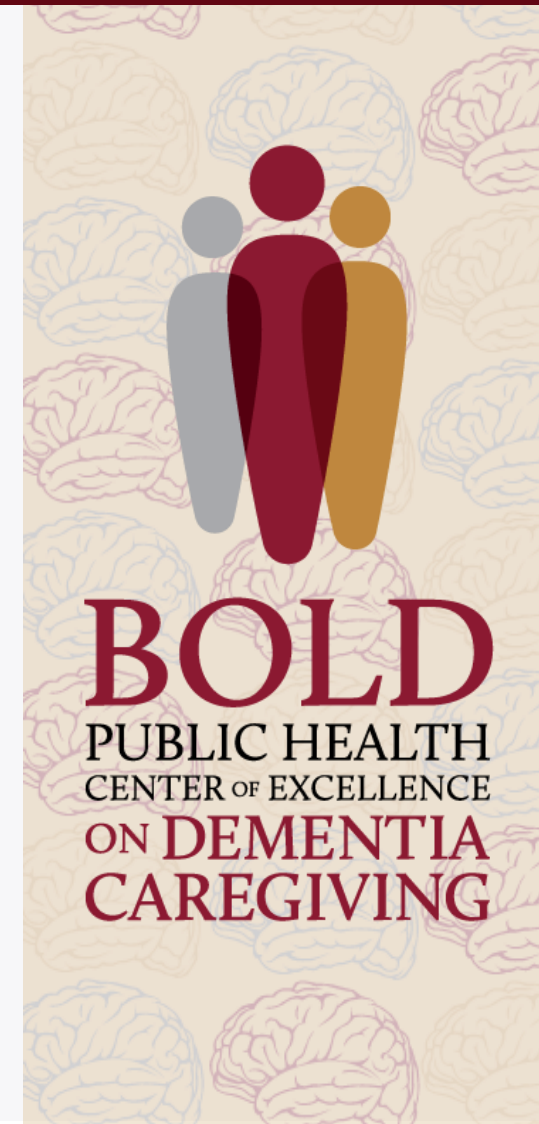


# *Keynote Address*

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# The Public Health Opportunities and Challenges of Dementia Caregiving

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***Robert L. Kane Endowed Chair in Long-Term Care and  
Aging***

***Director, Center for Healthy Aging and Innovation***

***Director, BOLD Public Health Center of Excellence on  
Dementia Caregiving***

# Aims

1. Dementia caregiving: Why is it a public health priority?
2. Public health approaches/strategies to dementia caregiving
3. Understand how caregiving operates as a social determinant of health
4. Understand the mission, vision, and activities of the BOLD Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC) can be a resource

# The Realm of Public Health (from Bouldin et al., 2021)

- Public health is concerned with improving the health of groups of people—populations—in an equitable way.
- Public health seeks to eliminate health disparities, which are potentially preventable systematic differences in health between groups of people based on a number of sociodemographic characteristics or the amount of power they have in their communities.
- Public health efforts are typically based on the socioecological framework ,
- Public health complements healthcare received in settings like hospitals and rehabilitation facilities.
  - Many local health departments offer vaccinations and provide nutrition services and some provide more comprehensive prenatal and preventive or primary care, e.g., as federally qualified health centers
- Any condition, exposure, event, or experience that negatively impacts health or quality of life at a population level is a public health issue.



**Fig. 1** Social-ecological framework.

# The Healthy Brain Initiative

- The CDC's efforts to elevate ADRD and dementia care as a public health issue came into focus with the 2007 and first Healthy Brain Initiative (HBI) Road Map (Olivari et al., 2020)
- The most recent iteration of the HBI Road Map is the 2018-2023 version



# Principal HBI Actions (from Bouldin et al., 2021)

- The HBI Road Map addresses caregiving through a number of overarching actions, including:
  - Investigate, communicate, and educate about Alzheimer's disease, caregiving, and healthy aging through data-informed products;
  - Communicate about caregiving as a public health issue and promote available resources to providers and the public; and
  - Provide information to empower caregivers



# HBI: Eliminating Health Disparities

- Partnerships with communities experiencing disparities to ensure culturally, linguistically, and age appropriate development of strategies
- Increase dissemination effectiveness
- Example: *HBI Road Map for Intervention Country*

## **BOX 2 Eight public health strategies to consider in Indian country**

### ***Educate and Empower Community Members***

1. Work with community members to understand brain health, early warning signs of dementia, and benefits of early detection and diagnosis for persons with dementia and their caregivers.
2. Encourage community members to use effective interventions, best practices, and traditional wellness practices to protect brain health, address cognitive impairment, and support persons with dementia and their caregivers.
3. Provide information and tools to help older adults with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia.
4. Promote engagement among tribal leaders in dementia issues by offering information and education on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health approaches in addressing this priority problem.

