Aging in Place with Dementia: An Interventionist Perspective

Laura N. Gitlin, Ph.D., FGSA, FAAN
Distinguished Professor, Dean Emeritus College of Nursing and Health Professions, Drexel University
Executive Director, AgeWell Collaboratory
Adjunct Professor, Johns Hopkins University

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DREXEL UNIVERSITY AgeWell Collaboratory College of Nursing and Health Professions

lng45@drexel.edu

DREXEL UNIVERSITY College of Nursing and Health Professions

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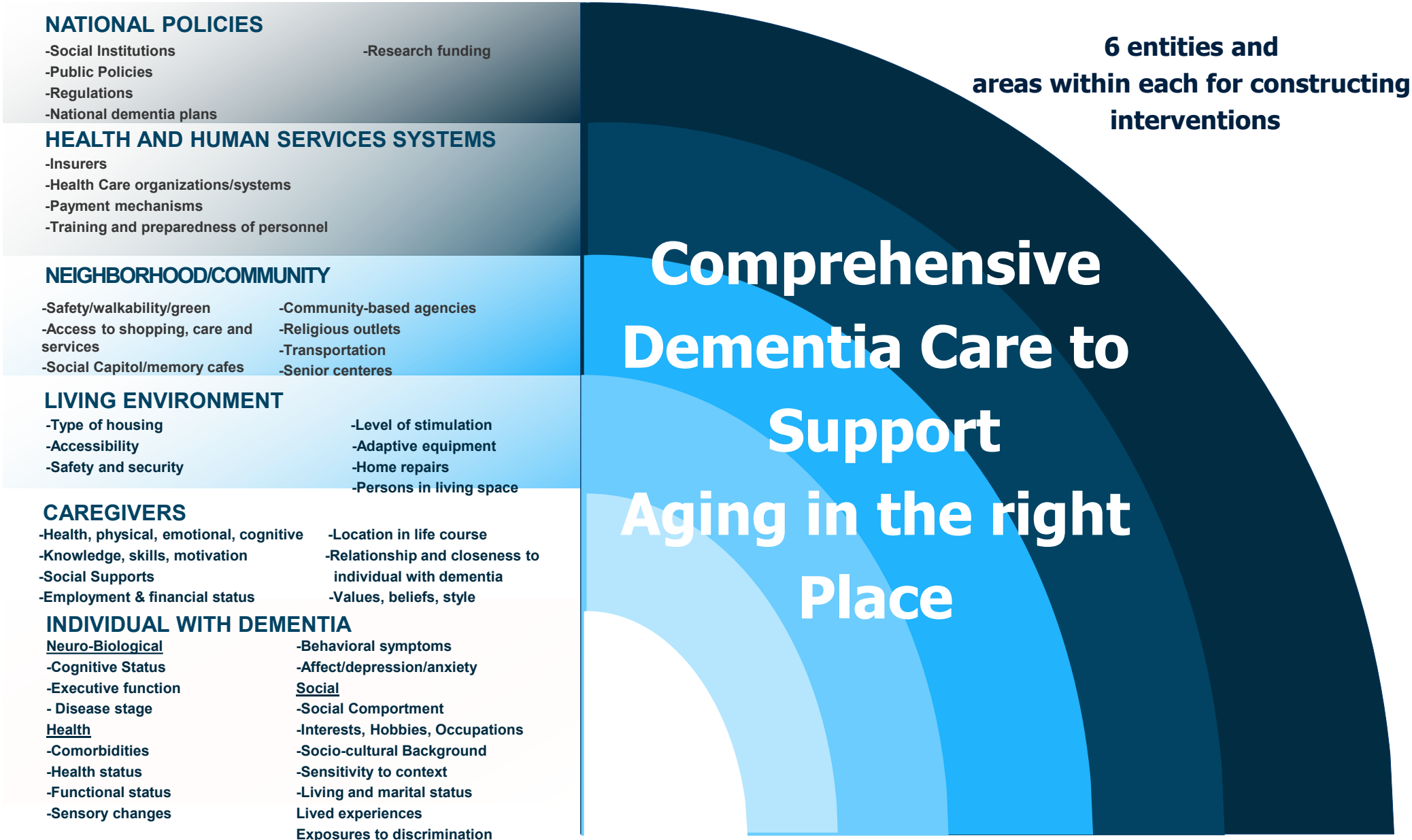
Consultant to various community-based agencies concerning dementia care;

Inventor of online programs for health providers to learn evidence-based intervention for which Johns Hopkins University, Drexel University, and Dr. Gitlin are entitled to fees.

