

THEME 2

Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons with Dementia and their Caregivers

This theme includes issues related to the organization, financing, and delivery of long-term services and supports (LTSS) in the home and community and in residential settings, such as assisted living and nursing homes. Issues related to the formal care and provider workforce, services provided by community-based organizations, payment and financing, industry, and caregiver needs will be addressed.



Sheryl Zimmerman, PhD
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Co-Director, Program on Aging,
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LeadingAge

OVERVIEW

Presentations by National Experts

Research Gaps and Opportunities

Panelist Perspectives

Question and Answer

Presentations

Evidence-based person-centered practices for persons living with dementia and their caregivers: What do we know, where to next?

Kimberly VanHaitsma, PhD, FGSA, Associate Professor and Director, Program for Person Centered Living Systems of Care
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Adjunct Senior Research Scientist, Polisher Research Institute, Abramson Senior Care

Understanding the long-term care workforce in a new way

Joanne Spetz, PhD, FAAN
Director, UCSF Health Workforce Research Center on Long-Term Care
Professor, Philip R. Lee Institute for Health Policy Studies, University of California, San Francisco

Organization and financing of long-term services and supports for persons living with dementia

David Stevenson, PhD
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Panelists

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Evidence-based Person-centered Practices for Persons
Living with Dementia and Their Care Partners:
WHAT DO WE KNOW, WHERE TO NEXT?

Kimberly VanHaitisma, PhD

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Polisher Research Institute, Abramson Senior Care

March 24-25, 2020

Disclosures

- Dr. VanHaitsma has no financial conflicts of interest to report.

Objectives



What do we know about evidence-based approaches for **persons living with dementia (PLWD)** and their **care partners**?



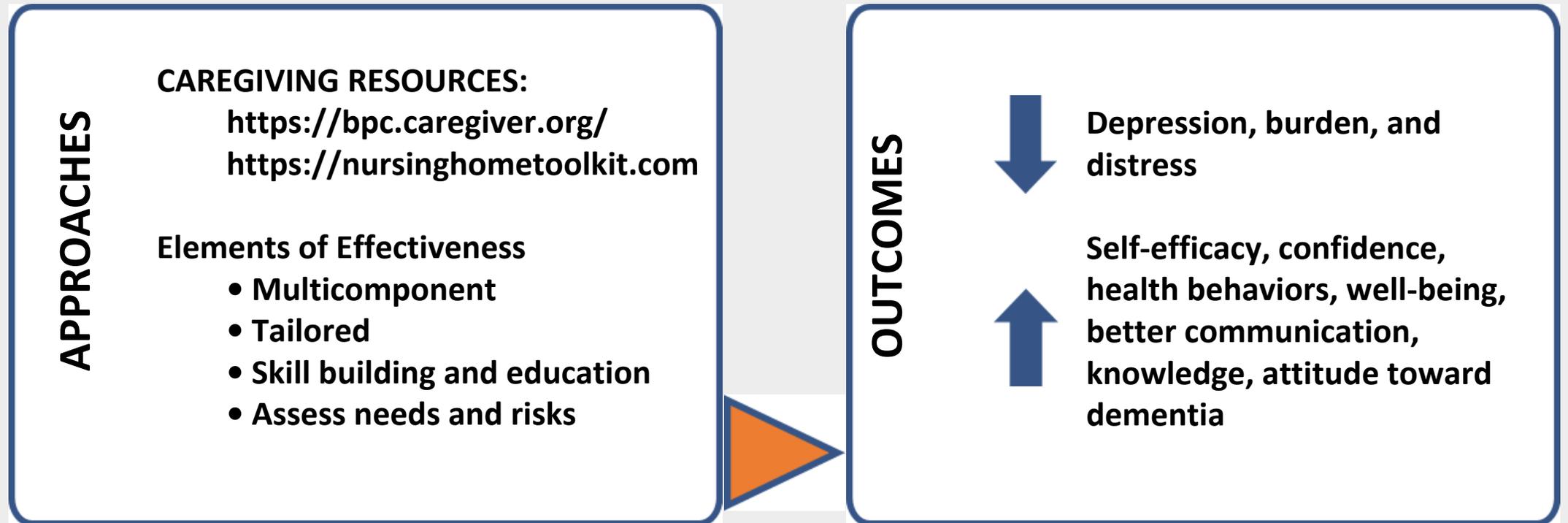
What don't we know that we should?



What are promising opportunities for further research?

This talk addresses the cross-cutting theme of *perspectives of PLWDs and their care partners*

Promising Evidence-based approaches for family care partners & staff care providers



