If Family Caregiving Were a Public Health Priority

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National Rehabilitation Research and Training Center on Family Support

Outline

- Criteria of public health challenges



Why is Family Caregiving a Public Health Issue?



Unintended and unanticipated negative health consequences:

- Do caregivers face different **risk factors** compared to non-caregivers?
  - If so, it can inform us that as a population of 26+ million, caregivers are particularly vulnerable and public health can intervene
- If caregiving **causes** worse health then it can be considered a public health issue

New to Frame Caregiving as Public Health Issue



Caregiving for Family and Friends — A Public Health Issue

2018

NATIONAL ASSOCIATION OF CHRONIC DISEASE DIRECTORS
Promoting Health, Preventing Disease.

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

https://www.cdc.gov/aging/agingdata/docs/caregiver-brief-508.pdf

CDC Offers Recommendations

Public health professionals can stimulate needed changes to systems that promote the health and well-being of both caregivers and their care recipients.

1. **Increase messaging** that emphasizes both the important role of caregivers and the importance of maintaining caregivers' health and well-being.
2. **Educate the public** about the importance of caregiving before they begin and the resources and supports available.
3. **Educate healthcare** ...urage caregivers' use of available information and to
4. **Evaluate caregiver** ...ity, effectiveness, and impact.
5. **Estimate the gap b** ...**es** to support people with dementia and disab
6. Increase awareness of and access to **evidence-based programs and services** that can help caregivers and care recipients and increase access to these programs and services.
7. **Encourage caregivers** to get regular check-ups, use preventive services and engage in **self-care** to maintain health.
8. Ensure that caregivers with a disability and/or chronic diseases have access to **self-management programs** to maintain their health.

CDC recommendations are relatively weak and insufficient…but they are a start…

https://www.cdc.gov/aging/caregiving/caregiver-brief.html

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ROSALYNN CARTER INSTITUTE FOR CAREGIVERS 2020

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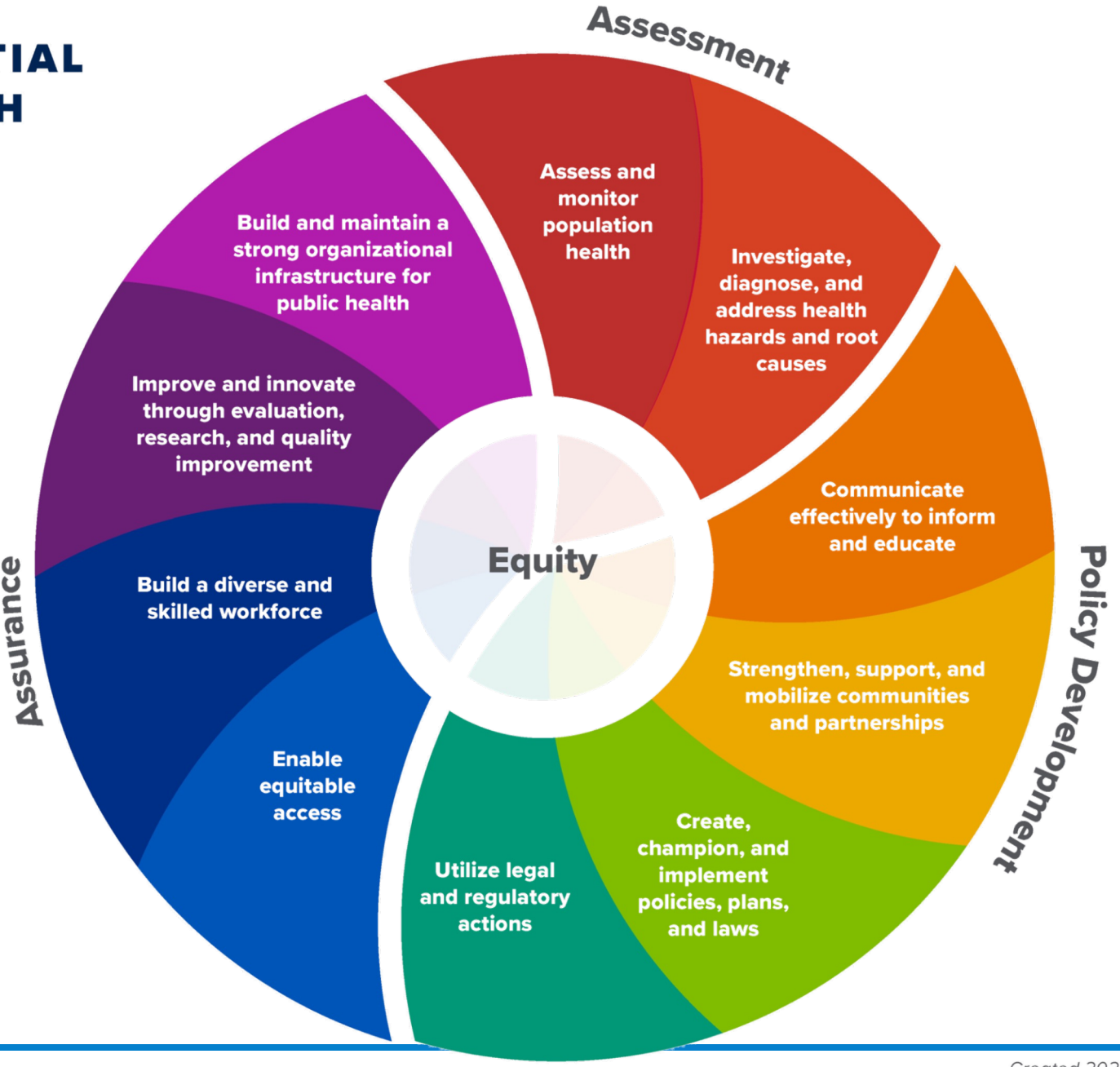
2022 nac
National Alliance for Caregiving

https://www.cdc.gov/aging/agingdata/docs/caregiver-brief-508.pdf

THE 10 ESSENTIAL PUBLIC HEALTH SERVICES

To protect and promote the health of all people in all communities

The 10 Essential Public Health Services provide a framework for public health to protect and promote the health of all people in all communities. To achieve optimal health for all, the Essential Public Health Services actively promote policies, systems, and services that enable good health and seek to remove obstacles and systemic and structural barriers, such as poverty, racism, gender discrimination, and other forms of oppression, that have resulted in health inequities. Everyone should have a fair and just opportunity to achieve good health and well-being.



