers***
  - about their own health and well-being
  - potential work strain from juggling a paying job and caregiving
  - supports that they may need to be better prepared for their caregiving role
- 2. CMS should provide guidance to states on promising practices in developing and administering *family caregiver assessment tools* in MLTSS programs**

## Recommendations (cont'd)

- 3. All state MLTSS programs should provide ample and meaningful opportunity, including but not limited to member advisory committees, for family caregivers to have a voice in the program to improve care delivery**
  - Especially if the family caregiver is part of the care team
  - Other examples of ways that family caregivers can be involved with the MTLSS program:
    - Phone surveys, designated phone lines or email boxes, care manager outreach, or caregiver town hall meetings

# Takeaways

- **While significant inroads have been made in recognizing the value of family caregivers in MLTSS, states can take additional steps to**
  - design services and supports around the needs and goals of members and their family caregivers
- **States that have clearly defined requirements in their contracts with respect to inclusion and explicit support of family caregivers send a strong message to all MLTSS stakeholders to**
  - improve the culture of care
  - promote person- and family-centered care as a standard focus of practice



# Questions?

**Lynn Friss Feinberg, MSW**

[lfeinberg@aarp.org](mailto:lfeinberg@aarp.org)

Twitter: @FeinbergLynn

**Edem Hado, MPH**

[shado@aarp.org](mailto:shado@aarp.org)

Twitter: @edem\_hado

**Jessica Kasten, MA**

[jkasten@us.ibm.com](mailto:jkasten@us.ibm.com)

Twitter: @IBMWatsonHealth

**Elizabeth Lewis, MS, LCPC**

[elizabeth.lewis1@ibm.com](mailto:elizabeth.lewis1@ibm.com)

Twitter: @IBMWatsonHealth

**Thank You**