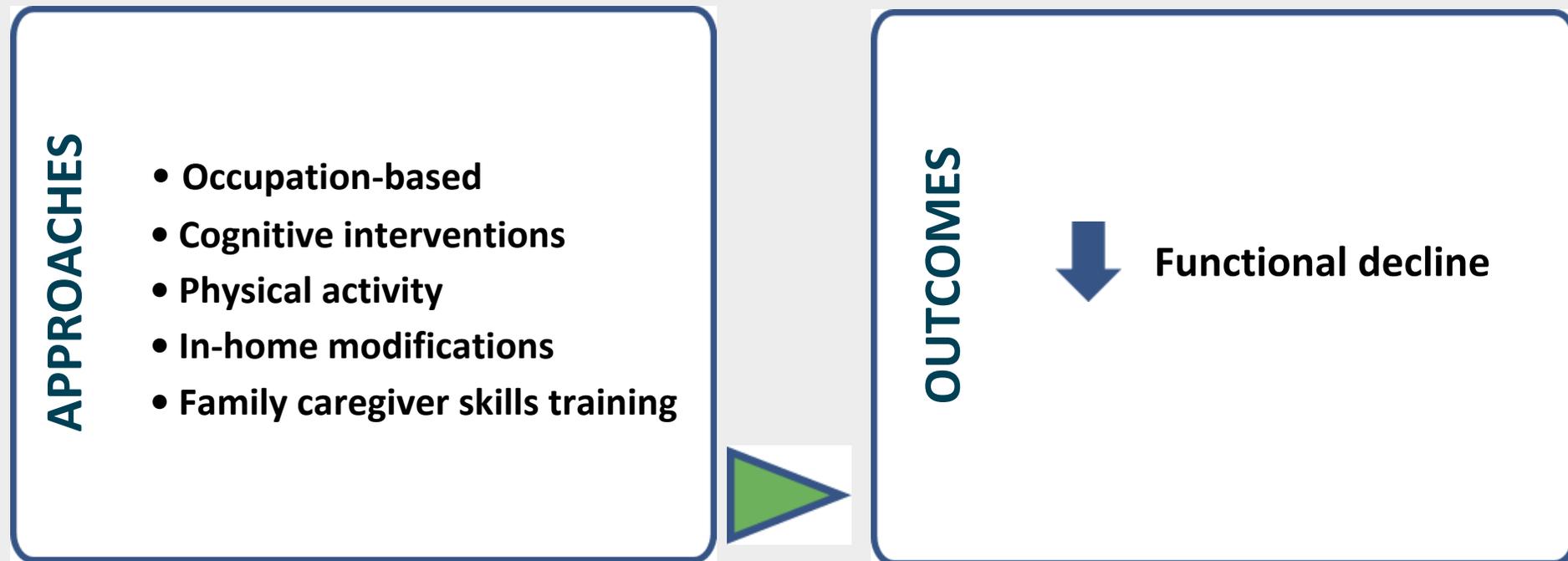
Promising Evidence-based approaches for PLWD

Target of Approach: COGNITIVE DECLINE



Promising Evidence-based approaches for PLWD (cont.)

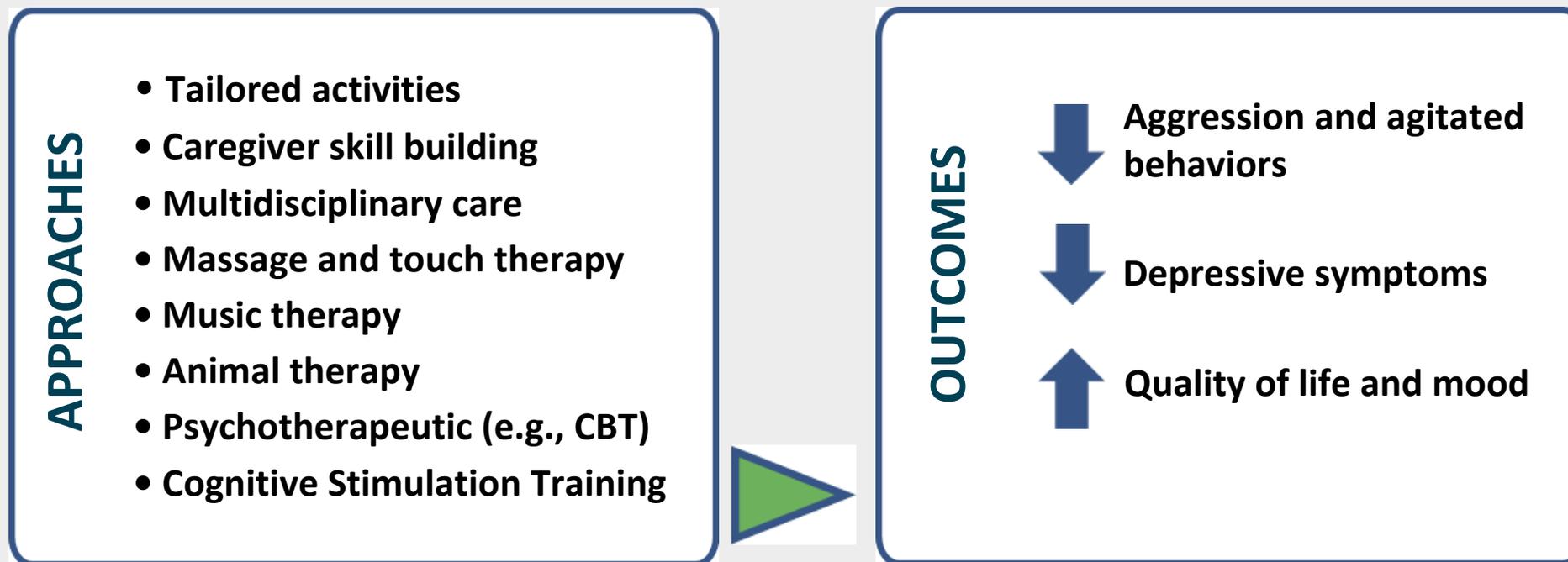
Target of Approach: FUNCTIONAL DECLINE



[Gaugler, Jutkowski, & Gitlin (2020)]

Promising Evidence-based approaches for PLWD (cont.)

