



Tailoring, Targeting and Addressing what Matters: Supporting People with Intellectual and Developmental Disabilities who are Living with Dementia

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Consultant to various community-based agencies concerning dementia care;
Inventor of an online program for an intervention (Tailored Activity Program) for which
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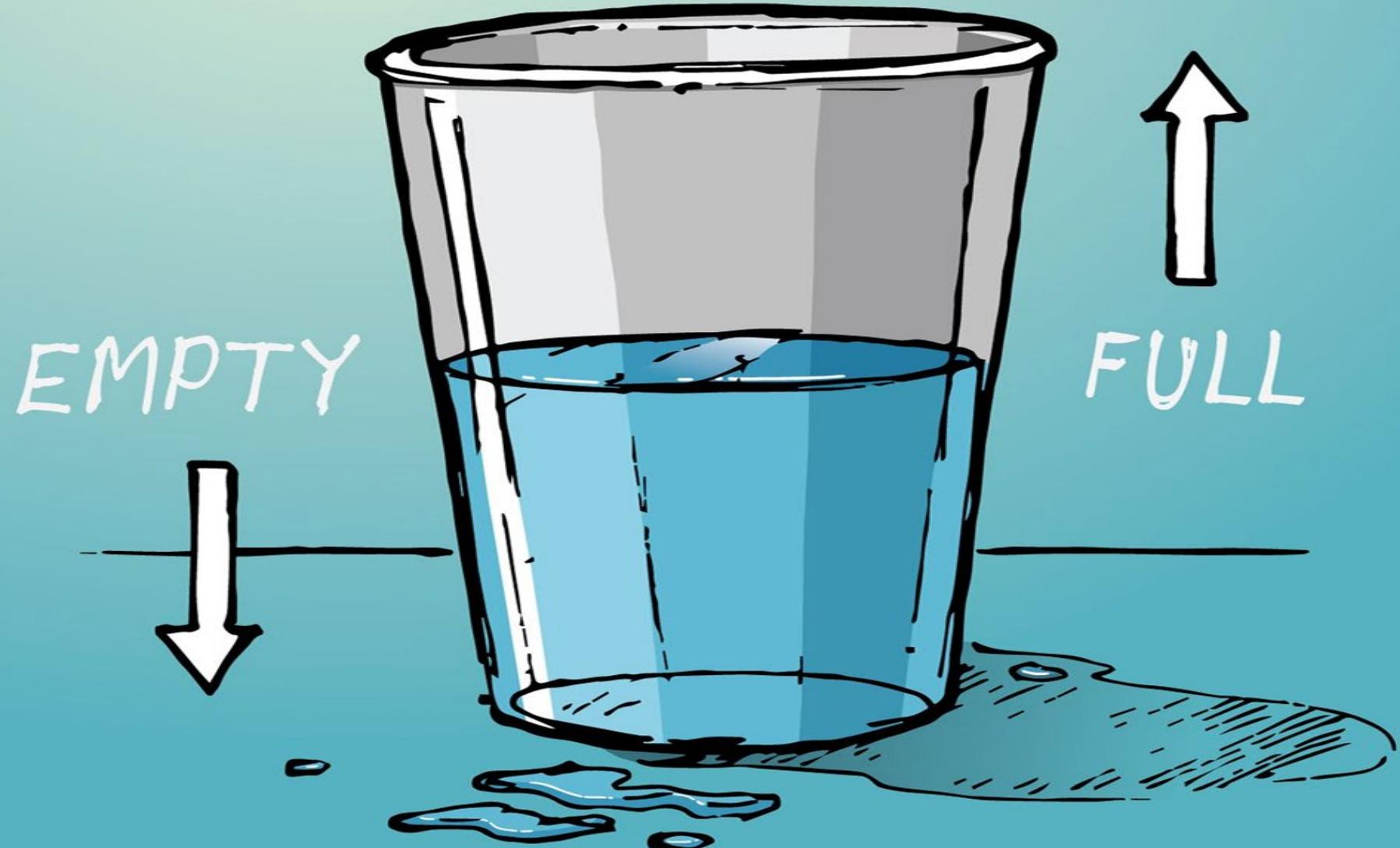


Objectives

- ❖ State of dementia care research
- ❖ Promising interventions that support quality of life
 - DICE approach (targeted to addressing specific behavioral symptoms)
 - Tailored Activity Program (activity engagement)
 - COPE (care challenges)
- ❖ Best practices for people with IDD and dementia
- ❖ Enhancing clinical relevance
 - Targeting
 - Tailoring

A photograph of six seniors of various ethnicities and ages walking together on a paved path in a park. They are dressed casually in shirts, pants, and jackets. The background shows trees and a fence.

State of Dementia Care Research





Recent Reports on Dementia Care

❑ Agency for Healthcare Research and Quality Report (August 2020):

Butler et al., <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

❑ NASEM (Feb.2021): *Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward.* <https://www.nationalacademies.org/our-work/care-interventions-for-individuals-with-dementia-and-their-caregivers---phase-two>

- ❑ Gitlin, Jutkowitz, Gaugler – Summation of interventions for caregivers
- ❑ Gaugler, Jutkowitz, Gitlin – Summation of interventions for people living with dementia

❑ Lancet Commission Report: Livingston, et al., (2020). Dementia prevention, intervention, and care: [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

❑ Best Practice Caregiving – Family Caregiver Alliance/Benjamin Rose - <https://bpc.caregiver.org/#home>

Lessons Learned From Hundreds of Clinical Trials



Support programs for carers are highly effective; Evidence for programs for people living with dementia more inconsistent



Most effective programs are multicomponent combining counselling, support, education, stress, mood management, skills training

