Consumer-Directed Care Models

Julie Robison, PhD
University of Connecticut

RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports

#DementiaCareSummit

How Consumer-Direction Works for People with Dementia

Most states offer consumer-direction options

- flexible choice of services, who delivers them & when
- manage individual budgets

Variety of assessment processes to determine

- capacity to self-direct
- which tasks need assistance

Variety of rules for who can be a representative

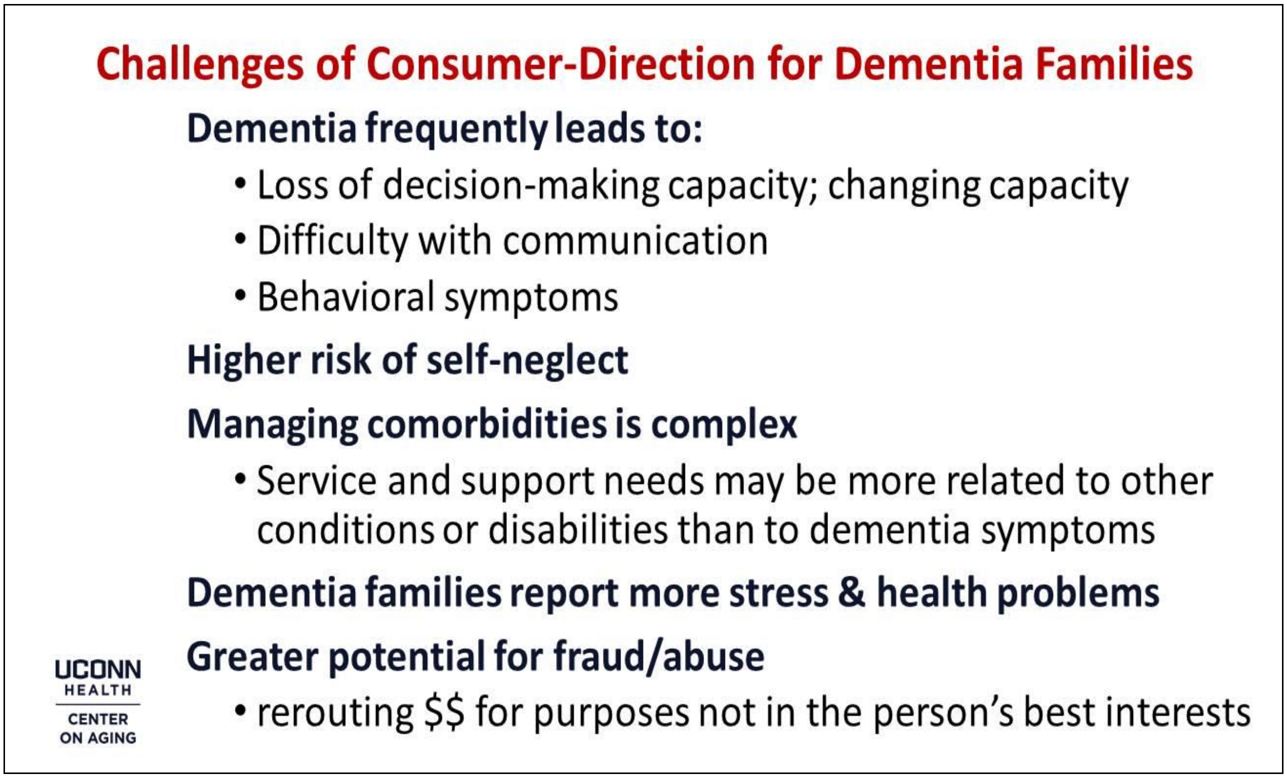
- do/do not allow paid caregiver

"Dignity of Risk"

- Risk assessment and signed risk agreements

Quality monitoring at varied intervals

UCONN HEALTH
CENTER ON AGING



Challenges of Consumer-Direction for Dementia Families

Dementia frequently leads to:

- Loss of decision-making capacity; changing capacity
- Difficulty with communication
- Behavioral symptoms