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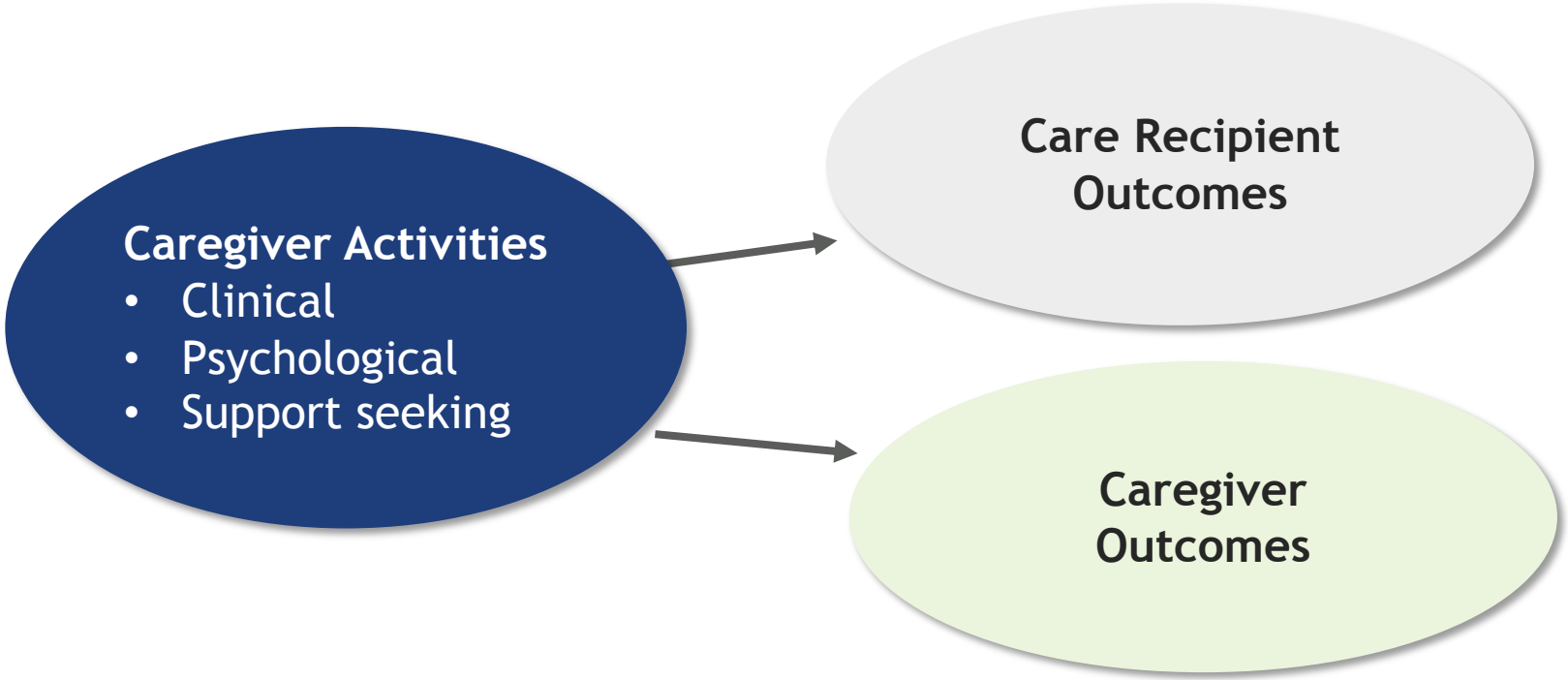
https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html

Identifying Caregivers

"Do you care for a family member or friend because of their ongoing health problems (for example, helping them get around the house, bathe, or pay bills)?"

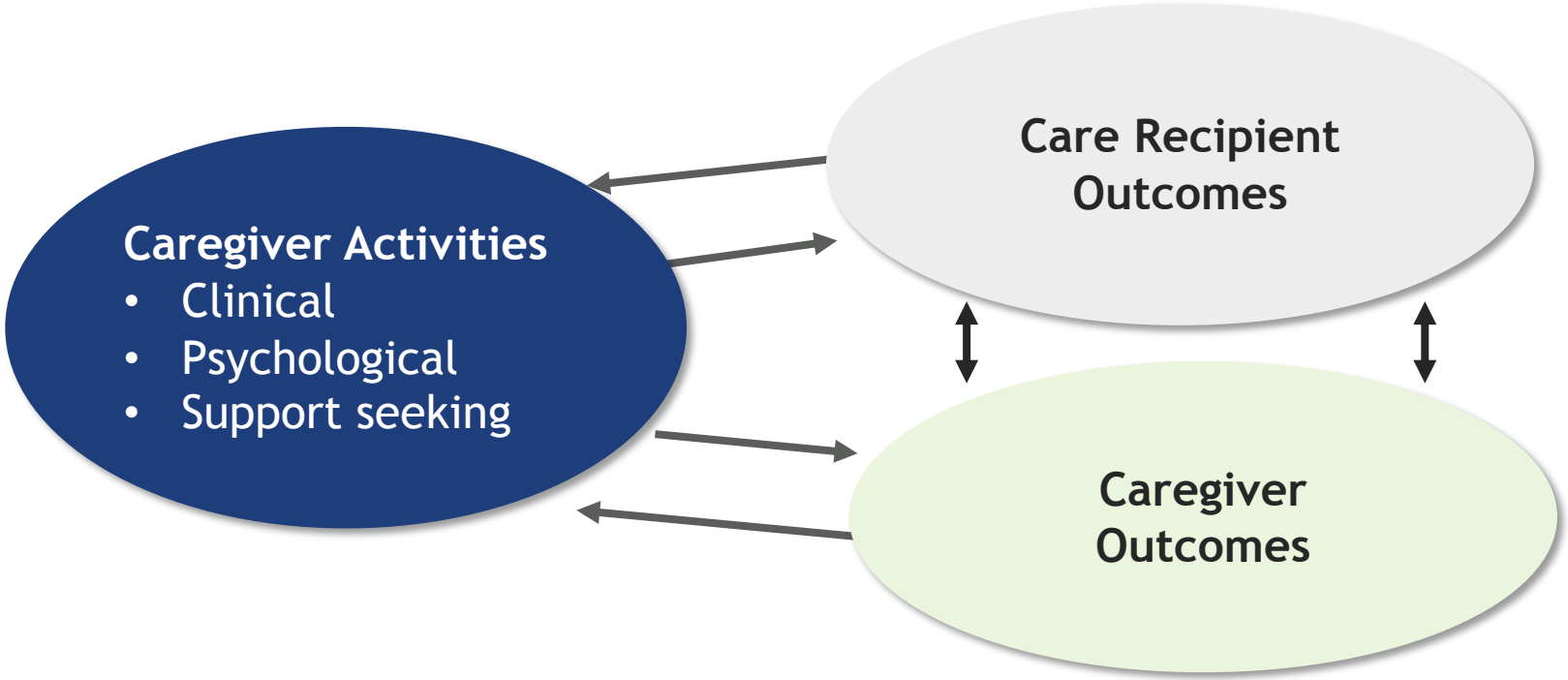
What do we know about the "causal" effects of caregiving on outcomes that public health initiatives could address?