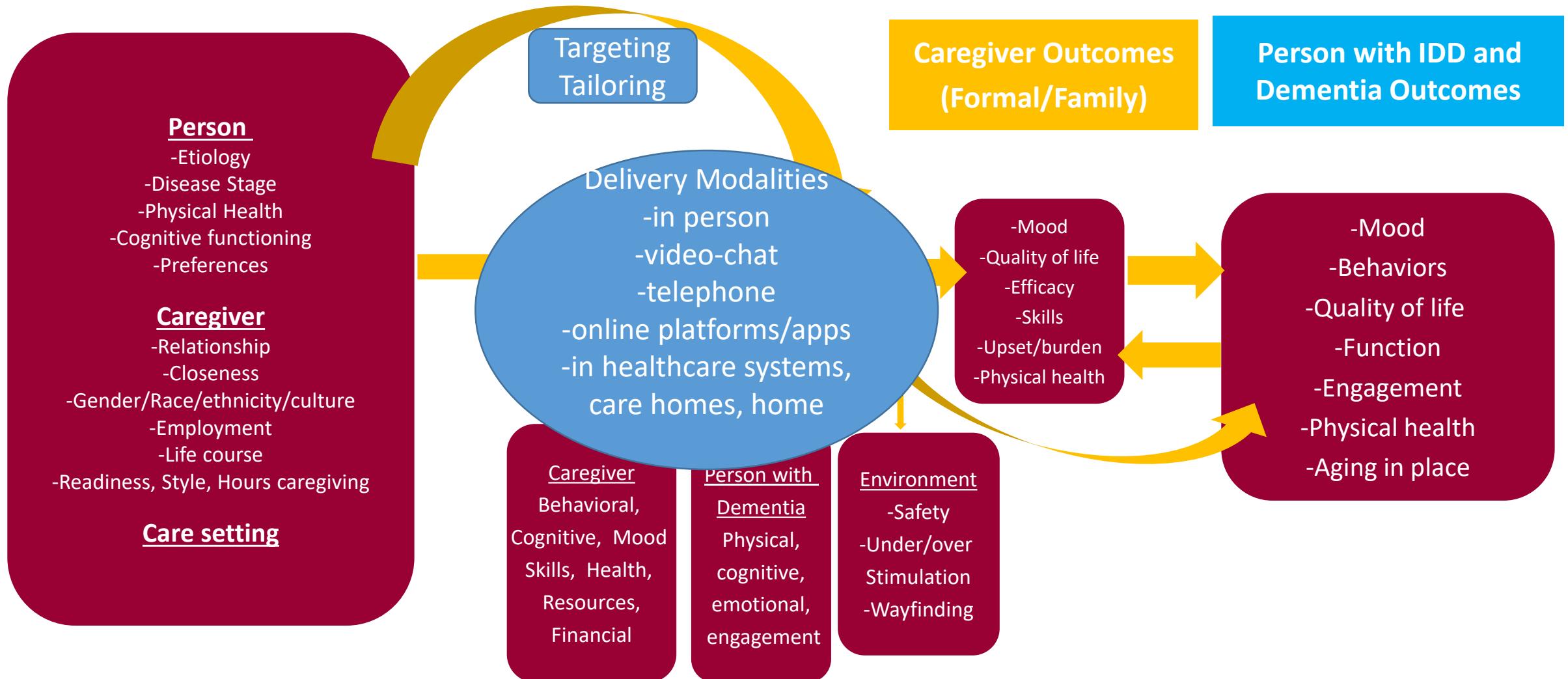


No one program is effective for all desired outcomes



Need to select an approach based on desired outcomes

Pathways for Supporting Quality of Life in People with IDD and Living with Dementia





Promising Interventions to Support Quality of Life

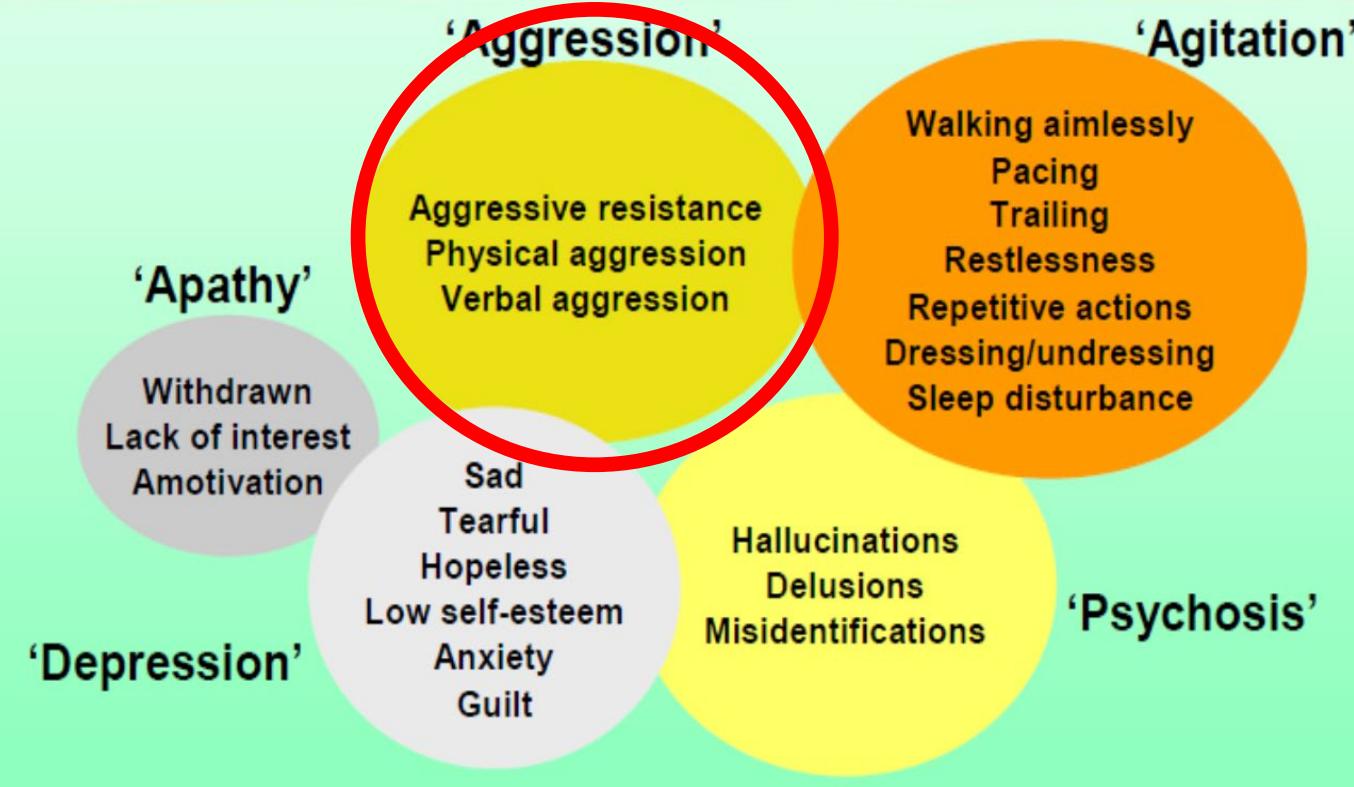
DICE APPROACH

Managing Challenging Behavioral and Psychological Symptoms



What are Behaviors?