Higher risk of self-neglect

Managing comorbidities is complex

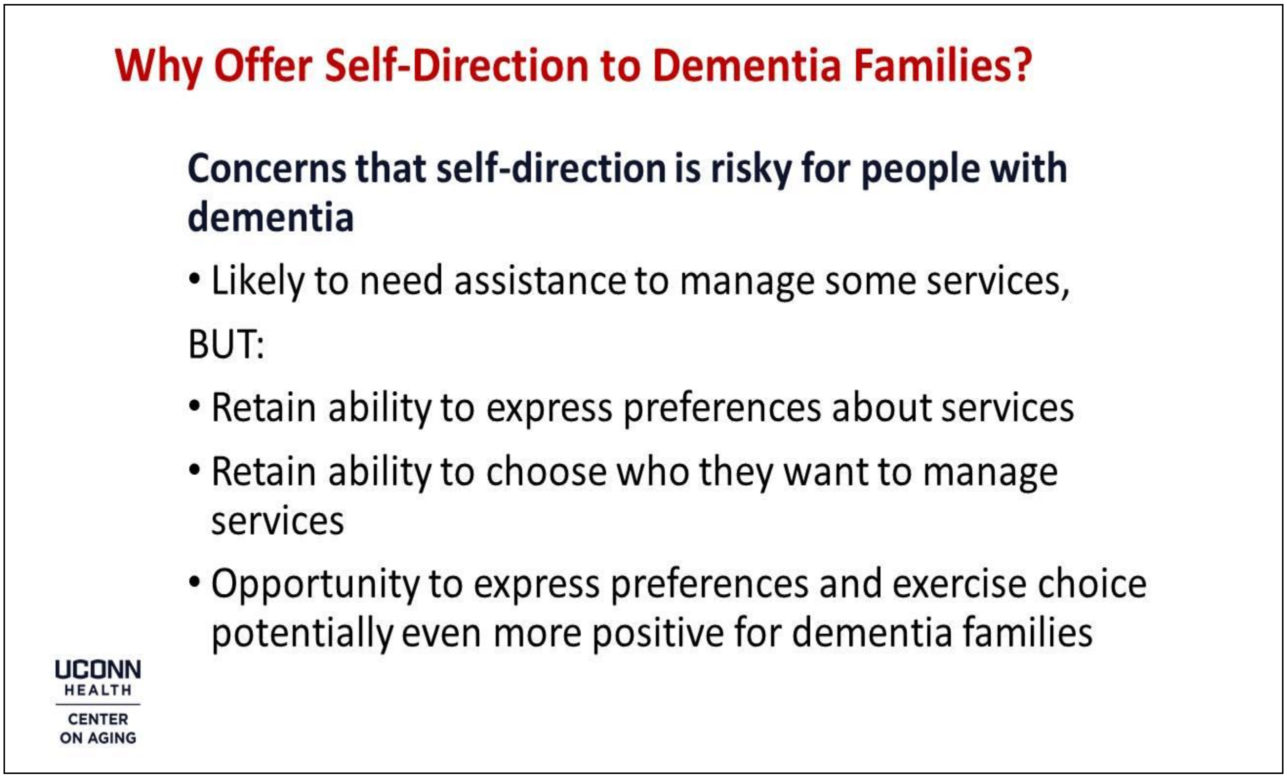
- Service and support needs may be more related to other conditions or disabilities than to dementia symptoms

Dementia families report more stress & health problems

Greater potential for fraud/abuse

- rerouting $$ for purposes not in the person's best interests

UCONN HEALTH
CENTER ON AGING



Why Offer Self-Direction to Dementia Families?

Concerns that self-direction is risky for people with dementia

- Likely to need assistance to manage some services,

BUT:

- Retain ability to express preferences about services
- Retain ability to choose who they want to manage services
- Opportunity to express preferences and exercise choice potentially even more positive for dementia families

UCONN HEALTH
CENTER ON AGING

What we know about Consumer-Direction, in general

Consumer-direction participants and families do better…

- Quality of life, independence, satisfaction with care
- Equal or better quality of care, less abuse/neglect
- Families reduce time caregiving, report less strain

Well-established consumer-directed programs operate for others with reduced cognition

