

# Caregiver Supports: What's in your toolbox?



**2019 Home and Community Based Services Conference**

August 29, 2019

# Welcome & Session Objectives

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The Caregiving Landscape

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The Value to Anthem and Our Members

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Anthem's Holistic Approach

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Continued Caregiver Collaboration



**NATIONAL ALLIANCE *for* CAREGIVING**

*Advancing Family Caregiving Through Research, Innovation, and Advocacy*

# The Caregiving Landscape

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Director of Advocacy and Engagement



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# About Anthem, Inc.



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

## Access to Quality Care



**95%**  
of physicians

**96%**  
of hospitals

**1 in 8**  
**Americans or**

more than  
**40 million**  
total medical members in  
affiliated health plans

more than  
**78 million**  
total lives served

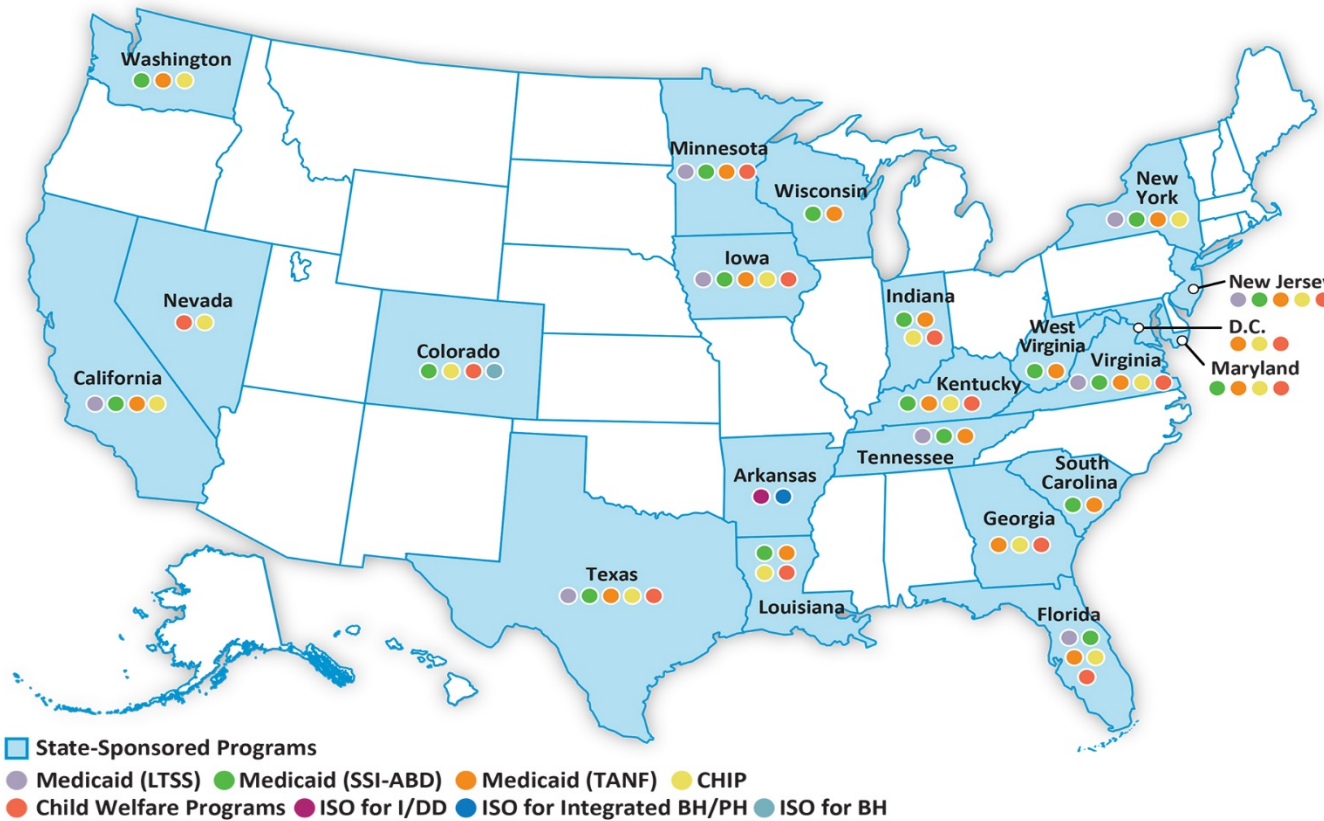
*Q1 2019 data*

Member access through BCBSA's national BlueCard® PPO program

## Mission:

**Improving** Lives and Communities. **Simplifying** Healthcare. **Expecting** More.

# 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

Terms	
LTSS: Long Term Services and Supports	CHIP: Children's Health Insurance Program
SSI-ABD: Supplemental Security Income / Aged, Blind and Disabled	ISO: Insurance Service Organization
TANF: Temporary Assistance for Needy Families	I/DD: Intellectual / Developmental Disabilities
	BH: Behavioral Health
	PH: Physical Health

# 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]

16 million people in the US are caring for someone with Alzheimer's or other dementias [4]

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]