Caregiving and (Un)intended Consequences



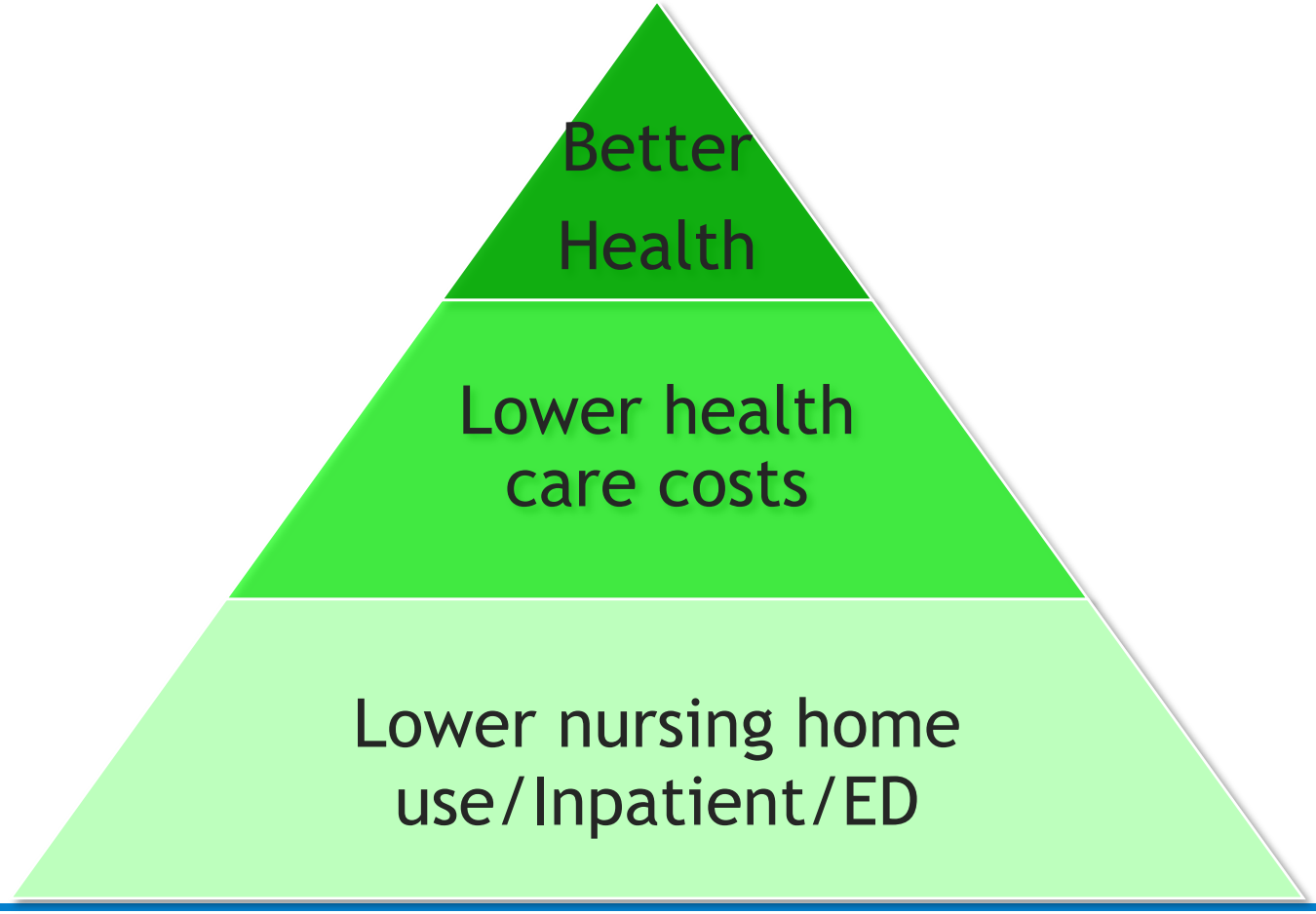
Adapted from Van Houtven, Voils, Weinberger, 2011

Caregiving and (Un)intended Consequences

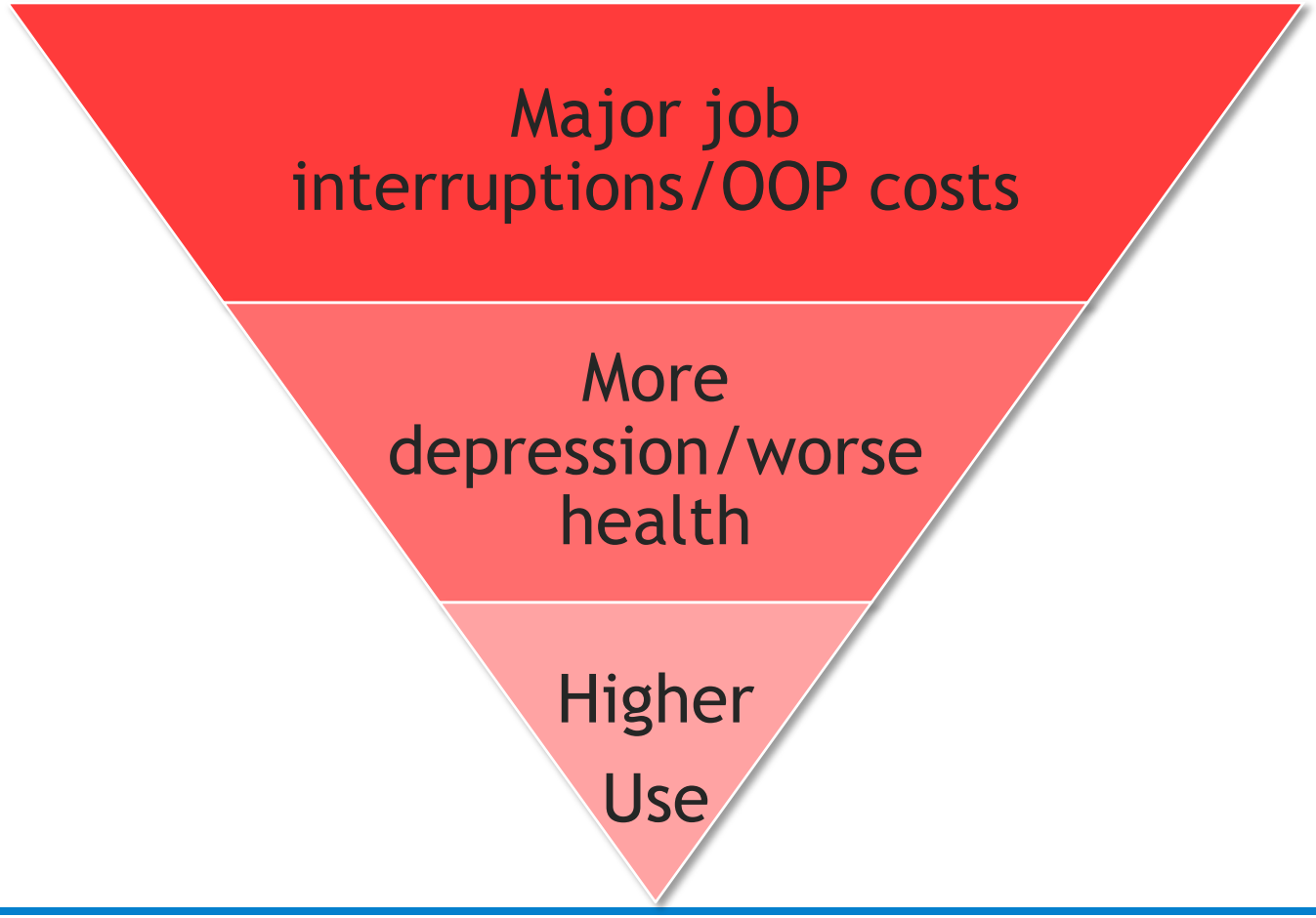


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Average Effects on Care Recipient Outcomes



