

# Best Practices in Supporting Family Caregivers Who Care for Older Adults

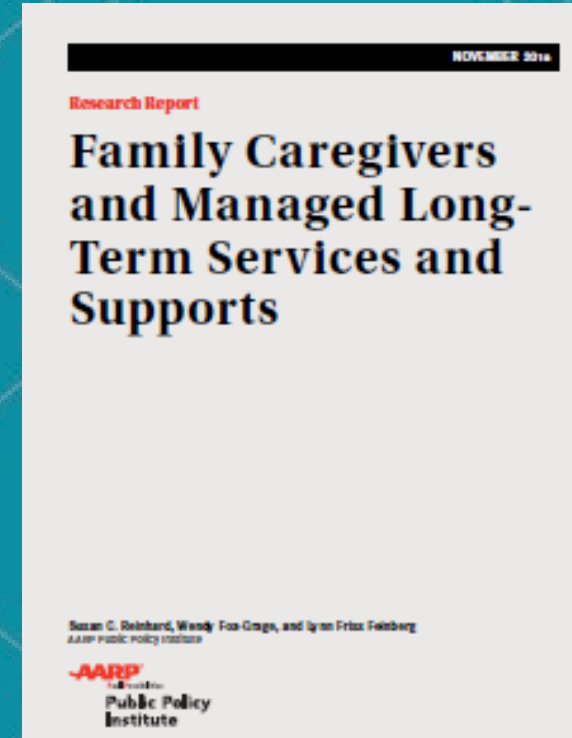
August 28, 2019

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# 1<sup>st</sup> Major Research Report in this Emerging Field of Managed Long-Term Services and Supports and Family Caregivers

## Rationale:

- Family caregivers are major providers of care
- Some family caregivers are in need of support themselves
- Managed long-term services and supports is rapidly expanding
- Managed care plans can lead the way toward person- and family-centered care



# Emerging Issue for Managed Care Plans

Family caregivers should include family, friends, neighbors, or anyone considered “family” by the member

Family caregiving supports are growing but not yet commonplace in managed long-term services and supports

Focus has been on support for the individual member, not the family unit

Stakeholders have focused on “preventing harm” and consumer protections

Several promising practices and lots of opportunities

# Health Plan Best Practices to Help Family Caregivers

- The medical record and service plan can identify family caregivers
- Family caregivers are assessed for their own needs and well-being
- Family caregivers can participate in care planning
- Family caregivers and care coordinators can have each others' contact information
- Care coordinator can refer them to training to learn caregiving skills such as administering meds and wound care
- Care coordinator can refer them to respite care and other needed services such as evidence-based caregiver support services, especially for dementia
- Consumers and family caregivers are on advisory committees

# Truven Study for AARP: 19 Managed LTSS Contracts (2014 data)

\*\* New Study to be Published in Dec. 2019

<b>Acknowledgement of Family Caregivers</b>	<b>Care Coordinator Contact Info Given to Family Caregivers</b>	<b>Training of Family Caregivers is a Covered Benefit</b>
15 state contracts	9 state contracts	3 state contracts

# Plan Innovations

To highlight how progressive managed care plans are supporting family caregivers who are caring for plan members with LTSS needs

To learn from each other and to adopt practices to better care for members and their family caregivers


AARP PUBLIC POLICY INSTITUTE NOVEMBER 2017

**Long-Term Services and Supports Scorecard  
Emerging Innovations**

**Emerging Innovations in Managed  
Long-Term Services and Supports  
for Family Caregivers**

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[www.longtermscorecard.org](http://www.longtermscorecard.org)

AARP FOUNDATION THE COMMONWEALTH FUND THE scan FOUNDATION

## Most Encouraging:

- Multiple plans identified that understanding and addressing the needs of family caregivers was a current priority for the plan
- All administrators expressed interest in learning more about promising practices and staying in dialogue on the topic



# New AARP Study with IBM Watson Health: Review of 23 State MLTSS Contracts

- Eligibility for care plan development (family caregiver assessment)
- Care coordination standards regarding family caregivers
- Benefits (services to family caregivers and how they are defined and capped)
- Studies, experiments, and innovative practice developments involving family caregivers



# Best Practices in Supporting Family Caregivers Who Care for Older Adults

August 28, 2019

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# PACE NATIONAL CAREGIVER SURVEY



# I-SAT Family/Caregiver Survey





## Overall Satisfaction

Very Satisfied

Very Dissatisfied

51. Overall, how satisfied are you with the services PACE provides?

Definitely

Probably

Probably Not

Definitely Not

52. Has PACE helped you be a better caregiver?

53. Would you recommend this PACE program to a friend?

54. What do you like best about the PACE program?

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55. How can the PACE program be enhanced?

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56. How has PACE helped you?

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# CAREGIVER BURDEN

Please read each question and indicate on the **left** how you felt **before** the person you care for was enrolled in PACE. Then, on the **right**, tell us how you feel **now** that the person you care for is enrolled in PACE.

## Before PACE

## Now

<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Quite Frequently</b>	<b>Nearly Always</b>	<b>Do you feel...?</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Quite Frequently</b>	<b>Nearly Always</b>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	39. That because of the time you spend with the person you care for that you don't have enough time for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	40. Stressed between caring for the person you care for and trying to meet other responsibilities (work/family)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	41. Angry when you are around the person you care for?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	42. That the person you care for currently affects your relationship with family members or friends in a negative way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	43. Strained when you are around the person you care for?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	44. That your health suffered because of your involvement with the person you care for?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Mailed** survey with **telephone follow-up** for some centers.

**30** PACE Centers

**973** Caregiver Responses

## SURVEY COMPONENTS

- Zarit-12 Caregiver Burden Scale
- Overall Satisfaction with PACE
- Recommend PACE to a friend
- Better Caregiver because of PACE

