Caregiver Supports: What’s in your toolbox?

2019 Home and Community Based Services Conference
August 29, 2019
Welcome & Session Objectives

- The Caregiving Landscape
- The Value to Anthem and Our Members
- Anthem’s Holistic Approach
- Continued Caregiver Collaboration
The Caregiving Landscape

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The Value to Members and Anthem

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About Anthem, Inc.

Anthem is a leading health benefits company dedicated to improving lives and communities, and making healthcare simpler.

Anthem’s Medicaid Landscape

Currently in over 22 Medicaid states covering over 7 million individuals with over 28 years of experience

Approximately 753,000 ABD members in 18 states

Over 21 years of experience supporting LTSS programs in 10 states representing over 340,000 individuals

76% of Anthem’s LTSS members live in the community of their choice

<table>
<thead>
<tr>
<th>Terms</th>
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<td>LTSS: Long Term Services and Supports</td>
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<tr>
<td>SSI-ABD: Supplemental Security Income / Aged, Blind and Disabled</td>
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<td>TANF: Temporary Assistance for Needy Families</td>
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<td>CHIP: Children’s Health Insurance Program</td>
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<td>ISO: Insurance Service Organization</td>
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<td>I/DD: Intellectual / Developmental Disabilities</td>
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<td>BH: Behavioral Health</td>
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<td>PH: Physical Health</td>
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The Challenges

- At any given time, approximately 66 million Americans are providing support for an adult family member with limitations in daily activities [1]
- 75% of individuals with I/DD live with families and don’t receive assistance from public systems [2]
- Nearly 10 million adult children over the age of 50 care for their aging parents [3]
- 16 million people in the US are caring for someone with Alzheimer’s or other dementias [4]
- 30,000 people with ALS currently, with 6,000 diagnosed each year, receive care from families [5]
- More than 1 million children care for a parent, grandparent or sibling with a disability or illness [7]
- 8.4 million provide care for adults with an emotional or mental health issue [6]
- More than 1 in 5 households with children in the US have at least one child with special health care needs [8]
In 2009, AARP estimated the value of unpaid family caregiving at $450 billion per year.

In 2015, that value was increased to $470 billion; estimates have gone as high as $550 billion.

This amount is 6 times greater than what we currently spend on Medicaid HCBS.

The baby boom population blip will only push the need and these costs up.

The income-related loss to caregivers over 50 averages $115,900 over their lifetime; $200,000 in lost Social Security and pension benefits.
The Human Impact

69% of family caregivers report that caregiving is their major source of stress; 40-70% report depression.

77% of caregivers report missing work in order to provide care, 52% work less hours, 51% feel a negative impact on their career, and 11% report losing their job.

Family Caregivers also experience significantly higher rates of stroke, heart disease, hypertension, sleep problems, drug use, and lower immune function.

80% report a strain on marriage with 25% stating that caregiving played a significant role in divorce or separation.

The average family caregiver for an adult is female, 49 years old, and works outside the home, but spends 20 hours a week caregiving for an average of 5 years.

Families of individuals with I/DD can spend 40 to 80 hours a week providing support.
Caregiving keeps people from community and family connections, increasing their social isolation; impacts physical health, mental health and emotional wellbeing \[12\]

American Companies report $33.6 billion per year in lost productivity, and $13.4 billion in higher health care costs due to the physical toll on working caregivers \[13\]

Smaller families, geographic separation, and increased life expectancy add further pressures; in addition, most caregivers are employed women, forcing difficult career and financial decisions on families \[14\]
The Value of Supporting Caregivers

Caregivers provide supports to individuals living in the community, both home and placement, and are an integral part of the team.

Caregiver supports can:

The increased impacts of caregiving on our Members** demands a comprehensive strategy to identify and build a suite of offerings that provide and/or facilitate Caregiver Supports.

** Additional statistics on caregiver trends and impacts is included in the Appendix.

Declining Caregiver health is a major risk factor for institutionalization of the member.

