Older Adults with Intellectual and Developmental Disabilities

A Joint Webinar Presented by UnitedHealthcare & National Association of Councils on Developmental Disabilities (NACDD)

May 13, 2015

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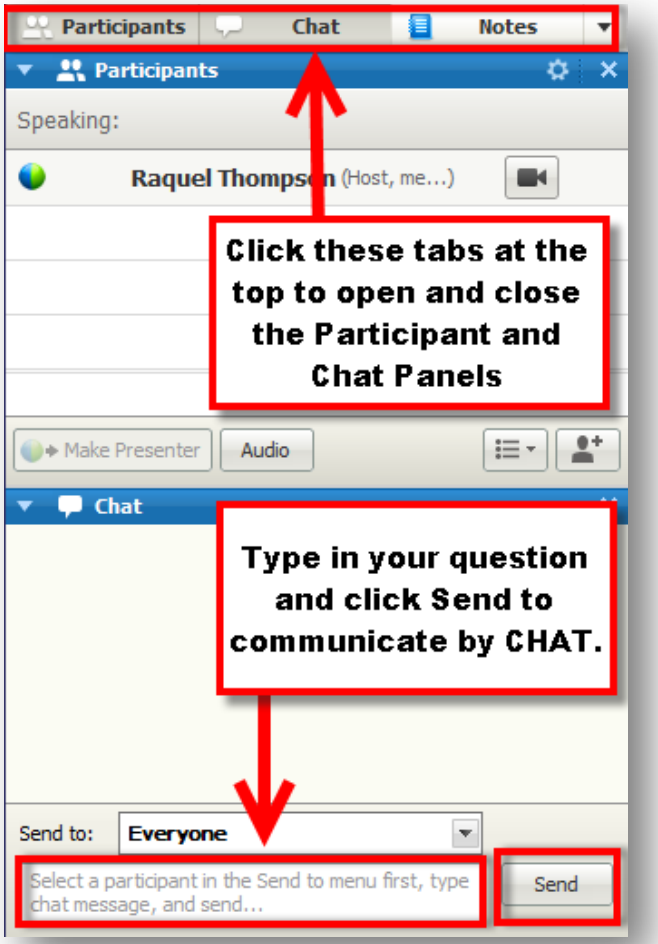

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Welcome and Thank You

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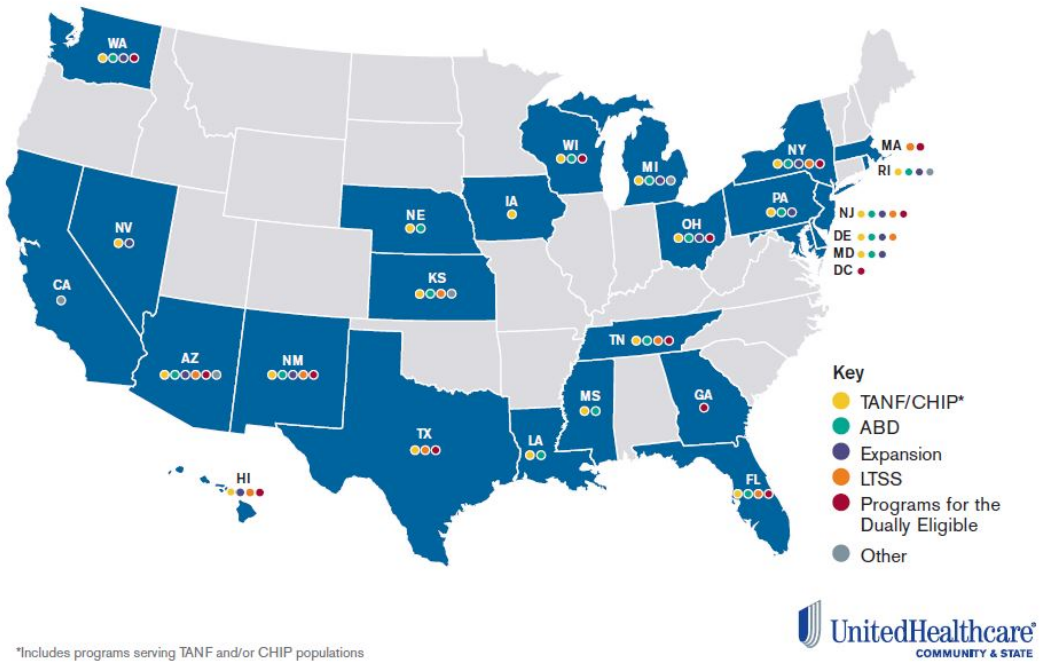
UnitedHealthcare Community & State Background

- We are the part of UnitedHealthcare that focuses on providing services to individuals who are eligible for Medicaid
- We contract with 23 states to manage Medicaid services to eligible individuals
- In 11 states we managed long term supports and services
- Additionally, we provide Medicare plans for individuals who are Medicare and Medicaid eligible in 14 states



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DONNA MELTZER

Donna Meltzer is CEO of the National Association of Councils on Developmental Disabilities (NACDD), a national nonprofit organization that supports the nation's 56 governor-appointed DD Councils that work within state government to promote independence, productivity, and integration of people with disabilities through systems change activities. Previously she held the titles of Senior Director of Government Relations for the Epilepsy Foundation and Legislative Director of the Association of University Centers on Disability. She previously served a three-year term as Chair of the Consortium for Citizens with Disabilities (CCD). She is currently President-elect of the Coalition for Health Funding and a member of the board of advisors of RespectAbility.

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Agenda

- Overview of Aging and Intellectual and Developmental Disabilities
- Overview of Health Care Considerations for Aging and Intellectual and Developmental Disabilities
- Case Study: Maine Developmental Disabilities Council Study of Aging and Developmental Disabilities
- Question & Answer Panel

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Matthew P. Janicki, Ph.D. is research professor of human development at the Department of Disability and Human Development at the University of Illinois at Chicago, and serves as director for technical assistance for the Rehabilitation Research and Training Center in Developmental Disabilities and Health at the University. He is the author of numerous books and articles in the area of aging, dementia, public policy, and rehabilitation with regard to people with intellectual and developmental disabilities and has lectured and provided training in aging and intellectual disabilities across the world. Janicki serves as co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices.

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Aging and Intellectual and Developmental Disabilities Overview

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- Want do we mean by intellectual and developmental disabilities?

- What supports are needed when people with intellectual and developmental disabilities age?

- How do we connect the dots… bridging all those good folks who provide supports?

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WANT DO WE MEAN BY INTELLECTUAL AND DEVELOPMENTAL DISABILITIES?

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Definitions matter

- Who can be served?
- Who sets the criteria for being served?
- Who funds those who are served?

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Intellectual disability

Intellectual disability … characterizes adults who:

- have intellectual limitations that significantly limit their ability to successfully participate in normal day-to-day activities – such as self care, communication, work, or going to school, and
  - evolved or developed their intellectual limitation during the 'developmental period' (before approximately age 22), and
  - their limitations are anticipated to result in long term adaptive or functional support needs, and/or
- are eligible for State or Federal public support programs because they have been diagnosed as having an intellectual disability

Developmental disabilities

- Many conditions may originate prior to birth, in early infancy or during childhood, or before brain maturation (usually in the late teens)
  - Some impair senses, cognition, mobility, or severely compromise health and function

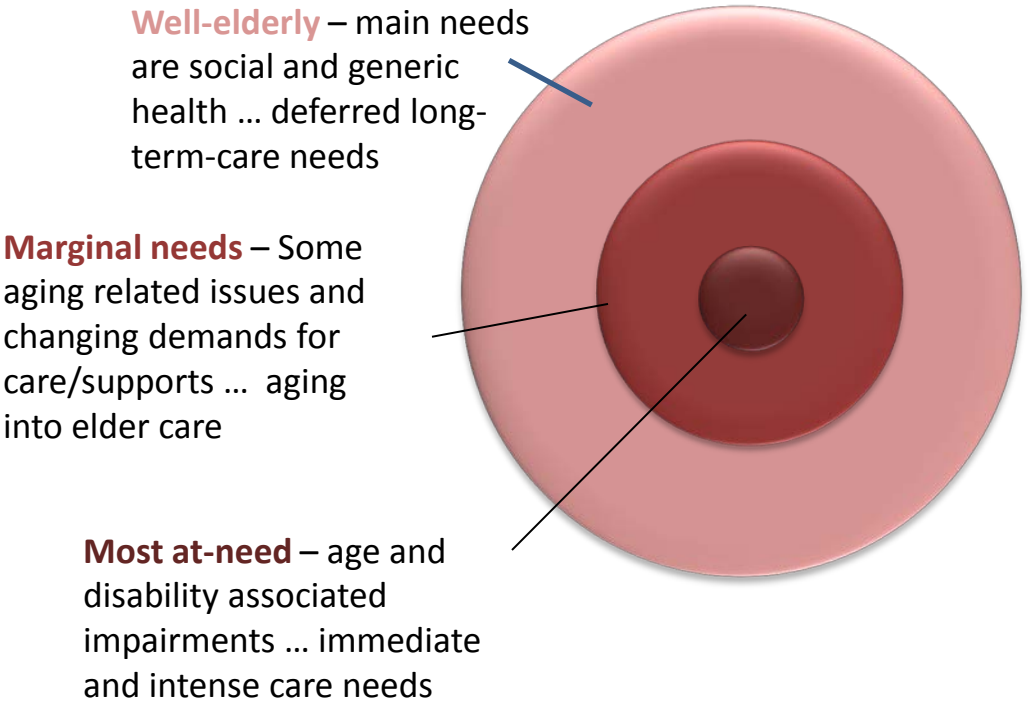
- An **intellectual disability** impairs cognitive and personal function (self-direction and self-care) over a lifetime
- A **development disability** (which may include an intellectual disability, but does not always imply intellectual impairment) impairs normal growth, development, and function over a lifetime
  - Categorical vs. functional -- neurodevelopmental conditions

- In some jurisdictions these terms are used interchangeably. In some, only specific conditions are included under the terms

- Definitions provide for eligibility… eligibility provides for funding
  - Those that fund provide the definitions - state vs. federal

Older people with ID with various levels of need

- Older adults lacking notable health problems
- Older persons with coincident issues
  - Older frail persons
  - Older adults with sensory impairments
  - Older adults with cognitive pathologies
  - Older adults with profound and multiple disabilities
  - Older adults with major psychiatric co-conditions



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What defines ‘aging’?

- Biological aging?
- Social aging?
- Chronological aging?
- Political definitions? OAA, Social Security, AARP
- Early aging? Down syndrome
- Genetics? Werner’s syndrome

WHAT SUPPORTS ARE NEEDED WHEN PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AGE?

