



# Elevating Dementia Caregiving as a Public Health Priority

November 19, 2021



# Presented by:



**BOLD**  
PUBLIC HEALTH  
CENTER OF EXCELLENCE  
ON DEMENTIA  
CAREGIVING

# In collaboration with:



The  
**John A. Hartford**  
Foundation



National Alliance for Caregiving

# Welcome from...



The  
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Rani E. Snyder, MPA  
Vice President, Program






# Land acknowledgement

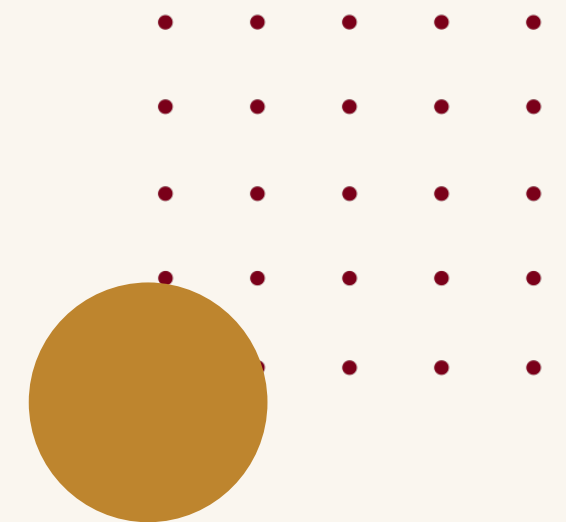
*The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. We acknowledge with gratitude the Land itself and the People. We take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.*



# The Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...

-  Improving access to evidence-based programs and best practices
-  Facilitating connections and collaboration among public health agencies and a wide range of service organizations
-  Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies



# Introducing our presenters...



**Mike Wittke, BSW, MPA**

Vice President,  
Research & Advocacy  
National Alliance for Caregiving



**Heidi M. Holt, MPA**

Public Health Advisor,  
Alzheimer's Disease and  
Healthy Aging Program,  
CDC



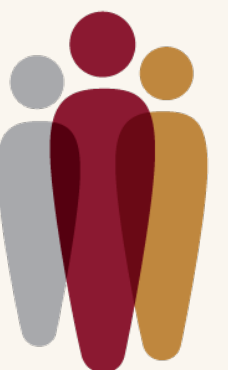
**Sandy Markwood, MS**

Chief Executive Officer,  
US Aging



**Robyn I. Stone, PhD**

Sr. Vice President, Research & Co-  
Director LeadingAge LTSS Center  
@ UMass Boston



# Caregiving is a Public Health Priority

## FAMILY CAREGIVER DEFINITION

“The term “family caregiver” means an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation”

As defined in the “Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017” or the “RAISE Family Caregivers Act”. PUBLIC LAW 115–119—115th Congress, to provide for the establishment and maintenance of a Family Caregiving Strategy.

**Over 53 million people over the age of 18 are caregivers.**

# Caregiving is a Public Health Priority

**Caregivers play a critical role in the care of those with chronic conditions, especially for older adults who wish to avoid institutional settings.**

- The reason for providing care is commonly due to either “mobility issues”, “Alzheimer’s or dementia”, “cancer”, “mental or emotional illness”, “stroke”, “diabetes”, and “heart disease”.
- An increasing number of caregivers struggle to balance the cascading issues related to caring for people with multiple conditions.
- An increasing number of caregivers report having difficulty in coordinating care across various care settings.



# Caregiving is a Public Health Priority

**Caregivers themselves are an at-risk population and need recognition and support independent of the care recipient.**

- Many caregivers have two or more chronic diseases.
- An increasing number of caregivers say caregiving has made their health worse.
- Over half of caregivers indicated that a decline in their health compromises their ability to provide care.

# Dementia Caregiving

- About **1 in 3** caregivers for people with Alzheimer's report worsening health
- Over half of caregivers indicated that a decline in their health compromises their ability to provide care.
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for children under age 18.
- Compared with caregivers of people without dementia, **twice** as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.
- Of the total lifetime cost of caring for someone with dementia, **70%** is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care.

# Public Health can Build Linkages



# Chronic Disease Caregiving through a Public Health Lens

Michael Reese Wittke  
Vice President, Research & Advocacy



# Key Essential Public Health Services

**Support and recognition for caregivers can be achieved via a range of public health functions.**

- Assess and monitor population health status, factors that influence health, and community needs and assets
- Investigate, diagnose, and address health problems and hazards affecting the population
- Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it
- Strengthen, support, and mobilize communities and partnerships to improve health
- Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement.

