

# Caregiving for People with Dementia and Intellectual Disabilities such as Down Syndrome

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National Task Group  
on Intellectual Disabilities  
and Dementia Practices

# Lifelong vs. Late Life Disability

Disability can be the function of

- Developmental disability
  - *Conditions present before the age of 22* (intellectual disabilities, sensory impairments, physical disabilities, psychiatric impairments, etc.)
- Late life impairment
  - *Conditions resulting from injury, disease, decline or other factors later in life* (Cognitive decline, injury resulting in physical or sensory impairments, mobility impairments, etc.)

Also, secondary conditions may occur in either group and doubly impact people

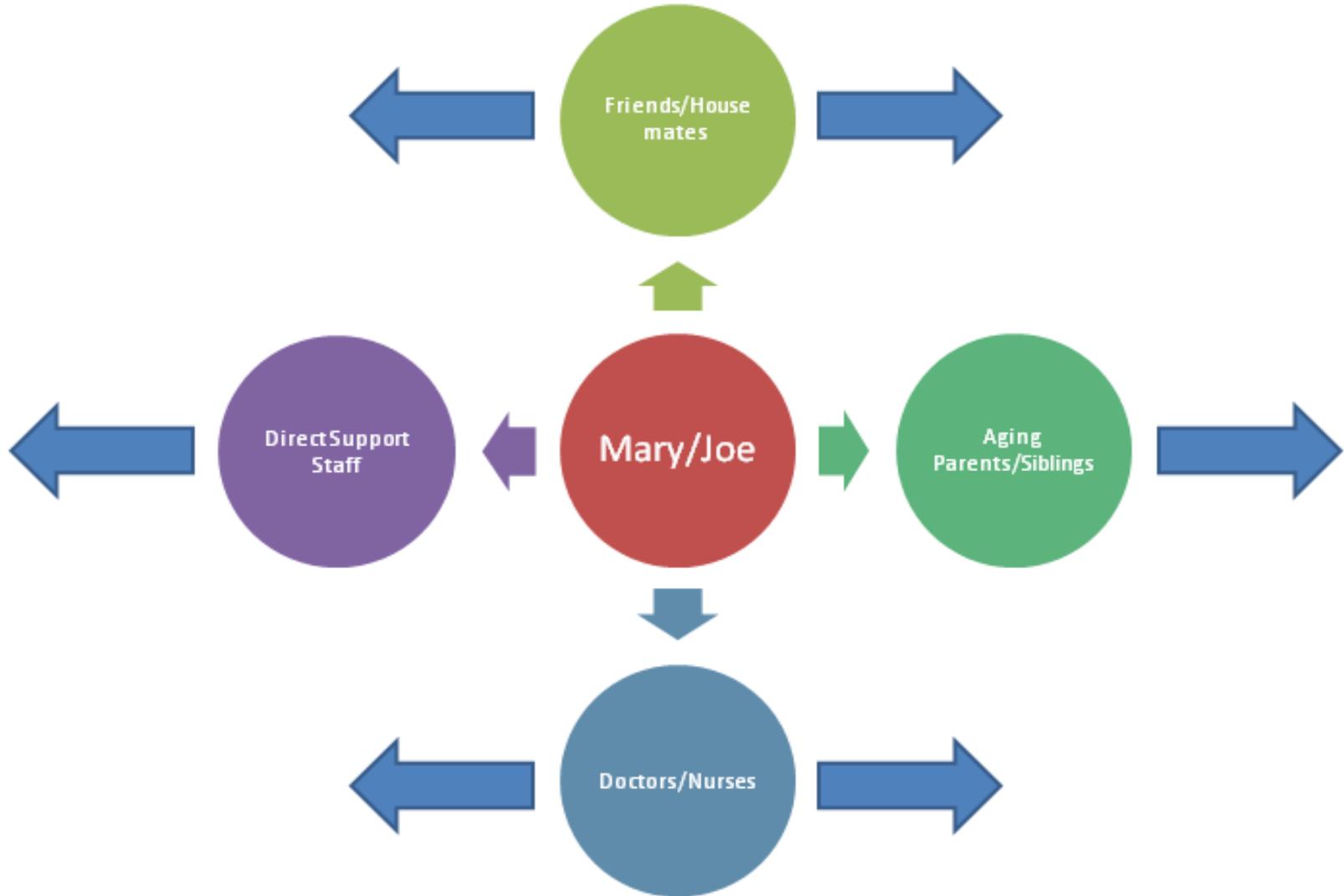
# Intellectual Disabilities (ID) and Dementia

- Increased life expectancy in the ID population is the result of constructive public policies, more focus on health and better community support services
- Greater numbers of aging people are result of 'baby boom' cohort, and increased life expectancy including those with ID
- The population of persons with ID and dementia will double in the next twenty years.

# Down Syndrome and Dementia

- It is estimated that 6% of adults with an ID will be affected by some form of dementia after the age of 60 (with the percentage increasing with age).
- There is a genetic propensity for adults with Down syndrome to develop early onset Alzheimer's disease.
- For adults with Down syndrome, studies show that at least 25% will be affected with dementia after age 40 and at least 50 to 70% will be affected with dementia after age 60.
- A significant percentage of the older ID population will be adults with Down syndrome, who usually make up about 10% of most ID providers' service populations of adults age 40 and older.