### ***Collect and Use Data***

5. Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches.
6. Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to AI/ANs with dementia.

### ***Strengthen the Workforce***

7. Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.
8. Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.

# CAREGIVING

2015-2018 Behavioral Risk Factor Surveillance System (BRFSS) Data  
from adults in 44 States, Puerto Rico, and the District of Columbia.



**1 in 5** adults  
are caregivers

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

## CAREGIVING CAN BE

### LENGTHY

**Half** have provided care for at least two years



### INTENSE

**Almost 1/3** have provided care for at least 20 hours per week



## WHO ARE CAREGIVERS?

**58%** are women

**19%** are 65 years old or older

**37%** are caring for a parent or parent-in-law

**9%** are providing care to someone with dementia



## HOW DO CAREGIVERS HELP?



**Nearly 80%** manage household tasks

**Over 50%** assist with personal care



U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention

## FUTURE CAREGIVERS

**1 in 6** NON-CAREGIVERS expect to **BECOME CAREGIVERS** within 2 years



[cdc.gov/aging](https://www.cdc.gov/aging)

CS 204326-A April 2020

# Data-Driven Public Health (Bouldin et al., 2021)

- Data should be used to prioritize topics, inform relevant stakeholders and community members, and generate action.
- Action E-3 in the HBI Road Map is to “increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers’ health and well-being

# Why is Dementia Caregiving an Important Public Health Priority? (Bouldin et al., 2021)

- It affects the health of the population—including both caregivers and care recipients
- The effects may be unequally borne by some members of that population
- There are effective prevention strategies that could be employed to reduce these negative impacts.
- **What can public health do to help dementia caregivers?**

# What Can Public Health Do? (Bouldin et al., 2021)

- Public health has a role in measuring the number of caregivers and documenting their experiences and health status
- Educate caregivers about health risks they might be facing, providing them information about effective programs to reduce stress or their financial burden, and giving them skills to support the care recipient
- Develop health-related awareness and education campaigns
- Support community meetings and activities related to health advocacy
- Draft or provide input on ordinances, policies, and laws all fall under possible public health activities
- Assure that people have access to information and effective programs
  - Evidence-based interventions that reduce caregiver burden
  - Provide caregivers with training to complete medical tasks or manage difficult behaviors
    - Both may involve linking people to healthcare or service organizations or offering programs through entities like local public health departments.