# A Coordinated Approach to Public Health in Action

## **TIER 1 – National Level**

DATA GATHERING and REPORTING

PUBLIC HEALTH AWARENESS

## **TIER 2 – Community Level**

SERVICE COORDINATION

EDUCATION AND TRAINING



# Data Gathering and Reporting

## Family Caregiver Population Health Surveillance

- We need national level data collection across all 50 states on caregiver health conditions, risk factors, and better data on care recipients with comorbidities.

## Family Caregiver Public Health Research

- We need evidence-informed and peer-reviewed studies on issues caregivers face related to social determinants of health, health equity, and effective interventions.

# Data Collection and Reporting

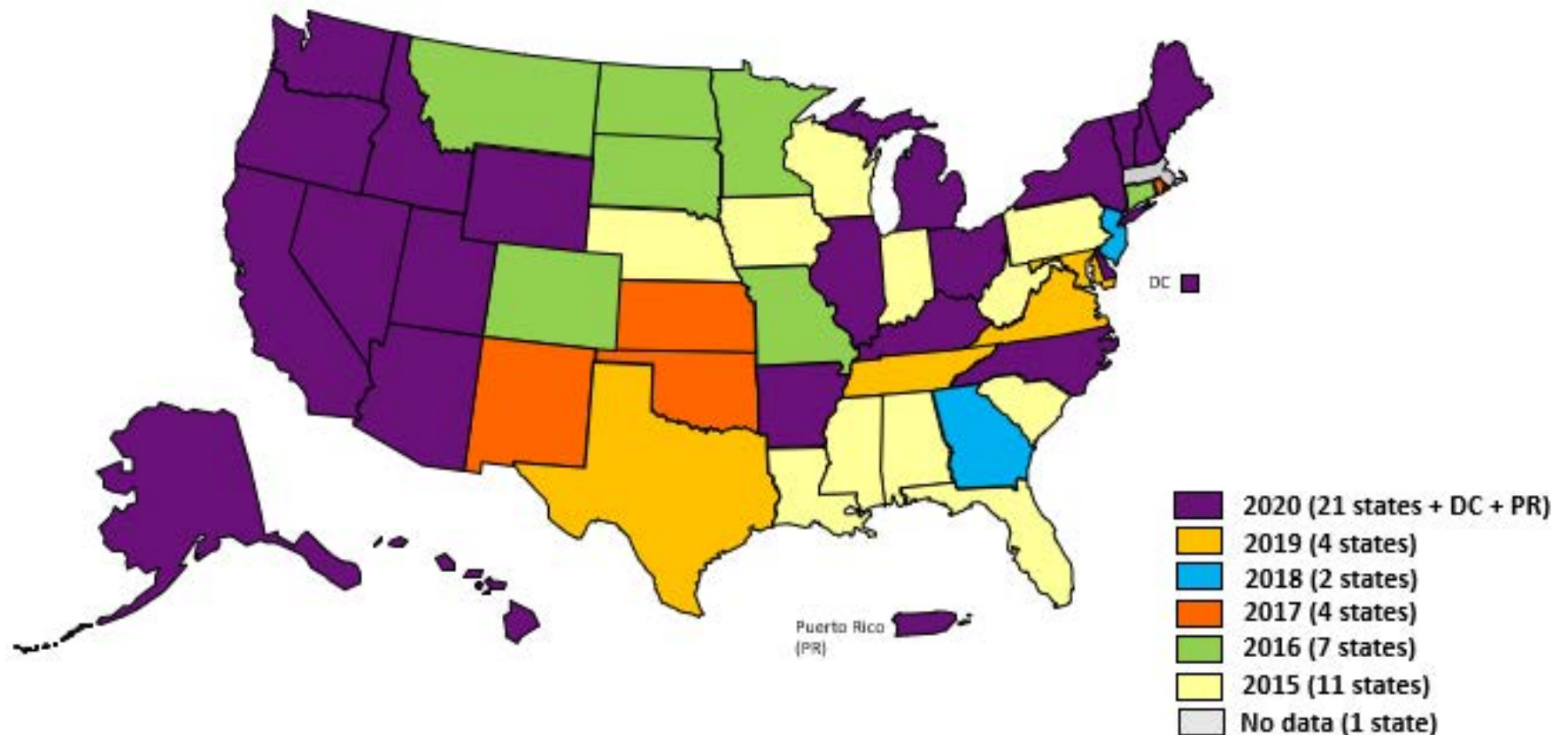




# Alzheimer's and Healthy Aging: BRFSS Data

Topic	Question	Responses	Data Years
Caregiver	During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?	Yes / No / Don't know / Caregiving recipient died in past 30 days / Refused	2009, 2021
	What is his or her relationship to you?	Mother / Father / Mother-in-law / Father-in-law / Child / Husband / Wife / Live-in partner / Brother or brother-in-law / Sister or sister-in-law / Grandmother / Grandfather / Grandchild / Other relative / Non-relative or family friend / Don't know / Refused	2021
	For how long have you provided care for that person?	Less than 30 days / 1 month to less than 6 months / 6 months to less than 2 years / 2 years to less than 5 years / 5 or more years / Don't know / Refused	2021
	In an average week, how many hours do you provide care or assistance?	Up to 8 hours per week / 9 to 19 hours per week / 20 to 39 hours per week / 40 hours or more / Don't know / Refused	2021
	What is the main health problem, long-term illness, or disability that the person you care for has?	Arthritis or rheumatism / Asthma / Cancer / Chronic respiratory conditions such as emphysema or COPD / Alzheimer's disease, dementia or other cognitive impairment disorder / Developmental disabilities such as autism, Down's Syndrome, and spina bifida / Diabetes / Heart disease, hypertension, stroke / Human Immunodeficiency Virus Infection (H.I.V.) / Mental illnesses, such as anxiety, depression, or schizophrenia / Other organ failure or diseases such as kidney or liver problems / Substance abuse or addiction disorders / Injuries, including broken bones / Old age, infirmity or frailty / Other / Don't know / Refused	2021
	Does the person you care for also have Alzheimer's disease, dementia or other cognitive impairment disorder?	Yes / No / Don't know / Refused	2021