- ID/DD, Serious Mental Illness

UCONN
HEALTH
CENTER
ON AGING

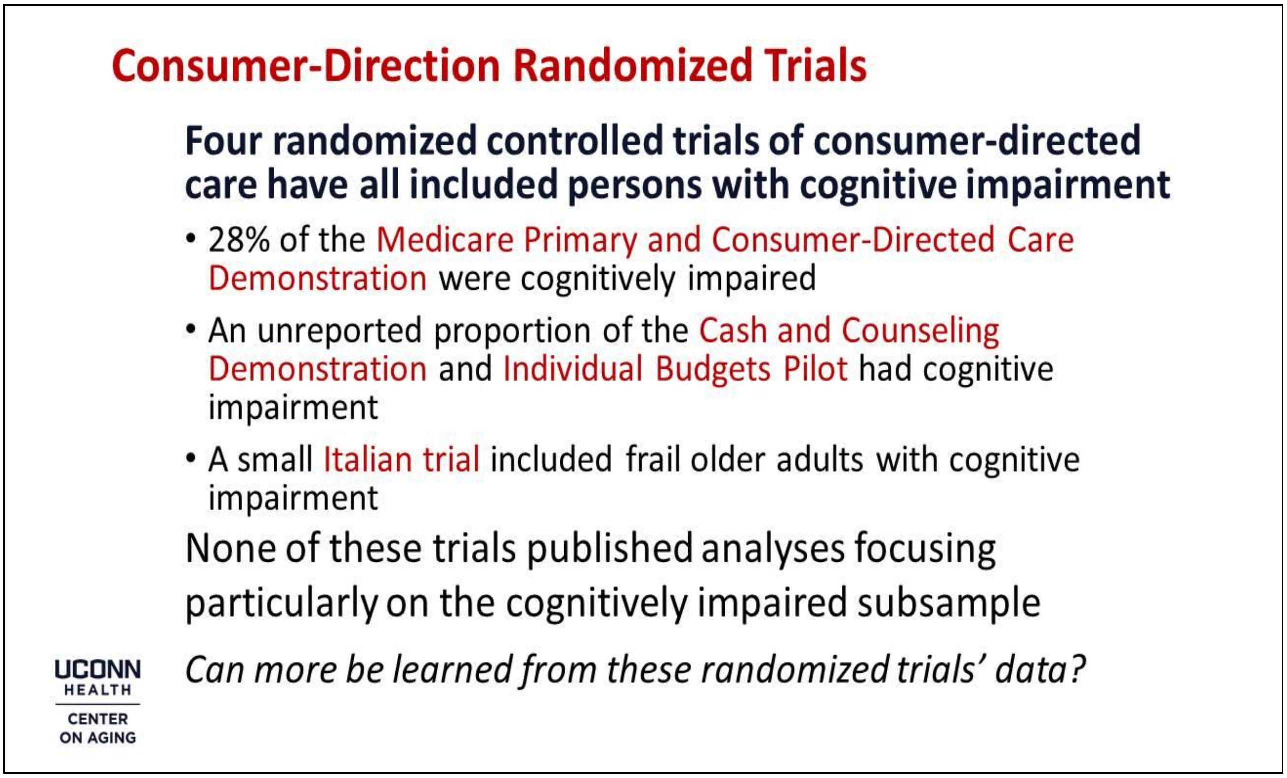
Gaps in Knowledge

Philosophy is well-articulated; model benefits found in general; not studied in dementia participants specifically

Practical implementation remains challenging

- Cognition tests don't translate into specific service needs
- Decision-making supports and guidelines are needed
- Characteristics of dementia families best suited to handle the demands of consumer-direction are not known
- Many have no available families/dysfunctional families
- What can be learned from ID/DD programs and research?