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Impact of aging

- Changes in
  - cognitive capacities
  - physical abilities
  - social support networks
  - financial conditions
  - physical health

• Effects of changes in vision, hearing, mobility, nutrition, medication use, stamina, etc.
• Adaptations to living environment (vision, temperature, grasping, slipping, etc.)
• Losses of family, friends, peers

- Transitioning from work age to 'third age'

- Most older people transition into 'aging' without problems…
  - adults with intellectual and developmental disabilities may enter or re-enter specialized services when they age

Where are older people with intellectual disability?

Most are at home with families

- Greatest needs
  - Helping identify cause of changes
  - Respite and other aids
  - Planning for eventualities
  - Helping families with own aging

Some are on their own

- Greatest needs
  - Identifying that dementia is present
  - Sorting out what natural supports are present
  - Aiding housemates
  - Locating alternative living

Others are in group living settings

- Greatest needs
  - Adapting housing
  - Educating staff
  - Continued follow-along for other conditions

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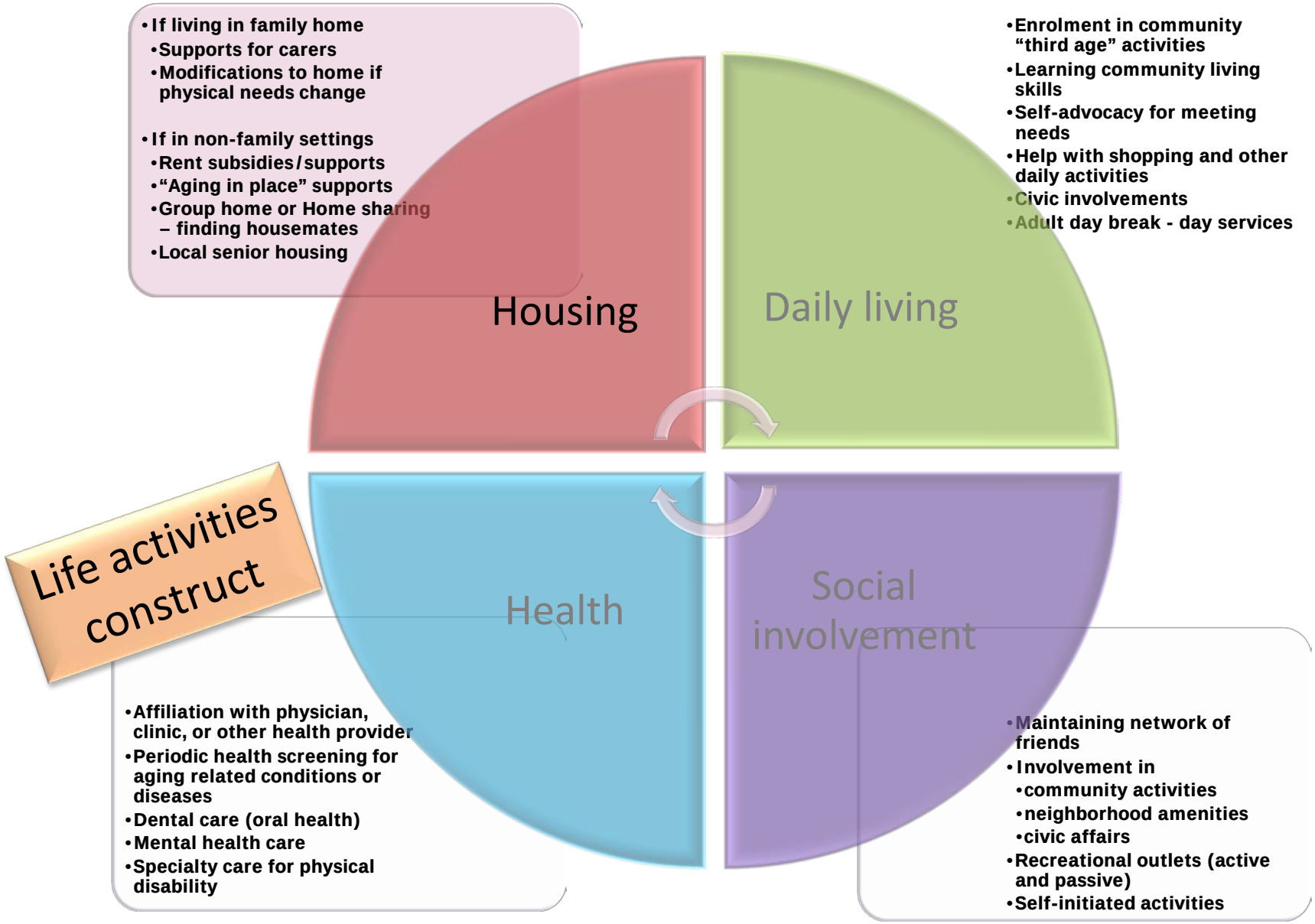
Age-associated issues confronting providers

- Neurodegenerative diseases and conditions
  - Alzheimer's disease and related dementias
- Worsening of secondary conditions
  - Seizures, sensory losses, lifelong health comorbidities
- Mobility/gait impairments
- Cardiovascular and other diseases
- Frailty
- Benign aging / cognitive decline / stamina

Key aging-related community supports for older adults with intellectual disability

- Supports for remaining at-home
- Physical and social barrier removal
- Access to community services for older adults
- Help with financial aid and benefits
- Medical/health services mediation
- Maintaining social supports/networks
- End-of-life supports



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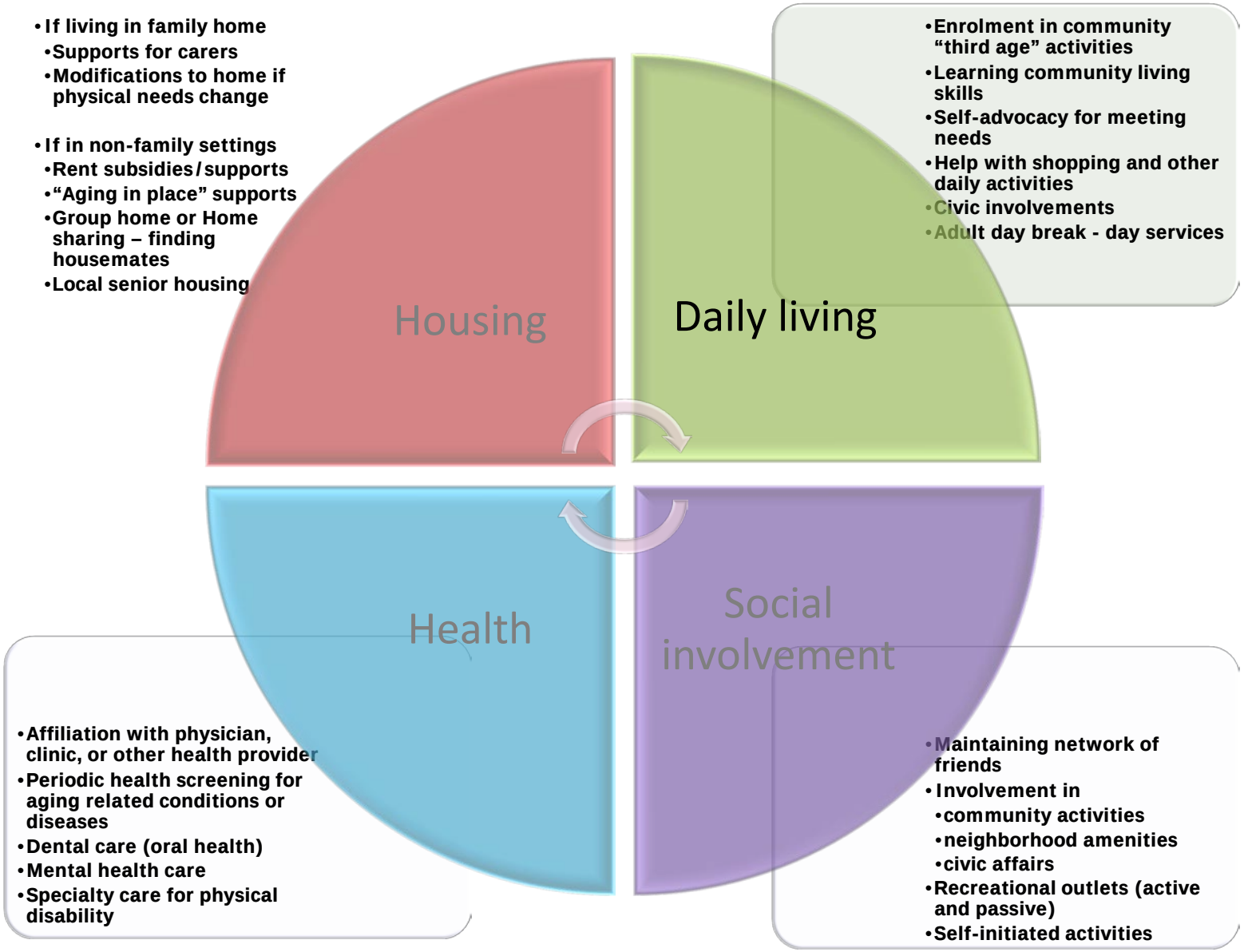

