Consumer-Directed Care Models

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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
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

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
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

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?
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?*

Research Recommendations

1) Determine whether people self-directing with dementia have different health and safety outcomes

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

3) Develop evidence-based models to align services/care with person’s treatment or quality of life goals

4) Test new/existing supportive technology

5) Develop models of consumer-directed care for PWD who don’t have informal care partners

6) Identify best practices to incorporate cultural competence and needs of other specific populations into consumer-direction models

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