Target of Approach: BEHAVIORAL EXPRESSIONS



Remaining questions about Evidence-based approaches for PLWD AND CARE PARTNERS

1

Research rigor

2

Pragmatic dissemination and implementation lacking

3

Address social determinants of health

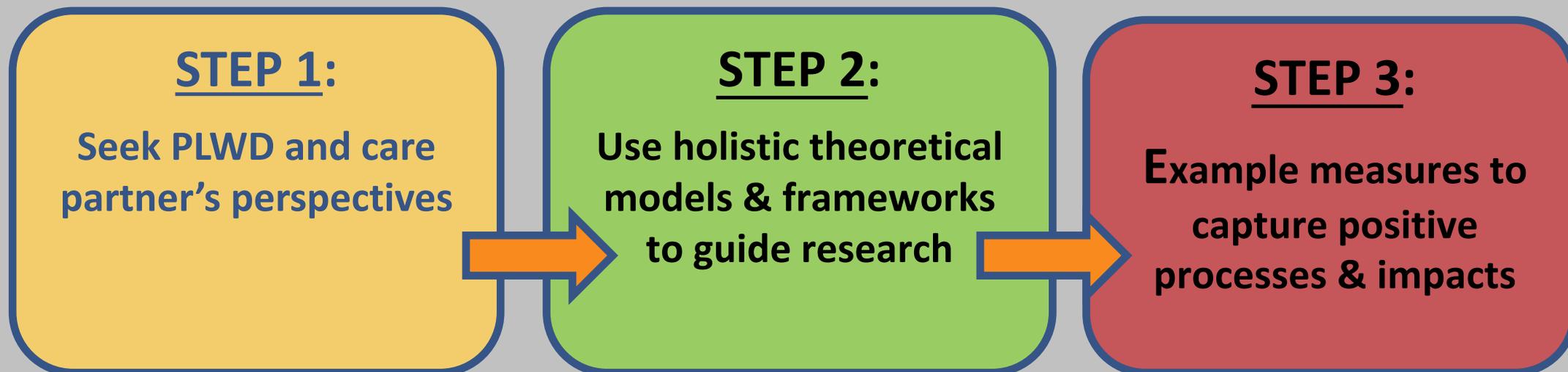
4

Outcomes deficit focused, need positive outcomes

Where do we go next: What outcomes should we be targeting?

“IF YOU DON’T KNOW WHERE YOU ARE GOING, ANY ROAD WILL GET YOU THERE.”

- Lewis Carroll



Step 1: What Outcomes Matter to PLWD & their care partners?

Outcomes related
TO IMPACT

How do we think about what a successful impact of an evidence-based approach would look like from the perspective of the PLWD and care partners?

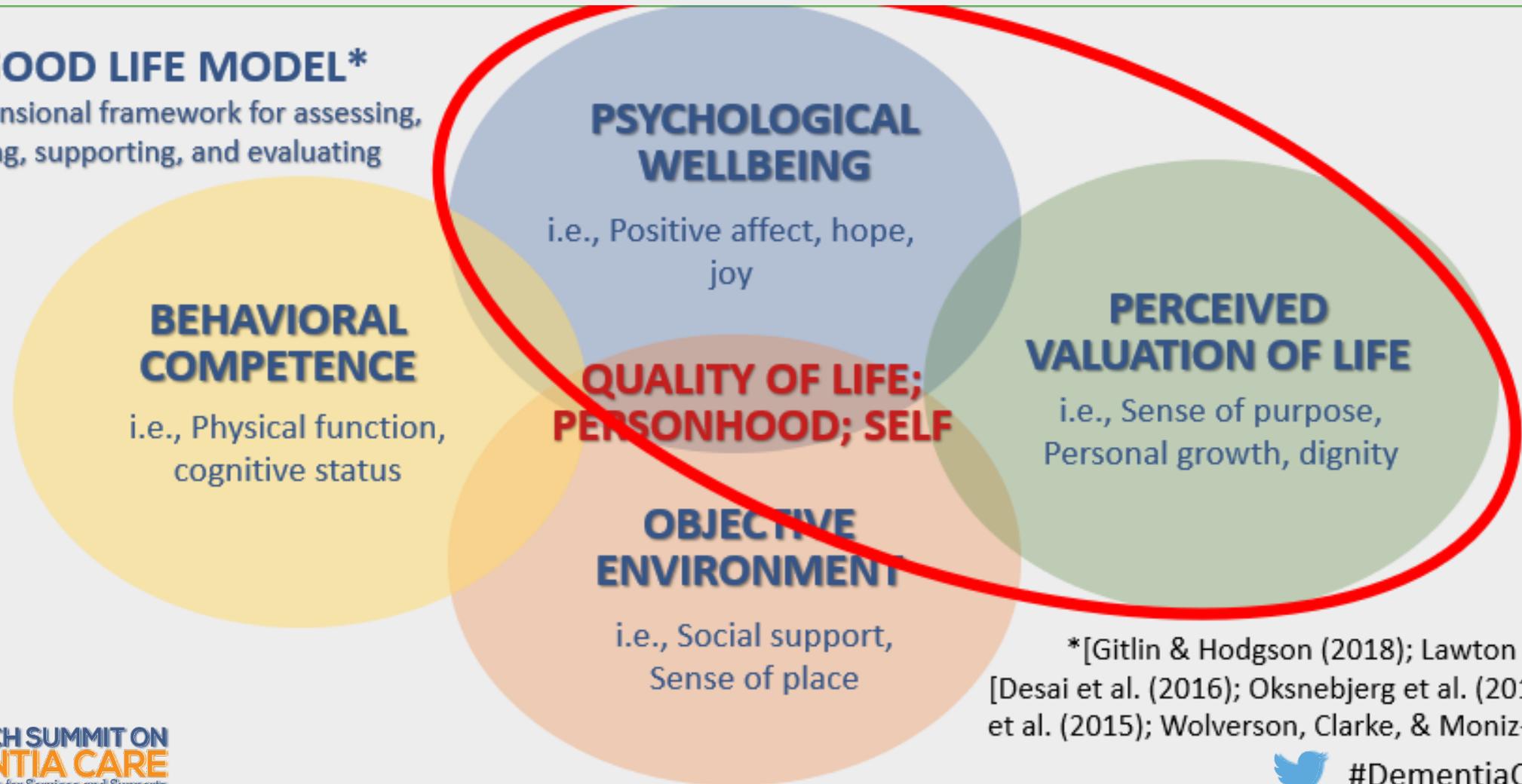
Outcomes related
TO CARE DELIVERY
& PROCESSES