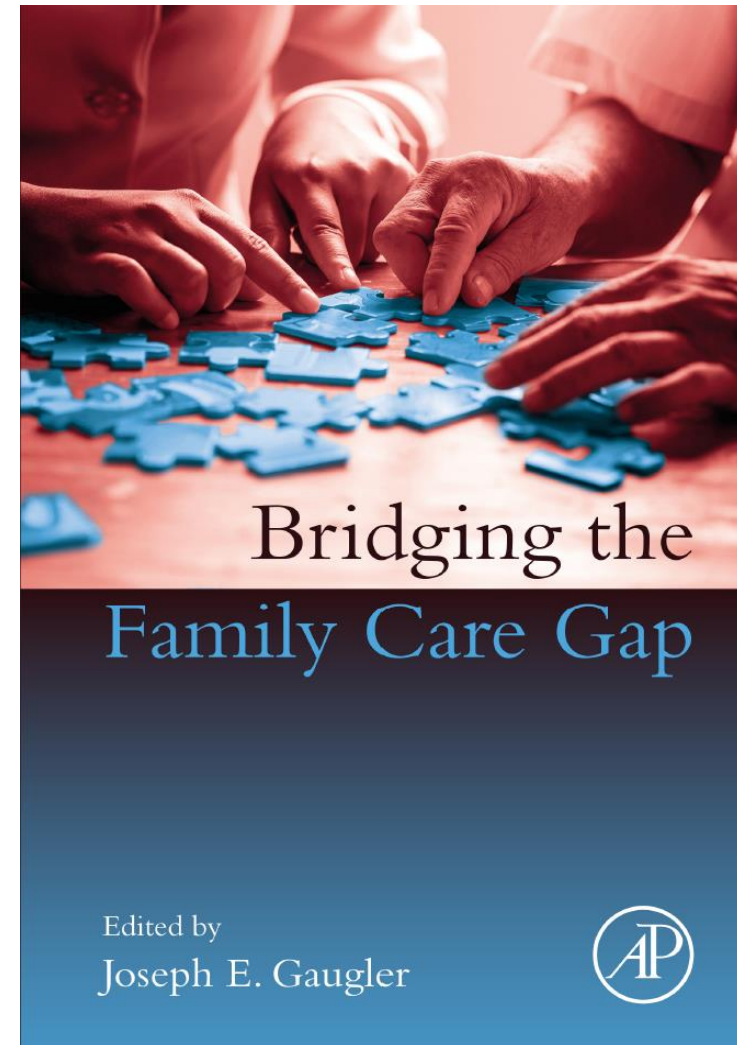
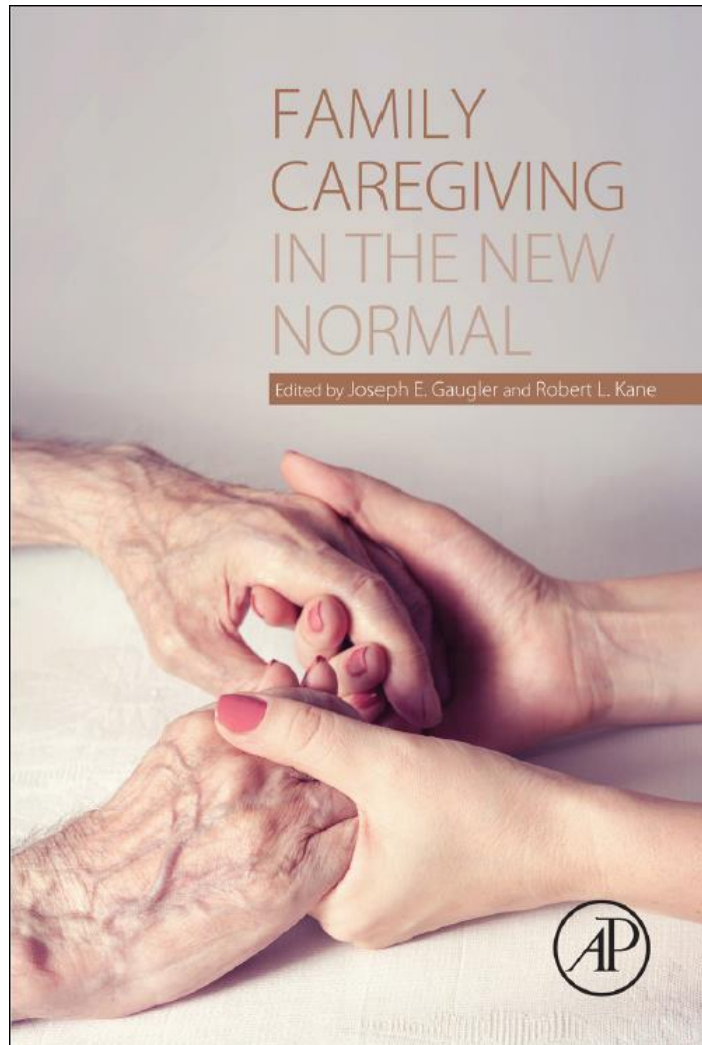
# Splaine, 2022: Public Health and Dementia Caregiving-What Next?

- **Group 1: “I Don’t See Dementia Caregiving as a Public Health Issue”**
  - Continue with data. Build some message visuals about caregiver health.
  - Tweak the message “Caregiver health”
  - Pull in KOL’s from NASEM report and Richard Schulz
  - Highlight in public health e news.
  - Point to BOLD center.
  - Stimulate new review articles/contest/AAIC/special journal issue.
  - Find testimonials (NY, AZ)
  - Address state public health associations.
  - Assess our academic public health curriculum for update or offering programs through entities like local public health departments.

