Considering Solutions for Caregiver Supports
Welcome & Session Objectives

Moderators

Merrill Friedman, Senior Director
Disability Policy Engagement
Anthem, Inc.

Pat Nobby, Director
Disability Policy Engagement
Anthem, Inc.

Understanding the caregiver crisis
Examining caregiving & persons aging with disability
Exploring promising solutions & innovations
The Challenges and Pathway Forward

Julia Kenny, Senior Director
Long Term Services & Supports Specialty Organization
Anthem, Inc.
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]

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]

8.4 million provide care for adults with an emotional or mental health issue [6]

More than 1 million children care for a parent, grandparent or sibling with a disability or illness [7]

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 Cost

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, 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 [10].

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 [11].
The Social Cost

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]
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.
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
Caregiving & Persons Aging with Disability

Michelle Putnam, PhD
Simmons University, School of Social Work
Boston, Massachusetts
### Older adults

47.8 million adults age 65 and older in the United States in 2015.

- In 2014, disability rates for non-institutionalized population were based on National Health Interview Study data:
  - 17.4% of persons 65-74 reported experiencing disability.
  - 41.9% of persons ages 85+.

(Federal Interagency Forum on Aging-Related Statistics, 2016, August)

### Adults 21-64

10.7% of persons ages 21-64 (19.7 million) reported experiencing disability in 2015. (Erickson, W. Lee, C., & von Schrader, S., 2016)

In 2010, 1.2 million adults report as having an intellectual disability and 944,000 report as having developmental disability (Brault, 2012)
Aging and disability are conceptually different.

Aging is a developmental process. It’s lifelong. Long life is typically hoped for.

Disability is an experience. It’s contextual. It’s about person-environment fit.

It may be one-time or long term. It may be episodic, or continual. It’s typically not hoped for.

But it is common, not unusual. It’s difference, not devastation.
Aging with disability pathways can be very different

Estimated 12.3% of population is aging with long-term disability.
(Clark & Latham, 2012)
INTERSECTIONS & INTEGRATIONS

Bridging Aging & Disability
## Caregiving & Support & Bridging

### Differences between aging with and aging into disability
- Length of caregiver career
- Expertise of caregiver
- Who is in caregiver network
- Familiarity with service systems
- Long-term effects of living with disability
- Accelerated aging, late-life effects & chronic conditions

### Similarities between aging with and aging into disability
- Cost, extinguishing of financial resources
- Caregiver knowledge and training
- Caregiver aging & own disability
- Need for affordable, high-quality LTSS
- Need to distinguish “typical” aging from disability
Considerations for Caregiving

- LTSS that is inclusive of persons aging with disability and their caregiver network
- Consideration of LTSS service & support outcome measures and social norms/expectations for caregivers
- Understanding of caregiver networks over time, role and activities of person aging with disability in own care
- Reflection on models of caregiving
- Consideration of evidence-based practices, translation across diverse members of aging populations
References


Sandy Markwood, CEO
National Association of Area Agencies on Aging
Discussion