## CAREGIVER CHARACTERISTICS

Female

71%

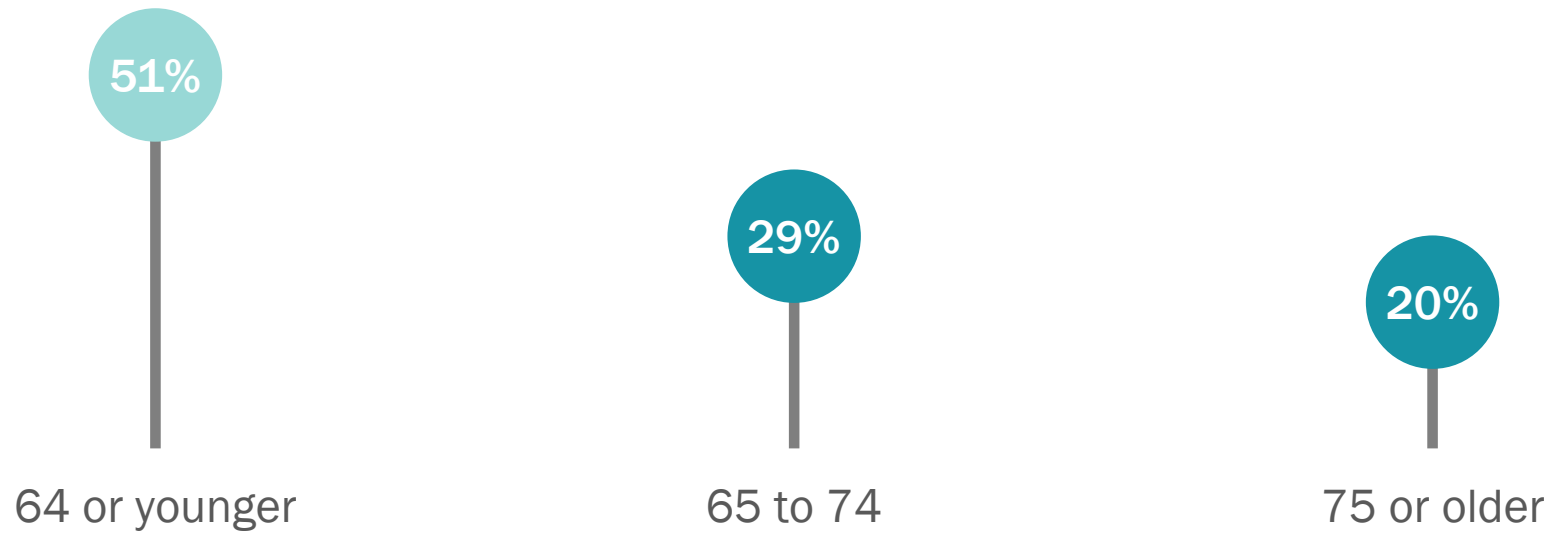
Live with Participant

50%



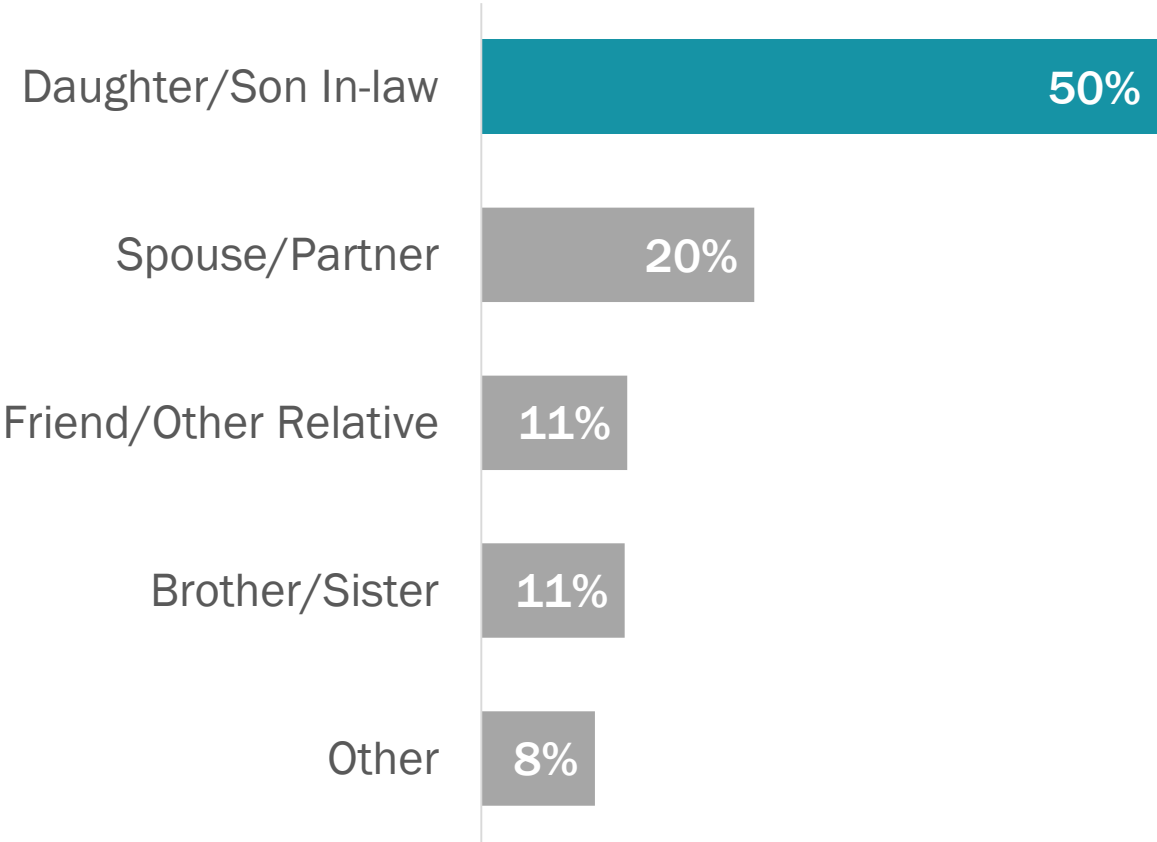
## CAREGIVER AGE

More than 50% of all caregivers are 64 years old or younger.



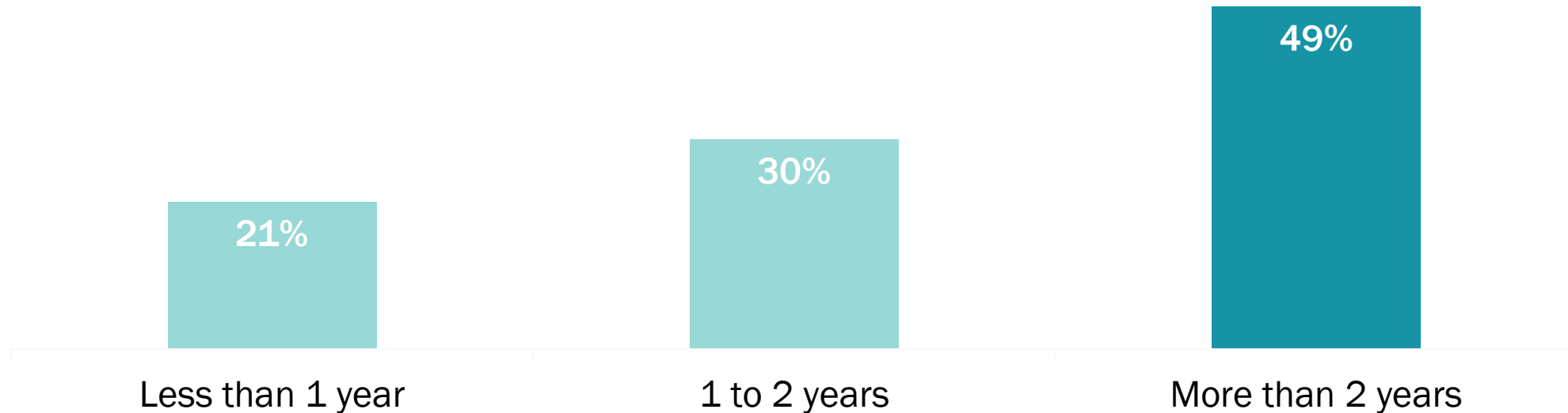
# CAREGIVER RELATIONSHIP

Half of all caregivers are **daughter or son in-law**.



# PARTICIPANT PACE ENROLLMENT

Close to **1/2** of all participants have been **enrolled in PACE for more than 2 years.**



## SATISFACTION AND LOYALTY

Overall Satisfaction

96%

Recommend

97%

# BETTER CAREGIVERS

9 out of 10 caregivers said that PACE has helped them become a better caregiver.



## THE IMPACT OF PACE

- I'm able to **focus more on my own health**.
- PACE **gave me back my sanity** and allowed me **to continue working**.
- I can **enjoy my father more** easily and I don't feel a need to strangle him much.
- Taken my **loneliness** in caring for my husband away.
- Given me **more time** with other family and friends.
- PACE has helped me gain more free time, **advice and assistance** with caregiving techniques.
- PACE has brought **cohesiveness and balance** to all the different and sometimes moving parts that is required to care for a loved one.

## BURDEN DEFINED

“**Caregiver burden** is the degree to which a **carer’s emotional or physical health, social life or financial status had suffered** as a results of caring for their relative. (Zarit et al., 1986).”

“**Caregiver burden** is the **strain** or **load** borne by a person who cares for a chronically ill, disabled, or elderly family member (Stucki & Mulvey, 2000). It is a multidimensional response to **physical, psychological, emotional, social, and financial stressors** associated with the **caregiving experience**.”

# IMPORTANCE OF CAREGIVER BURDEN

- One study found that **caregiver depressive symptoms** were found to be the most **consistent predictor of increases in healthcare cost**.
- **Caregiver burden and fatigue** exacerbates the patients' high hospital and emergency dept use.