# Splaine, 2022: Public Health and Dementia Caregiving-What Next?

- **Group 2: “I Get It. What Do You Want Me to Do About It?”**
  - More state specific BRFSS analysis with cross tabs.
  - Promote identification of caregivers in health systems.
  - A young (30-55 year old) caregivers town hall meeting
  - 99483 campaigns and capacity building on care planning.
  - Engage the consumer voice in policy process.





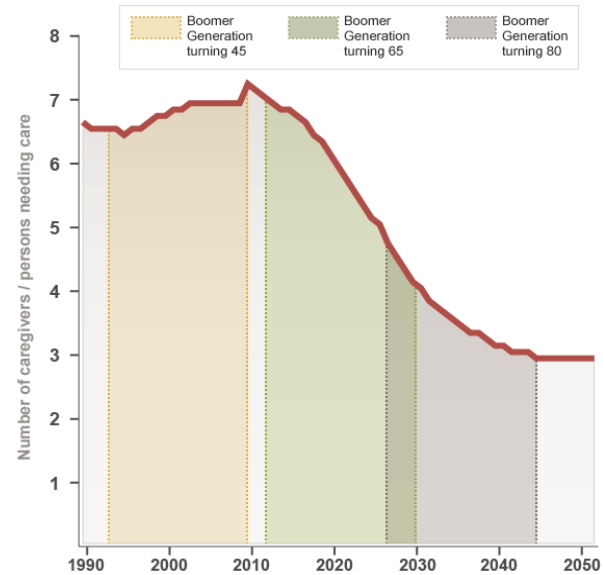
Gaugler, J. E., & Kane, R. L. (Eds.). (2015). *Family caregiving in the new normal*. San Diego, CA: Academic Press.  
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# Is Our Reliance on Family Caregiving Sustainable?

## You Take Care of Mom, But Who Will Take Care of You?

Family caregivers provide the majority of long-term services and supports (LTSS). But the supply of family caregivers is unlikely to keep pace with future demand. The Caregiver Support Ratio is defined as the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 and older—those most likely to need LTSS. The caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

### Caregiver Support Ratio



In **2010**, the caregiver support ratio was **more than 7 potential caregivers** for every person in the high-risk years of 80-plus.



In **2030**, the ratio is projected to decline sharply to **4 to 1**; and it is expected to further fall to less than **3 to 1** in **2050**.

**POLICY ACTION:** Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

Source: D. Redfoot, L. Feinberg, and A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, D.C.: AARP Public Policy Institute, August 2013). [www.aarp.org/research/ppi](http://www.aarp.org/research/ppi)

# Factors Driving/Contributing to/Complicating the Family Care Gap (Spillman, 2020; Stone, 2015)

- Rising educational attainment
- Longer time spent in the workforce
- Women more likely to participate in the workforce
- More complex family structures
- Diversity
- Geographic dispersion of families
- Changes in the how long-term care is financed/delivered
- The aging of/shortage of the geriatric workforce