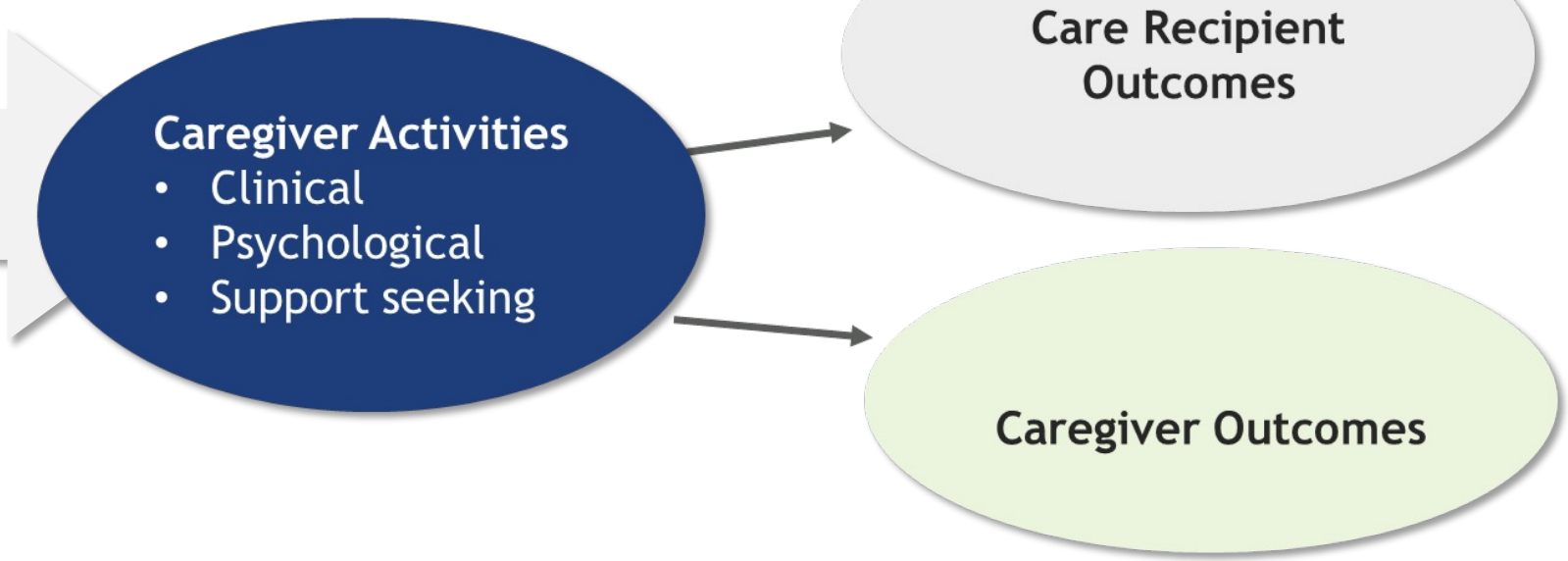
Average Effects on Caregiver Outcomes



Heterogeneity of Effects on Multiple Domains

Known <u>Risk Factors</u>

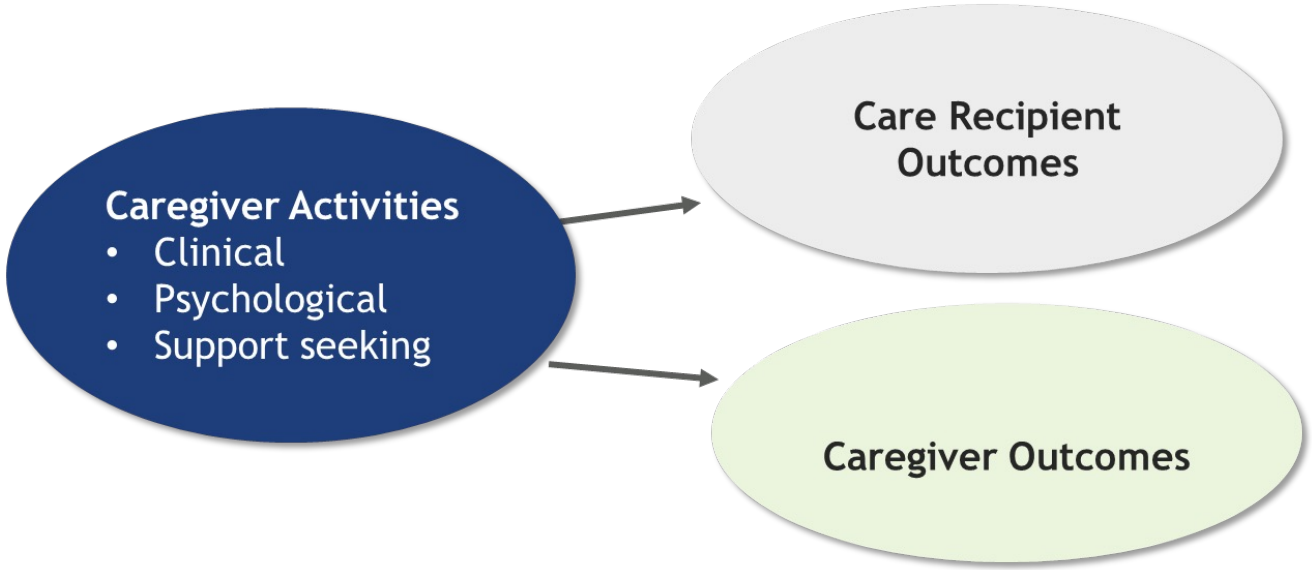
1. Intensity*/duration
2. SES/education
3. Health, esp. depression*
4. Race*
5. Structural Racism
6. Experiencing Bias*
7. ADRD*/Cancer*
8. Spouse/partners*
9. No other care in home*
10. Youth
11. Work* /paid/sick leave access
12. Rurality



Adapted from Van Houtven, Voils, Weinberger, 2011; Cohen, Ahmed, Brown, Meucci, Greaney, 2021; * signifies strong evidence base; Dionne-Odom et al, 2022

Caregiving and (Un)intended Consequences

- We now have extensive causal evidence on outcomes
- Heterogeneity of effects exist based on risk factors
- Interconnectedness
  - Health and wealth
  - Caregiver and care recipient outcomes



Adapted from Van Houtven, Voils, Weinberger, 2011

Today, caregiving is treated as a private health issue

Caregiver Supports the Exception Not the Rule

- Rare to receive adequate training to perform role
  - 7% CGs of older adults reported receiving training; 14% w/ recent hospitalization
  - 48% of CGs of Veterans w/ polytrauma reported any training
    - ~16% reported not needing training
- Rare to obtain supports and services
  - <10% of caregivers supported with direct programs
- Rare to be paid to be a family caregiver
- Rare to feel included as member of health care team

Burgdorf et al, 2019; Stevens et al, 2015; NASEM, 2019, Sperber et al, 2019; Bruening, et al, 2021

Caregivers Have No 'Caregiver Support System' to Navigate

- You get in a crisis or it comes on slowly and it is yours to deal with- finding resources finding community, finding support is extremely difficult
- Caregivers in my trainings and others nationally express feeling entirely alone

"It was so nice to know there are people like me, I thought I was the only one."