Socio-ecological Model Guiding Dementia Care Interventions
Gitlin and Hodgson, 2018



Socio-ecological Model Guiding Development and Evaluation of Dementia Care Interventions
Gitlin and Hodgson, 2018

NATIONAL POLICIES
-Social Institutions
-Public Policies
-Regulations
-National dementia plans
-Research funding

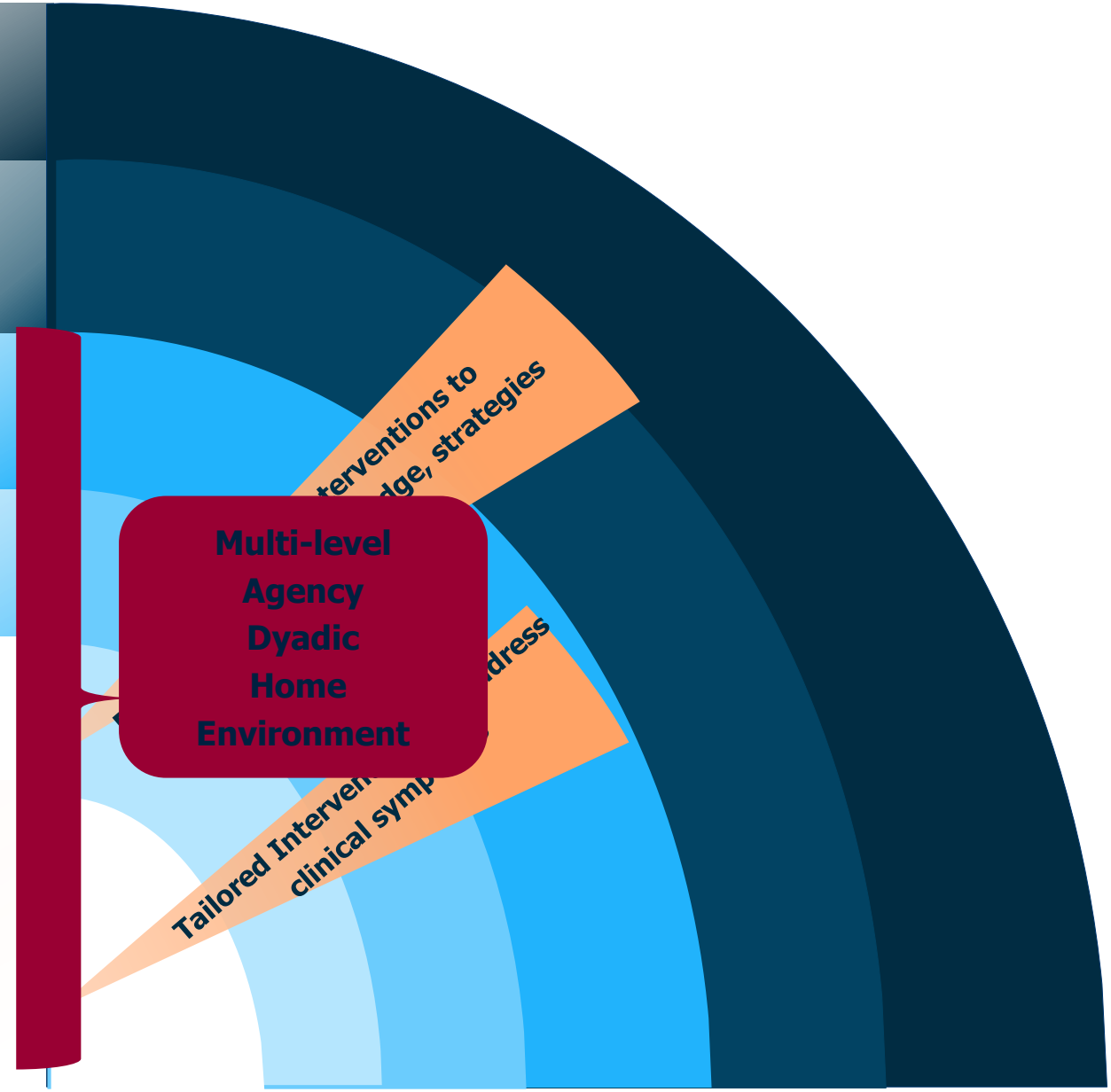
HEALTH AND HUMAN SERVICES SYSTEMS
-Insurers
-Health Care organizations/systems
-Payment mechanisms
-Training and preparedness of personnel

NEIGHBORHOOD/COMMUNITY
-Safety
-Access to shopping, care and services
-Social Capitol
-Community-based agencies
-Religious outlets
-Transportation
-Dementia friendly