Clusters of BPSD



Adapted from McShane R. Int Psychogeriatr 2000; 12(Suppl 1): 147–54

- Rejection of care; “Extreme stubbornness”
- Arguing
- Repetitive verbalizations/questioning
- Wandering
- Hoarding/rummaging
- “Inappropriate” behaviors (screaming, spitting, sexual behaviors)
- Sleep problems (day-night reversal)

Behaviors are Bad for Everyone

Person Living with Dementia

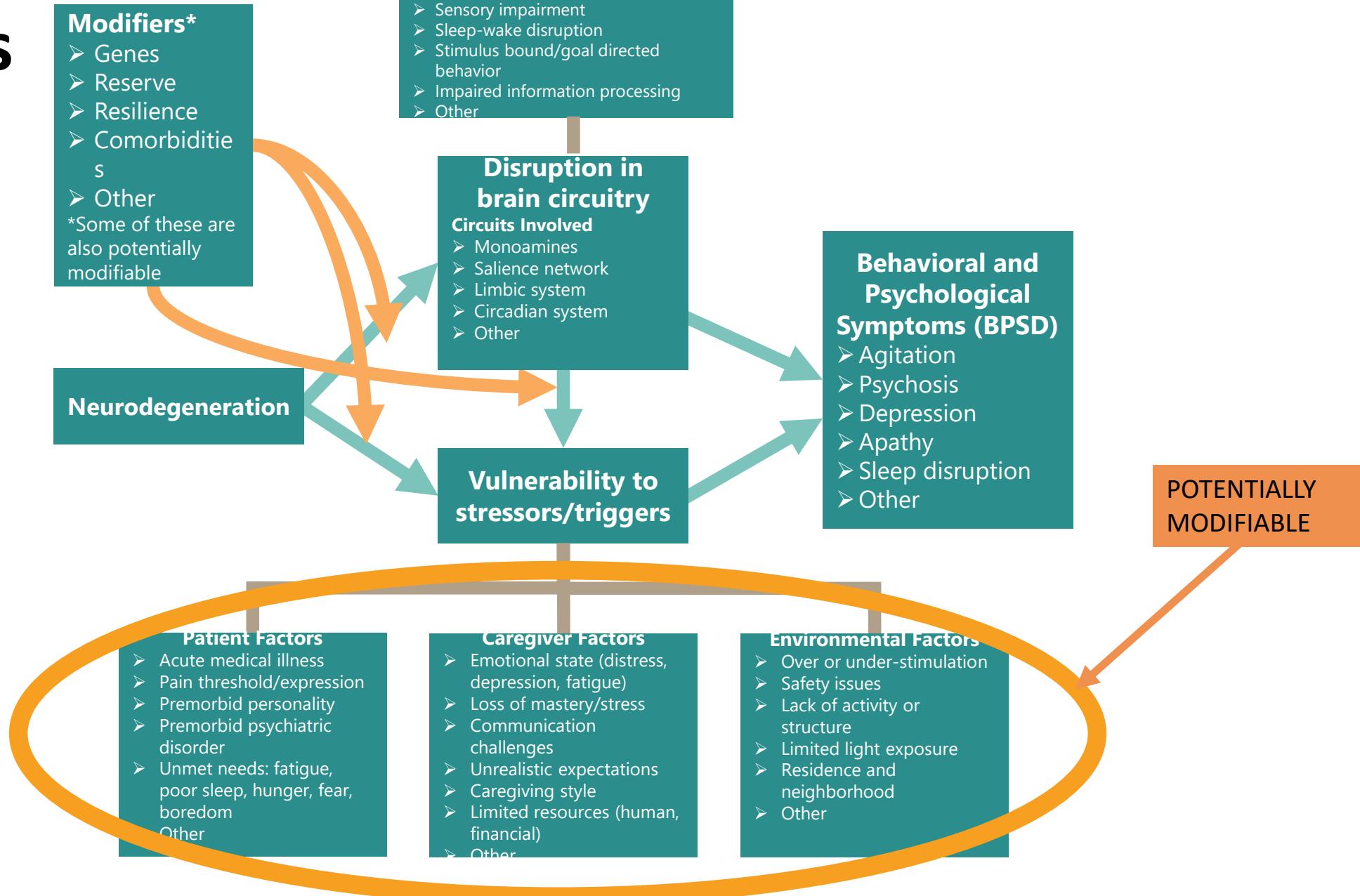
- More rapid declines
- Increased hospitalizations
- Poorer quality of life
- Distressing to person
- Rejection from care facilities