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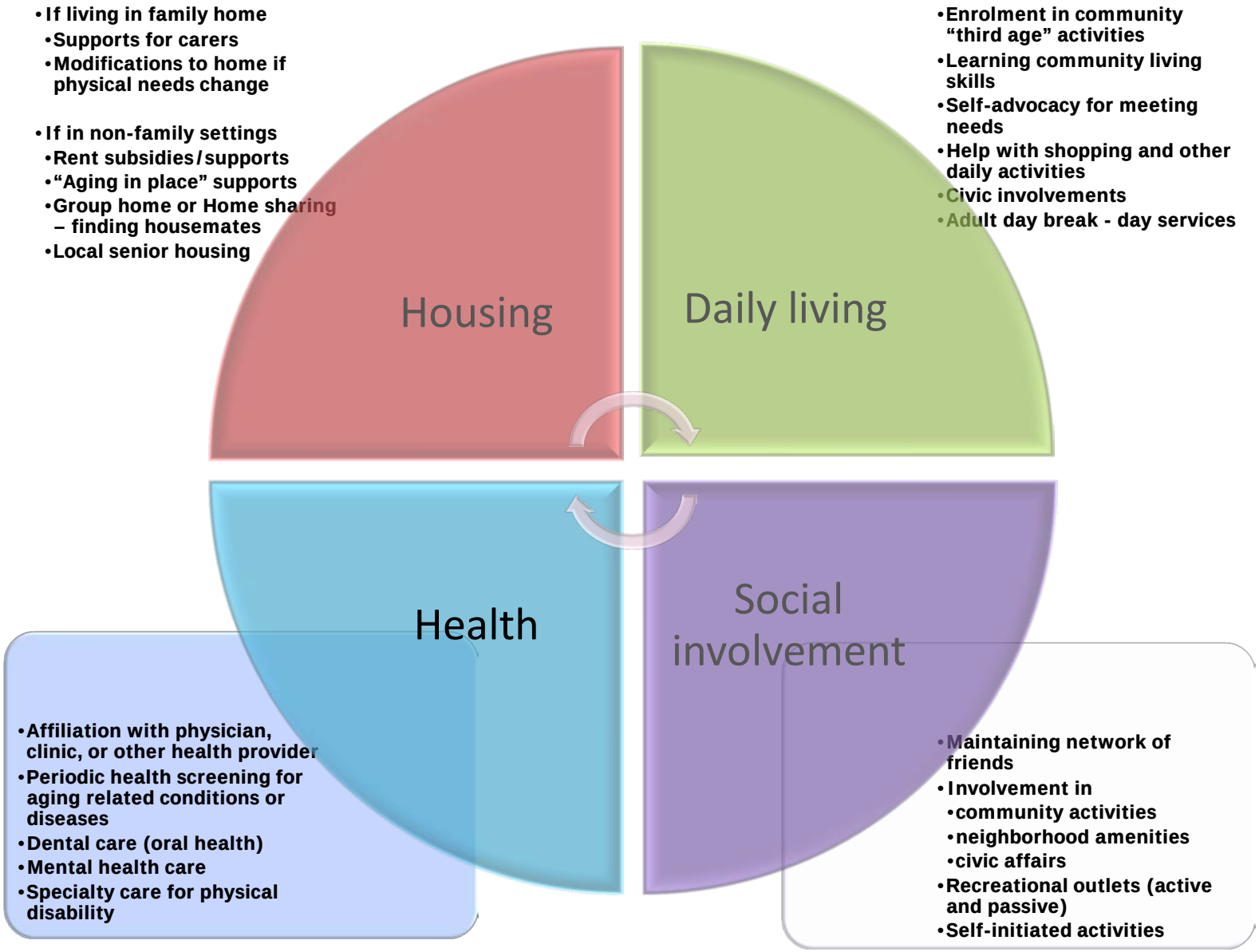

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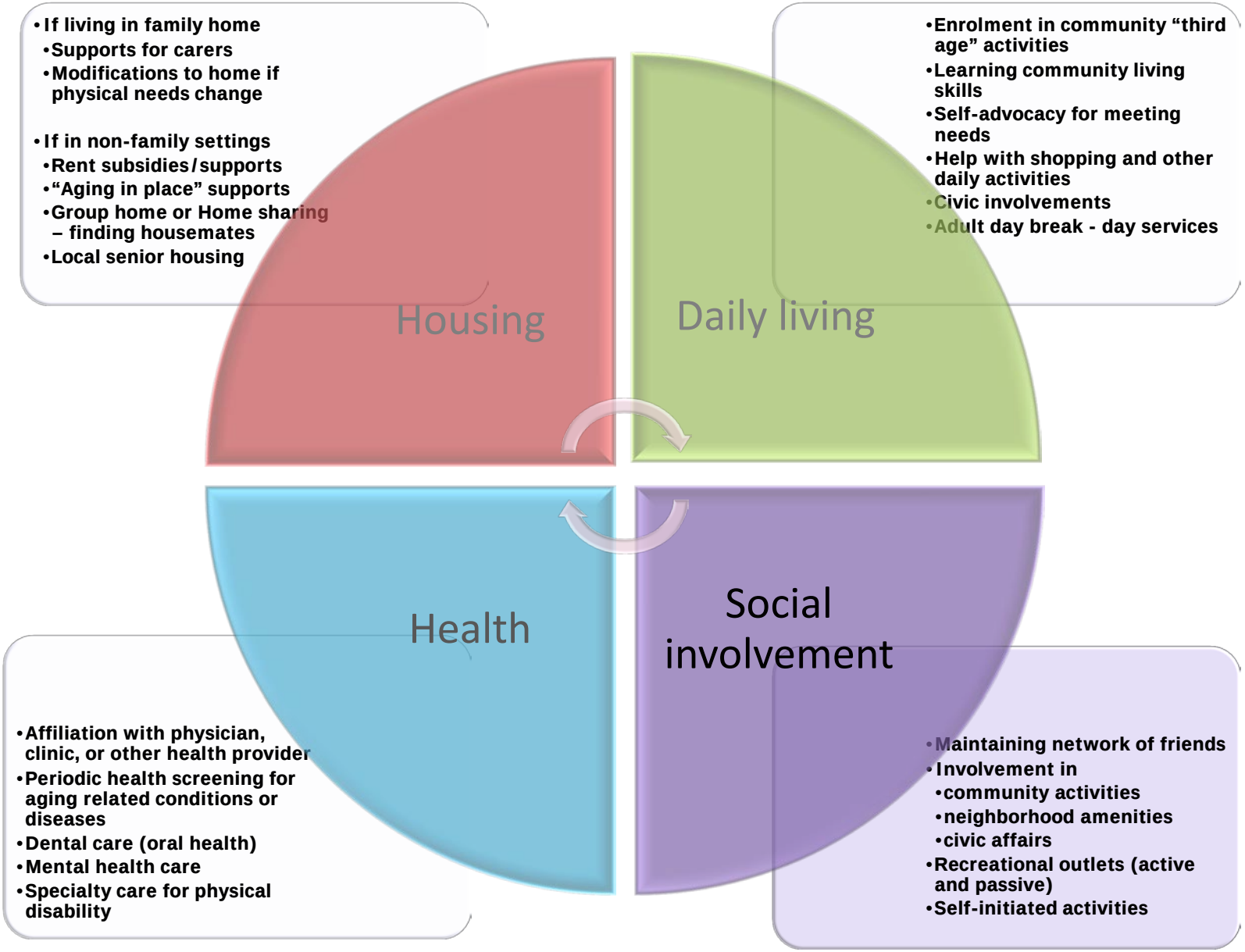

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Focus – family or individual

Helping Families

- Identify what they need
- Provide them with information
- Sort out who could best help
- Link them to the right provider (development disabilities agencies, health services, social services)
- Follow-up to make sure they have gotten what they need
- Shoring-up capacities

Helping Individuals

- Supporting at-home care
- Physical and social barrier removal
- Access to community services for pensioners
- Help with financial aid and benefits
- Medical/health services mediation
- Specialty housing/care for impairing secondary conditions
- End-of-life supports

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HOW DO WE CONNECT THE DOTS… BRIDGING ALL THOSE GOOD FOLKS WHO PROVIDE SUPPORTS?

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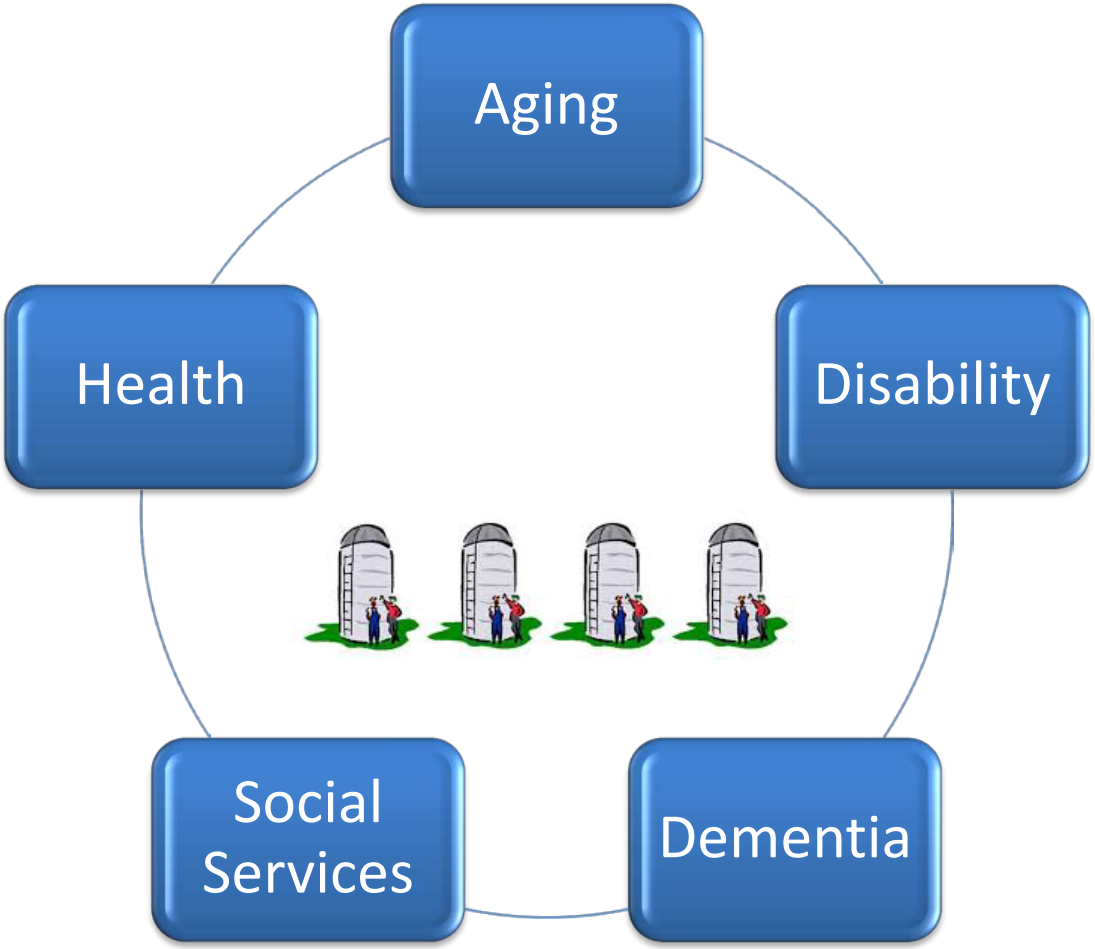
The silos



Focus of supports

Most care/supports for older adults with intellectual disabilities and their families come from developmental disabilities agencies

- When adults have been 'part' of the disability system prior to aging,
  - Services include housing supports, respite for family caregivers, vocational assistance, training of staff, clinical assessments, etc.
- When adults have not been 'part' of the disability system prior to aging, they may get services from
  - Public/social welfare (adult protective services), aging network, health care, and other generic resources