How do we think about what elements of care delivery are important from the perspective of the PLWD and care partners?

Step 2: Models to Guide Outcome Impact Development: How do we define success?

THE GOOD LIFE MODEL*

A multi-dimensional framework for assessing, intervening, supporting, and evaluating



*[Gitlin & Hodgson (2018); Lawton (1983)]
[Desai et al. (2016); Oksnebjerg et al. (2018); O'Rourke et al. (2015); Wolverson, Clarke, & Moniz-Cook (2016)]



#DementiaCareSummit

Step 2: Frameworks to guide alignment of care processes with care impact: How do we define optimal dementia care?

2018 DEMENTIA CARE PRACTICE RECOMMENDATIONS



Figure 1. Dementia Care Practice Recommendations.



Step 3: Example Outcome Measures to Consider

Self-reported Impact

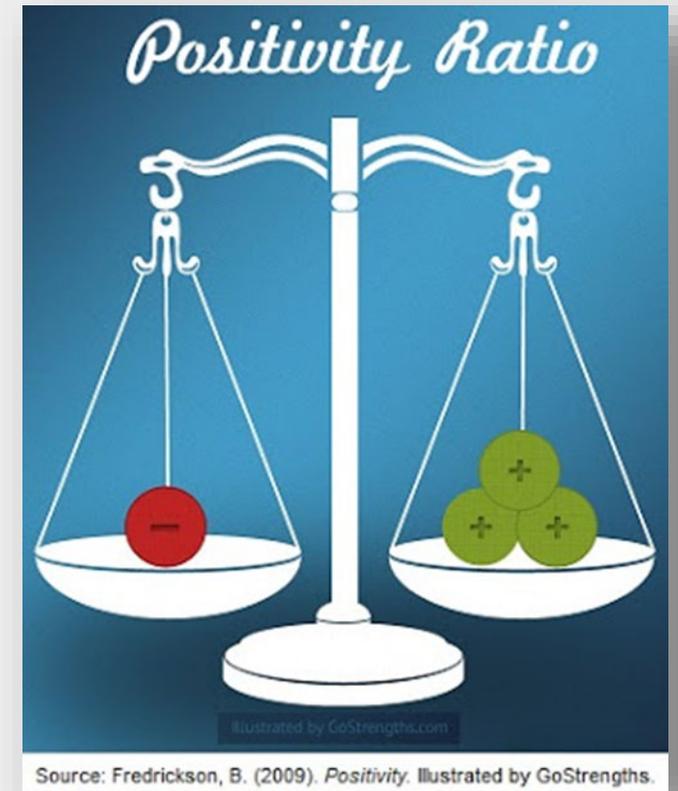
- Positive Psychology Outcome Measures¹
- Goal Attainment Scaling²

Observation of Impact

- Affect Balance^{3,4,5}

Process of Care

- Preference Congruence^{6,7}



[Stoner et al. (2019)¹; Jennings et al. (2018)²; Fredrickson (1998)³;
Kolanowski et al. (2014)⁴; Meeks et al. (2012)⁵; Van Haitsma et al. (2014)⁶;
Van Haitsma et al. (2016)⁷]

Conclusions



- Body of evidence-based practices is growing, but room for improvement in rigor
- A focus on rigorous pragmatic dissemination and implementation approaches are needed
- Prioritize process and impact outcome domains that matter to the PLWD and their care partners using models/frameworks to ensure a holistic array of outcomes

THANK YOU!

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Joanne Spetz, PhD, FAAN

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**Professor, Philip R. Lee Institute
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**Understanding the
long-term services &
supports workforce in a new
way**

Joanne Spetz, PhD

Philip R. Lee Institute for Health Policy Studies

University of California, San Francisco

March 24, 2020

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This presentation is relevant to several themes...

- Technology
- Health disparities
- Perspectives of persons living with dementia and/or caregivers

Who provides care for people living with dementia?

