

Considering Solutions for Caregiver Supports



Welcome & Session Objectives

Moderators

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Understanding the caregiver crisis

Examining caregiving & persons aging with disability

Exploring promising solutions & innovations

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The Challenges and Pathway Forward



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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]

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]

The Financial Cost ^[9]



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]

References

- [1] Caregiving in the U.S. – AARP 2015 Report <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- [2] *Supporting Families of Individuals with Intellectual and Developmental Disabilities*, The National Community of Practice – NASDDS, UMKC, IHD, UCEDD
<https://www.dhhs.nh.gov/dcbcs/bds/documents/hsriooverview062018.pdf>
- [3,10] The MetLife Study of Caregiving Costs to Working Caregivers, June 2011
<https://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>
- [4] *2018, Alzheimer's Disease Facts and Figures*, Alzheimer's Association
<https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>
- [5] ALS Association, Quick Facts <http://www.alsa.org/news/media/quick-facts.html>
- [6] *On Pins and Needles: Caregivers of Adults with Mental Illness*, National Alliance for Caregiving
http://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf
- [7] American Association Psychological Association, *Invisible Caregivers*
<http://www.apa.org/monitor/2015/09/caregivers.aspx>
- [8] The Center for Children with Special Needs <https://cshcn.org/children-special-needs/one-in-five-families-with-children-has-at-least-one-child-with-special-health-care-needs>
- [9] Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain, AARP Public Policy Institute
<https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>
- [11] The Arc of the United States, Family and Individual Needs for Disability Supports, Community Report, 2017
https://www.thearc.org/file/documents_finds/FINDS_report-2017-FINAL-VERSION.pdf
- [12] Why Loneliness May Be the Next Big Public-Health Issue, March 2015 <http://time.com/3747784/loneliness-mortality/>
- [13] Family Caregiver Alliance, National Center on Caregiving, Caregiver Statistics: Work and Caregiving
<https://www.caregiver.org/caregiver-statistics-work-and-caregiving>
- [14] National Alliance on Caregiving, Caregiving in the U.S 2015

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



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U.S. Demographic snapshot: Disability

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.

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**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.

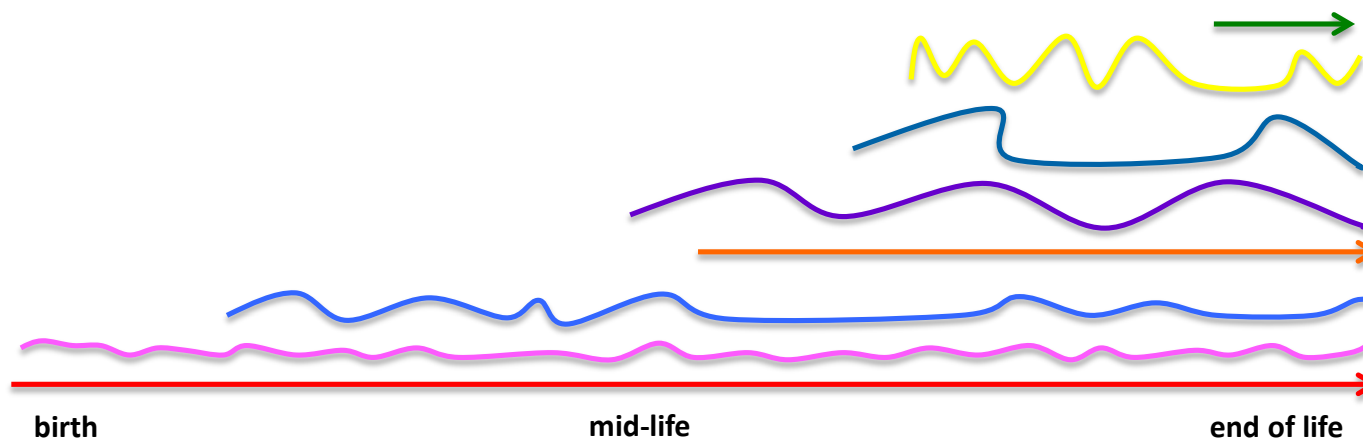
It may be one-time or long term. It may be episodic, or continual. It's typically not hoped for.

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

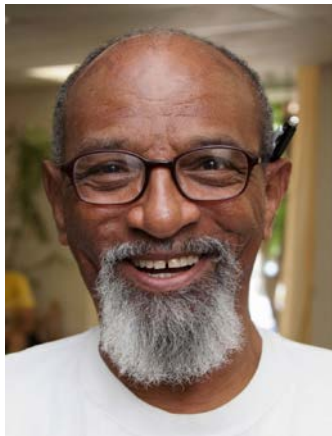
Consideration of evidence-based practices, translation across diverse members of aging populations

References

- Brault, M. (2012). Americans with Disabilities: 2010, Household Economic Studies, Current Population Reports, July, P70-131. Found at:
<http://www.census.gov/prod/2012pubs/p70-131.pdf>
- Clark, Ph. & Latham, L. (2014). Life course health and socioeconomic profiles of Americans aging with disability. *Disability and Health Journal*, 7(1), S15-S23.
- Erickson, W. Lee, C., & von Schrader, S. (2016). 2015 Disability Status Report: United States. Ithaca, NY: Cornell University Yang Tan Institute on Employment and Disability (YTI)
- Federal Interagency Forum on Aging-Related Statistics. (2016, August). Older Americans 2016: Key Indicators of Well-Being. Federal Interagency Forum on Aging-Related Statistics. Washington, DC: U.S. Government Printing Office.



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Sandy Markwood, CEO
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Discussion



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