# The Ripple Effect



# ‘Aging in Place’: Goals

- What is ‘aging-in-place’ for people with ID and dementia and their families?
- What do we consider best practices?
- Supporting family caregivers
  - Recognize the challenges faced by the aging caregiver
  - Support sibling and parent care providers
- Change of care focus
  - Going from making gains to that of maintaining as much function as possible and dealing with eventual loss and decline
- Develop and emulate current models of care that anticipate the increasing support needs as dementia progresses

# What kinds of services are needed for aging people with ID and Dementia?

- Supports for continued living with families when available and appropriate
- Engaging activities in community settings
- Health reviews and surveillance
- Appropriate screening and assessments for aging-related conditions
- Health maintenance – nutrition and exercise
- Supports for ‘dementia-capable’ care in community care settings that can change as the disease progresses; including education and training

# Community Care Needs of Adults with ID and Dementia

- Dementia is a condition that lessens an individual's ability to self-direct and be left alone – thus long-term living on ones' own may not be an option as the disease progresses.
- What are the needs?
  - In home supports (to family caregivers and the person)
  - Advanced planning for alternative care
  - Diagnostic, medical and behavioral health care
  - Support groups for caregivers (family or staff)
  - Dementia capable community housing
  - Day care programs and respite for family caregivers

# Ensuring Healthier and Productive Aging for People with ID and Dementia

- Promote a better understanding of people aging with ID and dementia and their needs
- Work to make communities “disability friendly”
- Assure that services and supports have “quality” as a defining factor
- Promote greater education of personnel
- Involve people with ID and dementia in decision making
- Ensure availability of dementia capable community services and assistance for families

# Dementia Capable Services

- Identification of persons who have ID and dementia
- Staff Education and Training
  - Retain, educate, support staff and families
- Data collection
- Flexibility, stage related anticipatory guidance
- Communication amongst person with ID, family caregivers, care staff and providers
- Ensuring access to quality medical and behavioral health services
- End of life and palliative care
- Outcome assessments

# Benefits of Early Diagnosis

- Manage symptoms of dementia
- Maintain daily activities to the extent possible and preserve quality of life
- Anticipatory guidance
- Help offset caregiver stress
- Maintain 'aging-in-place,' whenever possible and appropriate

# Screening

- Who can do the screening?
- Where to get help with diagnostics?
- What the are the questions to ask?
- What to do with the outcome of the screening?
- What to do with the outcome of the diagnostic event?
- Who to tell?

# Outcomes

- Daily activities and quality of life
- Effects of behavioral and pharmacologic therapies
- Reduce possible LTC placement
- Reduce secondary health consequences including falls, injuries, emergency department/hospital care, polypharmacy
- Challenging behaviors
- Prevention and awareness of abuse and neglect
- Supports for families and care providers
- Research
- Economics of care and supports

# Telehealth

- Technology to maintain community living and person-centered services
- Data collection and sharing of information
- Integration of care
- Improvements in care outcomes
- Cost savings analysis

# Methods of Supporting families

- Identifying people with Down Syndrome to help plan for eventual needs
- Covering family support services
  - Respite, home aide supports, environmental modifications, day services, etc.
- Specialized training for state and/or caregiver program Staff
  - National Family Caregiver Support Program

# Examples of Community Supports

- Community support provider agencies
  - Private/parent based (e.g., Arc chapters)
  - Public – state/local government entities
- Area Agencies on Aging (AAAs)
  - Aging and Disability Resource Centers (ADRCs)
- Alzheimer's Association chapters
  - Other local dementia care groups
- State and local Protection and Advocacy Networks
- Faith-based organizations
- Statewide or Community-based Respite/Caregiver Coalitions

# Examples of Organizational Supports

- Administration on Community Living <http://www.hhs.gov/acl/>
  - Administration on Aging <http://www.aoa.gov/>
  - Administration on Intellectual and Developmental Disabilities <http://www.acf.hhs.gov/programs/aidd/>
- State Planning Councils on Developmental Disabilities <http://www.nacdd.org/site/home.aspx>
- University Centers for Excellence in Developmental Disabilities Education, Research & Service <http://www.aucd.org/>
- Alzheimer's Association [www.alz.org](http://www.alz.org)
- National Down Syndrome Society/ National Down Syndrome Congress <http://www.ndss.org/> <http://ndsccenter.org/>
- National Task Group on Intellectual Disabilities and Dementia Practices <http://www.aadmd.org/ntg>

# Rehabilitation Research and Training Center on Aging and DD at UIC; UCEDD

- NIDRR funded (5 year) center that specializes in issues related to the aging of people with I/DD
- It conducts research, provides training and technical assistance, and is involved in a range of other activities (such as training students, etc.)
- The RRTC has been instrumental in its work on research with families, problems facing elderly persons with I/DD (such as falls, obesity, dementia), and enabling self-advocates to have a voice in aging planning and services development.
- Studies related to dementia included looking at comorbidities and health status, community program options - particularly specialized group homes, and providing information.

<http://www.rrtcadd.org/>

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