Members with Caregivers who are experiencing depression or difficulty coping are at a higher risk for falls, developing secondary complications, and declines in functional abilities.*

Caregiver stress adds to member’s risk of poor quality care as well as abuse and neglect.

* Per the American Psychological Association

✓ Person Centered
✓ Family Driven
✓ Promote autonomy and stability
✓ Support the well-being of the family
✓ Minimize caregiver stressors

* Per the American Psychological Association

** Additional statistics on caregiver trends and impacts is included in the Appendix.
Benefits of Action

- Mitigation of family caregiver fatigue can divert caregivers and care recipients from intensive, disruptive and expensive services
- Improvement of overall well-being of the caregiver and family; enhanced self-management; maintained social connections
- Reduction and/or mitigation of need for costly and isolating out-of-home placements
- Ability to capture, grow and retain members while supporting the health, wellness and quality of life
Anthem’s Holistic Approach

Katelyn Fitzsimmons and Serena Thompson
LTSS Program Directors
Long Term Services & Supports Specialty Organization
Anthem, Inc.
Anthem’s Holistic Approach

Training and Information Resources – general and specialized caregiver resources to build knowledge and skills, incorporating an array of modalities, such: as peer-to-peer models, electronic and print resources, community workshops, organizational memberships and web-based learning.

Instrumental Supports – comprehensive suite of meaningful goods and services reflecting what caregivers’ value, use and need to facilitate sustainable systems of support.

Emotional and Social Supports – resources for social and emotional engagement consistent with best and emerging promising practices to assist caregivers find and maintain community connections, relationships and natural supports to alleviate stress and isolation.

ACL, Supporting Families Community of Practice, Rosalyn Carter Institute, Lifespan Respite Care, identify these as **basic pillars of support for families**.
The Caregiver Supports Toolkit
The Organized Caregiver
The Caregiver Supports Toolkit

Caregiver Sensory & Support Items relate to the promotion of self care, comfort, and health promoting ideas, and can be customized.
Related Services and Supports

Stakeholders emphasized that supports must be easy to access.

- Able to be used during weekends and evenings
- Uncomplicated access
- Respectful and nonjudgmental

We are working with vendors to customize supports that can be available 24 hours per day and 7 days per week and are able to be used in variety of different ways to suit the individual caregiver needs.

It is important that we recognize the contributions of the caregiver and avoid creating additional stressors throughout this process.
Other “Tools” in our Box:

- CG Web Portal
- Transportation
- Enhanced Respite
- In-Home Technologies
- Nutrition
Prototype Review/Next Steps

To date we have shared the toolkits with key stakeholders including family caregivers, advocates, national leaders, peers, and community based organizations to solicit feedback and ensure we are on track with the types of supports caregivers want and do not currently have available.

• Positive feedback
  – Useful
  – Relevant
  – Appealing
Continued Caregiver Collaboration

Pat Nobbie
Disability Policy Engagement Director
Anthem, Inc.
Community & Stakeholder Engagement

Disability Policy Engagement team:
• Led by Merrill Friedman, and comprised of national experts with real life experiences
• In the community engaging continually with families, people with disabilities and older adults
• Developing collaborations that address and prioritize the needs and preferences of individuals and families, to connect people to supports and resources such as respite and social and community connections

National Advisory Board:
• Convened by Lex Frieden, one of the architects of the ADA and a national leader in the independent living movement since the 1970’s
• Comprised of distinguished and culturally diverse community advocates, health care experts, and academics
• Provides recommendations for improving healthcare systems and services for older adult and people with disabilities.
Caregiver-focused Collaborations:

• Autism Health Home Initiative
• Peer Support strategy engagement
• Caregiver Toolkit (including both DPE, advocates and NAB engagement)
• Listening Sessions

Caregiving is an essential part of whole person care and support
Discussion
References


Other
• Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017
• The Kaiser Family Foundation, 2016
• Caregivers Face Many Challenges, American Psychiatric Association, APA Blog