- (HI-FIVES 2014 participant)

"I do not have a sense that there is a team, somebody coordinating his condition, saying, "Okay, that's your primary care doctor, that's the neurologist .. I'm the person coordinating all this and you're the caregiver and we're all part of this team." I don't have that sense at all."

- (participant in PGCSS Evaluation 2018)

Burgdorf et al, 2019; Stevens et al, 2015; NASEM, 2019, Sperber et al; Bruening, et al, 2021

2020+ not public health's best time… difficult to imagine a world where caregiving is treated as a public health priority

THE MILBANK QUARTERLY
A MULTIDISCIPLINARY JOURNAL OF POPULATION HEALTH AND HEALTH POLICY

Original Scholarship

COVID-19: The Time for Collaboration Between Long-Term Services and Supports, Health Care Systems, and Public Health Is Now

WALTER D. DAWSON,[*,†,‡] NATHAN A. BOUCHER,[§,#,**,‖] ROBYN STONE,[††] and COURTNEY H. VAN HOUTVEN[#,**,‖]

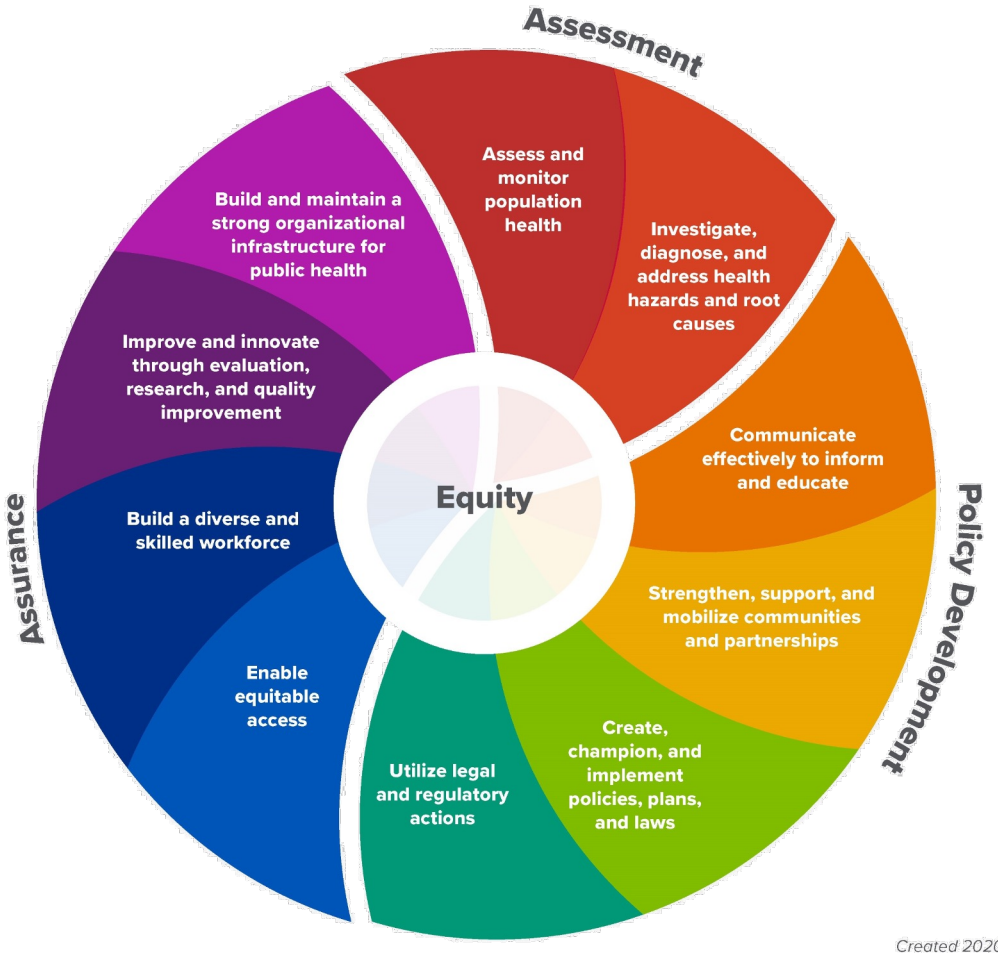
New Research: Pandemic Caregiver Well-being