Nearly 10 million adult children over the age of 50 care for their aging parents [3]

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]

# The Financial Impact <sup>[9]</sup>



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

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

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

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 <sup>[10]</sup>

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

Families of individuals with I/DD can spend 40 to 80 hours a week providing support <sup>[11]</sup>



# The Social Impact



Caregiving keeps people from community and family connections, increasing their social isolation; impacts physical health, mental health and emotional wellbeing <sup>[12]</sup>



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 <sup>[13]</sup>



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 <sup>[14]</sup>

# The Value of Supporting Caregivers

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



## Impacts LTSS

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

## Impacts Physical and Behavioral Health

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.\*

## Impacts Member Quality of Life

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

- ✓ 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



- ★ • Improvement of overall well-being of the caregiver and family; enhanced self-management; maintained social connections

- ★ • Mitigation of family caregiver fatigue can divert caregivers and care recipients from intensive, disruptive and expensive services

- ★ • 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



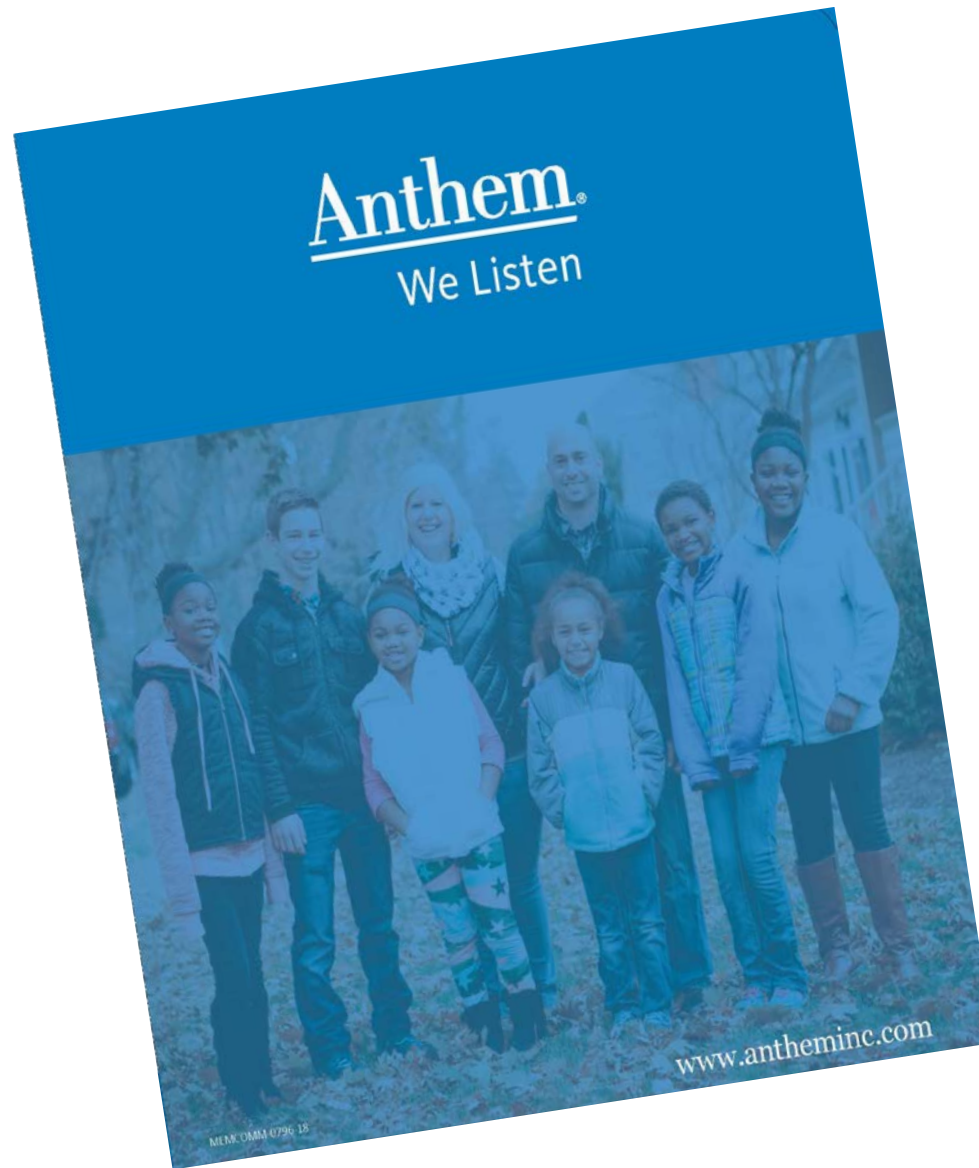
**Emotional and Social Supports** – resources for social and emotional engagement consistent with best and emerging promising practices to assist caregivers find and maintain community connections, relationships and natural supports to alleviate stress and isolation