LIVING ENVIRONMENT
-Type of housing
-Accessibility
-Safety and security
-Level of stimulation
-Adaptive equipment
-Home repairs
-Persons in living space

CAREGIVERS
-Health, physical, emotional, cognitive
-Knowledge, skills, motivation
-Social Supports
-Employment & financial status
-Location in life course
-Relationship and closeness to individual with dementia
-Values, beliefs, style

INDIVIDUAL WITH DEMENTIA
<u>Neuro-Biological</u>
-Cognitive Status
-Executive function
- Disease stage
<u>Health</u>
-Comorbidities
-Health status
-Functional status
-Sensory changes
<u>Behavioral and Psychological</u>
-Behavioral symptoms
-Affect/depression/anxiety
<u>Social</u>
-Social Comportment
-Interests, Hobbies, Occupations
-Socio-cultural Background
-Sensitivity to context
-Living and marital status



Lessons Learned From Hundreds of Clinical Trials Targeting Individuals and/or Caregivers

Supportive programs for carers are highly effective addressing psychosocial outcomes; Evidence for programs for people living with dementia more inconsistent

Most effective programs are: 1) multicomponent combining counseling, support, education, stress, mood, management, skills training; 2) tailored to needs. Unclear which groups benefit most; Samples underrepresent diversity (race, cultural, linguistic ethnicity, geography)

No one program is effective for all desired outcomes. Most programs/outcomes focus on mood, stress, health, quality of life, managing clinical symptoms, nursing home placement, health utilization

Unclear as to benefits of aging in place for family unit. Relocation typically due to need for 24/7 supervision; mobility changes; extraordinary care and medical needs; Unclear housing stock, housing repair needs,

Need to balance aging at home with family responsibilities/burdens; Unclear needs for people living alone

Example of Outcomes Relevant to Staying at Home Tailored Activity Program (TAP) and COPE Program

For People Living with Dementia

For Caregivers

Less upset

Improved wellbeing

Improved Caregiver confidence

Reduced behavioral symptoms

Reduced physical dependence

Enhanced engagement

Detection of underlying treatable medical issues

Increased home safety and cost Savings for Health Systems

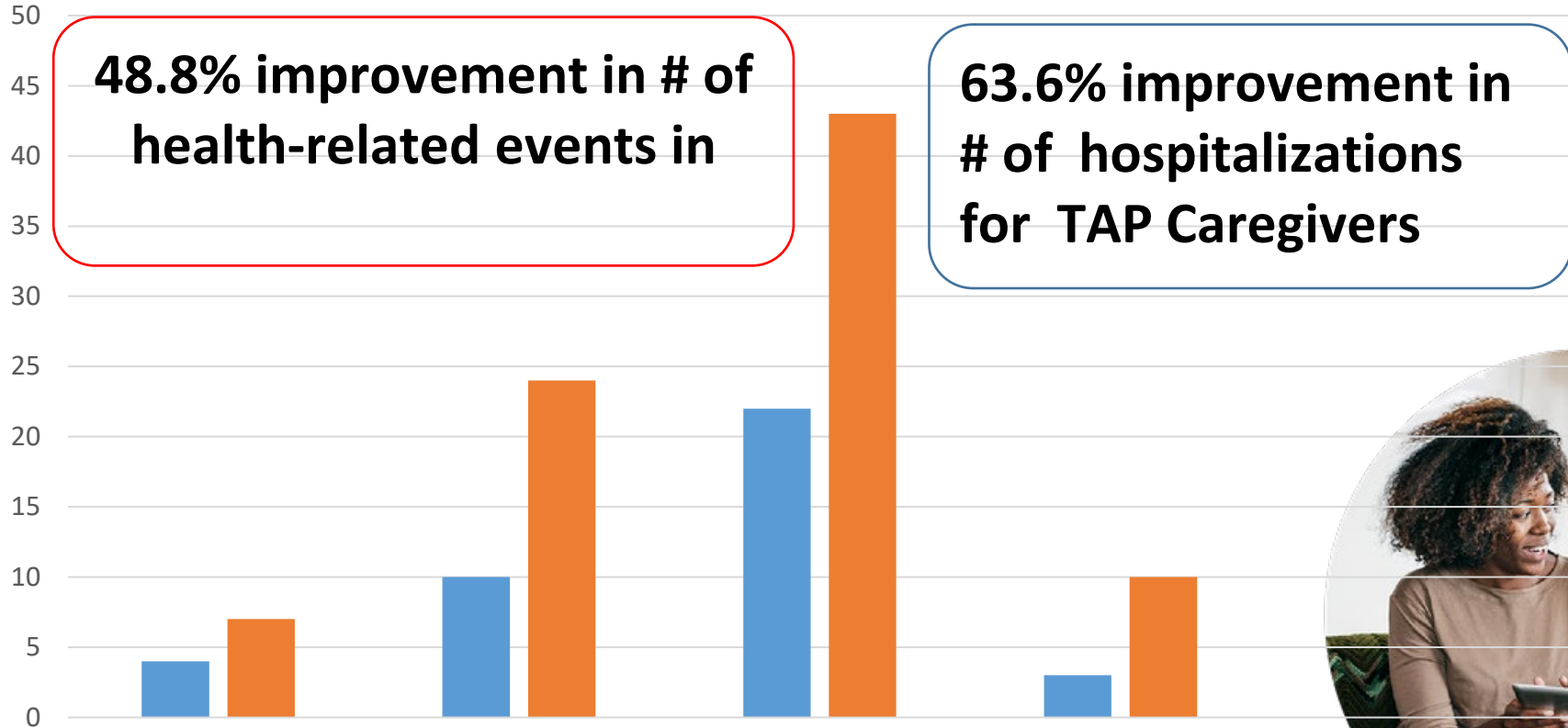
Pizzi et al., 2022, *Innovation in Aging*; Fortinsky et al., 2020, *Innovation in Aging*; Gitlin et al., 2010, *JAMA*; Clemson et al., 2020, *The Gerontologist; Gitlin et al, 2021, BMJ*