UCONN
HEALTH
CENTER
ON AGING



Consumer-Direction Randomized Trials

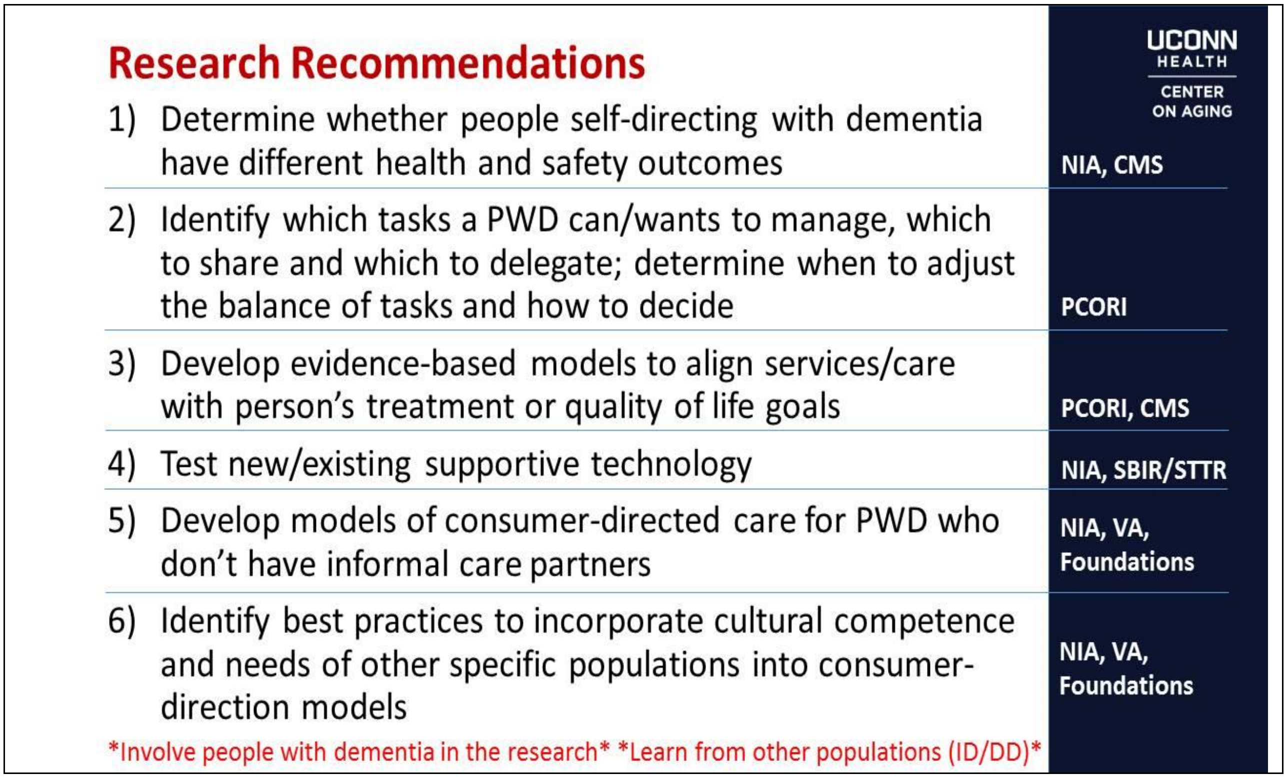
Four randomized controlled trials of consumer-directed care have all included persons with cognitive impairment

- 28% of the Medicare Primary and Consumer-Directed Care Demonstration were cognitively impaired
- An unreported proportion of the Cash and Counseling Demonstration and Individual Budgets Pilot had cognitive impairment
- A small Italian trial included frail older adults with cognitive impairment

None of these trials published analyses focusing particularly on the cognitively impaired subsample

Can more be learned from these randomized trials' data?

UCONN HEALTH CENTER ON AGING



Research Recommendations

UCONN HEALTH CENTER ON AGING

1) Determine whether people self-directing with dementia have different health and safety outcomes	**NIA, CMS**
2) Identify which tasks a PWD can/wants to manage, which to share and which to delegate; determine when to adjust the balance of tasks and how to decide	**PCORI**
3) Develop evidence-based models to align services/care with person's treatment or quality of life goals	**PCORI, CMS**
4) Test new/existing supportive technology	**NIA, SBIR/STTR**
5) Develop models of consumer-directed care for PWD who don't have informal care partners	**NIA, VA, Foundations**
6) Identify best practices to incorporate cultural competence and needs of other specific populations into consumer-direction models	**NIA, VA, Foundations**

Involve people with dementia in the research *Learn from other populations (ID/DD)*