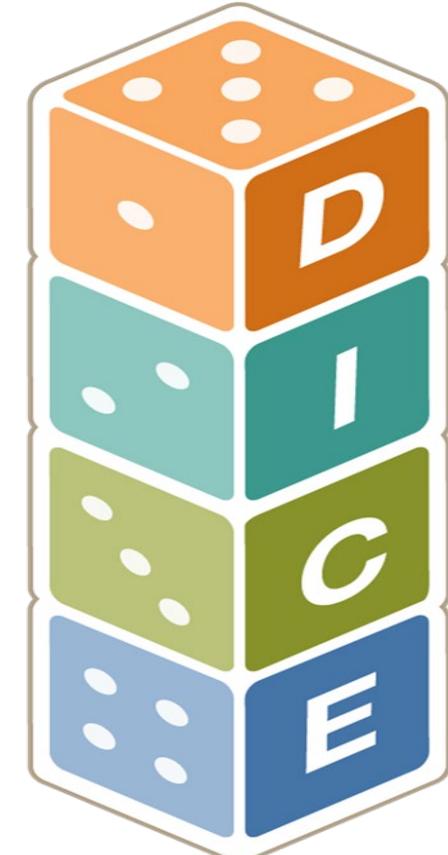
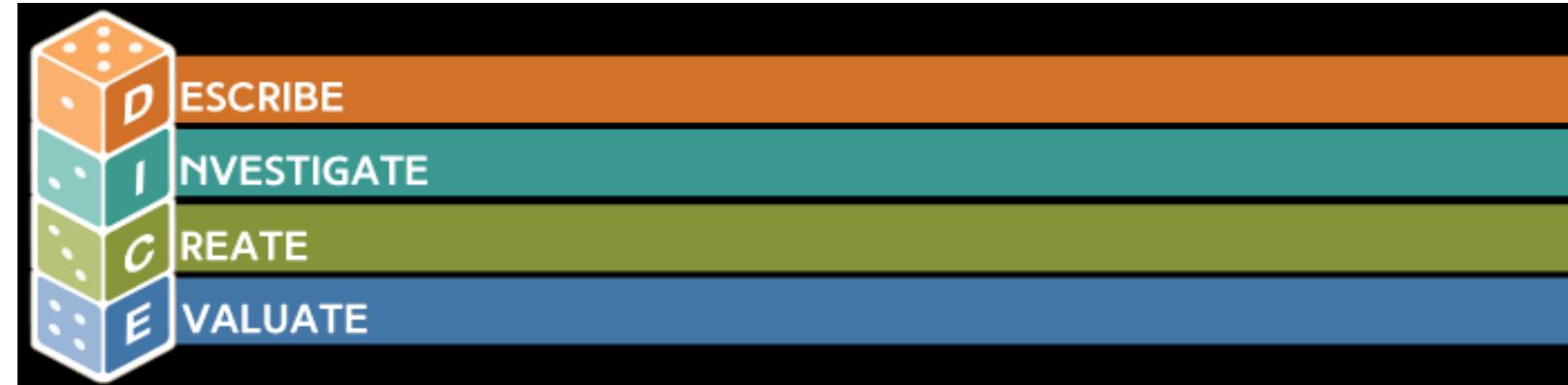
Caregivers

- More time providing care
- Increased depression and distress
- Distressing to person
- Trigger for residential placement
- Increased care costs

Why do behaviors occur?

Kales, Gitlin & Lyketsos, JAMDA, 2019





- **Describe** a behavior that challenges; who, what, where, when, and how the behavior occurs
- **Investigate** thinking like a detective and explore the person with dementia, the caregivers, and environment for possible clues to triggers underlying possible causes of behavior
- **Create** a prescription in collaboration with your team to help prevent and manage behaviors
- **Evaluate** and review prescription effectiveness, and modify or restart the process as needed



Example of DICE APPROACH

Describe

Resident (Mrs. J)

- Trying to leave the facility; Blocking door; Screaming and striking out; Escalating aggression with staff intervention

Caregivers

- Worried Mrs J might escape; Concerned about impression of new residents and families at entrance; Worried that Mrs J would fall; Staff concerns about being hurt

Environment

- Noisy music group; Saw front door when she exited; Surrounded by staff and residents as they left concert

Investigate

Resident

- Recent move from another part of building; Due to anxiety, had recent increase in meds; Functional and cognitive fluctuations of Parkinson's; Moderate dementia, poor executive function; History of rape as a teenager

Caregivers

- Taken off guard by sudden uncooperativeness; did not know her well; Communication style inappropriate; Fear and embarrassment increased their stress and led to physical intervention

Environment

- Over-stimulating; Routine was changed by move; Seeing door gave her a view of outside

DICE con't

Create

Resident:

- Rule out acute medical issues; Decrease SSRI back to original dose; Avoid antipsychotics which could worsen Parkinson's; Consider ways to decrease anxiety (e.g. music, exercise); Use of 4-wheeled walker for stability

Caregivers

- Identify less overstimulating activities; Use simple calm communications; Avoid evoking memories of sexual assault; Inform and explain any need for touch or direction; Educate staff about her history; If tries to leave event, walk with her, calmly redirect her back into facility when less agitated

Environment

- Create routines that are safe, not overstimulating and meaningful; using signage to redirect and cue

Evaluate

Resident:

- Monitor behavior change once SSRI is decreased; Evaluate effect of each strategy; Monitor anxiety levels

Caregivers

- What approaches did staff try? Were there any that they were resistant to? If so, why?; What worked? What didn't?; Any unintended consequences or "side effects" noted?

Environment

- What changes were made? Were new routines instituted? Any issues with that?





COPE Program





Clinical Trajectory

Pre-Clinical

No
Impairment

Mild
Cognitive
Impairment

Prevention

Early Stage
Mild Dementia

Middle Stage
Moderate Dementia

End Stage
Severe Dementia

COPE Program

- Person with dementia
 - Lives at home
 - Functional dependence
 - Behavioral symptoms
- Caregiver distress

COPE Treatment Goals

- Person with dementia
 - Reduce functional disability
 - Prevent/manage behavioral symptoms
- Caregiver
 - Enhance knowledge and skill

- Strength based (what a person can do)
 - Caregiver-centric (identify what matters)