	In the past 30 days, did you provide care for this person by managing personal care such as giving medications, feeding, dressing, or bathing?	Yes / No / Don't know / Refused	2021
	In the past 30 days, did you provide care for this person by managing household tasks such as cleaning, managing money, or preparing meals?	Yes / No / Don't know / Refused	2021
	In the next 2 years, do you expect to provide care or assistance to a friend or family member who has a health problem or disability?	Yes / No / Don't know / Refused	2021

# BRFSS Caregiver Module, 2015–2020 (Most Recent Year of Administration)



# Public Health Awareness

## **We need public health awareness efforts that describe:**

- The value of the caregiver in chronic disease management and intervention.
- The health challenges and risk factors that caregivers experience.

## **We need to ensure awareness efforts are separately targeted at:**

- Public health and health care sector professionals dealing with issues related to social determinants of health.
- Emergency preparedness and response professionals dealing with issues related to pandemics and natural disasters.
- Employers and the business community where private sector partnerships can be developed to help caregivers make healthy choices.

# Infographics

## alzheimer's association® dementia caregiving in maryland

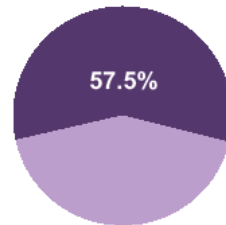
DATA FROM THE 2019 BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

In Maryland, more than **1 in 5** unpaid caregivers are providing care to a loved one with Alzheimer's or another dementia.

**More than half** of dementia caregivers have been providing care for at least two years. **More than 1 in 3** dementia caregivers provide 20 or more hours of care per week.

**More than 1 in 5** dementia caregivers are in the "sandwich generation" — caring for both someone with dementia and a child or grandchild.

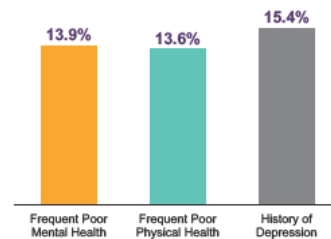
Percent of dementia caregivers providing care for at least 2 years



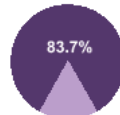
Characteristics of Alzheimer's and Other Dementias Caregivers

Gender		Age		Hours of Care per Week		Caring for Parent or Parent-in-law	Also Caring for Minor
Women	Men	45-64	65+	20+	40+		
70.0%	30.0%	46.8%	27.1%	37.0%	26.6%	40.2%	22.4%

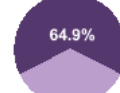
Impact of Alzheimer's and dementia caregiving



Percent who manage household care, such as cleaning or cooking



Percent who manage personal care, such as feeding or bathing



This Fact Sheet is supported by Cooperative Agreement #5 NU58OP006115 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the Alzheimer's Association and do not necessarily represent the official views of the CDC.