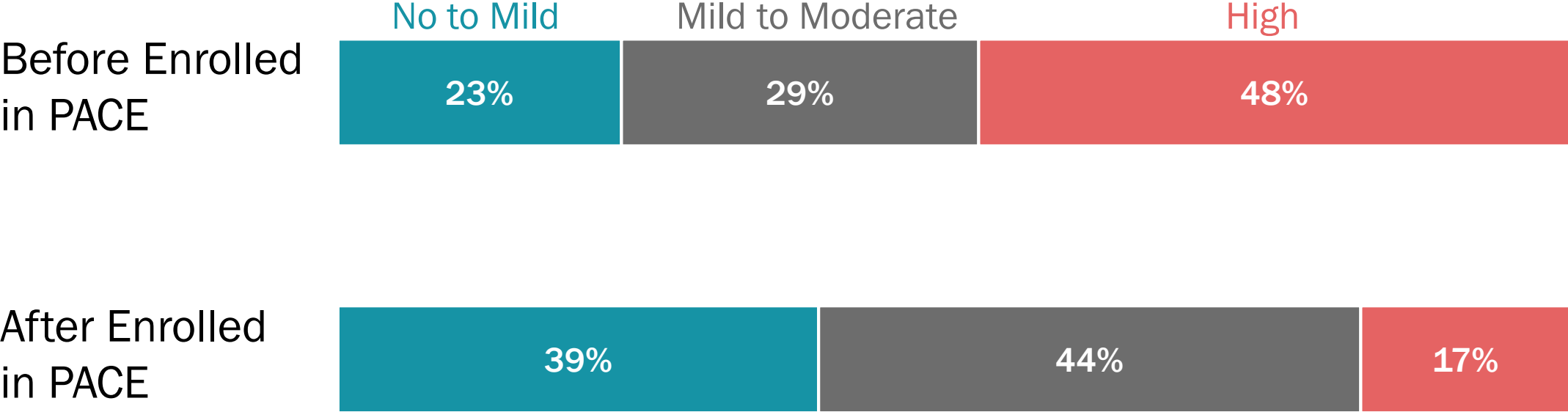
## BURDEN DECREASED

58%

of caregivers  
reduced their level  
of burden after  
their loved one was  
enrolled in PACE

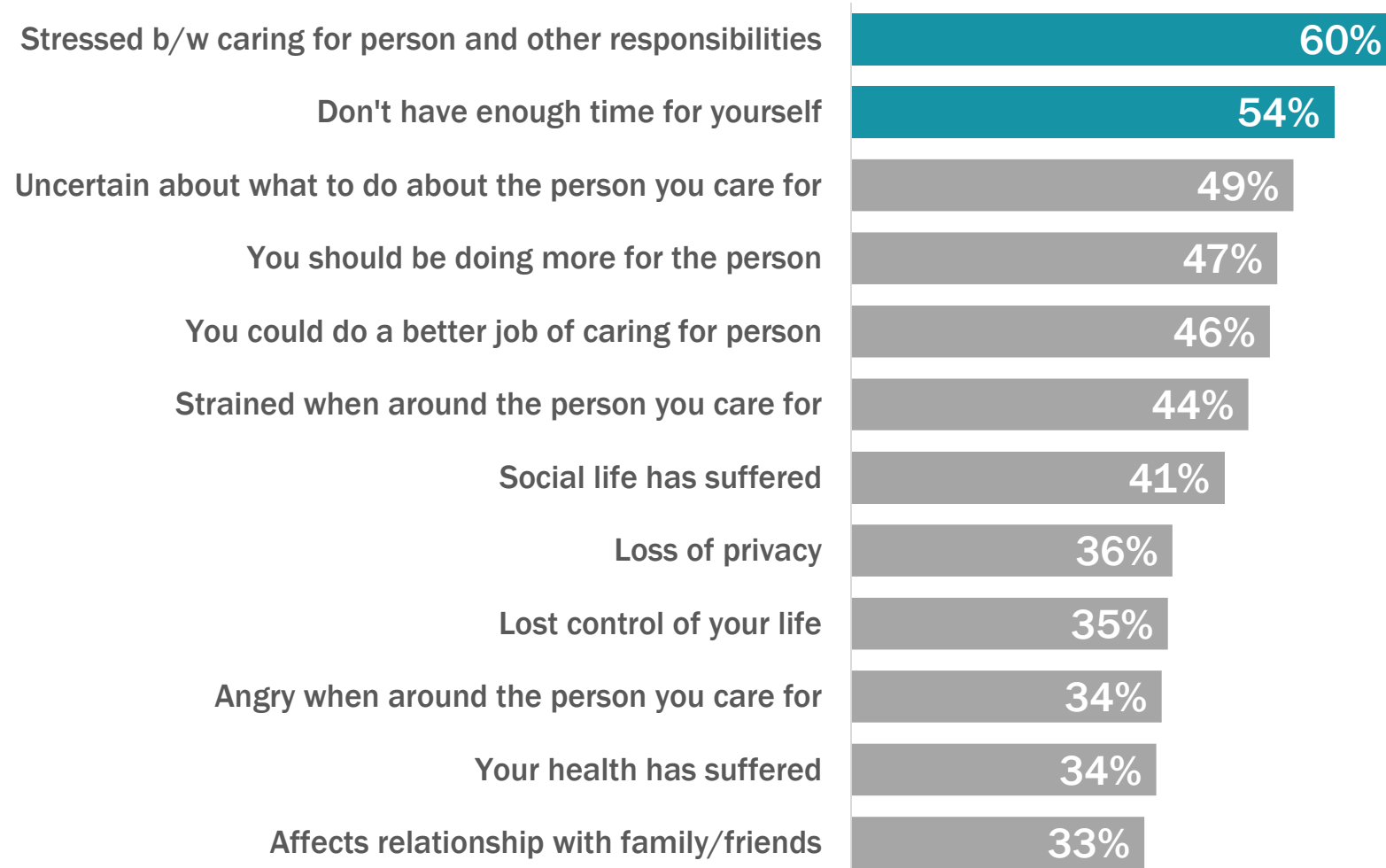
# BURDEN DECREASED

Caregiver burden decreased significantly after being enrolled in PACE.