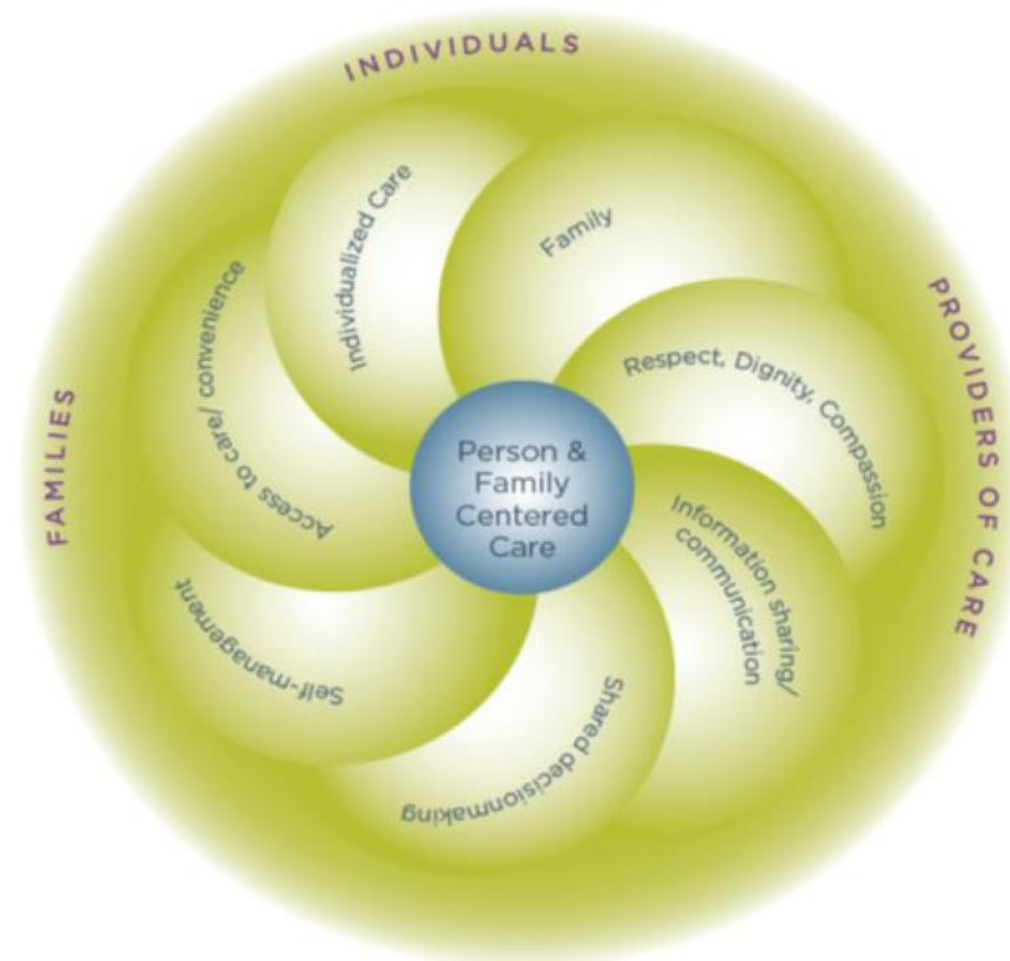
# How Can We Bridge the Family Care Gap? (Gaugler, 2021)

- Develop a national family caregiving strategy
- Achieve “family-centered” care, or approaches that more effectively incorporate family caregivers into healthcare delivery
- Advocate for the widespread dissemination and implementation of evidence-based supports and services for family caregivers
- Develop and/or support policies and programs that have a public health impact (Plichta, 2018)

# National Strategy: The RAISE Family Council

- The RAISE Family Caregivers Act became law on Jan. 22, 2018.
  - It directs the Secretary of Health and Human Services to develop a national family caregiving strategy
- The RAISE (Recognize, Assist, Include, Support, and Engage) Advisory Council included national experts as well as family caregivers
- 26 recommendations across five goals were delivered to Congress in Fall of 2021 following a 2-year information gathering effort
- Five priority areas:
  - **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**