## HAWAII CAREGIVING HI

2019 Behavioral Risk Factor Surveillance System (BRFSS) Data

**1 in 5 adults are caregivers**

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

### WHO ARE CAREGIVERS?

- 59% are women
- 26% are 65 years old or older
- 35% are caring for a parent or parent-in-law
- 25% of caregivers are providing care to someone with dementia

### CAREGIVING CAN BE

- LENGTHY** Half have provided care for at least two years
- INTENSE** A third have provided care for at least 20 hours per week

### HOW DO CAREGIVERS HELP?

- 75% manage household tasks
- Nearly half assist with personal care

### FUTURE CAREGIVERS

1 in 7 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years

cdc.gov/aging

<https://www.alz.org/media/Documents/Maryland-2019-CG-BRFSS-Fact-Sheet.pdf> <https://www.cdc.gov/aging/data/index.htm>



## Caregiving for Family and Friends — A Public Health Issue

Caregiving is an important public health issue that affects the quality of life for millions of individuals. Caregivers provide assistance with another person's social or health needs. Caregiving may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation. It also may involve emotional support and help with managing a chronic disease or disability. Caregiving responsibilities can increase and change as the recipient's needs increase, which may result in additional strain on the caregiver.<sup>1,2,3</sup>

Caregivers can be unpaid family members or friends or paid caregivers.<sup>1,2</sup> Informal or unpaid caregivers are the backbone of long-term care provided in people's homes. In particular, middle-aged and older adults provide a substantial portion of this care in the US, as they care for children, parents or spouses.<sup>2,3</sup> These informal caregivers are the focus of this brief.<sup>2,3</sup>

Caregiving can affect the caregiver's life in a myriad of ways including his/her ability to work, engage in social interactions and relationships, and maintain good physical and mental health.<sup>1</sup> Caregiving also can bring great satisfaction and strengthen relationships, thus enhancing the caregivers' quality of life. As the population ages and disability worsens, it is critical to understand the physical and mental health burden on caregivers, the range of tasks caregivers may perform, and the societal and economic impacts of long-term chronic diseases or disability.<sup>2</sup> Gathering information on these topics enables us to plan for public health approaches to assist individuals as well as their communities and maintain the health of caregivers and care recipients.<sup>1</sup>

**Informal caregivers provide regular care or assistance to a friend or family member who has a health problem or disability.<sup>2,4</sup>**



# Service Coordination

**We need systemic improvements in service coordination for family caregivers across public health and health care settings**

- Identify community-level entry points for caregivers
- Understand public health department roles in coordinating caregiver services that can be done in partnership with community-based organizations.
- Ensure caregivers of those across the range of conditions are identified, assessed, and referred to services early in their care journey.
- Ensure caregivers of all chronic or serious conditions are eligible for services.

# Education and Training

## We need expanded service delivery for family caregivers

- Implement educational programs for caregivers across all conditions that allow them to augment a care team and complement, not compete with, a clinical visit.
- Establish a cross-collaborative effort among community-based organizations and public health departments with the purpose of both expanding existing caregiver programs and establishing new caregiver support programs.
- Collect data on service usage to understand if caregivers are accessing the services they need, if they are improving outcomes, and if they are reaching disadvantaged communities.

# National Momentum

## RAISE National Family Caregiving Strategy

- Increased awareness of family caregiving.
- Increased emphasis on integrating the caregiver into processes and systems from which they have been traditionally excluded.
- Increased access to services and supports to assist family caregivers.
- Increased financial and workplace protections for caregivers.
- Better and more consistent research and data collection.



# Discussing this Approach to Public Health in Action

## **DATA GATHERING and REPORTING**

Family caregiver population health surveillance  
Family caregiver public health research

## **PUBLIC HEALTH AWARENESS**

Caregiver as provider of care AND caregiver as at-risk population  
Awareness efforts among practitioners, emergency response, businesses

## **SERVICE COORDINATION**

Systemic improvements addressing social determinants of health

## **EDUCATION AND TRAINING**

Expanded community level services for family caregivers across conditions



# Discussion

## Contact

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National Alliance for Caregiving

# Q&A

Please use the Q&A feature to submit your questions!



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