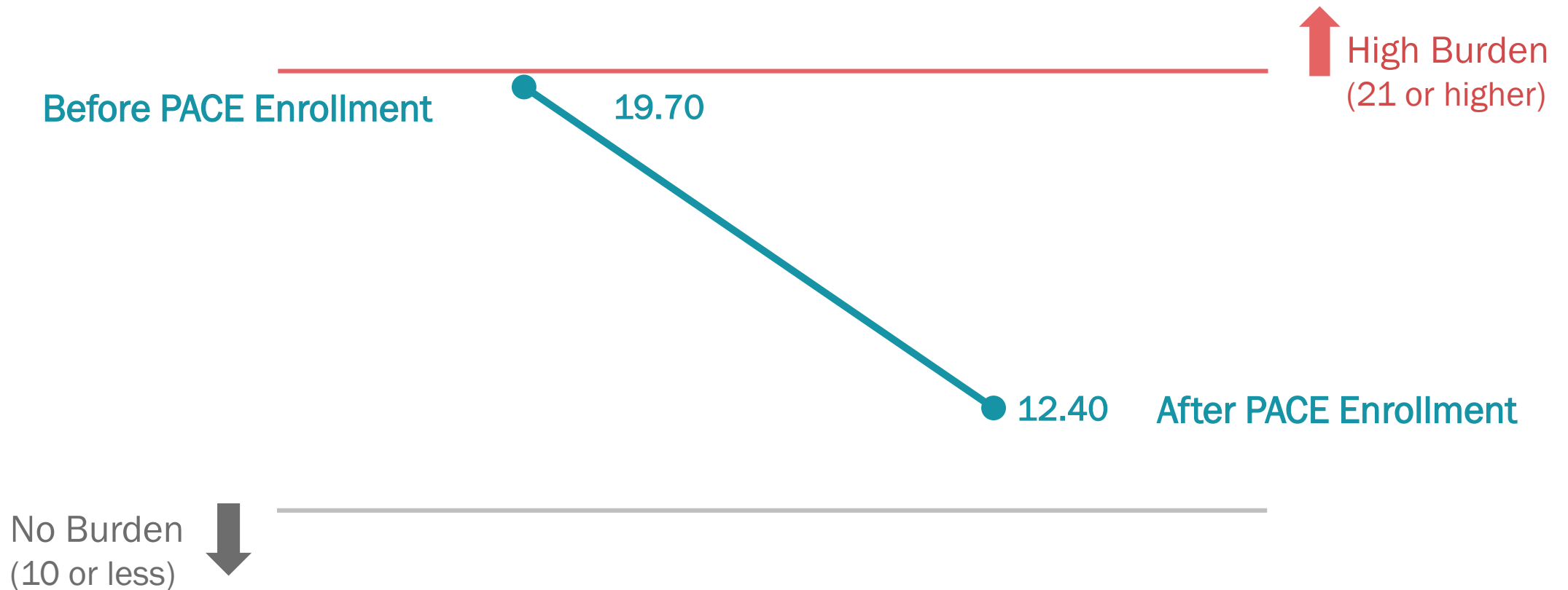
# POSITIVE CHANGES IN BURDEN


More than **1/2** of all caregivers feel they **have more time for themselves** and are **less stressed about meeting other responsibilities**.



# CAREGIVER BURDEN

Caregiver burden was **reduced from** nearly **high levels of burden** to **mild levels of burden**.