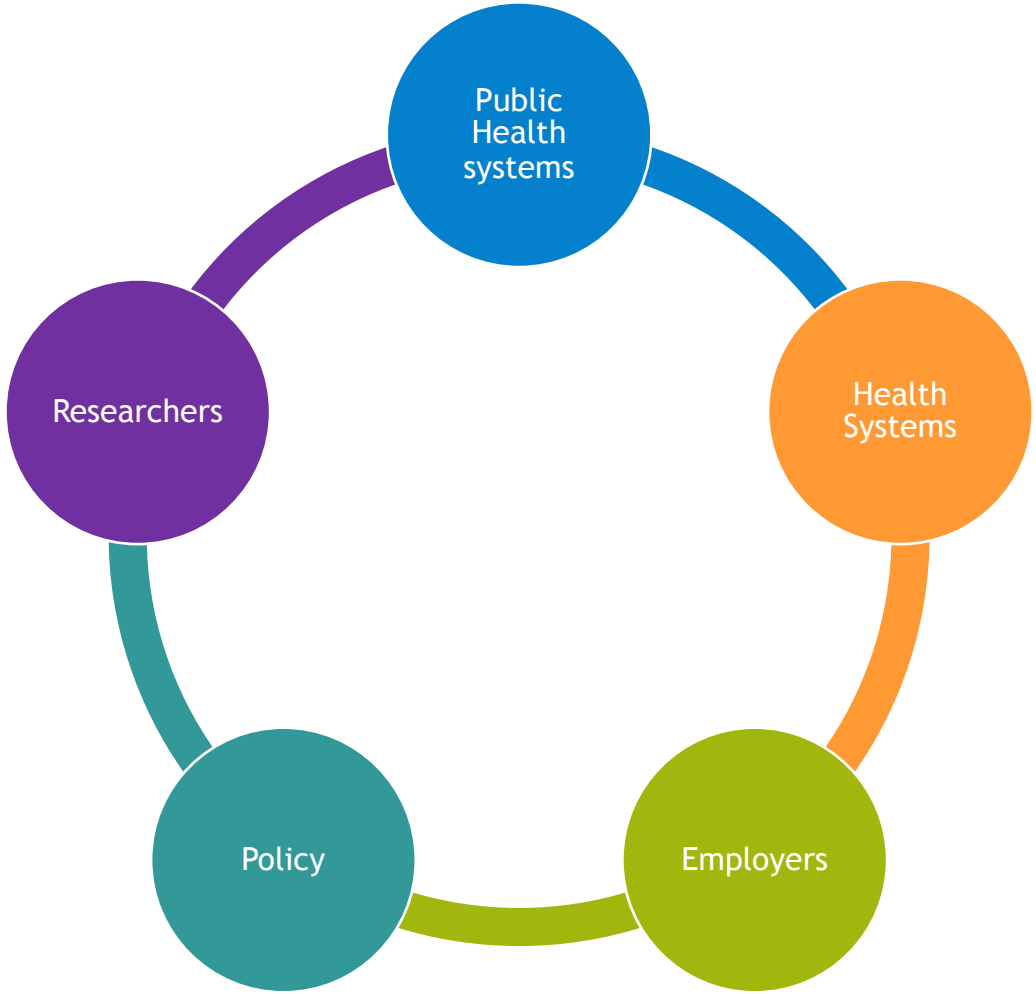
- Generally well-being much worse on average, and especially for Black, dementia, and intensive caregivers
  - “Such health disparities within the dementia-COVID-19-race nexus reflect structural racism and systemic issues facing communities of color” (Moon et al, 2022)
  - Inequitable impacts of caregiving exist and must be addressed
- Exception from VA where well-being improved but remained clinically poor.
  - VA shows rare exception of caregiving being treated as a public health priority. Services swerved to virtual. Caregivers not cut off from supports.

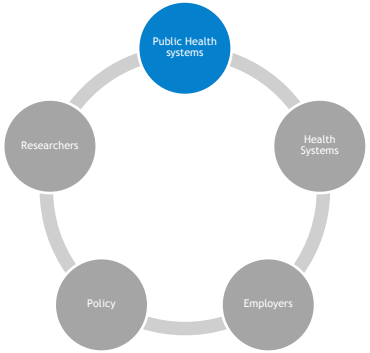
Alzheimer's Association, 2021; Garcia et al., 2020; Khazanchi et al., 2020; Truskinovsky et al, 2022; Cohen, Nash, Greaney, 2021; Longacre, Miller, Fang, 2021; Moon et al, 2022; Miller et al, 2022

A world where family caregiving was treated as a public health priority

If Caregiving Was Treated as Public Health Priority



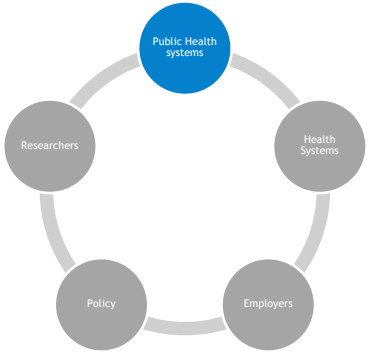




Public Health Solutions

- Increase funding
  - No appropriation with RAISE Act to implement the National Strategy
  - National Family Caregiver Support Program funding – $3 million/state
- Build the basic infrastructure to expand assessment
  - Screening, create registries, monitor risks through Area Agencies on Aging, collaborations with adult protective services
- Encourage consumer-directed programs that allow paying caregivers
  - Medicaid enrollment, Earned Income Tax Credit Program, tax credits, etc.

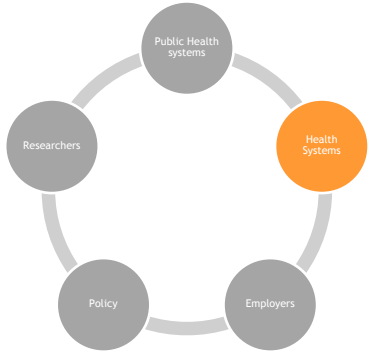
https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program



Public Health Solutions

- Target information to future caregivers most at-risk of bad outcomes:
  - Match to respite services and other government benefits
  - Black families will be most at-risk for economic calamities from caregiving
    - For every $1 of white family wealth, Black families have 12 cents

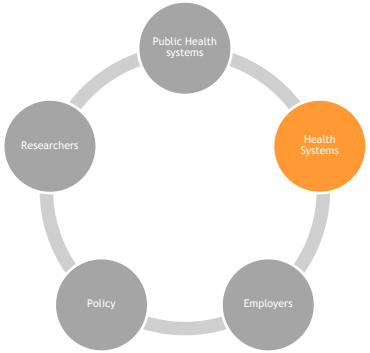
Sperber et al, 2017; Broyles et al, 2016; E South Dalembert Atheendar et al 2022



Health System Solutions

- Systematically identify caregivers for outreach during patient visits
  - Screen patients for caregiver status
  - Assess caregiver's ability to provide care
  - Monitor functioning over time
- Integrate caregivers in health care team
  - Caregivers engage in shared decision-making with patient and team
  - Caregivers need tools for what information is valuable to convey
  - Change the culture and reward inclusion

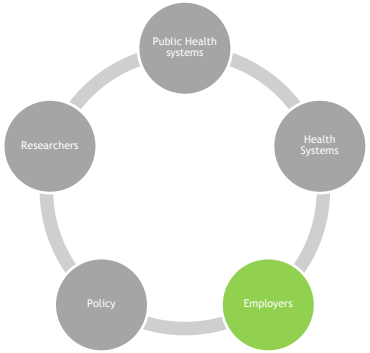
Ma et al, 2022; VH et al, 2022, Leykum et al, 2022; Gray et al, 2022; Leykum et al, 2022; Riffin, Wolf et al 2022; Van Houtven, forthcoming



Health System Solutions

- Expand caregiver training
  - Spread evidence-based trainings as a means of expanding support
- Improve and Innovate such as by expanding “joyful” supports
  - VA piloting art therapy, dance, Tai Chi, yoga for caregivers
  - Tailored treatment plans for caregivers

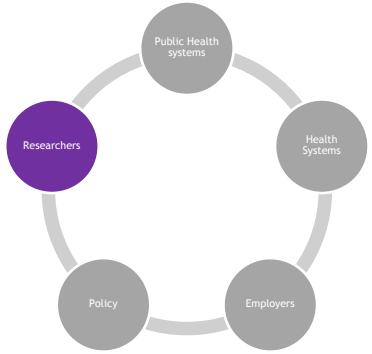
https://nam.edu/families-caring-for-an-aging-america/; Jen Henius Yogaforcaregivers



Employer Solutions

- Increase supports for caregivers to remain working and caregiving
  - Paid sick and family leave
  - Flexible work (e.g., job sharing, telework)
  - Employee assistance and geriatric care management resources
  - Employer-provided insurance plans that cover long-term care for employees and dependents