Tailored Activity Program
(n=250; Gitlin et al., BMJ, 2021)

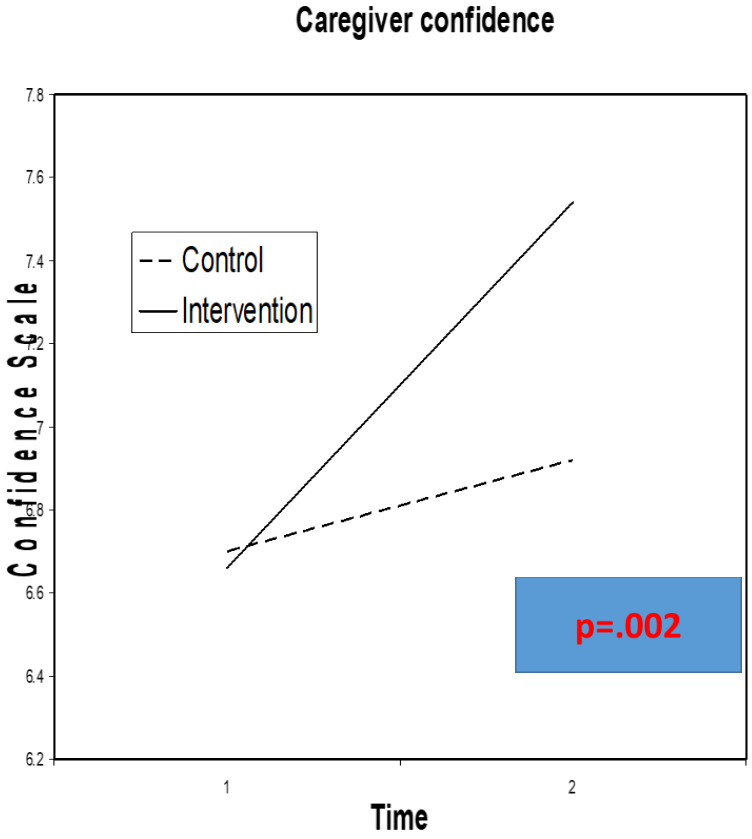
Health-Related Events

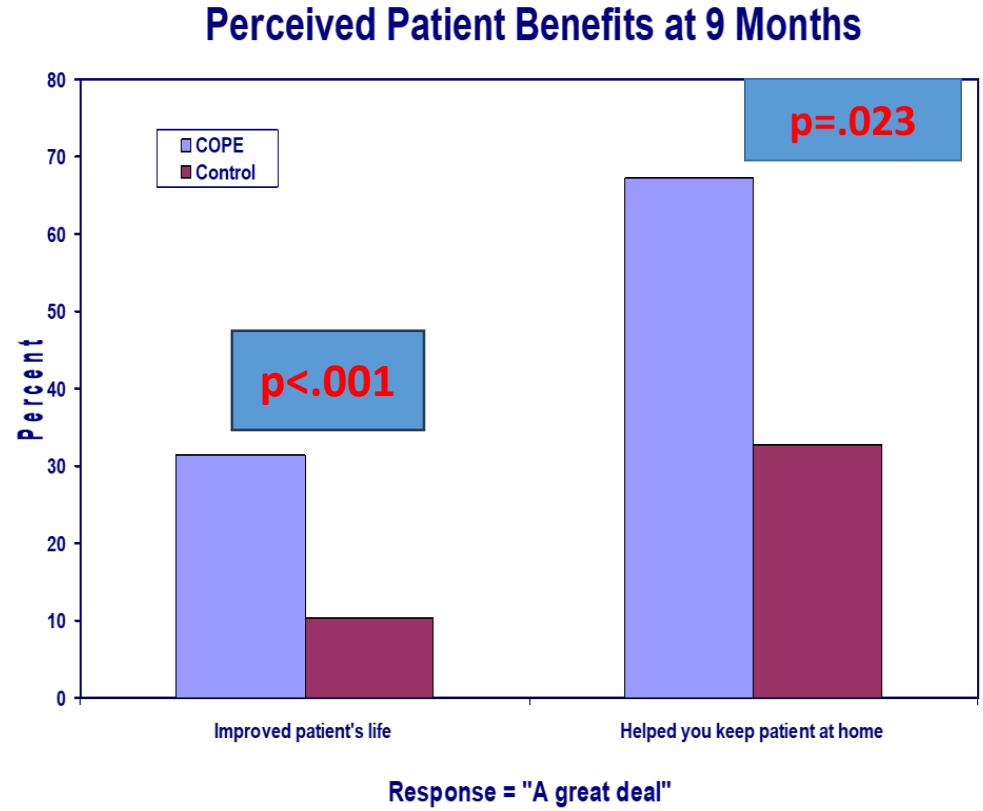