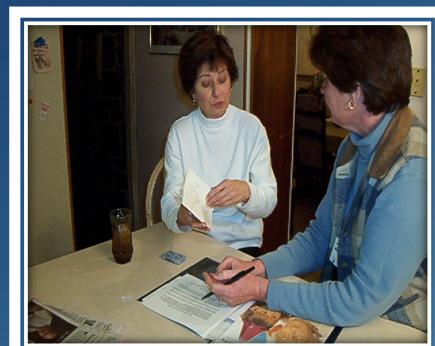
COPE Program



**Phase 1:
Assessment**
Person
Caregiver
Environment

**Phase 2:
Implementation**
3 Care challenges
1 Activity
4 COPE Prescriptions

**Phase 3:
Generalization**
Modify for future
Use strategies for other problems



Gitlin et al.,
JAMA 2010

COPE Nurse Visit

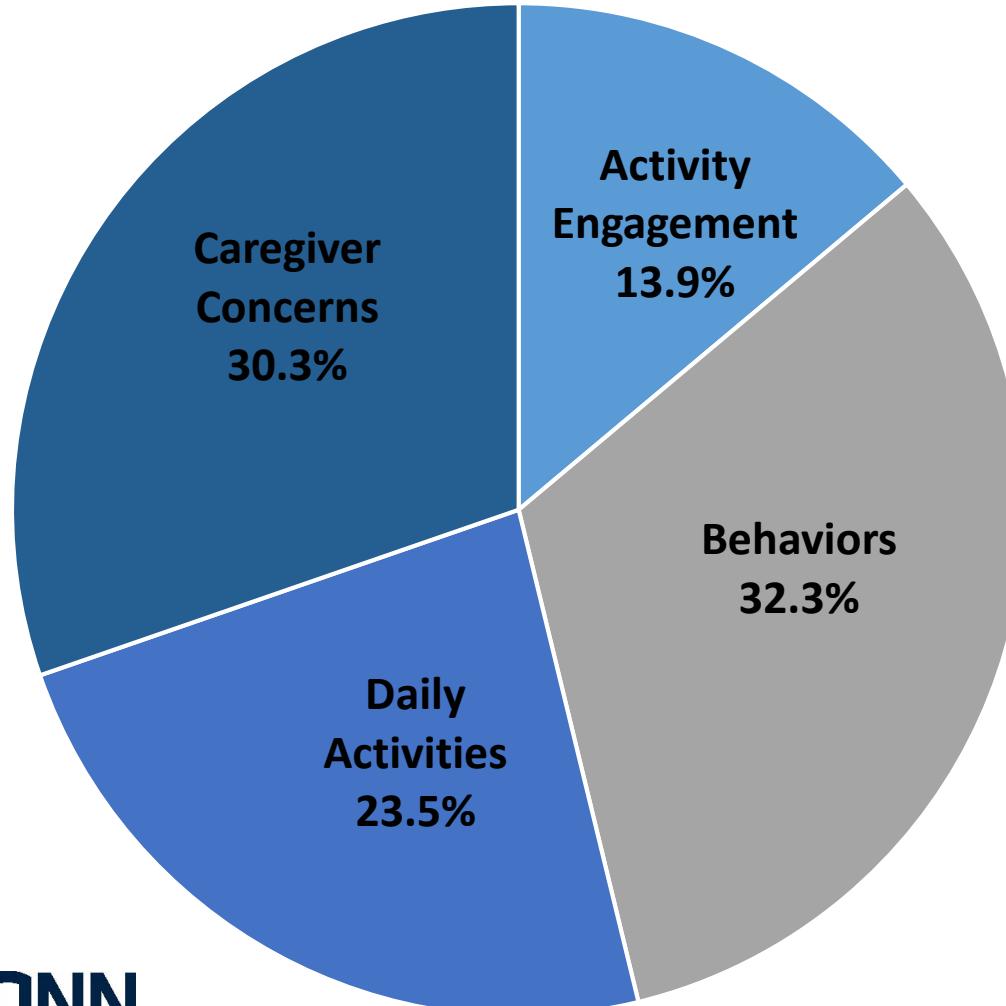
- Provide caregiver education (Pain, Dehydration, Infection, Constipation, Polypharmacy, Talking to doctor, Talking to family and others)
- Discuss strategies for self-care self (respite, health habits, sleep)
- Physical exam
 - Medication review
 - Blood and urine
 - Results shared with caregiver



COPE Prescription

What is the problem?			Strategies:	
			1. Communicate effectively	
			What to do: <input type="checkbox"/> _____ <input type="checkbox"/> _____	What to avoid doing: <input type="checkbox"/> _____ <input type="checkbox"/> _____
			2. Modify your home and make it safe	
			What to do: <input type="checkbox"/> _____ <input type="checkbox"/> _____	What to avoid doing: <input type="checkbox"/> _____ <input type="checkbox"/> _____
			3. Simplify the way you set up daily activities	
			What to do: <input type="checkbox"/> _____ <input type="checkbox"/> _____	What to avoid doing: <input type="checkbox"/> _____ <input type="checkbox"/> _____
			4. Enhance activity participation	
			What to do: <input type="checkbox"/> _____ <input type="checkbox"/> _____	What to avoid doing: <input type="checkbox"/> _____ <input type="checkbox"/> _____
Strategies for You: <input type="checkbox"/> _____ <input type="checkbox"/> _____				
How do I want the situation to change?				
Why the problem may occur:				
Person with Dementia	Caregiver	Environment		
<input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/> _____		
<input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/> _____		
<input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/> _____		
<input type="checkbox"/> _____	<input type="checkbox"/> _____	<input type="checkbox"/> _____		
Person's Abilities:				
1. _____				
2. _____				
3. _____				
4. _____				

Caregiver-identified Problems in the COPE Assessment Phase, by Percent of Problems (N=409)