Physical/mental aging supports

- Effective and accessible health services
  - *Ensuring diseases and conditions are caught early*
- Nutrition and exercise
  - *Preventing obesity, deconditioning, and malaise*
- Prevention of secondary conditions
  - *Avoiding additional impairments from occurring*
- Geriatric assessments
  - *Diagnosing ills and physical problems of older age*
- Mental health interventions
  - *Preventing depression and other ills*

- Services and supports are linked to needs
  - in most situations, these are delivered by the most appropriate provider
- Collective delivery of supports is most functional, but not always realistic or practical
- Defining who does what is a good place to start

Aging network

Older Americans Act

- Eligibility
  - Who can get services?
- Structure (SUAs & AAAs)
  - What are the component parts?
  - Local providers
- Availability and accessibility
  - What services are available and where are they?
- Focus
  - Social care –> well elderly
- Other players
  - Long term care
  - Ombudsman
  - Medical supports

Site Services

- Senior centers
  - Vary in nature, clientele, structure and location
- Congregate meals sites
  - Open to all; suggested donation
- Adult day service programs
  - State dependent for operations

Support Services

- Legal & financial counseling
- Home supports
- Home delivered meals
- Ombudsman
- Senior discounts
- Other

- No federal law equivalent in the DD system to that for aging under the Older Americans Act

- The federal Developmental Disabilities Assistance and Bill of Rights Act does not enable or fund state services… it funds:
  - State Developmental Disabilities Planning Councils
  - University Centers of Excellence in DD
  - Protection and Advocacy Services

State Developmental Disabilities System

- All states have a developmental disabilities authority – the 'state agency'
- Set up in state law
  - Generally headed by a designee appointed by governor
  - State bureaucracy that funds and administers services, sets standards, and assures quality
  - Differential eligibility criteria for services
    - Some have a broad definition of who may be served
    - Some have a very narrow definition of who may be served
- Funding provided by state appropriations or pass-through of federal Medicaid funds

The 'Developmental Disabilities' Services

What is provided will vary among the states; they generally fund

- Housing
  - Independent living, supported living, apartments, group homes
- Family supports
- Individual supports
- Work programs, work supports
- Service coordination
- Assessment and diagnostic services
- 'Waiver' services - targeted

Other sectors

- Health providers
- Social welfare
- Family services
- Alzheimer's and dementia services
- Adult protective services
- Others

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Bridging

- Aging adults with intellectual disabilities and their aging family caregivers may come in contact with following entities:
  - State developmental disabilities authority (the 'state agency')
  - Local intellectual disability provider agencies
  - The aging network
  - Health providers
  - Social/public welfare agencies
  - Alzheimer's (or other dementia) groups
  - Volunteer organizations

- 'Bridging' is <u>connecting diverse service networks</u>…
  - Connecting or bridging 'silos' for a common purpose

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Bridging: aging people with disabilities

Pre-bridging efforts and older adults

- Identifying older adults and carers
- Determining what they may need
- Looking at demographic trends
- Recognizing that needs are often linked to age groups (younger-older vs. older-older)
- Involvement with civic planning
- Advocacy for housing & integration within aging network
- Thinking in terms of creative approaches to community supports

What to bridge?

- Common housing
- Transport assistance
- Supporting retirement
  - Pensioning
  - Home care supports
  - Financial planning
  - Transition planning
- Providing Alzheimer's, decline-related, and frailty care
  - Community-located group home
  - Family support
- Aiding older family carers
  - Respite
  - Financial supports
  - Support groups and counseling

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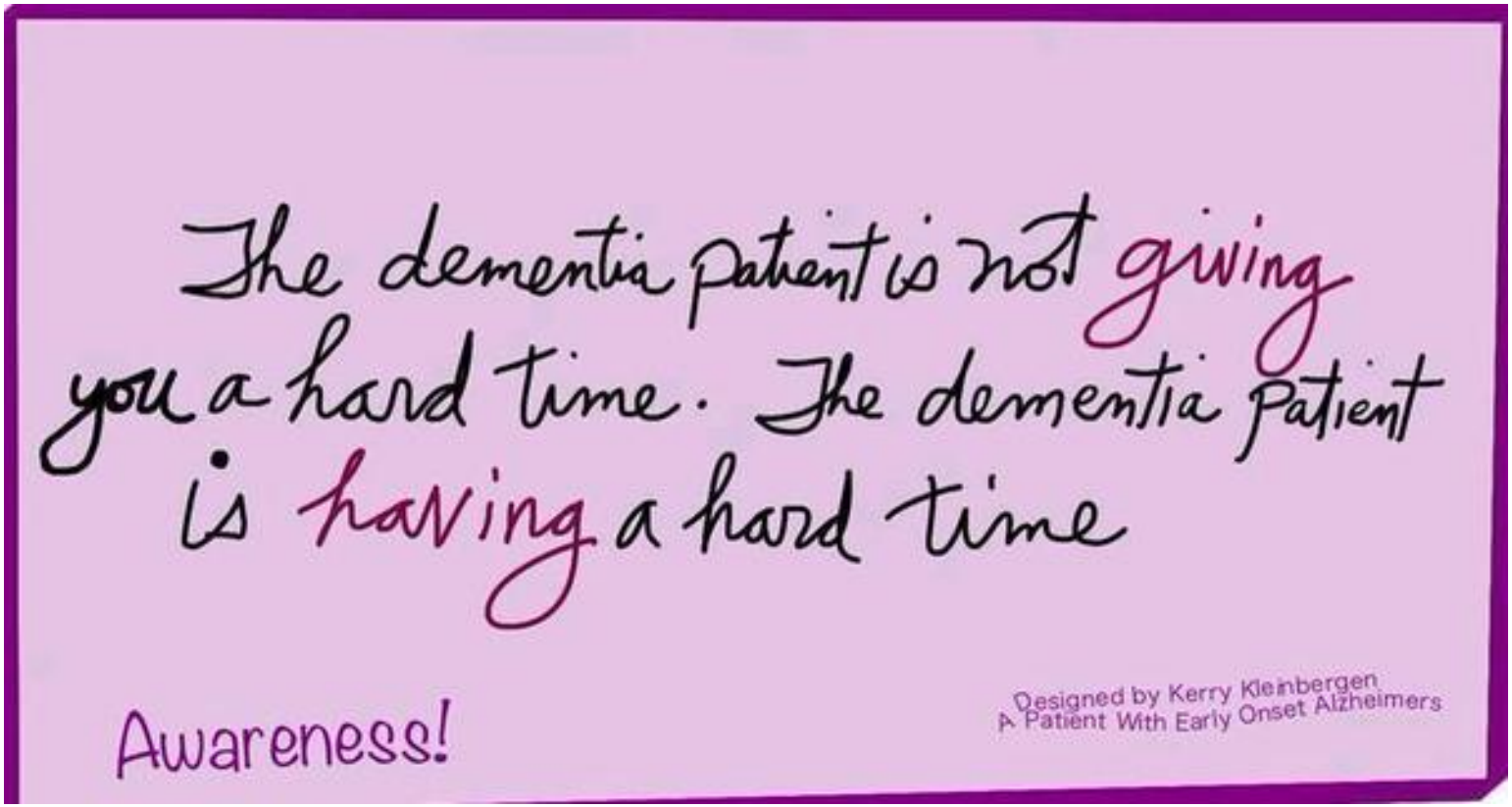

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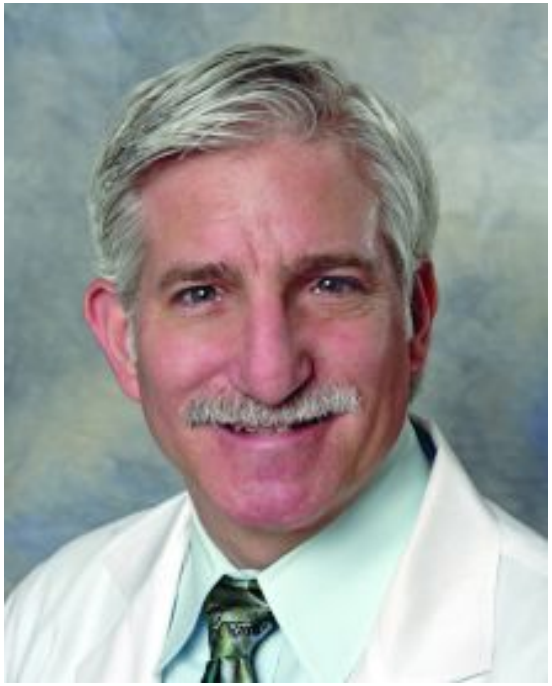

Seth M. Keller, MD, is a board certified neurologist in private practice with Advocare Neurology of South Jersey. He specializes in the evaluation and care of adults with Intellectual and Developmental Disabilities (ID/DD) with neurologic complications. He cares for individuals with ID/DD both in the community as well in New Jersey's ICF/DD centers. Dr Keller is on the Executive Board of the Arc of Burlington County as well as on the board for The Arc of New Jersey Mainstreaming Medical Care Board. He is a leading voice on care for individuals with ID/DD and serves as co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices.

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Aging and Intellectual and Developmental Disabilities; Healthcare

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The US is getting Older: can you feel it?