48.8% improvement in # of health-related events in

63.6% improvement in # of hospitalizations for TAP Caregivers



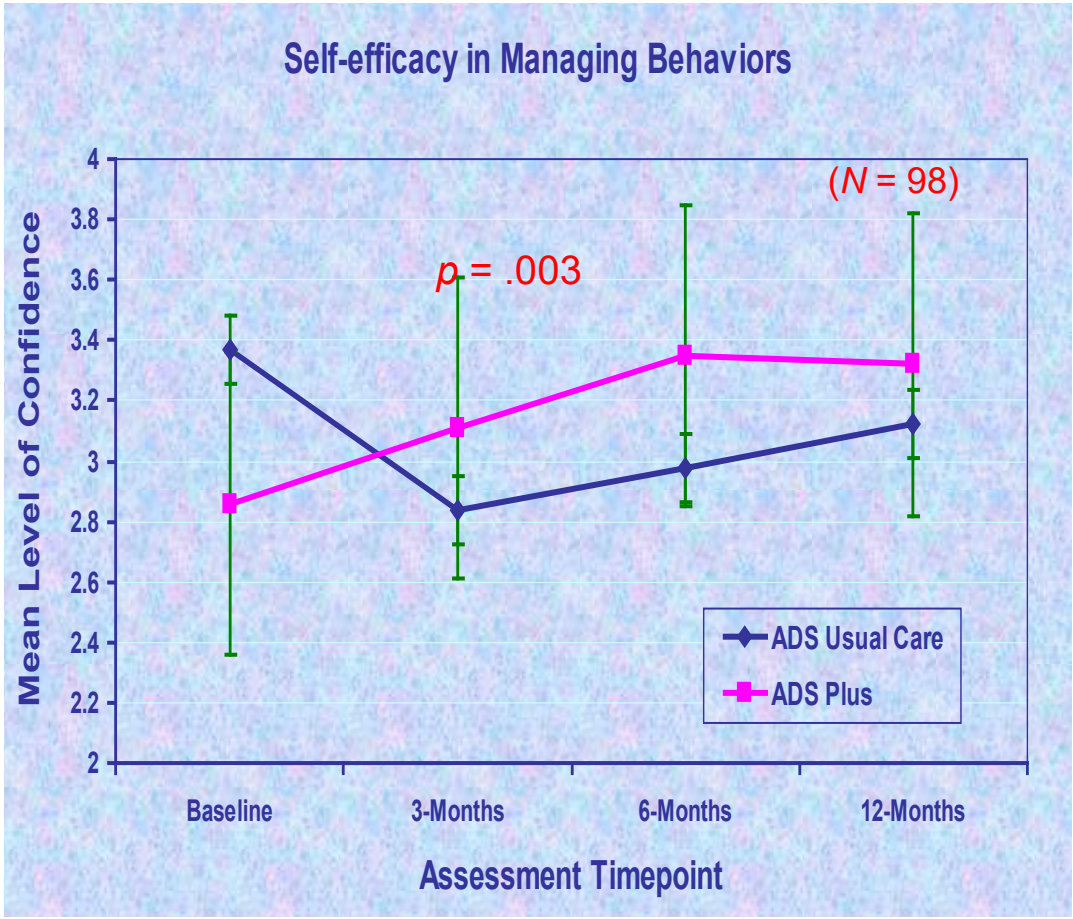
COPE Program (n=237)
Gitlin et al, JAMA, 2010