# Achieve Family-Centered Care

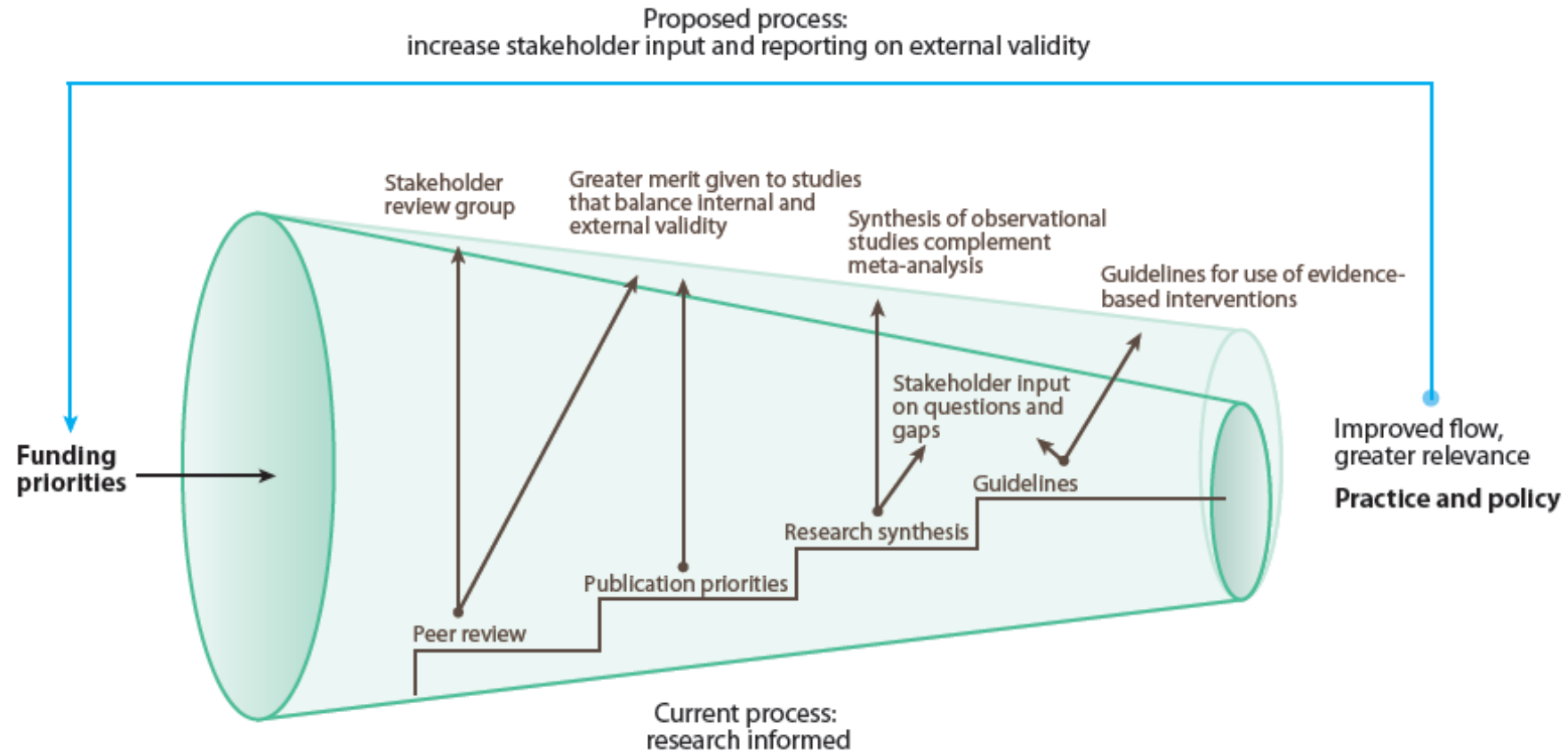


NQF, 2014a; see <https://www.nap.edu/read/23606/chapter/8#221>

# Supporting Policies that Have a Public Health Impact

- Relatively flat funding for the National Family Caregiver Support Program since its inception in 2000 until around 2013 or so
  - Only reaches about 700,000 caregivers
- Paying family caregivers
- Policy innovations: Refinancing long-term services and supports
  - Public-private models
  - Washington's Long-Term Services and Supports Trust Act
  - Universal Family Care

# The Urgent Need for Dissemination and Implementation



From Brownson & Colditz, 2015





# PHCOE on Dementia Caregiving

*Our **Mission** is to assist state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives.*

## **We achieve our mission by:**

- 1.** Providing expert **technical assistance** to public health agencies for selecting their caregiving-related goals.
- 2.** **Improving access to & use of** evidence-based programs, tools, materials and best-practices in dementia caregiving.
- 3.** **Facilitating connections and collaboration** between public health agencies and a wide network of providers and organizations serving dementia caregivers.

# Examples of how the PHCOE-DC can help...

1. Connect you with other public health agencies and key partners to advance your dementia caregiving goals.
2. Help you identify evidence-based interventions to support dementia caregivers in your community.
3. Provide guidance and advice on most effective public health approaches to supporting dementia caregivers.
4. Help you integrate dementia caregiving into your public health messaging.
5. Help you make the case for prioritizing dementia caregiving in your state, and many more.

# Citations

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# Engage with us...

- ✓ **Visit us regularly** at [bolddementiacaregiving.org](http://bolddementiacaregiving.org) for events, resources & more
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