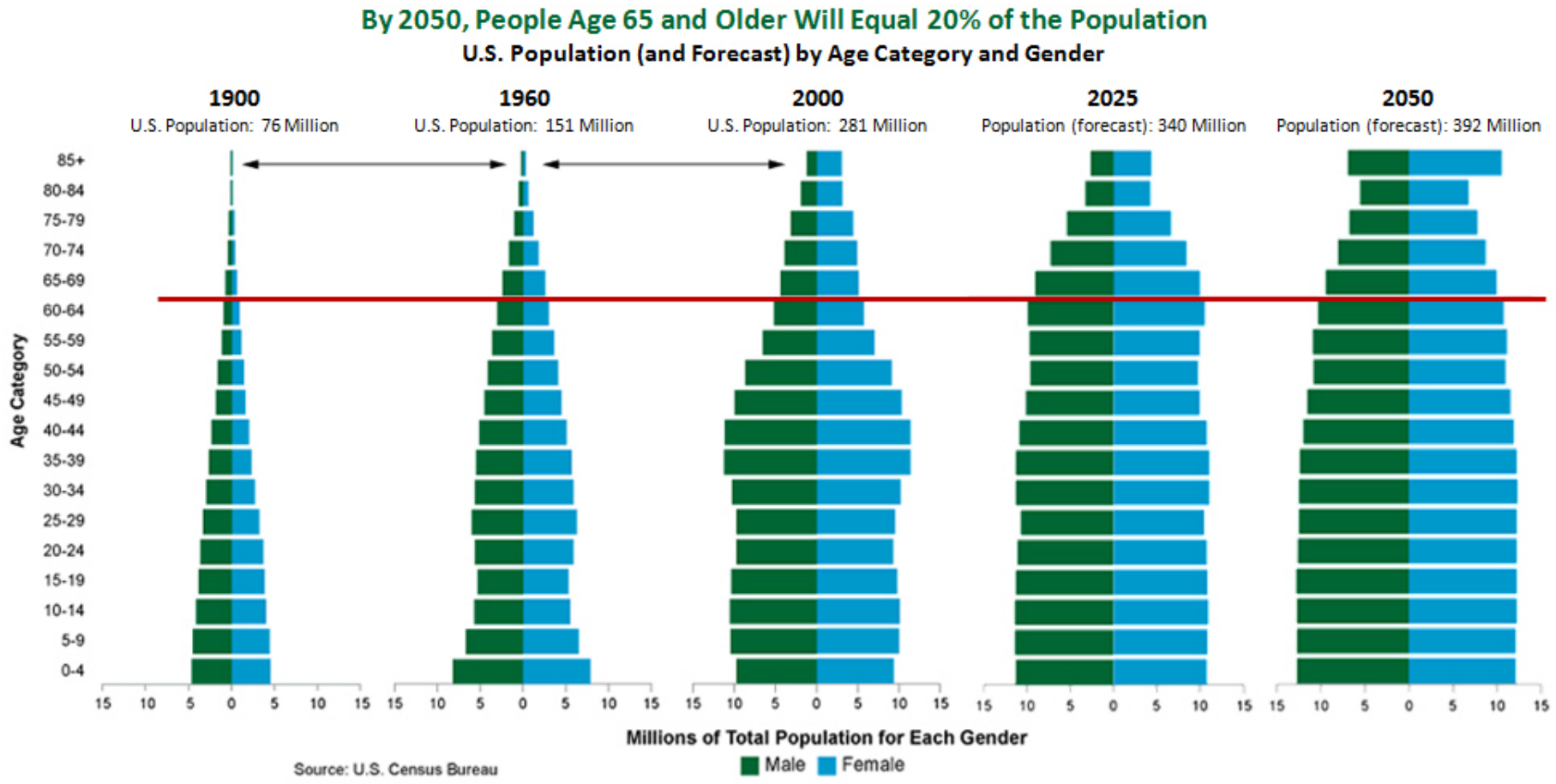

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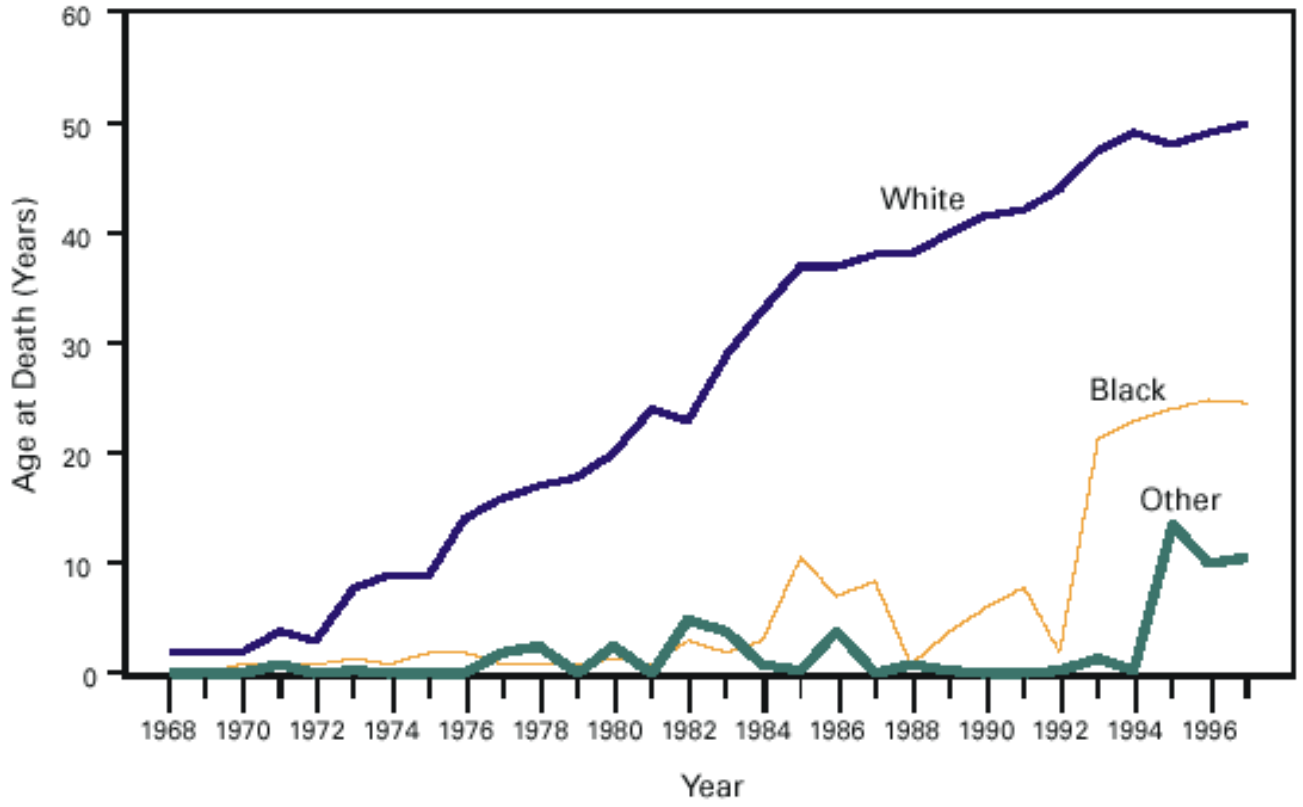
FIGURE 1. Median age at death of persons with Down Syndrome, by race — United States, 1968–1997



http://thesocietypages.org/socimages/2013/06/10/the-life-expectancy-of-people-with-downs-syndrom/

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Does Aging always bring decline in function?

What change is Normal or Not??

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What is the research telling us about "Normal" age-associated decline?

- Physical changes in old age occur with predictability
- Decline occurs in expected patterns
- Sensory loss, musculoskeletal changes
- Adults with motor, neurological and other significant co-conditions impacted much more adversely

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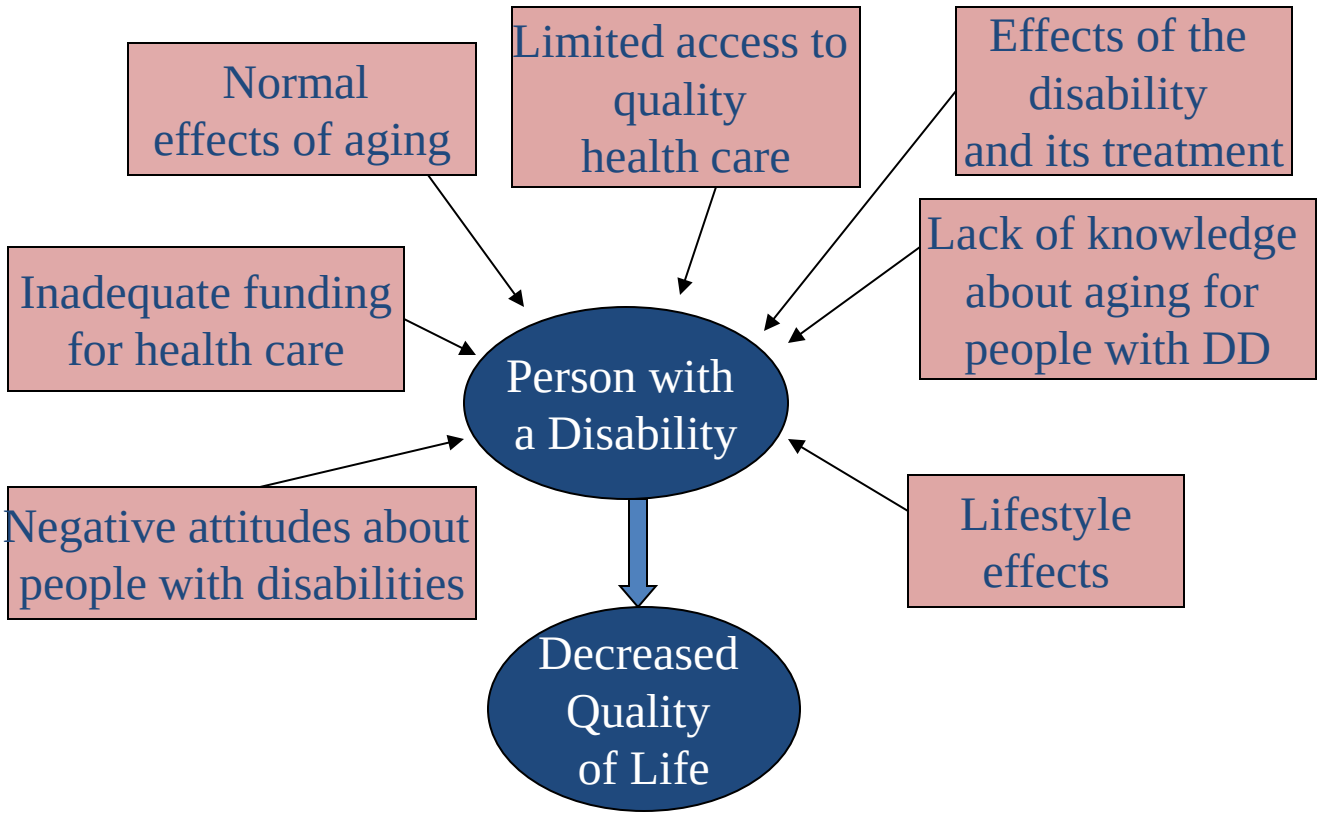
Aging With I/DD