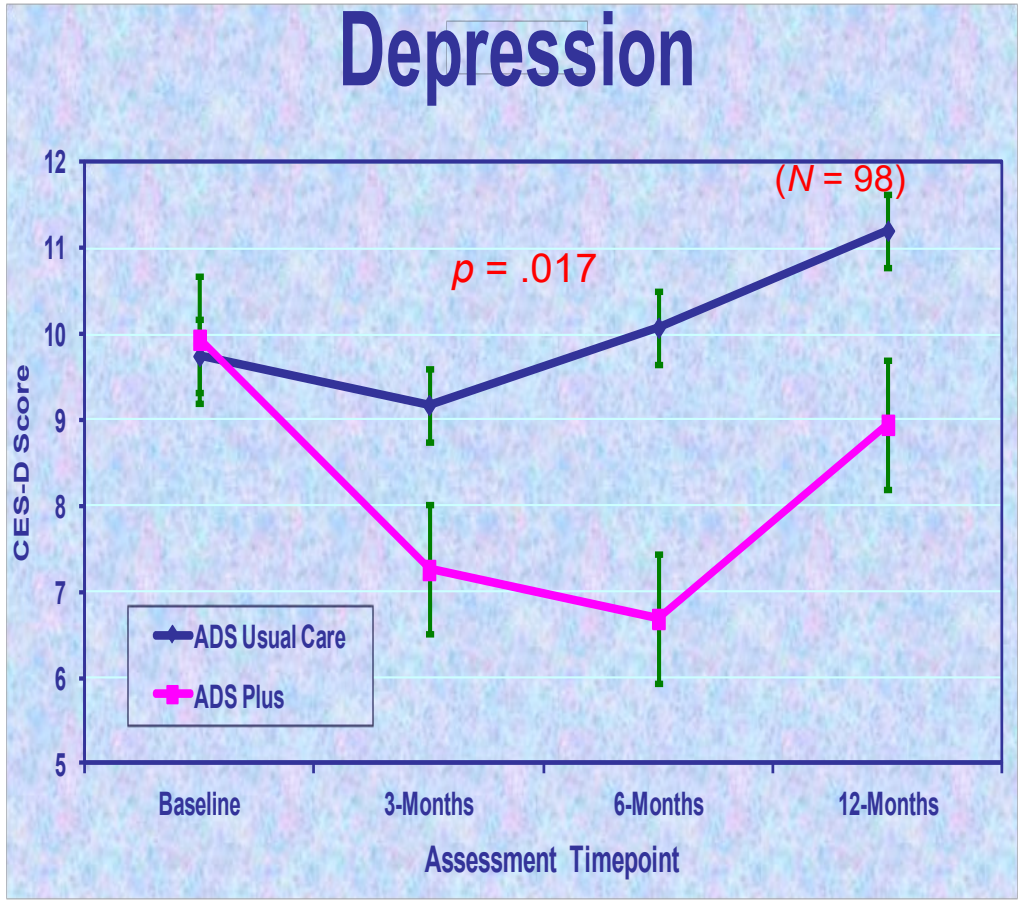




Enhancing Ability of Community-based Organizations to Support Families

ADS Plus Study (3 sites, N=165)





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Gitlin et al., 2023, The Gerontologist; Gitlin, et al., (2006). The Gerontologist, 46, 630-639; Reever, et al., (2004). Alzheimer's Care Quarterly, 5, 332 – 339. Funded by Administration on Community Living