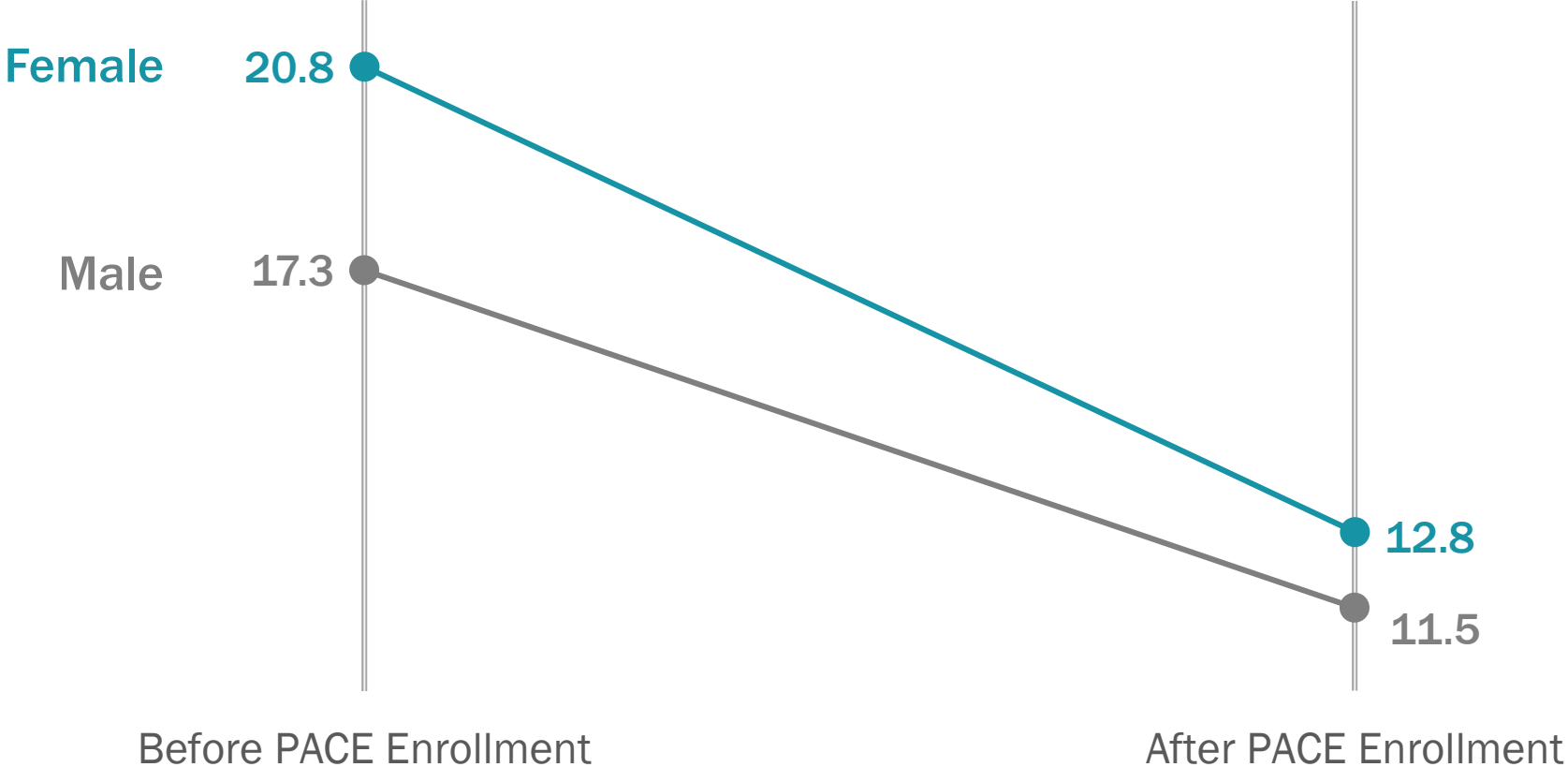




**CAREGIVER  
BURDEN  
BY  
BACKGROUND  
FACTORS**

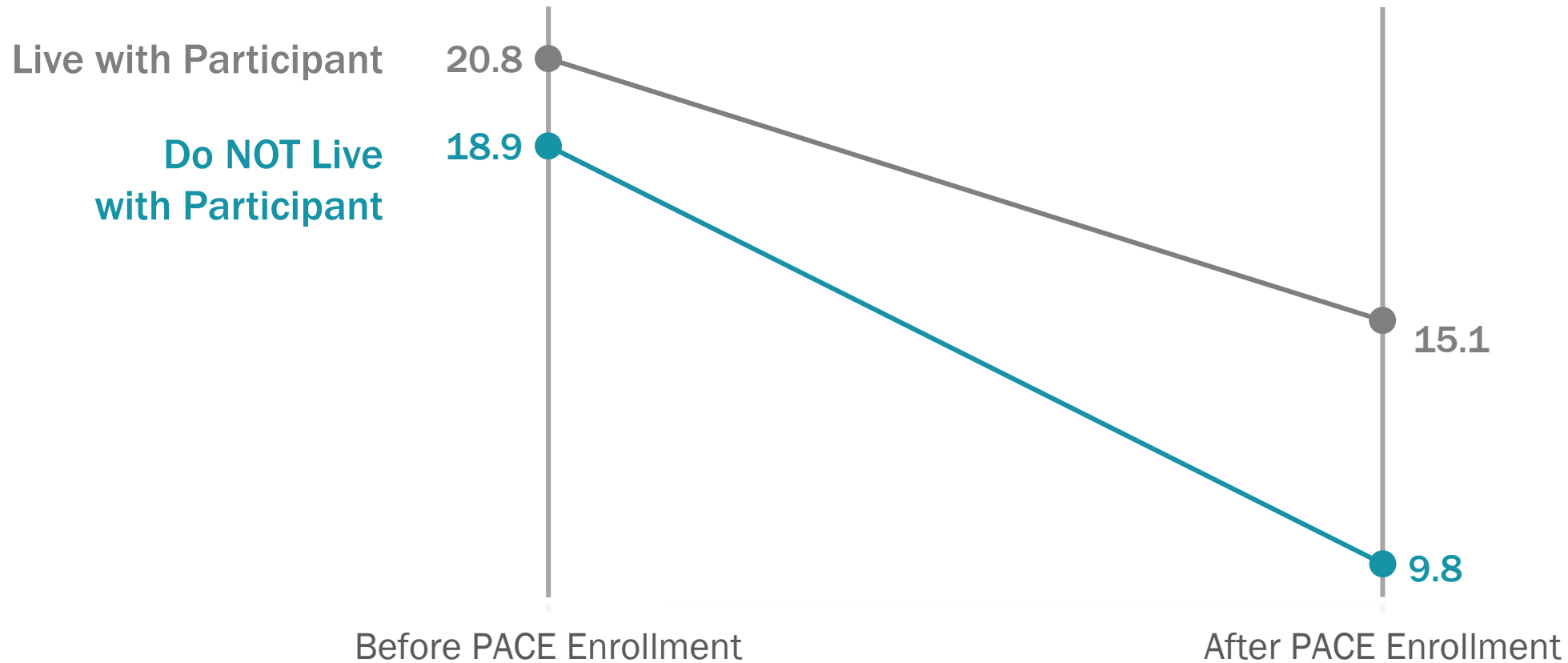
# CAREGIVER BURDEN BY GENDER

**Females** experienced an **8-point reduction in burden** compared to nearly **6-points** for **Males**.



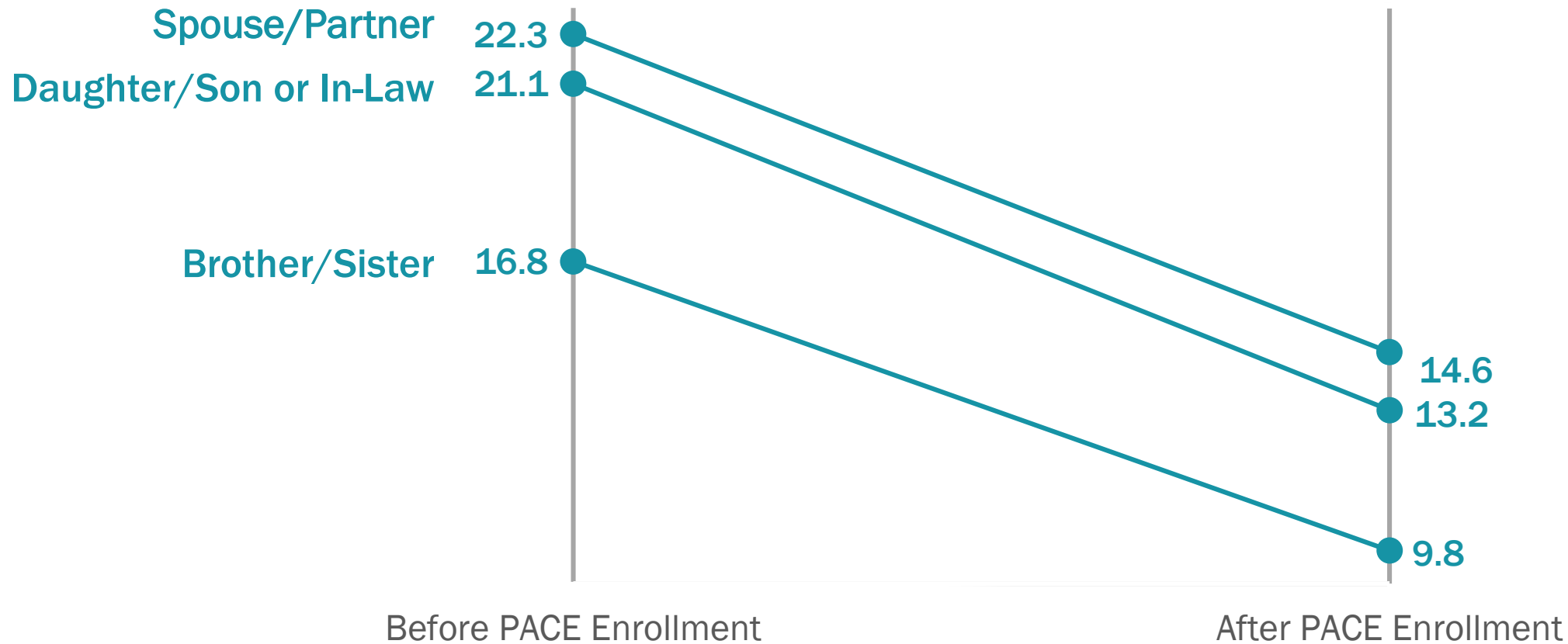
# CAREGIVER BURDEN BY LIVING SITUATION

Caregiver who **do NOT live with the participant** experience a **significantly greater reduction in burden.**



# CAREGIVER BURDEN BY RELATIONSHIP TO PARTICIPANT

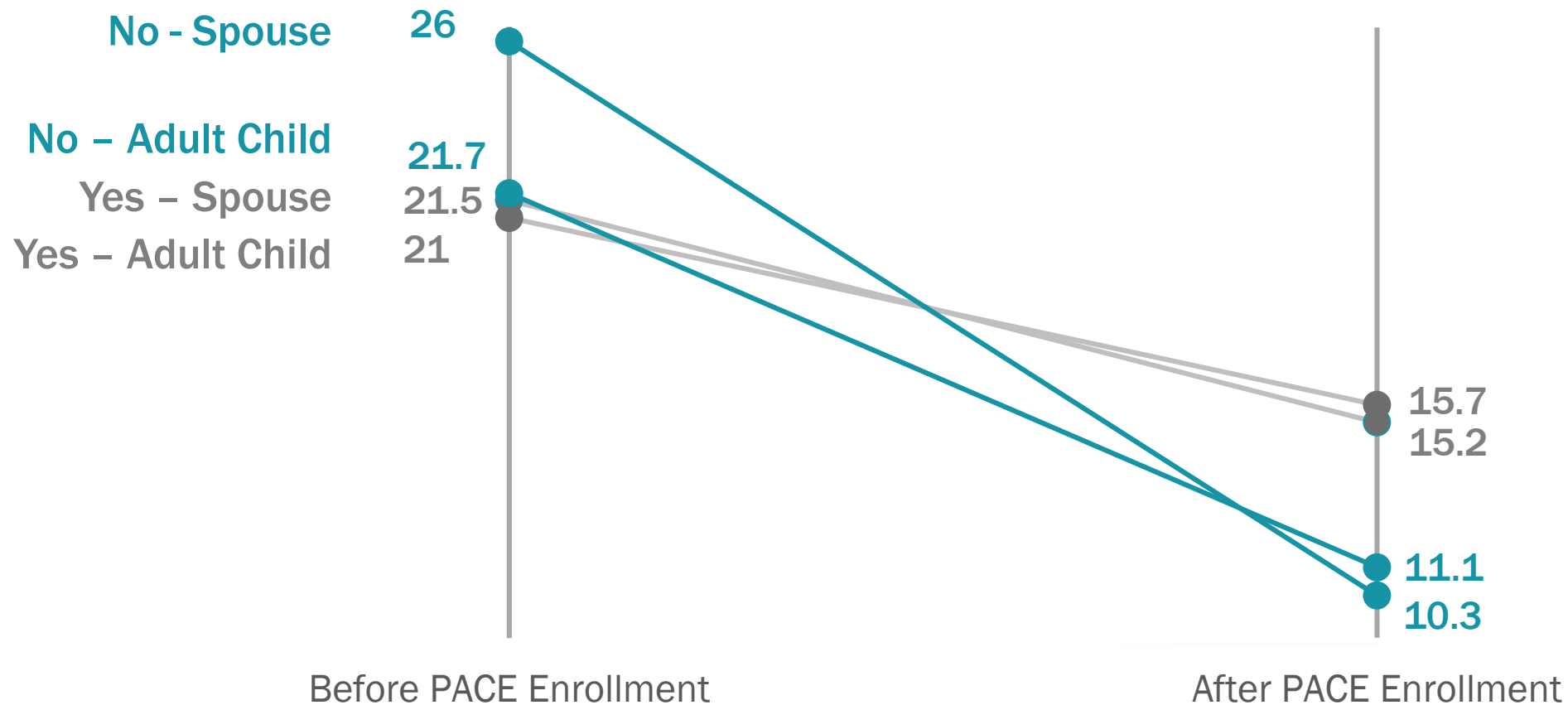
Caregiver burden is reduced for all individuals providing care to the PACE participant.