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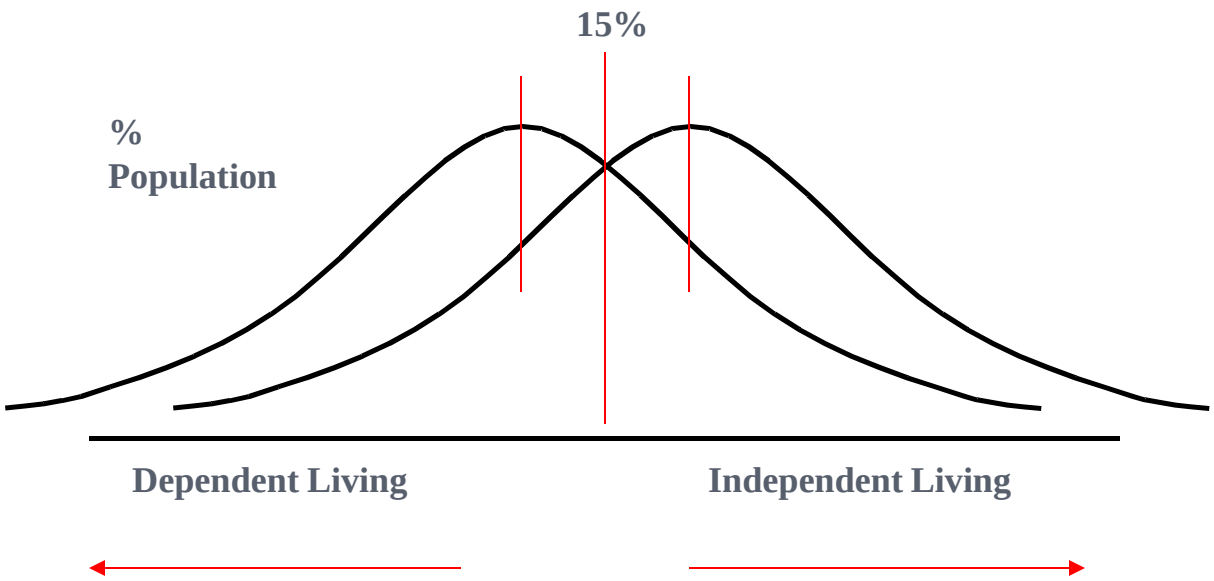
Small Change in Cognitive Capability could have Profound impact on Independence



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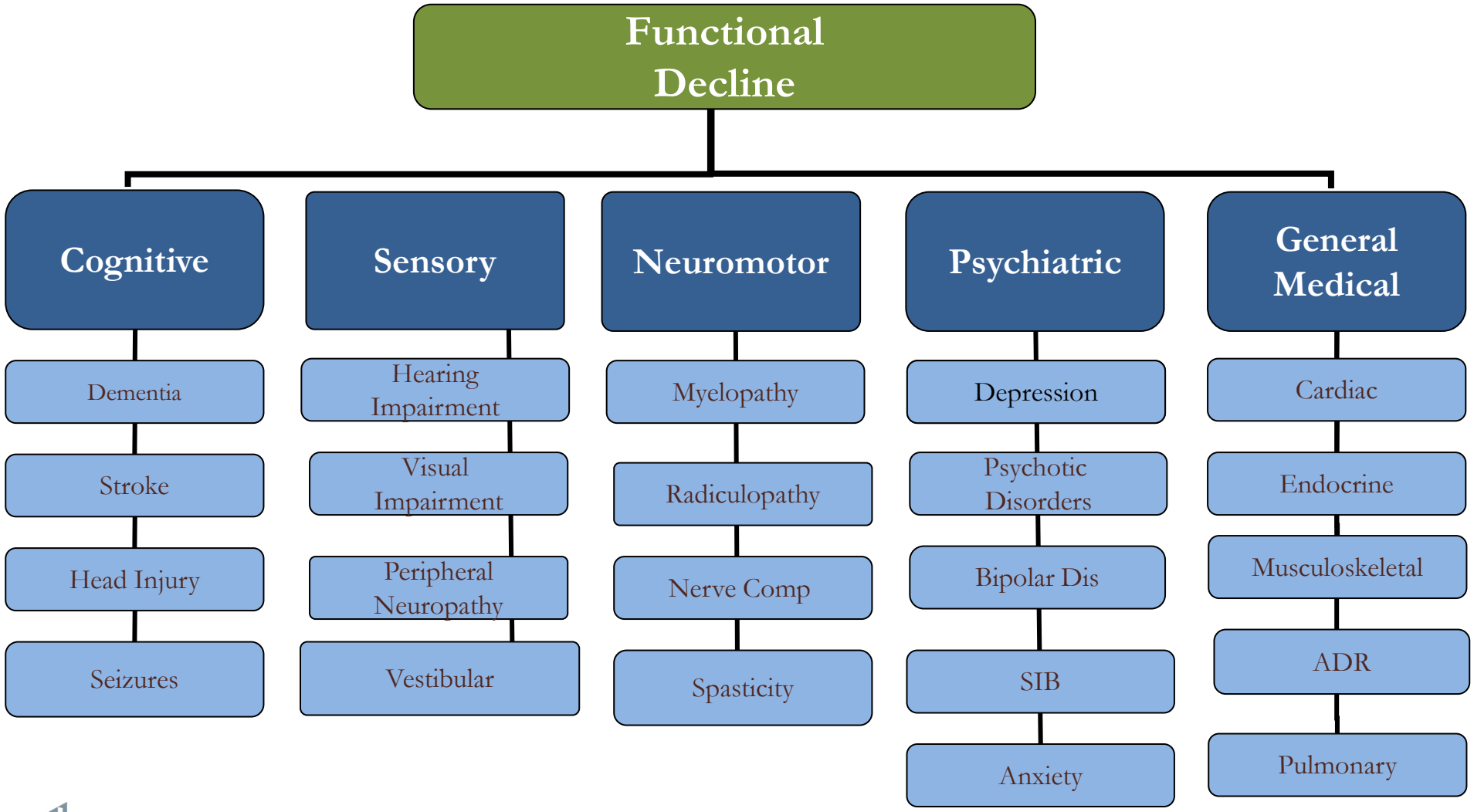

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Adverse Drug Reactions

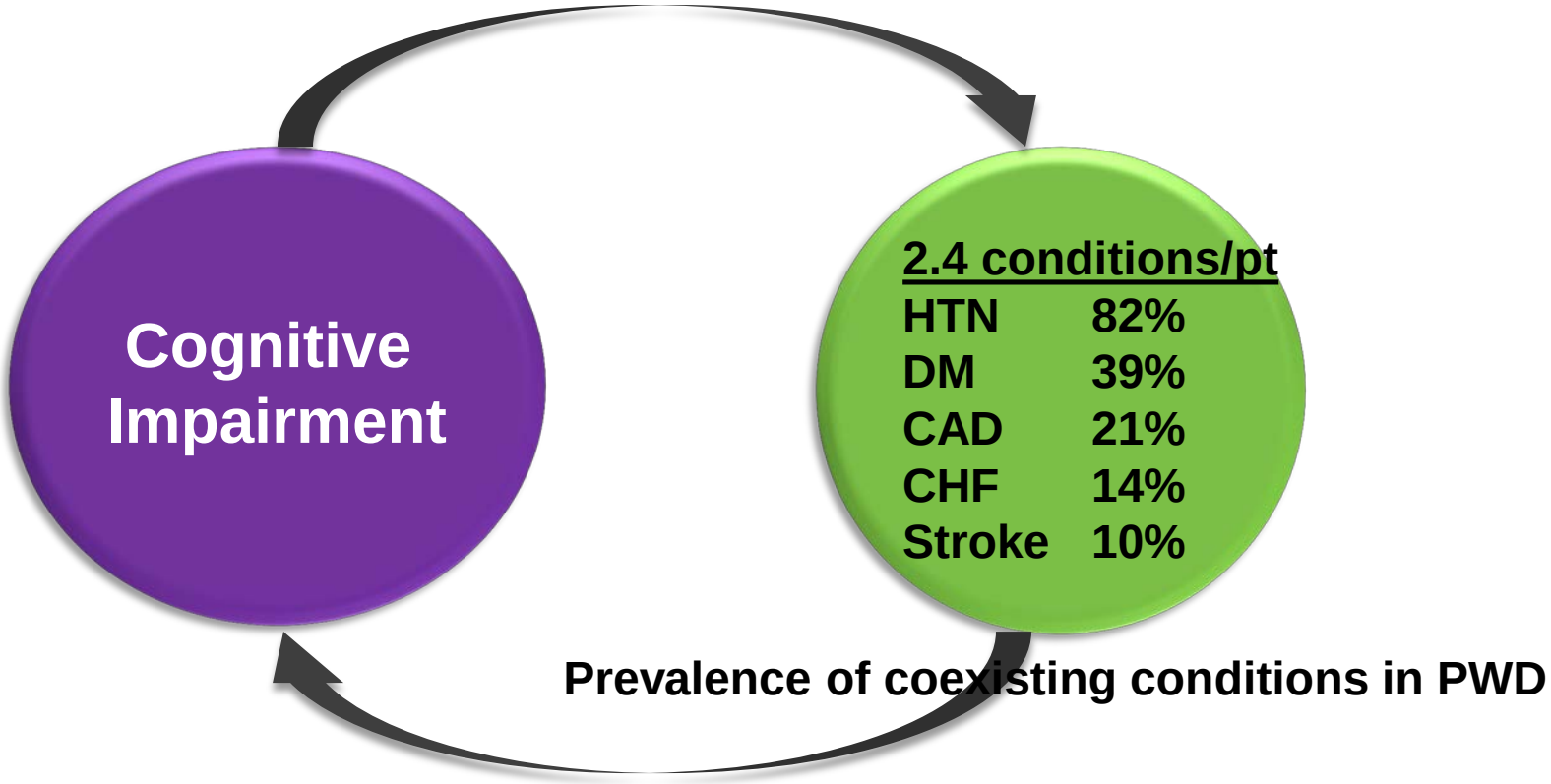
TABLE 1. Common Medication Classes Associated With Possible Worsening of Cognitive Function in Patients With Dementia

Medication class	Examples	Comments
Antihistamines, especially first generation	Diphenhydramine Hydroxyzine Promethazine	Anticholinergic adverse effects, urine retention, confusion, sedation
Bladder agents	Oxybutynin Tolterodine	Anticholinergic adverse effects, urine retention, confusion, sedation
Certain pain medications	Meperidine Propoxyphene	Meperidine: increased risk of seizures with renal impairment
Tricyclic antidepressants	Amitriptyline Clomipramine Doxepin	Risks and benefits of this medication should be guided by a psychiatrist with familiarity with patients with I/DD
Certain antipsychotics	Chlorpromazine Clozapine Pimozide	Atypicals have been associated with increased mortality when used to treat behavioral problems in elderly patients with dementia, but no such studies have been conducted in Down syndrome or I/DD in general
Long-acting benzodiazepines	Clonazepam Temazepam Diazepam	Very sedating; caution for gait impairment, dizziness If a benzodiazepine is required for anxiety, consider short-acting agents (appropriately dosed): alprazolam, lorazepam

I/DD = intellectual and developmental disabilities.

Moran JA, et al "The national task group on intellectual disabilities and dementia practices consensus recommendations for the evaluation and management of dementia in adults With intellectual disabilities" Mayo Clin Proc 2013; 88(8): 831-840. http://www.medpagetoday.com/TheGuptaGuide/Neurology/41094

Impact of Coexisting Medical Conditions



Schubert CC, et al. *J Am Geriatr Soc*. 2006;54(1):104–109.

