Best Practices in Supporting Family Caregivers Who Care for Older Adults

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1st 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

<table>
<thead>
<tr>
<th>Acknowledgement of Family Caregivers</th>
<th>Care Coordinator Contact Info Given to Family Caregivers</th>
<th>Training of Family Caregivers is a Covered Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 state contracts</td>
<td>9 state contracts</td>
<td>3 state contracts</td>
</tr>
</tbody>
</table>
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.
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
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August 28, 2019
PACE NATIONAL CAREGIVER SURVEY
I-SAT Family/Caregiver Survey

OVERALL SATISFACTION
94%
(91% - 2018)

- 94% COMMUNICATION (90% - 2018)
- 96% HELP & ASSISTANCE (96% - 2018)
- 99% ENVIRONMENT & SAFETY (96% - 2018)
- 96% PACE TEAM (94% - 2018)
- 89% MEALS & NUTRITION (87% - 2018)
- 94% RECREATIONAL ACTIVITIES (86% - 2018)
- 99% HOME SERVICES (98% - 2018)
- 87% THERAPEUTIC & REHABILITATIVE EXERCISE (83% - 2018)
### Overall Satisfaction

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

<table>
<thead>
<tr>
<th>Very Satisfied</th>
<th>Definitely</th>
<th>Probably</th>
<th>Probably Not</th>
<th>Definitely Not</th>
</tr>
</thead>
<tbody>
<tr>
<td>○</td>
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</tr>
</tbody>
</table>

52. Has PACE helped you be a better caregiver?

<table>
<thead>
<tr>
<th></th>
<th>Definitely</th>
<th>Probably</th>
<th>Probably Not</th>
<th>Definitely Not</th>
</tr>
</thead>
<tbody>
<tr>
<td>○</td>
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</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Definitely</th>
<th>Probably</th>
<th>Probably Not</th>
<th>Definitely Not</th>
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<tbody>
<tr>
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</tr>
</tbody>
</table>

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

   
   
   
   

55. How can the PACE program be enhanced?

   
   
   
   

56. How has PACE helped you?

   
   
   
   

   
   
   
   

   
   
   
   

   
   
   
   

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.

<table>
<thead>
<tr>
<th>Question</th>
<th>Before PACE</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>39. That because of the time you spend with the person you care for that you don't have enough time for yourself?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. Stressed between caring for the person you care for and trying to meet other responsibilities (work/family)?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>41. Angry when you are around the person you care for?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. That the person you care for currently affects your relationship with family members or friends in a negative way?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>43. Strained when you are around the person you care for?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>44. That your health suffered because of your involvement with the person you care for?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
30 PACE Centers

973 Caregiver Responses

Mailed survey with telephone follow-up for some centers.
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%
More than 50% of all caregivers are 64 years old or younger.
Half of all caregivers are **daughter or son in-law**.
Close to \( \frac{1}{2} \) of all participants have been enrolled in PACE for more than 2 years.
Overall Satisfaction: 96%
Recommend: 97%
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.
“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.”
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
Caregiver burden decreased significantly after being enrolled in PACE.

Before Enrolled in PACE
- No to Mild: 23%
- Mild to Moderate: 29%
- High: 48%

After Enrolled in PACE
- No to Mild: 39%
- Mild to Moderate: 44%
- High: 17%
### 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.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stressed b/w caring for person and other responsibilities</td>
<td>60%</td>
</tr>
<tr>
<td>Don't have enough time for yourself</td>
<td>54%</td>
</tr>
<tr>
<td>Uncertain about what to do about the person you care for</td>
<td>49%</td>
</tr>
<tr>
<td>You should be doing more for the person</td>
<td>47%</td>
</tr>
<tr>
<td>You could do a better job of caring for person</td>
<td>46%</td>
</tr>
<tr>
<td>Strained when around the person you care for</td>
<td>44%</td>
</tr>
<tr>
<td>Social life has suffered</td>
<td>41%</td>
</tr>
<tr>
<td>Loss of privacy</td>
<td>36%</td>
</tr>
<tr>
<td>Lost control of your life</td>
<td>35%</td>
</tr>
<tr>
<td>Angry when around the person you care for</td>
<td>34%</td>
</tr>
<tr>
<td>Your health has suffered</td>
<td>34%</td>
</tr>
<tr>
<td>Affects relationship with family/friends</td>
<td>33%</td>
</tr>
</tbody>
</table>
Caregiver burden was *reduced from* nearly high levels of burden to mild levels of burden.

**Diagram:**
- Before PACE Enrollment: 19.70
- After PACE Enrollment: 12.40
Females experienced an **8-point reduction in burden** compared to nearly 6-points for Males.
Caregiver who do NOT live with the participant experience a significantly greater reduction in burden.
Caregiver burden is reduced for all individuals providing care to the PACE participant.

**CAREGIVER BURDEN BY RELATIONSHIP TO PARTICIPANT**

- **Spouse/Partner**: Before PACE Enrollment - 22.3, After PACE Enrollment - 14.6
- **Daughter/Son or In-Law**: Before PACE Enrollment - 21.1, After PACE Enrollment - 13.2
- **Brother/Sister**: Before PACE Enrollment - 16.8, After PACE Enrollment - 9.8
Caregiver who do NOT live with the participant experience a significantly greater reduction in burden regardless of relationship.
No difference in caregiver burden by years of enrollment in PACE.
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
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 2nd 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)

31 states have PACE programs

129 Sponsoring Organizations
263 PACE Centers
as of July 2019
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

PACE INTERDISCIPLINARY TEAM

- Physical therapist
- Registered nurse
- Recreation therapist
- Master’s of Social Work
- Primary care provider
- Dietitian
- Occupational therapist
- Driver
- Personal care attendant
- Home care coordinator
- PACE center manager
Capitated, Pooled Financing

- Medicare capitation rate adjusted for the frailty of the PACE enrollees

- Integration of Medicare, Medicaid and private pay payments

PACE PARTICIPANTS

- **90%** are dually eligible for Medicaid and Medicare
- **9%** are Medicaid-only
- **1%** pay a premium (Medicare-only or other)
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

- 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?