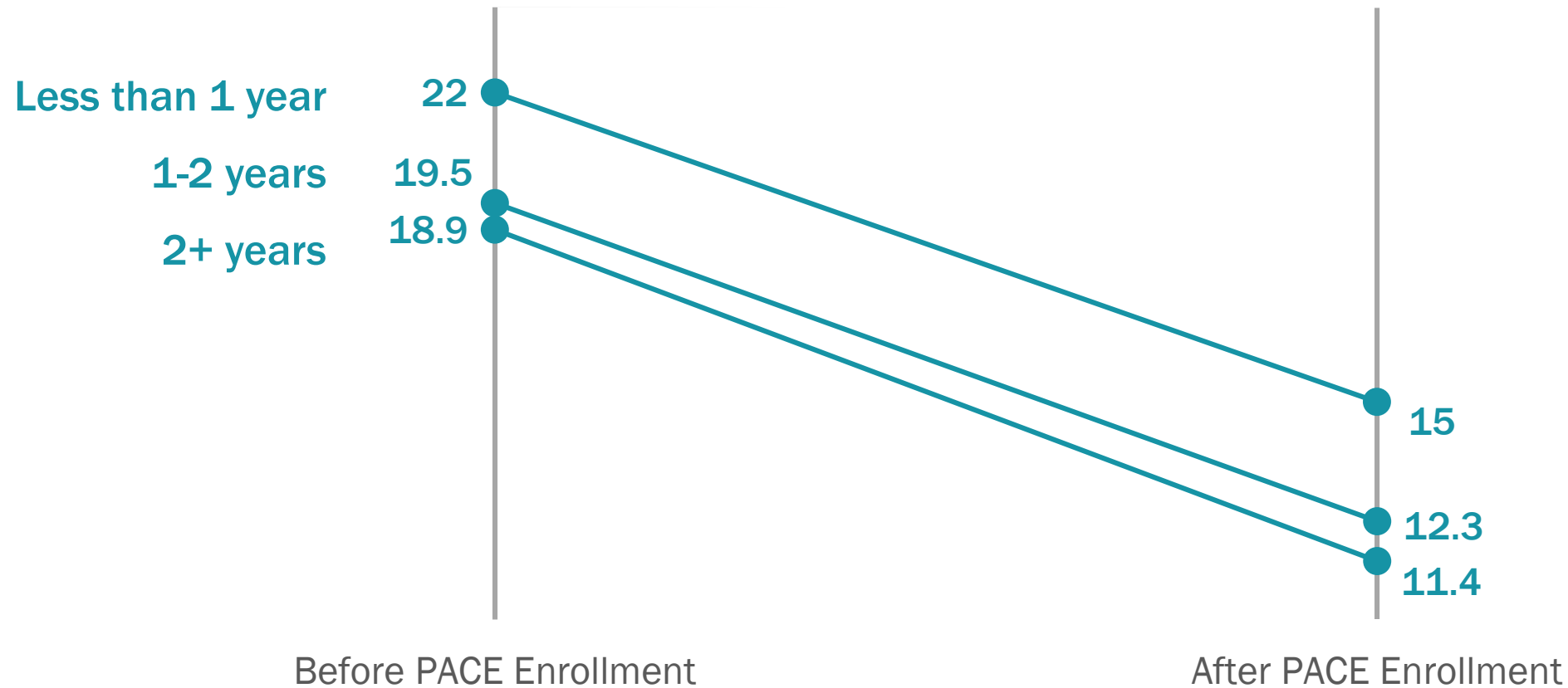
# CAREGIVER BURDEN BY RELATIONSHIP & LIVING SITUATION

Caregiver who do NOT live with the participant experience a significantly greater reduction in burden regardless of relationship.



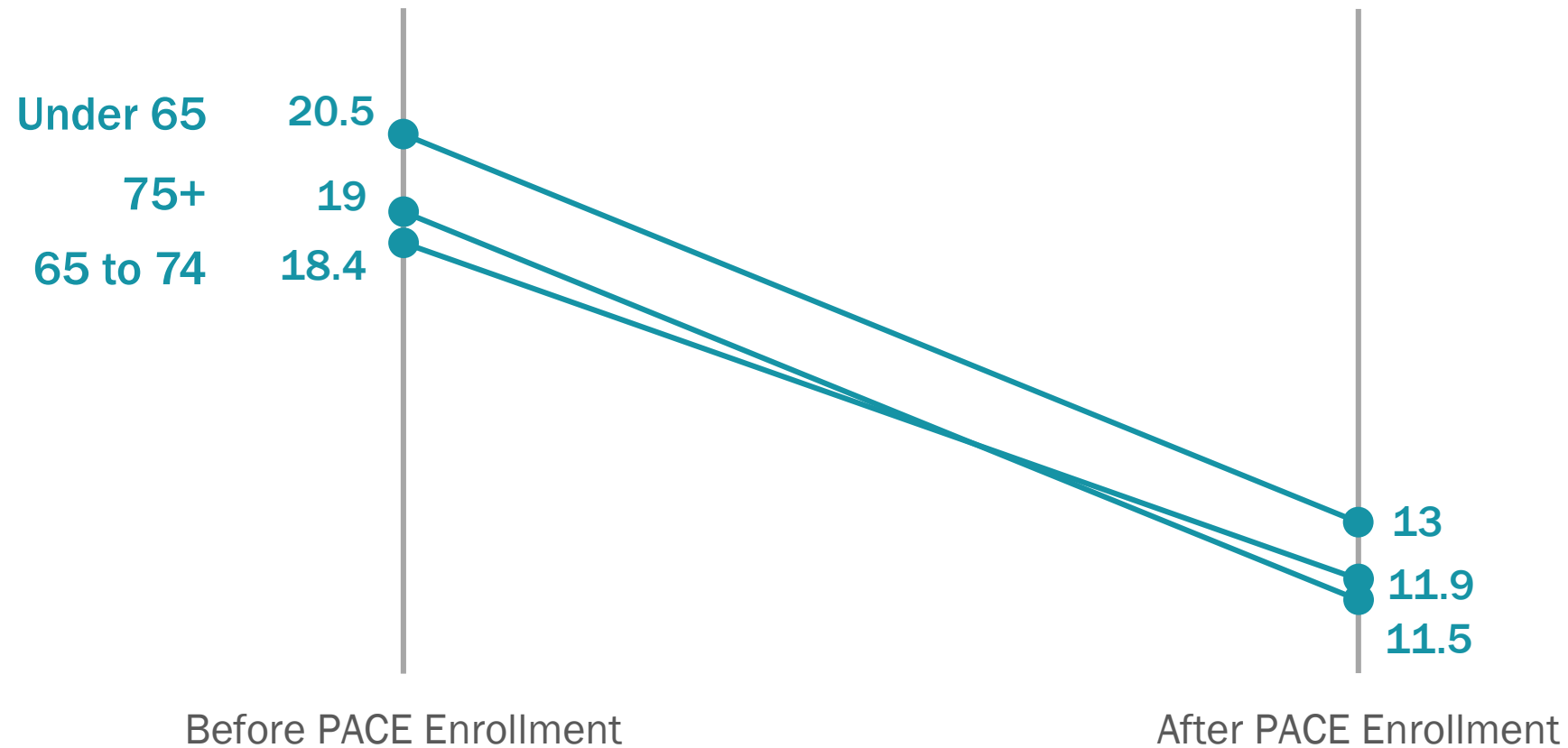
# CAREGIVER BURDEN BY LENGTH OF ENROLLMENT

No difference in caregiver burden by years of enrollment in PACE.



# CAREGIVER BURDEN BY AGE

Age of the caregiver does not **affect** caregiver burden.