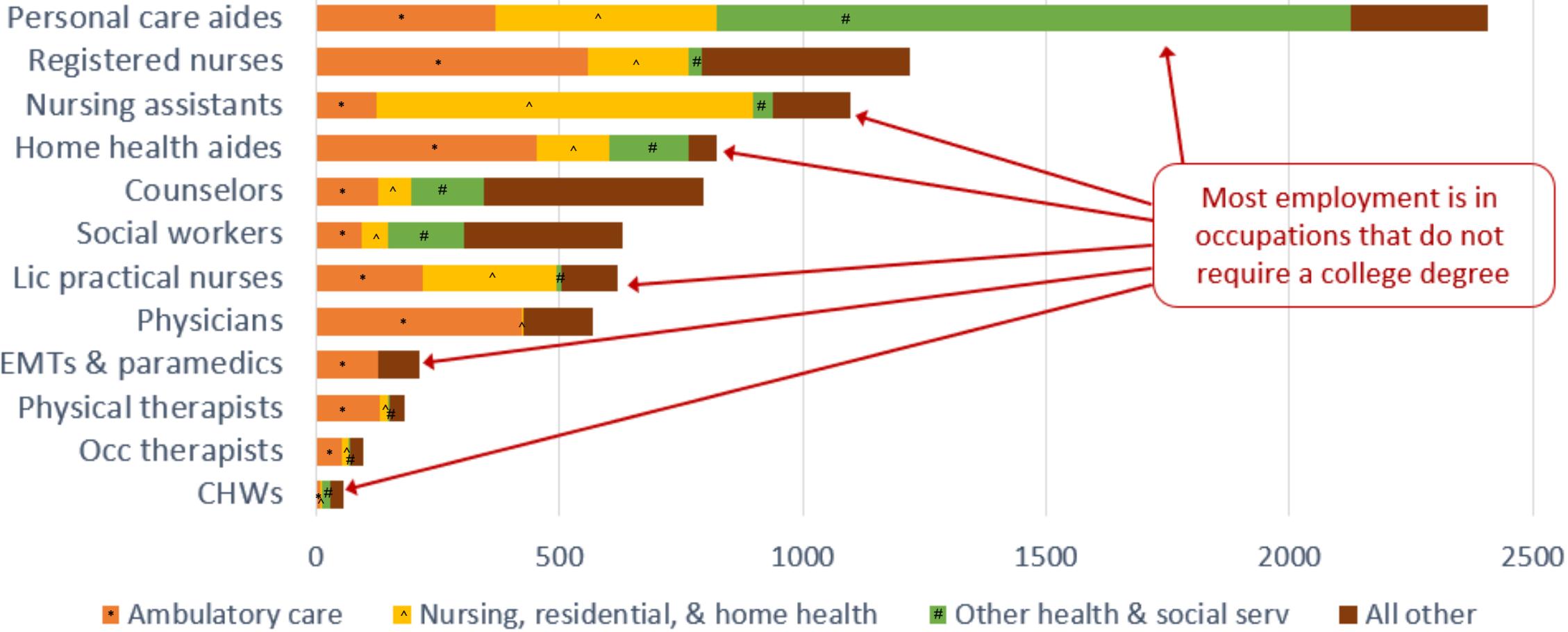
- Personal care aides and home health aides
- Community health workers / navigators
- Home health nurses
- Certified nursing assistants
- Community paramedics
- Social workers
- Spiritual care providers
- Peer providers
- Family caregivers



...and physicians, nurses, pharmacists, physical/occ therapists...

How many people hold these jobs?

Employment (in thousands)



Most employment is in occupations that do not require a college degree

Source: U.S. Bureau of Labor Statistics, industry-occupation matrix, 2018

We know little about the impact of training of direct care workers

- Does training impact client outcomes?
 - Health (physical and behavioral)
 - Quality of life
 - Social engagement
- Does training of direct care workers impact the family?
- Does training of direct care workers impact health care team effectiveness?
- Does training lead to cost savings?



National evaluation of CMS Innovation Awards: California, Arkansas, & South Carolina

- 3 Innovation Awards focused on training home care aides
 - Identification of emergent conditions
 - Management of chronic conditions
 - Integration into the larger health care team
- Workers reported high satisfaction with training, that they learned skills and increased knowledge, and felt more prepared or confident to perform their job
- Care recipients & informal caregivers reported better quality of care
- Outcomes analysis was limited to 16-26% of participants
 - CA: decrease of 44 emergency department visits per 1000, \$1,522 cost savings per beneficiary in 2nd year
 - SC: no cost savings

We know little about the impact of different policies regarding direct care worker training

- Tremendous variation across state Medicaid programs
 - 10 had no training requirements in 2014
 - 19 had uniform requirements across Medicaid programs
 - Are there differences in outcomes across states?
- Centers for Medicare & Medicaid Services has developed core competencies for home health aides
 - No evaluation of which competencies are essential