Activity Engagement

Engaging person with dementia in meaningful/familiar activities

Behavioral Symptoms

Addressing behavioral symptoms in person with dementia

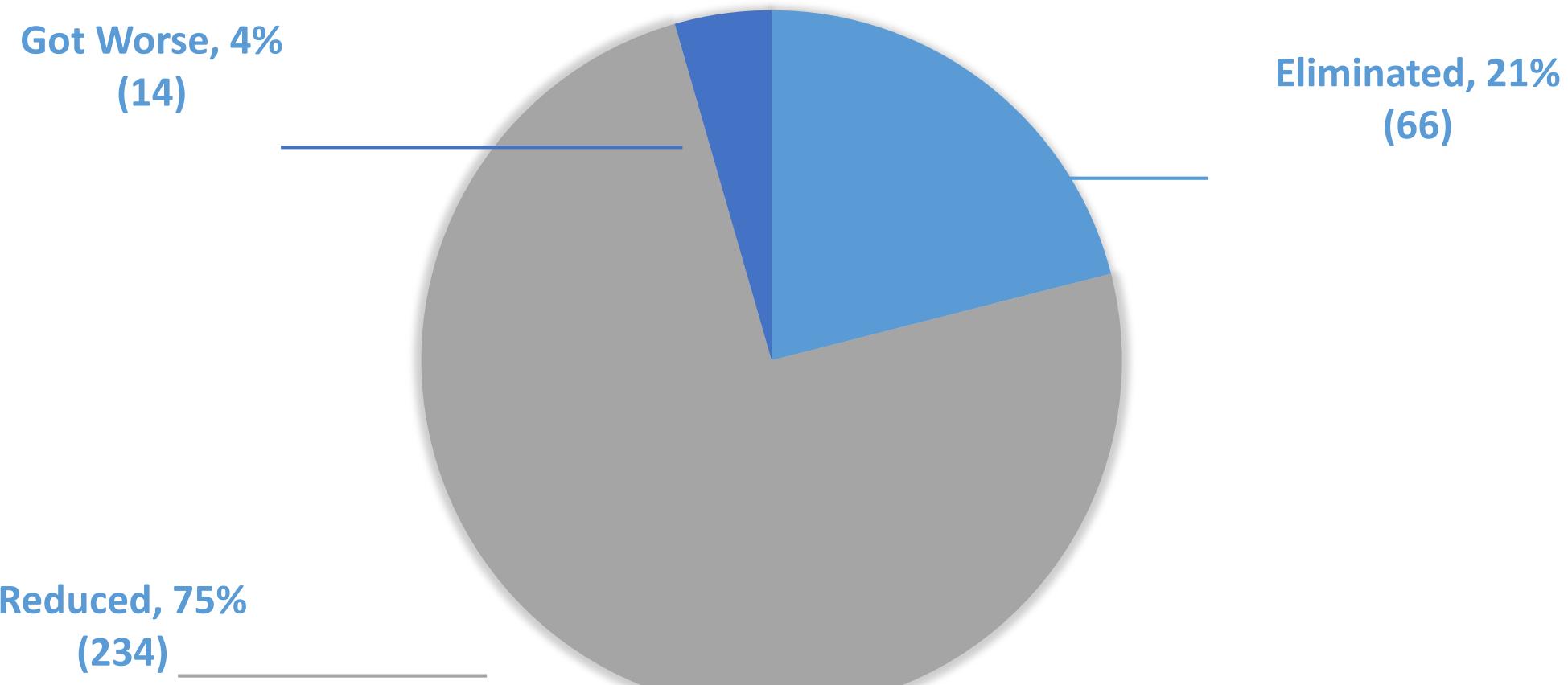
Caregiver Concerns

Taking care of self, handling care coordination, communicating with family members, feeling overwhelmed, and understanding/accepting dementia

Daily Activities

Assisting the person with dementia with self-care activities (e.g. bathing, dressing, grooming), and other daily activities (e.g. medication management, financial management, meal preparation)

Level of Resolution of Problems at End of COPE-Connecticut by % Problems (N=314)





COPE Trial Outcomes

For Persons Living with Dementia

Enhanced activity engagement

Improved quality of life

For Caregivers

Improved Caregiver confidence

Reduced targeted problem area

Reduced physical dependence

Improved caregiver wellbeing

Less Upset

And for Health Systems, cost savings

Select sources: Gitlin et al., 2010; Fortinsky et al., 2020

Tailored Activity Program (TAP)

An evidence-based program that improves quality of life of people living with dementia and their caregivers.

It uses activities tailored to abilities and interests of people living with dementia, instructs caregivers in setting up and using activities, and provides disease education and stress reduction techniques.



Tailored Activity Program (TAP) is Local and Global



TAP
ADAPTED
FOR AND
TESTED IN
Different
SETTINGS
and around
the World

Hospitals



Homes



Adult Day Services



Residential Facilities

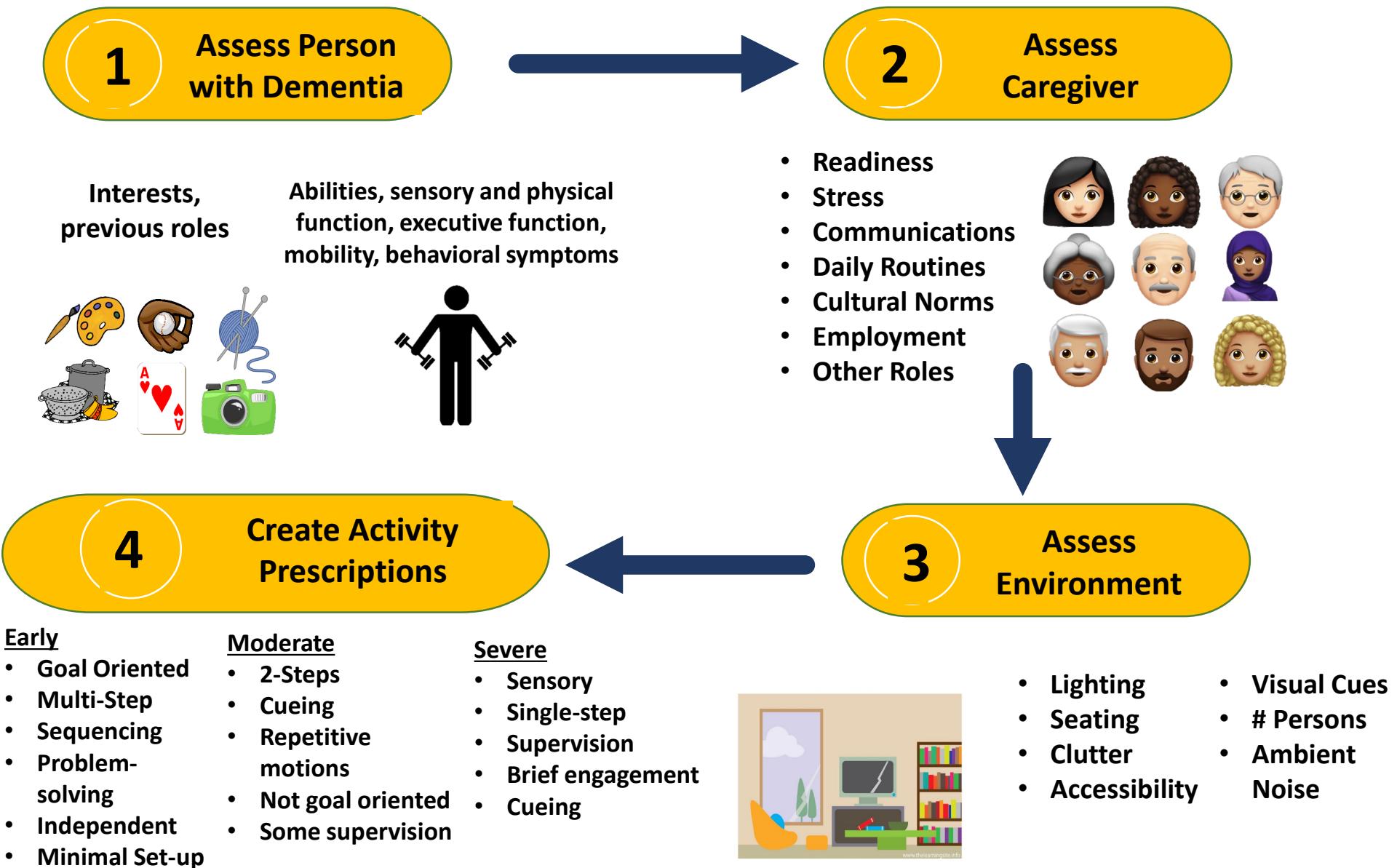


WHY ACTIVITY?