# WHAT CAN PACE DO?

- Some caregivers feel **disconnected, ignored or degraded by health care providers.**
- Be aware of some of the **symptoms** that may accompany caregiver burden
- **Communication** with caregivers is **critical.**
- In one study, **caregivers** said they **preferred** to receive information from **peer-to-peer forums, fact sheets, checklists and educational videos.**
- **Assess** the **problem areas** caregivers are experiencing.



**LET'S TALK  
ABOUT IT**

Impact  
Full

Wow

chat

# PACE

**Program of All-inclusive  
Care for the Elderly**

## **An Overview**

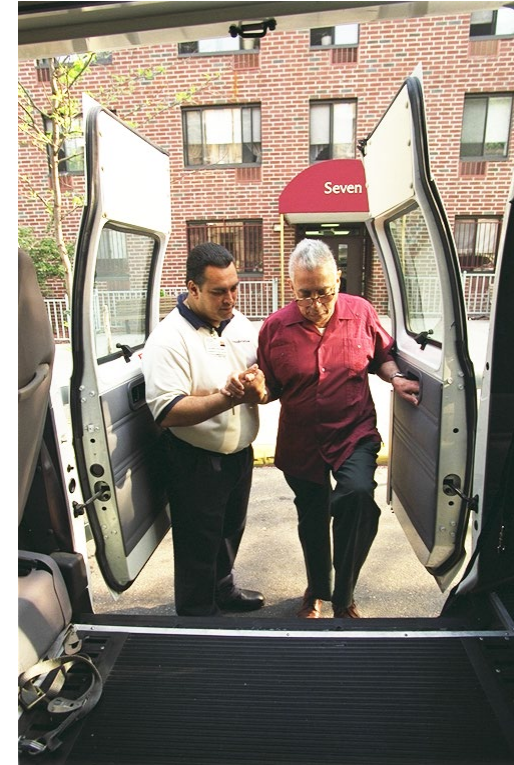
**August 2019**

# What is PACE?

## Program of All Inclusive Care for the Elderly

An integrated system of care for the frail elderly that is:

- Community-based
- Comprehensive
- Capitated
- Coordinated



# What Makes PACE Work?

- Aligned incentives
  - PACE – fully at-risk payment drives focus on good care outcomes
  - Payors – Cost saving and predictable payments
  - Participants – want to maintain health and remain living at home






## The PACE Model

# Who Does It Serve?

- 55 years of age or older
- Living in a PACE service area
- Certified as needing nursing home care
- Able to live safely in the community with the services of the PACE program at the time of enrollment


# Milestones in the PACE Model History

1986



Legislation authorizing PACE Demonstration

1990



First demonstration sites operational

1997



Congress authorizes permanent provider status

1999




Publication of interim final PACE regulations

2001




First program achieves permanent PACE provider status

2002



Publication of 2<sup>nd</sup> interim final PACE regulations enhancing opportunity for program flexibility

2006



Final PACE rule

2014




Reached first 100 PACE programs

2015



PACE Innovation Act is signed into law

2016

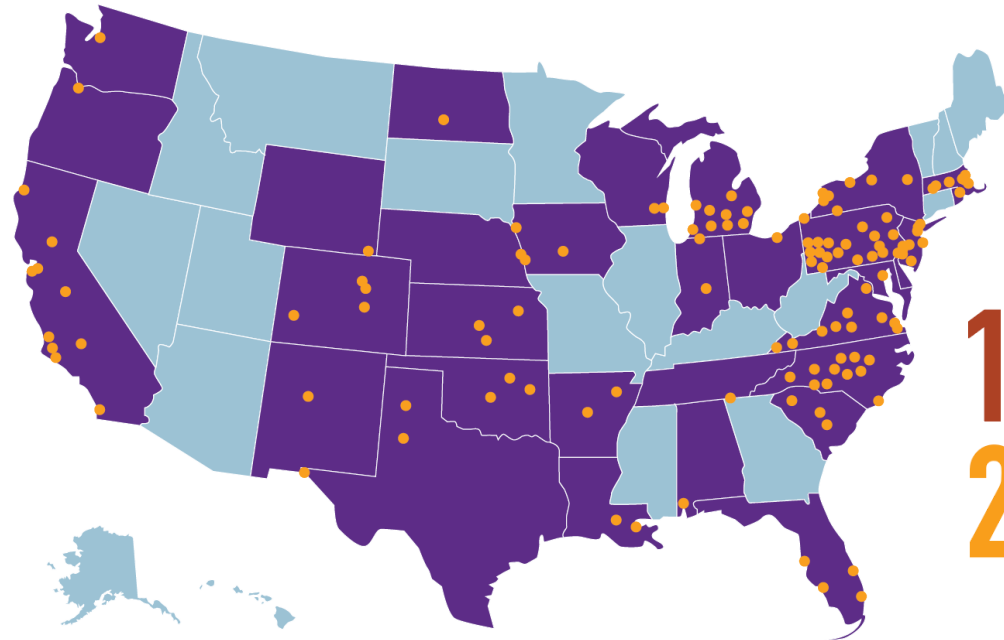


CMS issues proposed PACE rule

**2019**  
New PACE Regulation

# Status of PACE Development

(as of July 2019)



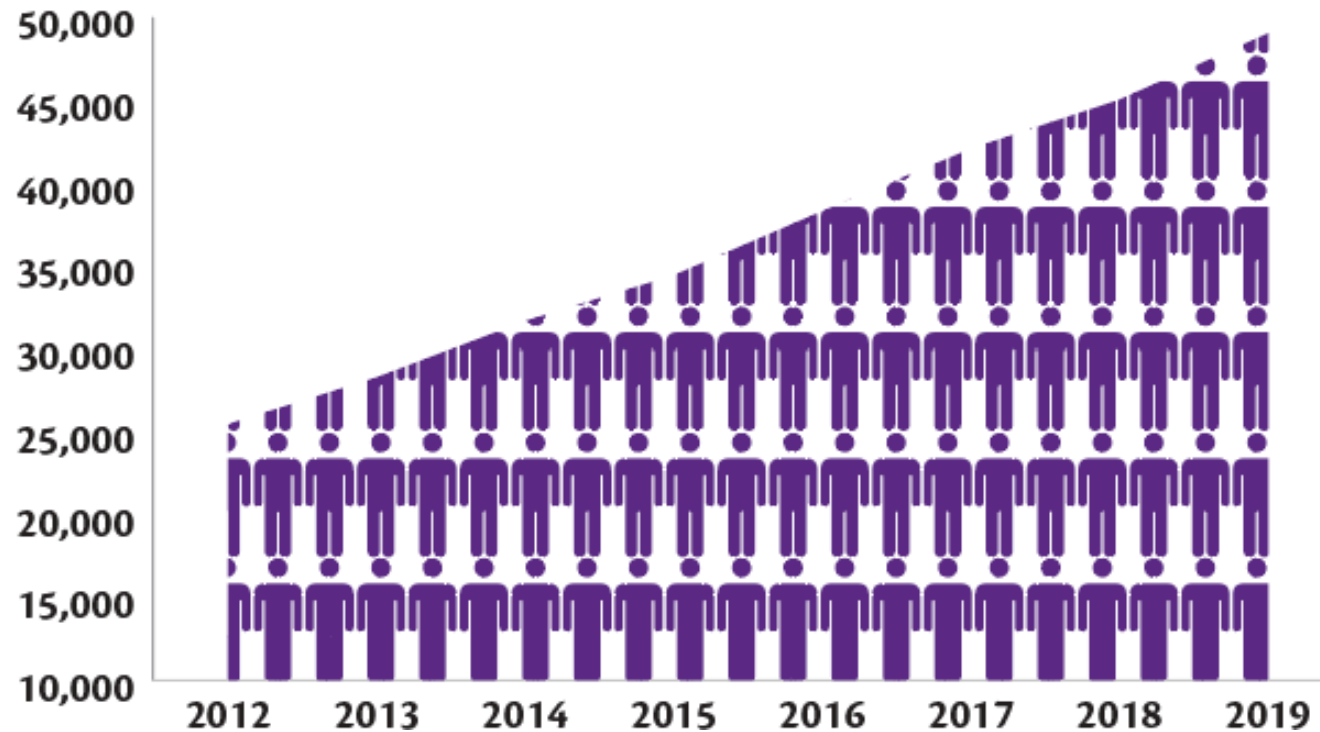
**129** Sponsoring Organizations  
**263** PACE Centers  
as of July 2019