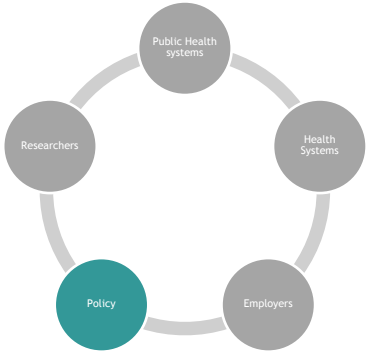
Wolff, Drabo, Van Houtven, 2018



Research Solutions

- Look beyond average effects
  - We need causal estimates of effects for low wage workers; Black workers; immigrant workers; and how intensity affects all of these groups
  - We need interventions specifically targeting those at highest risk
- Use Implementation science to spread promising practices
  - Cultural appropriateness and context should frame intervention design; employ user-centered design and evaluate as you go to make sure program has ‘fit for purpose’ and communicate back findings so caregivers know what a program can and can’t do; prepare toolkits and grab and go curriculum

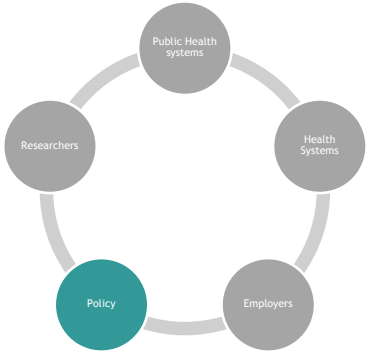
Sperber et al, Gerontologist, 2022



Policy Solutions

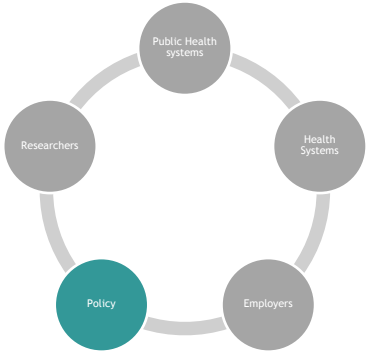
- Provide universal coverage for long-term services and supports
  - This would enable choice in type of home care
  - Comprehensive public coverage would free up adult children who are most at-risk of bad economic outcomes to participate in the economy or have lesser intensity of CG
- Zero momentum exists for universal LTSS benefit in US so attention turning to caregiver supports
  - Bipartisan, more palatable, but it is important to pause and ask if this is optimal

Sperber et al, 2017; Brown, Goda, McGarry, 2014; Coe, Goda, VH, forthcoming



Policy Solutions

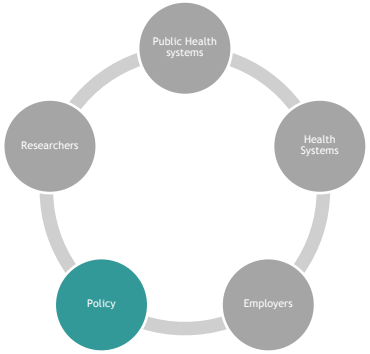
- Expand funding for RAISE national caregiver strategy implementation
- Cover caregiving with Federal Paid Family Leave
- Coordinate across federal agencies for unified plan
- Create caregiver benefits
  - Stipends and/or Social Security Credits and could be targeted to Earned Income Tax Credit eligible (‘caregiving’=work)
  - Caregiver education benefits, scholarships, student loan forgiveness



Policy Solutions

- More on payments to caregivers…
- RAISE report goal: "…decrease the negative financial impacts for caregivers on both a short-[25] and long-term basis"
  - 1600 individuals responded to the *Request for Information* in the Federal Register, many expressed paying caregivers was a vital and necessary policy to meet a need for "lifetime financial and employment security to be protected and enhanced"
  - Tradeoffs exist between paying caregivers and expanding home and community-based services

Nadash, 2022; RAISE Act initial report to Congress, 2021



Policy Solutions

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Nadash, 2022; RAISE Act initial report to Congress, 2021

How should evidence-based caregiver policy be fashioned? Based on the evidence

Emerging Evidence of Caregiver Policy Effects

Average Effects of One Caregiver Policy:
Veterans Affairs Program of Comprehensive Assistance for Family Caregivers

-stipend
-counseling
-trainings
-health insurance
-respite
-travel benefits



Care Recipient Outcomes
-no change ED, inpatient
-increases outpatient primary and MH care
-increases costs

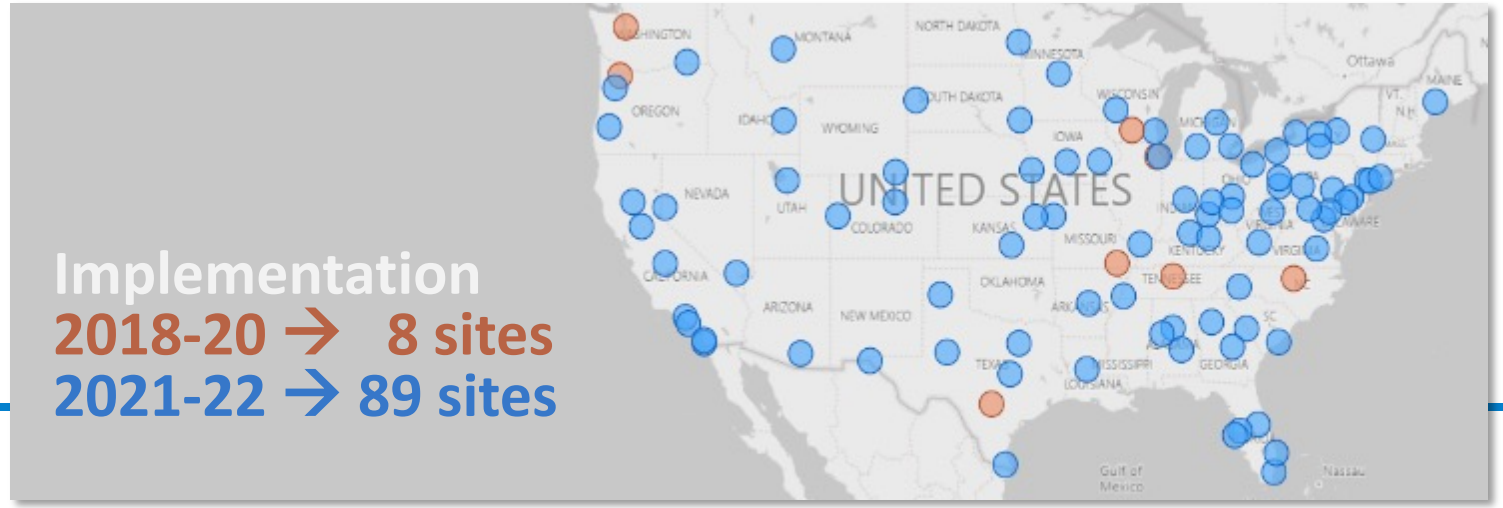
Caregiver Outcomes
-reduces financial strain
-no change in depression but worse for non-participants

Adapted from Van Houtven, Voils, Weinberger, 2011; van Houtven et al, 2018, 2021; Smith et al, 2018; Miller et al, 2022

VA is taking a public health approach to supporting caregivers. Other entities can adapt/use some of VA's strategies now in absence of major reforms.