- It matters to people and caregivers
- Associated with life quality
- Lack of activity associated with behavioral and psychological symptoms
- Provides sense of purpose, connectivity, a role, relief from situational stress and anxiety
- May have physiological benefits



Phase I of TAP





Phase II = Instruct Caregivers in Use of Activities

Caregiver learns person's capabilities,
activity is demonstrated, and
activity prescription provided



Caregiver learns stress reduction
techniques, tries activities &
adjustments made if necessary



Phase III = Generalization

Caregiver learns to modify activities for future declines and how to use strategies
(communication, simplification) for other care challenges



For Caregivers

More time
for self

Improved
caregiver
wellbeing

Improved
Caregiver
confidence

For Persons Living with Dementia

Reduced
behavioral
symptoms

Reduced
physical
dependence

Fewer
health
events

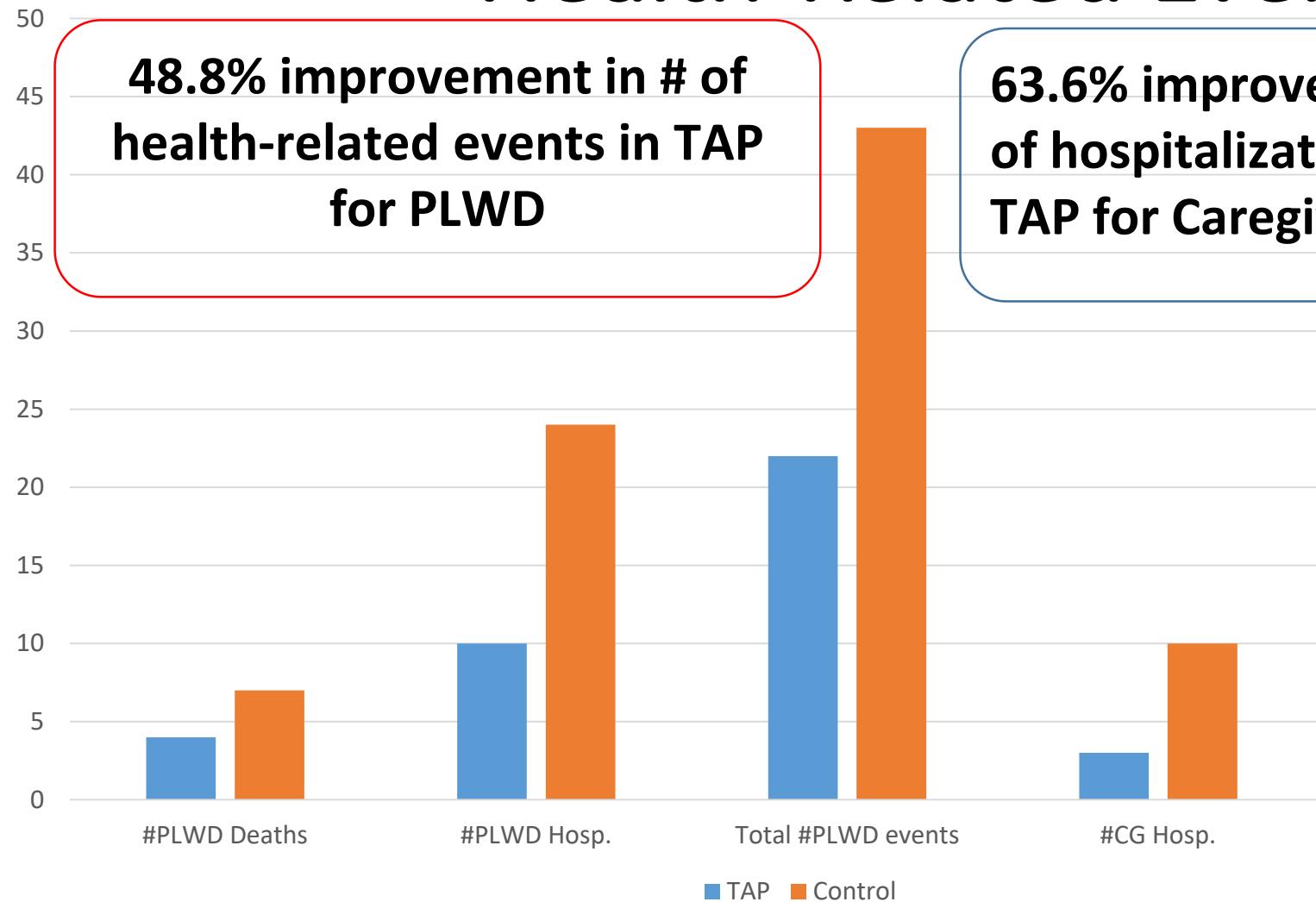
Improved
quality of
life

And for Health Systems, cost savings

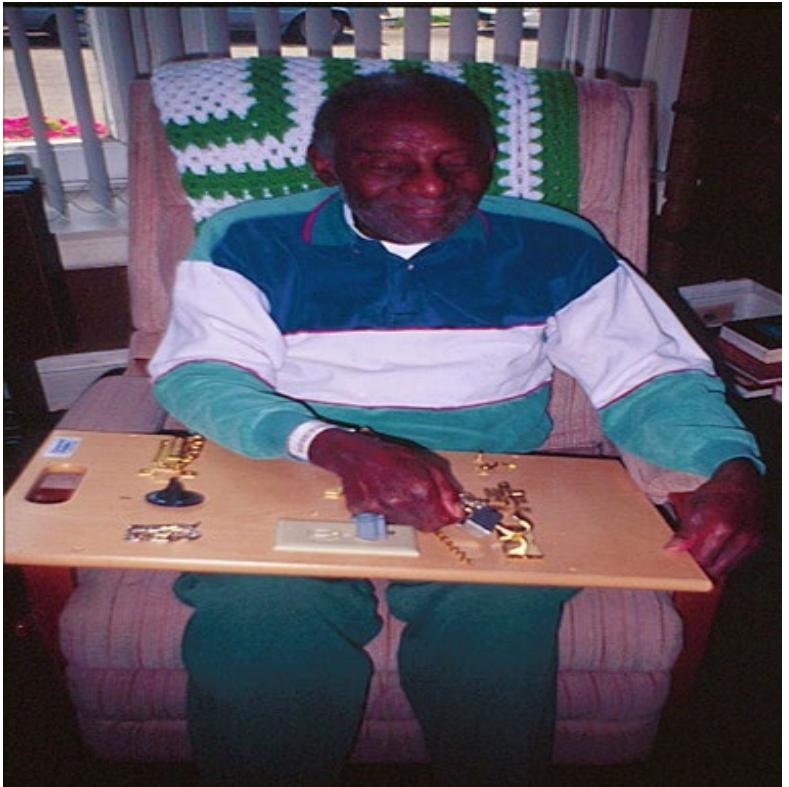
Select sources: Gitlin et al., under review; Gitlin et al., 2008; 2010; 2014; 2017; Novieli et al., 2018; O'Connor et al., 2017)

Tailored Activity Program (n=250; Gitlin et al., under review)

Health-Related Events



Activities





Best Practices for People Living with IDD and Dementia



Strength-based

- Identify what a person can do and build on strengths
- Optimize environments to support daily function and activity engagement
- Attend to preferences and values

Support of quality of life

- Prevent excess disability
- Maintain function
- Predictable routines
- Support activity engagement (purpose, meaning, roles)

Caregiver (staff; family) training

- Communicating effectively
- Setting up activities
- Dementia (Behaviors not intentional)

Multi-component

- Tailoring to needs
- Targeting care challenges
- One size does not fit all
- Education, skills training, coping, environmental simplification, activity engagement

Best Practice

Assess

- Strengths/Deficits
- Behaviors, Function
- Interests, Preferences
- Previous roles
- Environment
- Unmet needs

Implement

- Strategies tailored to care challenge and living context
- Communication
- Cueing
- Establish routines