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







# Related Services and Supports

Stakeholders emphasized that supports must be easy to access

Able to be used  
during weekends  
and evenings

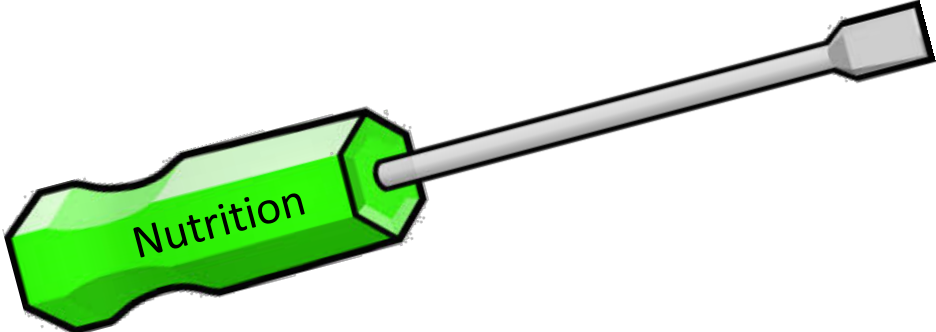
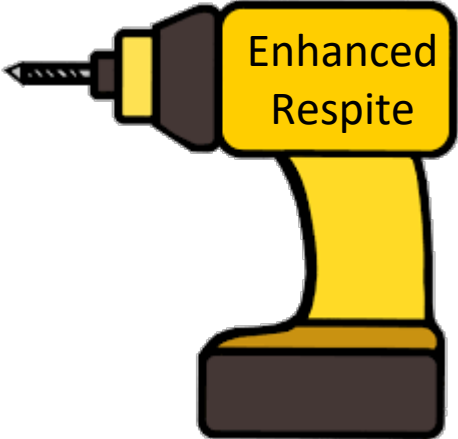
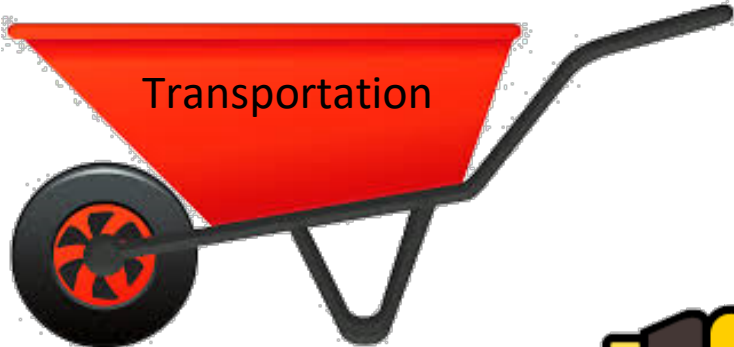
Uncomplicated  
access

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:



# 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





# 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.



First, We  
Listen

# 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





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