Research/Operations Partnerships Can Scale Up Caregiver Supports Now

- Using Replicating Effective Programs implementation strategy which balances fidelity and need for sites to tailor to local conditions
- Expanding training nationally to all 150 VA hospitals (so far, 97 total hospitals implementing)
  - To date, approximately 1800 caregivers trained
  - Adapting curriculum for Homemaker Home Health Aides (Franzosa, CDA)

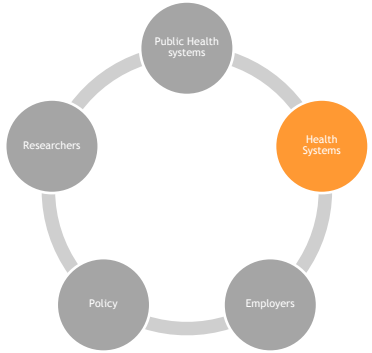


Interprofessional Health Care Teams Can Change the Culture around Caregivers Now

- Screen for whether patients have a caregiver and document it in EHR
- Ask caregivers if they understand the treatment plan, can manage their tasks at home, if their role meets their preferences, about financial strain
- Match resources with caregivers at most risk (e.g., Black, intensive, ADRD CGs)
- Complete VA Academy for Inclusive Care Training to systematize approaches to include caregiver expertise



Van Houtven et al, CAPACITY, 2017; 2020; Ma et al, 2022; Van Houtven et al, 2022
EDF website https://campaignforinclusivecare.elizabethdolefoundation.org/academy-for-inclusive-care/



REMEMBER, CARE

CONSIDER

Consider who else needs to be present. Ask the Veteran "Is there someone you would like in the room during your visit?" "Is there someone who you rely on for support that you would like to have here as part of this conversation about planning your care?" or "Is there someone who helps you with your everyday medical needs?" Do not assume the Veteran can handle their medical care by themselves. Ask them directly to ensure clarity.

ACKNOWLEDGE

Recognize that the Veteran's caregiver has taken on extra work, and that it will impact their wellness. Empathetic remarks such as "I imagine it's a big responsibility to care for your loved one" and" I appreciate your dedication to their health" can go a long way to establish rapport.

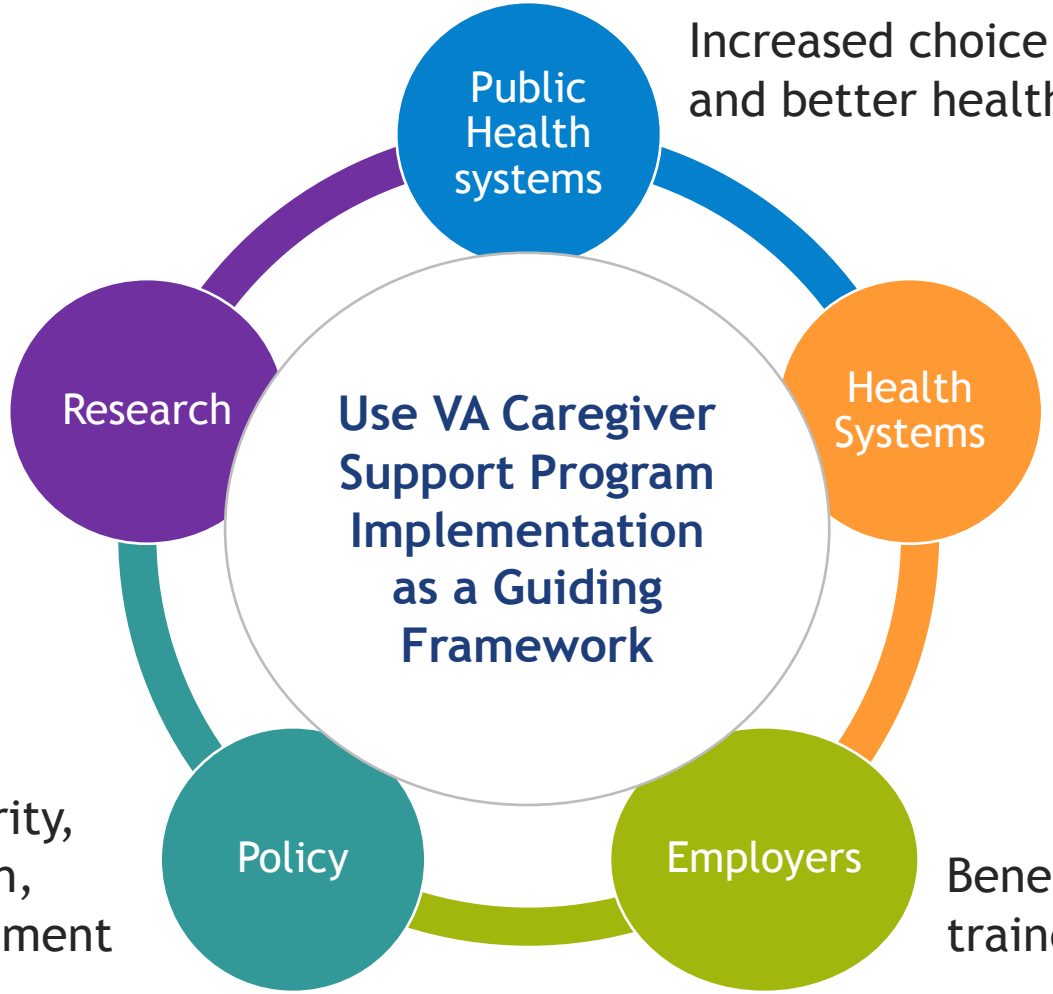
REVIEW ROLE

Determine the responsibilities that the caregiver is comfortable with. Questions for the caregiver can include "what tasks are easy for you to perform?" and "are there any duties that cause you to feel uneasy while you are performing them?" Early identification of what the caregiver can and can't do will help ensure that the Veteran achieves their highest possible level of health and well-being.

ENCOURAGE

Find out any barriers that exist and how you can help overcome them to make the caregiver's responsibilities easier. Simple questions such as "how can I help with your at-home responsibilities for the Veteran?" and "what would make taking care of your Veteran simpler?" If you believe the caregiver could benefit from additional supports, refer to the Caregiver Support Program at your facility and encourage the caregiver to use the free Caregiver Support Line: 1-855-260-3274.

A World Where Caregiving is a Public Health Priority



Increased choice and supports, and better health outcome

Identification and inclusion, assessment and monitoring

Benefits to help retain valuable, trained workers. Women protected

Reduce economic insecurity, improve long-term health, coordinate across government

Research beyond average effects, use implementation science to expand supports

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Questions and Discussion

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