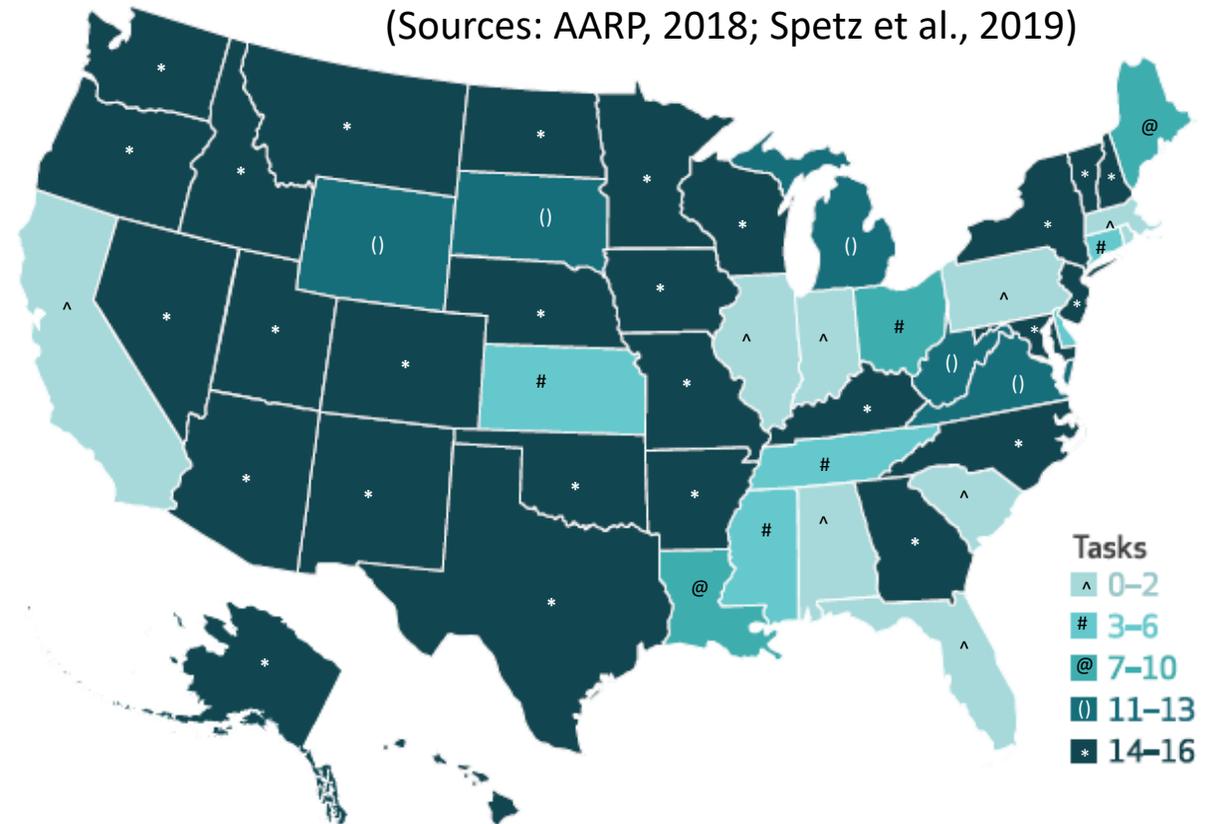


We know little about how variation in scope of practice for direct care workers affects outcomes

- Do restrictions on delegation improve or worsen client outcomes?
 - How do they impact families?
- What education and oversight is needed to safely expand delegation?
 - Education of direct care workers & those delegating

Number of tasks that can be delegated to home care aides

(Sources: AARP, 2018; Spetz et al., 2019)



We know little about how to advance interprofessional person-centered care teams

- Shortages of geriatricians, gerontologists, gero-psychiatrists...
- New job classifications like Dementia Care Specialists can play important roles
- What payment structures will support team-based care?
- What implementation and sustainability approaches are effective?
- How do we ensure teams are person-centered?
- There may be more than one “best practice”



We know little about how emerging technologies might best improve care

- New technologies emerging in many domains
- Little attention to workforce interactions or implications
- Development often is in a vacuum without rich community input



Source: UCSF Health Workforce Research Center on Long-Term Care (July 2019)

We know little about how to leverage diversity to advance person-centered care

- There are some promising culturally-focused programs for care for people living with dementia
 - For example, Stanford's iSAGE program
- There is growing evidence that education for clinicians in patient-centered community is highly impactful
 - For example, VitalTalk
- We have a long way to go

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Organization and financing of long-term services and supports for people living with dementia (PLWD)

David Stevenson

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March 24, 2020

Disclosures

- Dr. Stevenson has no relevant financial disclosures to report.

Overview

- Background context
 - Dementia prevalence and the role of long-term services and supports
 - Costs of care
 - Care fragmentation and end-of-life care
- Key policy challenges and evidence gaps
 - Financing gaps
 - Delivery system reforms
 - Quality assurance and development of quality measures

Understanding the policy challenge

- To develop a comprehensive policy approach, need a clear understanding of the needs of PLWD and their families
- Key initial hurdle relates to diagnosis
 - Many PLWD remain undiagnosed, especially in the community
 - New Medicare CPT code for comprehensive assessment and planning for PLWD could help but has been underutilized to date
- Administrative data (e.g., from claims) can help but with important caveats
- Surveys have played key roles in advancing knowledge
 - National Health and Aging Trends Survey, Health and Retirement Survey, and National Survey of Residential Care Facilities
- Capturing care from family and other unpaid care partners is an especially important challenge

Dementia prevalence and the key role of long-term services and supports

- Almost 6 million PLWD in the United States
 - Most are older and live at home or in other community-based settings
- Most have limitations in self-care, mobility, and household activities
- Nearly all receive *some* help, but two-thirds get care from family and unpaid care partners only
- Dementia prevalence especially high in assisted living facilities and nursing homes
 - Almost half of residents estimated to have dementia and most have some cognitive impairment

Dementia costs substantial, especially for long-term services and supports

- Total dementia costs estimated to be \$290 billion in 2019
 - Per person costs around \$50K annually and \$350K over lifetime
- Vast majority of these costs are for supportive services as opposed to medical costs
 - Largely an uncovered risk – families incur most of the cost burden
- Medicare and Medicaid programs are central
 - Medicare covers 95% of all people with dementia
 - Medicaid covers 25% of people with dementia in the community and around 70% of people with dementia in nursing homes
- Value/cost of care from family and unpaid care partners is substantial

Dementia care fragmented across payers and settings

Service needs for PLWD currently fragmented by:

- Payer/benefit type:
 - acute and post-acute (Medicare inpatient, skilled nursing facility, and home health)
 - end-of-life (Medicare hospice)
 - long-term services and supports (Medicaid/out-of-pocket)
- Provider type/setting:
 - Hospitals, nursing homes, home health, assisted living, and hospice
- Paid and unpaid services

→ Implications are higher costs and worse outcomes

- Lack of continuity in dementia care associated with more hospitalizations and emergency department use, unnecessary procedures, and higher costs