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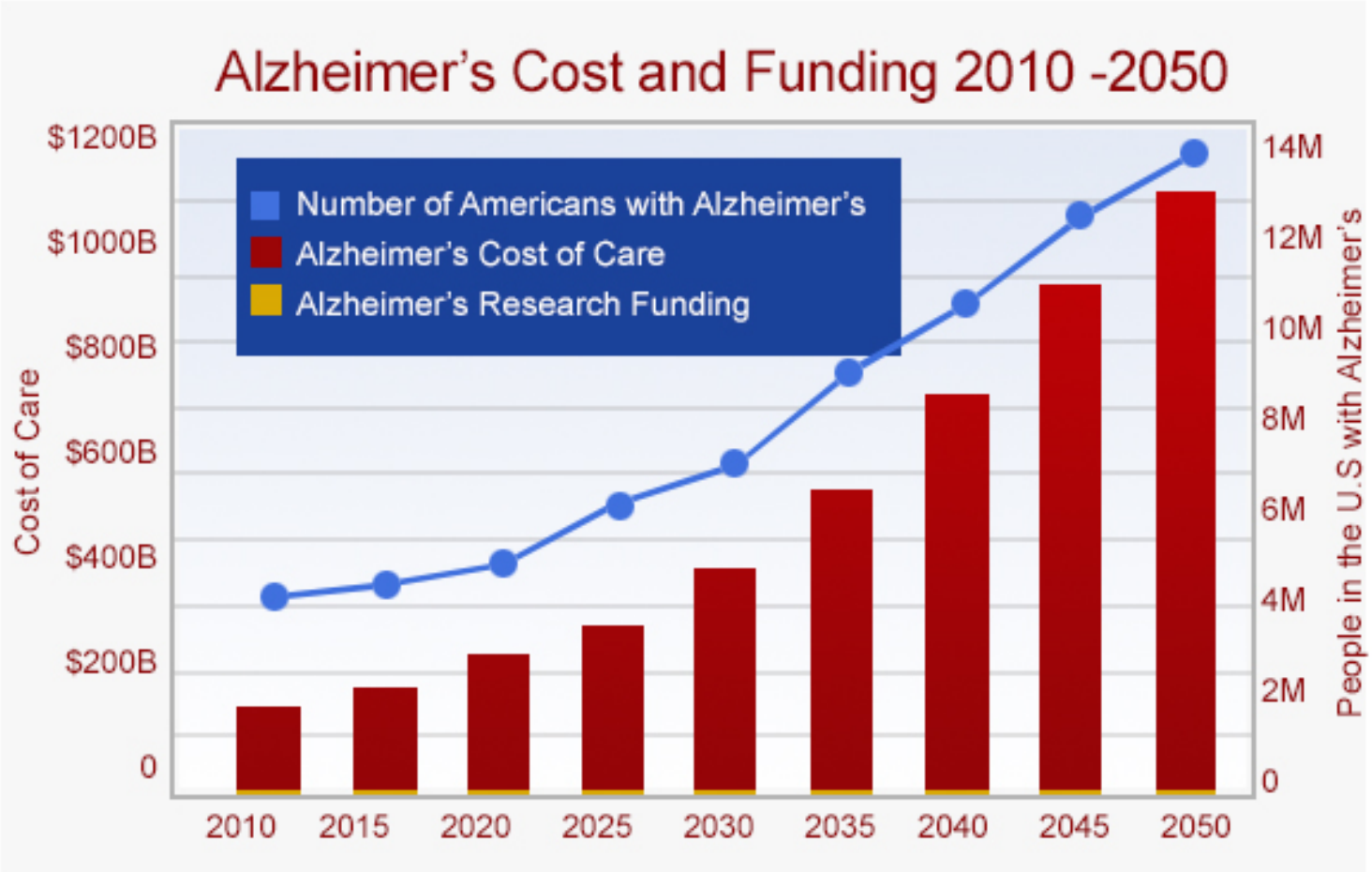

Source: Alzheimer's Study Group, A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Studt Group (March 2009); Alzheimer's Association, Changing the Trajectory of Alzheimer's Disease: A National Imperative (May 2010); National Institute of Health Office of the Budget website.

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Alzheimer's Disease in Down Syndrome

- Women with Down's syndrome are more at risk of developing Alzheimer's disease than men in the 40 to 65 age group
- People with Down's syndrome who develop Alzheimer's disease live, on average, 9-10 years from first symptoms
- Infrequently rapid decline can occur
- Late on-set seizures
- From diagnosis to death is on average 8.2 years
- Excessive production of Beta Amyloid from extra 21st Chromosome

Percentage of people with Down syndrome who develop dementia at different ages: Age percentage with clinical signs of dementia	
30's	2%
40's	10-15%
50's	33%
60's	50-70%

Source: Neil, M. (2007). Alzheimer's dementia: What you need to know, what you need to do. Understanding intellectual disability and health. Accessed from http://www.intellectualdisability.info/mental-health/alzheimers-dementia-what-you-need-to-know-what-you-need-to-do.

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Adults with Down Syndrome: Specialty Clinic Perspectives

Chicoine, B., McGuire, D., Rubin, S.

Dementia, Aging and Intellectual Disabilities: A Handbook
ed. by Janicki and Dalton (Taylor and Francis, 1999)

Diagnosed Disorders for 148 Adults Who Presented with a Decline in Function		
Disorder	**Frequency**	**Percent of Diagnosed Disorders (%)**
Mood	76	31
Anxiety	31	13
Obsessive-Compulsive	29	12
Behavior	23	9
Hypothyroid	22	9
Adjustment	12	5
Alzheimer's	11	4
B12 Deficiency	7	3
Menopause	7	3
Attention Deficit / Hyperactive	6	2
Gastrointestinal or Urinary	6	2
Sensory Impairment	6	2
Psychotic	4	2
Other Medical Conditions*	4	2
Cardiac Conditions	3	1
TOTAL	247	100

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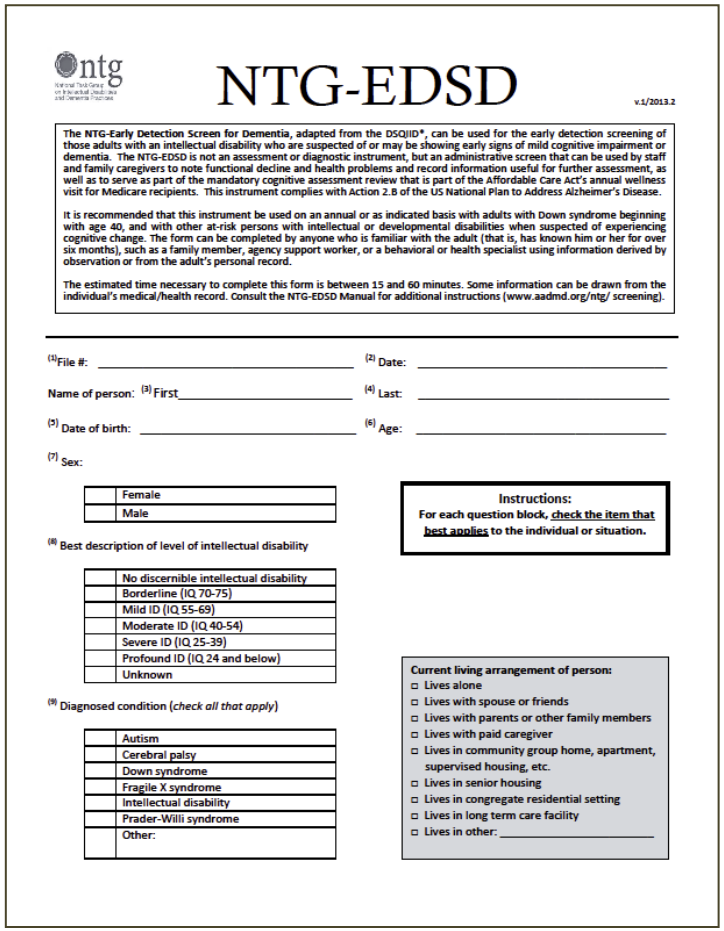
Challenges to diagnosis and care

- Individuals with I/DD may not be able to report signs and symptoms
- Subtle changes may not be observed
- Commonly used dementia assessment tools are not relevant for people with I/DD
- Difficulty of measuring change from previous level of functioning
- Conditions associated with I/DD maybe mistaken for symptoms of dementia
- Diagnostic overshadowing
- Aging parents and siblings
- Lack of research, education, and training

Early detection/screening

NTG-Early Detection Screen for Dementia' (NTG-EDSD)

- Usable by support staff and caregivers to note presence of key behaviors associated with dementia
- Picks up on health status, ADLs, behavior and function, memory, self-reported problems
- Available in multiple languages
- Use: to provide information to physician or diagnostician on function and to begin the conversation leading to possible assessment/diagnosis



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NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID®, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

(1) File #: _____ (2) Date: _____

Name of person: (3) First_____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

	Female
	Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

Current living arrangement of person:
- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ Lives in senior housing
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: _____

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

http://aadmd.org/ntg/screening

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Goals of Care of Dementia

- Maintaining QOL
- Prolonging life
- Prevent functional decline
- Slow progression
- Decrease psychiatric/behavioral problems
- Fall reduction program
- Dysphagia care/Aspiration awareness
- Seizure management
- Reduce hospitalization
- Watch for signs of abuse and neglect
- Caregiver support, what out for provider Burn out
- Cholinesterase Inhibition and Memantine
- Palliative Care
- End of Life Care
- Team approach to care
- Future pharmacologic/non-pharmacologic interventions

Progression of Disease;
Anticipatory Guidance

- Cognitive Skills will decline
- Support needs will increase
- Increase risks of falls, injuries
- Swallowing dysfunction, clots, pneumonia, bladder infections
- Seizures
- Watch for signs of abuse and neglect
- Watch for signs of caregiver burn out
- End of life decisions

Palliative and End of Life Care

- The realization that Alzheimer's disease progresses with increasing risks of health complications impacting ones Quality of Life and Activities of Daily Living
- Respecting ones wishes for level of care and quality of life
- Defining, anticipating, and preparing for end of life

Outcome Assessment of Care:
Are Therapeutic Interventions Effective?