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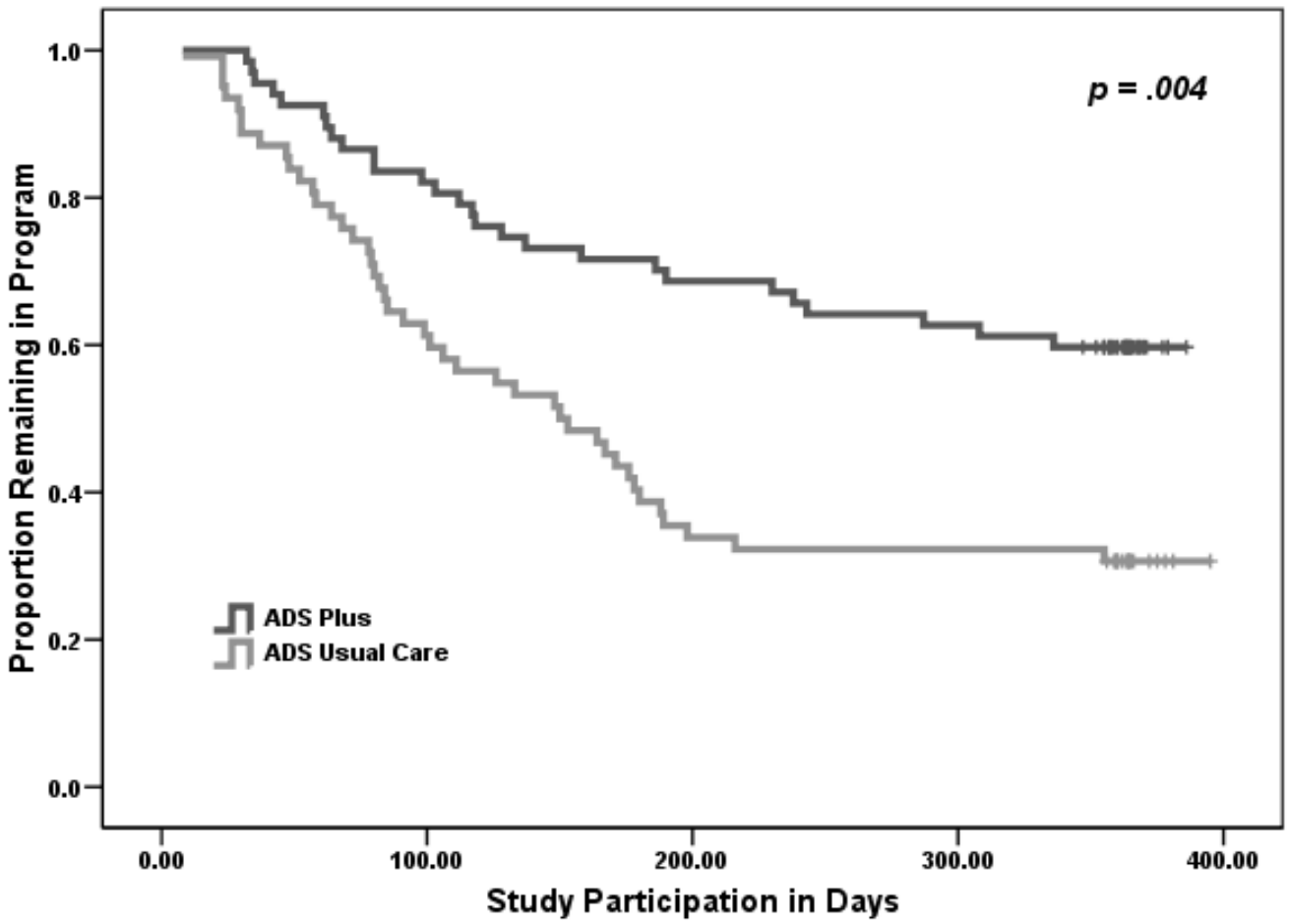
Increased Adult Day Service Use in Intervention Sites



ADS Plus Vs. ADS

37+ more ADS days for ADS Plus sites
50% reduction in nursing home placement
Gitlin et al., 2006, *The Gerontologist*

ADS Use Study (N=203; 34 sites)

47 more ADS Days for 9 ADS Plus sites compare to 9 ADS only sites
Gitlin et al., 2023, *The Gerontologist*

ADS Use Study (N=509)

49% reduction in missed doctors appointments among Black Caregivers using adult day services
Parker et al., 2019, *JAGS*

Nursing Home Placement as Primary Outcome of Aging in Place in Intervention Research

4 Interventions (MIND, NYU, ADC and ADS Plus)

- Reduce nursing home admissions
- Save societal costs compared to usual care
- Small QALY improvements
- More time in community
- More effective than usual care
- Cost for delivery <than median annual cost ($93,075) of NH and <than incremental cost per QALY of aducanumab
- Policies should incentivize providers and health systems to implement non-pharmacologic interventions.

Jutkowitz et al., 2023, *Alzheimer's & Dementia*

TABLE 2 Societal and health-care payer perspective: intervention cost, incremental lifetime costs ($), quality-adjusted life-years, and incremental cost-effectiveness ratio of each intervention compared to usual care.