End-of-life care shaped by nursing homes and the Medicare hospice benefit

- PLWD more likely to die in nursing homes
 - 1-in-4 Americans die in nursing homes → ***around 7-in-10 of those with advanced dementia***
- End-of-life care for PLWD often poor quality
 - Aggressive practices like tube-feeding, burdensome transitions, intravenous therapies, and restraint use
- Hospice use has increased over past few decades
 - Dementia is among the most common hospice diagnoses overall
- Hospice use has improved end-of-life care broadly but with some fiscal concerns

Overview

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- Key policy challenges and evidence gaps
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 - Delivery system reforms
 - Quality assurance and development of quality measures

Inadequate coverage for long-term services and supports

- No universal coverage
- Few people purchase private insurance
 - Roughly 10% among people 65+ (few new policies purchased)
 - Efforts to expand have largely faltered
- Implications of coverage gap especially severe for PLWD
 - Reliance on family and unpaid care, out-of-pocket payments, and Medicaid
- Some bipartisan discussions of national coverage, in addition to being included in some Medicare-for-All plans
- State efforts may hold greater promise for now
 - Washington is most notable example - just underway
 - Payroll-tax funded, \$100/day up to 100 days (starting in 2025)

System Redesign: rebalancing

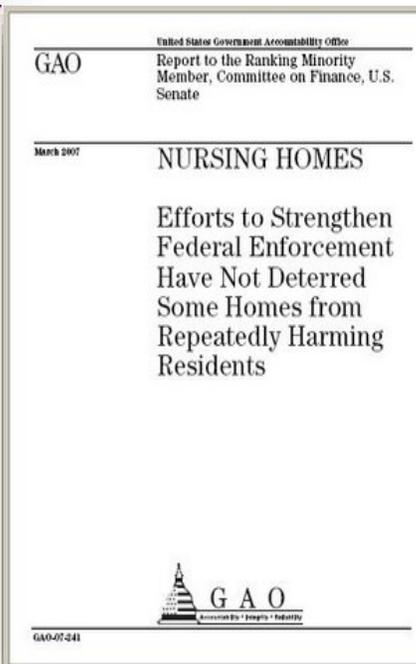
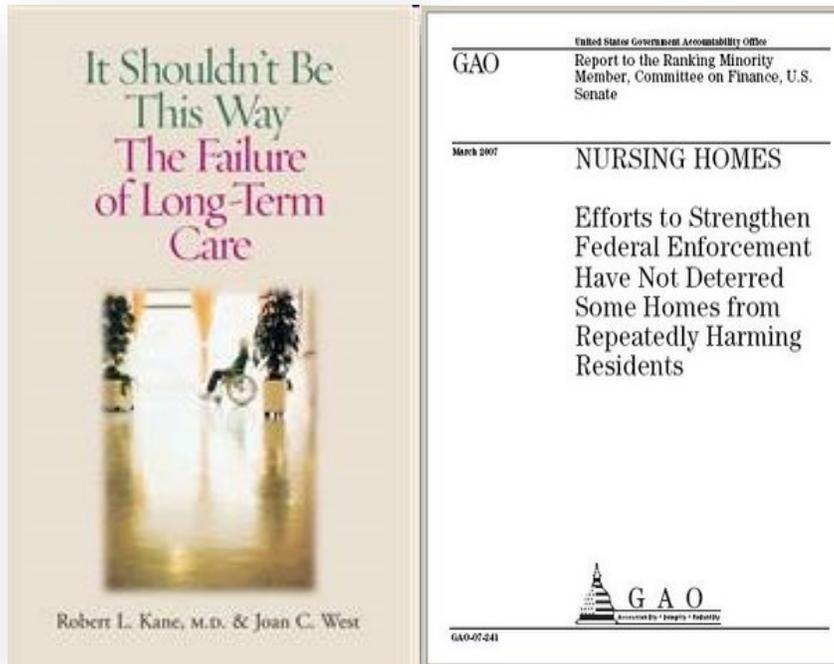
- Long-term services and supports system historically dominated by nursing homes
- Primarily through waivers, states have rebalanced systems away from nursing homes with hope that changes are cost effective
 - Further spurred by financial incentives in the Affordable Care Act
- Percent of Medicaid long-term services and supports dollars for community-based care surpassed 50% for first time in 2014
 - BUT – substantial variation across states (13-73%)
 - Relatively less progress has been made for older people

System Redesign: integrating long-term services and supports and other services

- Reliance on managed care is predominant approach used by Medicaid and Medicare
 - Almost half of states enroll ~2M Medicaid enrollees in managed long-term services and supports plans
 - Range of efforts for duals – Federal alignment demonstration and state initiatives
- Limited evidence base on the impact of these programs
 - Some results suggest plans can reduce use of institutional services
 - Yet, no definitive evidence about overall impact on costs and quality
 - *No evidence at all specific for people with dementia*
- Plan emphasis on care coordination and patient engagement can present challenges for people with dementia
 - Many plans have little experience meeting nursing home residents' needs