31 states have PACE programs

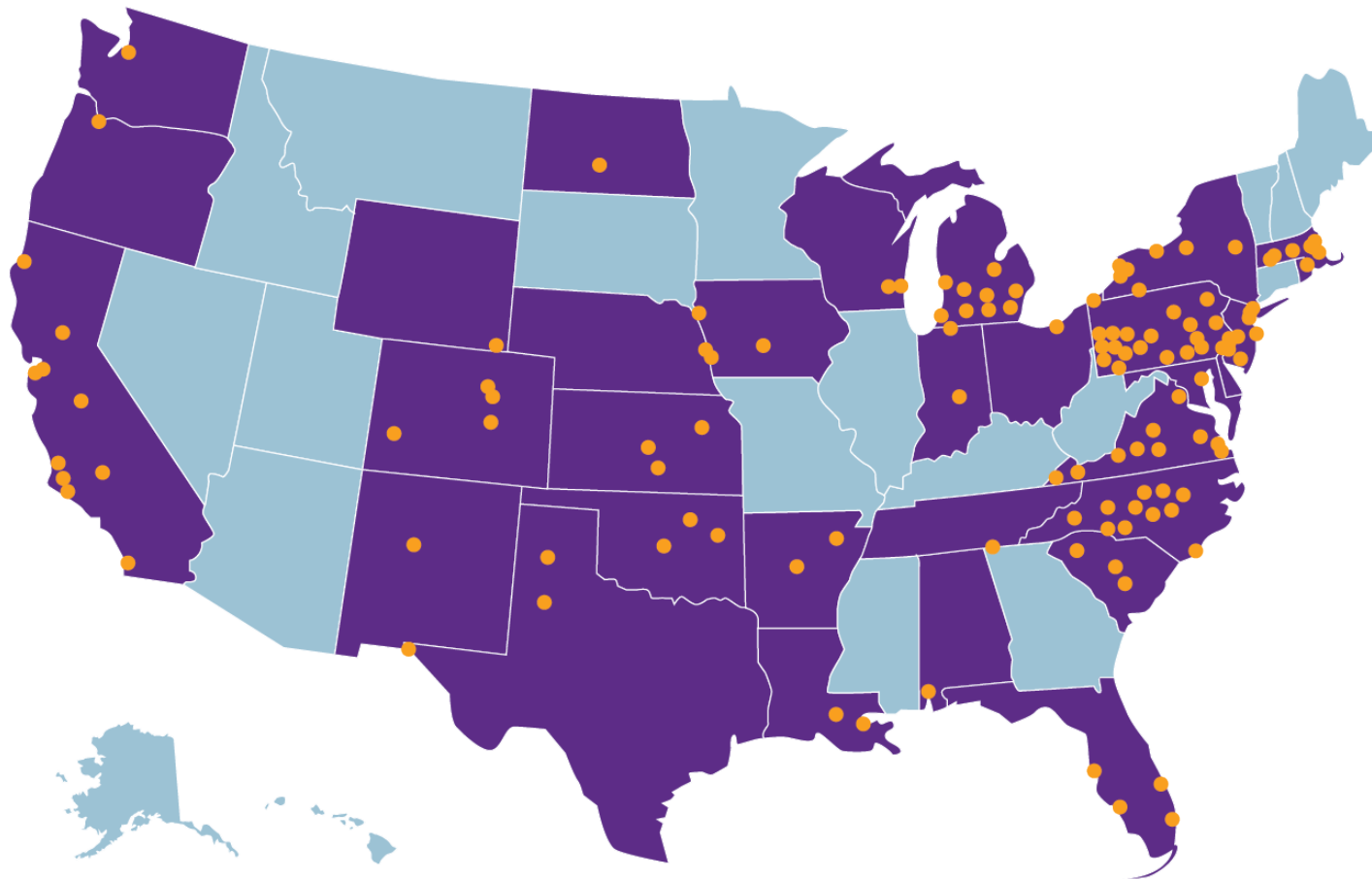
# National Census Growth

2011 – 2019

**PACE ENROLLMENT 51,000**



# PACE Programs Around The Country



31 states have PACE programs

# The PACE Model

## Services Provided

- nursing
- physical therapy
- occupational therapy
- recreational therapy
- meals
- nutritional counseling
- social work
- medical care
- home health care
- personal care
- prescription drugs
- social services
- audiology
- dentistry
- optometry
- podiatry
- speech therapy
- respite care

**All Medicare, Medicaid and medically necessary services**

# Integrated, Team Managed Care

- An interdisciplinary team
- Team managed care vs. individual case manager
- Continuous process of assessment, treatment planning, service provision and monitoring
- Focus on primary, secondary, tertiary prevention

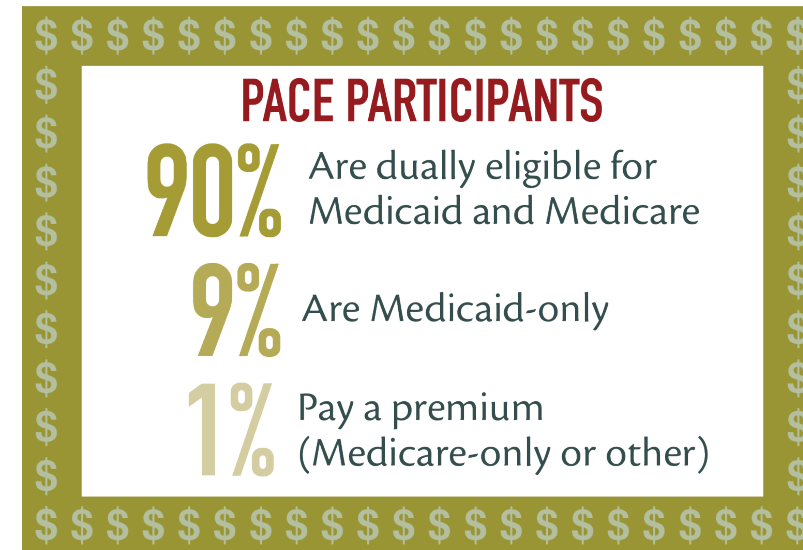
# Integrated Service Delivery and Team Managed Care





# Capitated, Pooled Financing

- Medicare capitation rate adjusted for the frailty of the PACE enrollees
- Integration of Medicare, Medicaid and private pay payments



# Source of Service Revenue

- PACE Programs receive approximately:
  - 61% of its revenue from Medicaid
  - 39% from Medicare
    - (A small percentage of program revenue comes from private sources or enrollees paying privately)*
    - 2019 Mean Medicare PMPM Rate: \$2,494
    - 2019 Mean Medicaid PMPM Rate: \$3,933
- PACE Programs are Medicare D providers

# PACE Core Competencies

- Provider based model
- Tightly controlled care management and utilization systems
- Serves largely a nursing home eligible population in the community when enrolled
- Good care outcomes, high enrollee satisfaction and low disenrollment rates
- Established existing program with a proven track record
- Supporting family caregivers

# National PACE Association Resources

[www.NPAonline.org](http://www.NPAonline.org)

- Core Resources Set for PACE (CRSP) (copyright NPA)
  - Core operational program components (i.e. policies, procedures and model materials)
  - Model PACE provider applications
- Financial Planning Tools (copyright NPA)
  - Case studies of successful sites
  - Baseline Scenario
  - Financial Proforma and Users Guide
  - Business Planning Checklist
- Exploring PACE Membership Category
- Resources for States

# Questions?