- Meaningful activities
- Environmental simplification

Evaluate

- What works/what does not
- Simplification of tasks, communications, environment
- Prepare for future declines
- Repeat assessments with change in abilities

Enhancing Clinical Significance: Who and What to Target

Family, staff-
identified need or
care challenge

Depression/burden

Communication
styles

Number of hours
providing care

Behavioral
symptoms

Excess disability

Poor relationship

Considerations in Tailoring

Caregiver readiness

Caregiver styles (Leggett et al, 2021):

- Externalizer- symptoms of dementia volitional; responds with frustration and anger
- Doer- view only one solution forward
- Learner- approaching adaptability but keep getting stuck
- Adapter – use trial and error & keeps trying
- Cheerleader- other-focused; express positive emotions

Risk profiles

Culture, care preferences, values

Resources, Environmental context

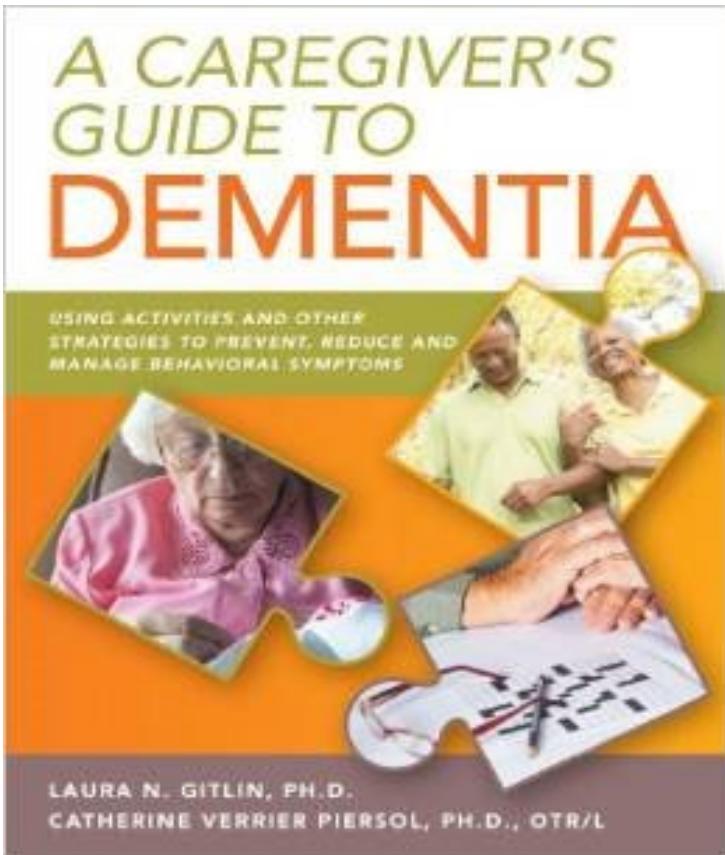
Take Home Points

- Adapt evidence for people with IDD and dementia
- Nonpharmacological strategies are front line
- “Many ways to Many” – one size does not fit all
- No one “magic pill”
- Considerations include disease trajectory, etiology, life course, familial and living context, unmet needs, pre-morbid abilities, interests
- Evidence for multi-component approaches
- Principles for intervening:
 - Person/family centered
 - Tailoring, consideration of preferences
 - Problem-solving



Resources for Families and Health Providers

“Sometimes you just need a checklist.” (Washington Post)



Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies

Massive Open Online Course (MOOC)



Drs. Nancy Hodgson and Laura Gitlin lead the MOOC, an international educational forum for health professionals, students, family caregivers, and anyone affected by dementia.

ON DEMAND

SIGN UP TODAY! www.coursera.org/course/dementiacare

https://www.amazon.com/Caregivers-Guide-Dementia-Activities-Strategies/dp/1933822902/ref=sr_1_1?s=books&ie=UTF8&qid=1454599837&sr=1-1&keywords=gitlin+and+piersol

Better Living With Dementia

Implications for Individuals, Families, Communities, and Societies



<https://www.amazon.com/Better-Living-Dementia-Implications-Individuals-ebook/dp/B07DLRQY4G>