		Incremental benefit		Societal perspective			Health-care payer perspective		
Comparison	Intervention cost, $	QALYs	Years (days) in the community	Incremental lifetime costs, $[a]	ICER	ICER, $/year in the community	Incremental lifetime costs, $[a]	ICER, $/QALY	ICER, $/year in the community
Maximizing Independence at Home (MIND) versus usual care	$1445	0.002	0.057 (21)	−$13,282	Cost saving	Cost saving	$617	$268,476	$10,901
NYU Caregiver (NYU) versus usual care	$2571	0.005	0.118 (43)	−$5297	Cost saving	Cost saving	$12	$2224	$98
Alzheimer's and Dementia Care (ADC) versus usual care	$2345	0.003	0.061 (22)	−$3668	Cost saving	Cost saving	−$720	Cost saving	Cost saving
Adult Day Service Plus (ADS Plus) versus usual care	$762	0.002	0.038 (14)	−$2813	Cost saving	Cost saving	$192	$126,148	$5015

Abbreviations: Cost saving, the intervention costs less and is more effective than usual care; ICER, incremental cost-effectiveness ratio; QALY, quality-adjusted life-year.

[a]Incremental cost is the difference in treatment [inclusive of treatment cost] – usual care cost.

Research Recommendations in 4 Areas

#1: New Approaches to Intervention Development

Gitlin & Czaja, 2016; Gitlin & Czaja, in press

- ❑ Involve interested parties/stakeholders in development, evaluation using community-participatory processes
- ❑ Use mixed methods to understand feasibility, acceptability, effectiveness and implementation outcomes for diverse individuals and communities
- ❑ Consider end in mind from the start
  - What context will intervention be delivered?
  - Who would deliver intervention? Training needed?
  - What is pathway to sustaining intervention?
  - Cost savings? Cost benefit? Or what outcomes align with different stakeholders
- ❑ Theory & mechanism based
- ❑ Equity considerations in every methodological decision point
  - Accessibility
  - Inclusive inclusion criteria (be ware of hidden biases)
  - Cultural viability/acceptability
  - Adaptations (linguistic, cultural, values, workflows)
- ❑ Multi-level interventions (e.g., individual, caregiver and dementia friendly communities) add complexity but emerging evidence for reducing health disparities
- ❑ New interventions needed to:
  - Support people with dementia living alone to age in place
  - Offset roles/responsibilities of family caregivers they assume when keeping person at home
  - Address broader range of needs and for different disease stages, preferences, values
  - Examine dyadic relationships and which types of interventions impact carer and person;
  - Move beyond isolating primary caregiver and examine informal networks, family decision-making

#2: New or Adapted Models to Understand the Meaning of and Ability to Age in Place

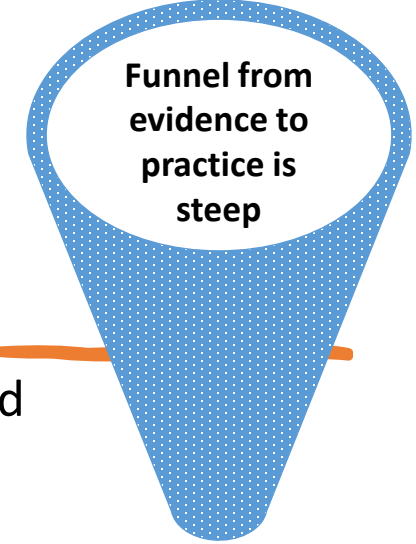
- ❑ Expand models to address the unique lived experience and clinical symptoms of dementia
  - Change in cognition and function and hence needs
  - Degenerative process
    - Needs vary by each disease stage
- ❑ Expand or adapt model to address needs of family member, long distance caregivers
- ❑ Develop models for people living alone
- ❑ Theories/models to understand impact of relocations for individual and family members

#3 New Measures

- Align outcome measures with partner/stakeholder values/preferences
- Use targeted measurement strategies to reflect what matters most to families/stakeholders/partners (e.g, Goal attainment scaling)
- Potential Multi-level Metrics

Individual

#4 Implementation



- Adopt new methodologies for quickly moving evidence to real world
  - Adaptive Designs
  - Pragmatic trial methodology (NIA Impact Collaboratory https://impactcollaboratory.org/)
  - Hybrid Effectiveness/implementation Designs (Gaugler et al., in press, JAMDA)
  - Implementation studies
- Evaluate implementation outcomes (Proctor et al., 2011):
  - Acceptability
  - Adoption
  - Appropriateness
  - Costs
  - Feasibility
  - Fidelity
  - Penetration
  - Sustainability

Implementation Challenges

-Payment models; Cost
-Staff availability; Training needs
-Fit with workflow; Adaptations needed
-Savings for health systems may result in increased burdens for families
-Savings for health systems not shared with community-based programs

Questions