Long-term services and supports quality of care

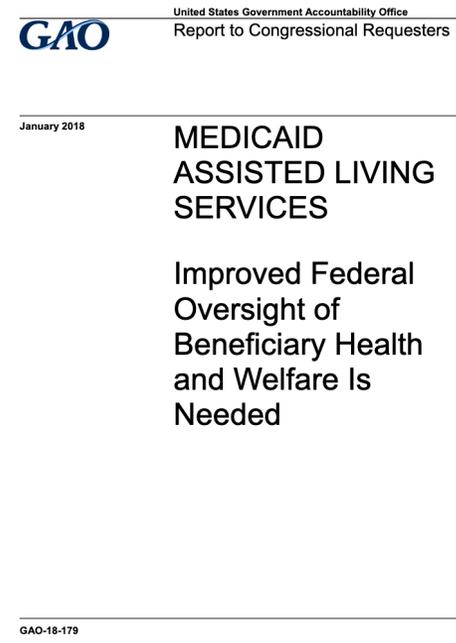
- PLWD especially vulnerable to poor quality care and often have limited set of choices
 - Poor quality care has been documented for decades, especially in nursing homes
 - We know far less about other settings



Improving the Quality of Care in Nursing Homes

Committee on Nursing Home Regulation
Institute of Medicine

NATIONAL ACADEMY PRESS
Washington, D.C. 1986



Government strategies to improve quality

- Historical reliance on regulation, especially in nursing homes
 - Reflects consumers' inability to assess and respond to poor quality
 - Much less evidence for other settings and unpaid care
- Newer efforts – like public reporting and pay-for-performance – explore ability of market incentives to create competition on quality
 - Evidence somewhat mixed about the impact of these programs, which can vary widely
- Concurrent emphasis on care coordination across payer types and settings
 - Quality and cost rationale, but gains have been hard to achieve (e.g., underuse of new Medicare billing code for care management)

Importance of quality measurement for policy

- Quality measures integral to achieve range of policy goals
 - Monitor and assure quality of care
 - Promote accountability and incentives for quality
 - Assess payment adequacy and facilitate value
- Groundwork laid through National Plan to Address Alzheimer's Disease and other efforts
- Yet, dementia-specific measures still underused to assess plan performance and quality in long-term services and supports settings
- Even with uncertainty about expected outcomes, must do better than defining quality as the “absence of bad events”
 - Perspectives of PLWD and their families is critical

Example: improving end-of-life care for PLWD

- PLWD among fastest growing populations of hospice users
- Hospice can improve end-of-life care but eligibility standards pose challenges
 - Prognosis requirement and election to forgo curative therapies
- Disproportionately served by newer for-profit hospices
 - Documented quality concerns including higher live discharge rates
- Hospice enrollment doesn't address other systemic challenges
 - Not a long-term services and supports substitute
 - Doesn't address broader nursing home quality challenges
 - Importantly, substantial racial/ethnic disparities in hospice enrollment
- Improvements must be supported by greater attention to comprehensive needs at end of life and commitment to patient-centered quality

Concluding thoughts

- Hard to overstate importance of long-term services and supports for PLWD
- General policy challenges have impact, often with more severe consequences for PLWD
 - Gaps in financial coverage
 - Care fragmentation
 - Poor quality of care
- Also distinct challenges that must be addressed in more targeted way
 - Patient engagement and care coordination
 - Expanded use of specific quality measures
 - End-of-life care solutions that are aligned with needs

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Research Gaps and Opportunities

Research Gap and Opportunity 1

Develop and implement person-centered and broader conceptualizations of outcomes that are informed by the perspective of persons with dementia (PWD), holistic in focus, positive in nature, and can be used pragmatically across long-term services and supports settings.

Research Gap and Opportunity 2

Use theory-driven frameworks to develop and test multi-level evidence-based interventions that address the complex heterogeneous and interacting challenges experienced by PWD and their caregivers over the full course of the disease; for example, approaches can be guided by socio-ecological levels and social determinants of health, and heterogeneity can reflect cultural diversity.

Research Gap and Opportunity 3

Assess how interventions' effect on intermediate endpoints (e.g., cognition, function, well-being) relate to longer-term outcomes including caregiving intensity, caregiver health, movement into residential long-term care, and costs to individuals, families, and society.

Research Gap and Opportunity 4

Develop and evaluate training for direct care workers to identify specific competencies and modalities that best contribute to improved health, quality of life, financial, and social outcomes for PWD and their caregivers.

Research Gap and Opportunity 5

Analyze the impact of diversity among PWD and the health workforce providing their care, and develop and test approaches that promote cultural humility, cultural competence, and communication skills.

Research Gap and Opportunity 6

Determine the relative effectiveness and efficiency of different interprofessional workforce models in providing high-quality care to PWD, and how to support workforce collaboration across home, community, and residential settings.

Research Gap and Opportunity 7

Analyze the interactions between caregivers and health care workers and technologies designed for the care of PWD; determine how technological change will affect future workforce needs, and design and evaluate effective education and training for caregivers and health care workers to use new technologies effectively.

Research Gap and Opportunity 8

Using measures that evaluate quality across LTSS settings in which PWD receive care, evaluate and refine alternative payment models, quality oversight efforts, and public reporting initiatives.

Research Gap and Opportunity 9

Conduct research to examine the adequacy of payments for care received by PWD in value-based payment efforts in the Medicaid and Medicare programs (including Medicaid managed care plans, Medicare Advantage and Special Needs Plans) and other alternative payment models (e.g., accountable care organizations, bundled payment initiatives), as well as their effects on out-of-pocket expenses.

Research Gap and Opportunity 10

Assess whether and how eligibility and payment policies for specific benefits (e.g., hospice, post-acute care, psychological services) pose barriers to PWD from receiving the supportive, palliative, and end-of-life care services they need, and evaluate ways in which these policies might be reformed to better meet beneficiaries' needs.

Panelist Perspectives



Panelist Perspective

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Panelist Perspective

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Dementia Mentor

Question and Answer

Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons with Dementia and their Caregivers