- Therapies can be positive, ineffective, or detrimental
- The degree and impact of the treatment needs to be known
- Clarity of expectations need to be discussed
- Communication of objective outcome assessments need to be defined
- Care tied to reimbursements

Expected Outcomes

- Maintain Quality of Life as long as possible
- Prolong Longevity
- Improve and maintain behavior and cognitive function
- Reduction of medications for aberrant behavior
- Aging in Place; prevent or delay institutionalization
- Reduced ED and hospitalizations
- Reduced falls, injuries and fractures
- Training and education of support personnel
- Cost savings

'My Thinker's Not Working'

A National Strategy for Enabling Adults wit
Intellectual Disabilities Affected by Dement
to Remain in Their Community and Receiv
Quality Supports

Executive Summary to the
Report of the National Task Group on
Intellectual Disabilities and Dementia Practices

2012

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ntg National Task Group on Intellectu
Disabilities and Dementia Practic

The NTG FAQ: Some Basic Questions about Adul with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias

Index

Alzheimer's and related dementias

Q1. *What is cognition?*

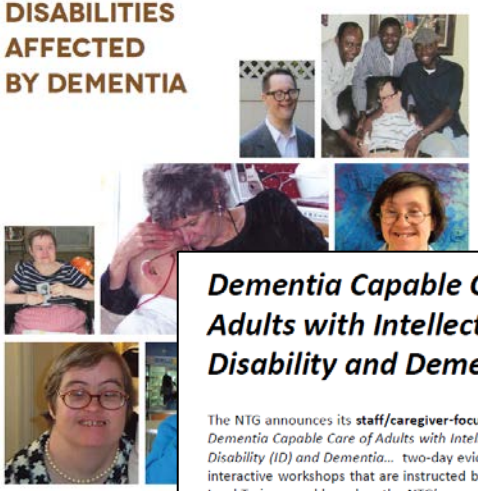
A1. "Cognition" is a term used to describe our mental processes and activities, such as attention, memory, language understanding and expression, solving problems.

Q2. *What is dementia?*

A2. "Dementia" is a term used to describe cognitive decline from any cause (e.g. brain disease, head injury, stroke, or loss of oxygen to the brain) that results in impaired personal, social, or occupational adaptation. It is persistent and progressive and is associated with a chronic generalized brain disorder, such as Alzheimer's disease, or a multifocal neurological condition, such as multiple strokes involving several discrete areas of the brain.

Dementia resulting from Alzheimer's disease is the most common ty

GUIDELINES FOR STRUCTURING COMMUNITY CARE AND SUPPORTS FOR PEOPLE WITH INTELLECTUAL DISABILITIES AFFECTED BY DEMENTIA



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Viability of a Dementia Advocacy Effort for Adults with Intellectual Disability

Using a National Task Group Approach

Matthew P. Janicki & Seth M. Keller

Dementia Capable Care of Adults with Intellectual Disability and Dementia

The NTG announces its **staff/caregiver-focused workshops**, *Dementia Capable Care of Adults with Intellectual Disability (ID) and Dementia...* two-day evidence-informed, interactive workshops that are instructed by NTG Master and Lead Trainers and based on the NTG's new ***Education and Training Curriculum on Dementia and Intellectual and Developmental Disabilities***

The workshops are designed for staff/caregivers with direct or ancillary care responsibilities for supporting older adults with intellectual disability at disability, health care, and aging-related agencies or staff/caregivers providing supports in home settings

Certificates of Completion for 12 hours education credit available upon successful passing of on-line test

A train-the-trainer component is available for organizations with in-house education capacities

Content Modules

- Abuse and Safety
- Adapting Physical Environments
- Bridging Aging and Disability Services
- Communication Strategies
- Community Supports
- Dementia and ID Capable Residences
- Dementia In Adults with ID
- Dementia-related Challenging Behaviors
- Early Detection and Screening for Dementia
- Family Supports
- Health, Wellness, and Dementia
- Health Care Advocacy and ID and Dementia
- Introduction to Aging and ID
- Non-pharmacologic Interventions for Behavior
- Obtaining a Diagnosis
- Stage-based Care Considerations

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For more information, listing of scheduled workshops, faculty, costs, and to contract for a workshop:
www.aadmd.org/ntg/training

Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia of the National Task Group on Intellectual Disabilities and Dementia Practices

ntg National Task Group on Intellectual Disabilities and Dementia Practices

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities

Julie A. Moran, DO; Michael S. Rafii, MD, PhD; Seth M. Keller, MD; Baldev K. Singh, MD; and Matthew P. Janicki, PhD

Abstract

Adults with intellectual and developmental disabilities (I/DD) are increasingly presenting to their health care professionals with concerns related to growing older. One particularly challenging clinical question is related to the evaluation of suspected cognitive decline or dementia in older adults with I/DD, a question that most physicians feel ill-prepared to answer. The National Task Group on Intellectual Disabilities and Dementia Practices was convened to help formally address this topic, which remains largely underrepresented in the medical literature. The task group, comprising specialists who work extensively with adults with I/DD, has promulgated the following Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities as a framework for the practicing physician who seeks to approach this clinical question practically, thoughtfully, and comprehensively.

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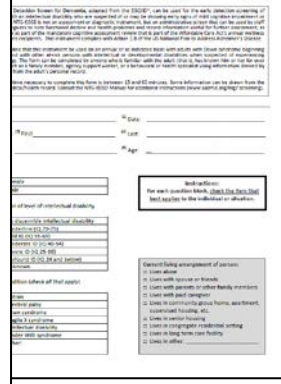

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Matthew P. Janicki, Ph.D., & Seth M. Keller, M.D.
Co-chairs, NTG

www.aadmd.org/ntg

Rachel Dyer

Associate Director
Maine Developmental Disabilities Council
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Maine Developmental Disabilities Council

Rachel Dyer is the Associate Director of the Maine DD Council. The Maine DD Council:

- Promotes activities that expand the capacity of communities to provide opportunities for individuals with DD to actively participate in community life
- Advocates for systemic changes that allow individuals with DD to achieve full integration and to pursue meaningful and productive lives
- Increases public awareness and work to eliminate barriers that impact independence, productivity and inclusion of people with DD
- Fosters and supports coalitions and other advocacy and community groups
- Supports close working relationships among the various public and private service providers

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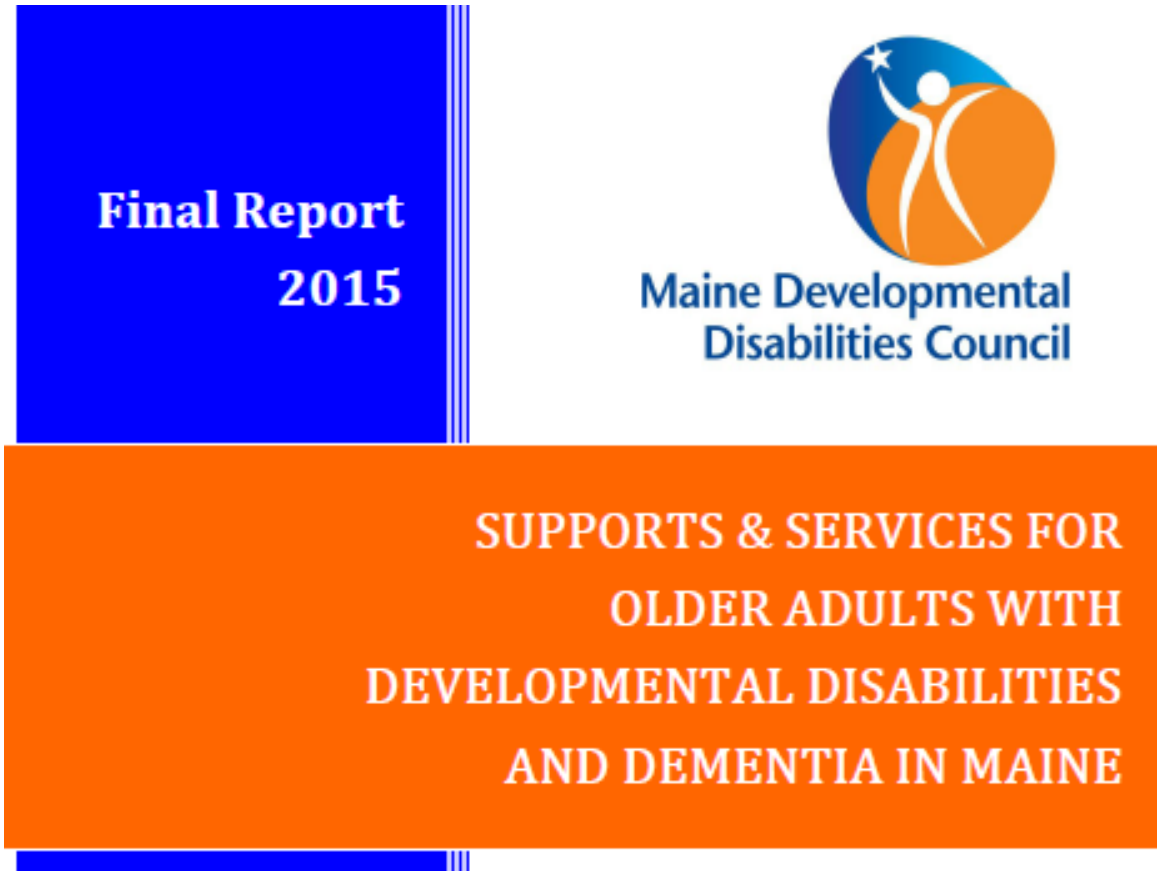

Case Study

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Recent Health Care Projects

- Accessing Health Care: The Experience of Individuals with ASD in Maine
- Act Early Campaign
- Care Coordination for Children with Developmental Disabilities
- Dementia Services and Supports
- Quality Mental Health Services for Persons with Intellectual Disabilities

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“I Lead”

“The Oldest State”: Highest Median Age

Contains the Largest Rural County East of the Mississippi

#41 in Population #39 in Size

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Context

Longstanding economic challenges

Relatively generous social benefits

Historically high levels of health coverage

Background to the Developmental Disabilities and Dementia Project

- 2010: Dementia identified as an issue of concern.
- 2012: MDDC was asked to cosponsor an educational event regarding DD and Dementia. Anticipated attendance was estimated at 50; actual registrations exceeded 200.
- 2013-14: MDDC contract for report.

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Developmental Disabilities Service System in Maine*

*Braddock, 2015

Community-based

State institution closed in 1996
Relatively low utilization of Nursing Facilities
Relatively high utilization of Out of Home residential placements
Low utilization of Intermediate Care Facilities
Low levels of Family Support

Eligibility

Based upon diagnosis as well as function

Availability

From December 2008 to March 2015, the wait list for waiver services increased approximately 1500%.

Demographics

Reflect national trends of people with DD living longer and healthier lives.

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Aging and Developmental Disabilities?

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Healthcare & Persons with Developmental Disabilities

- Low rates of preventive screening and primary care utilization
- High rates of chronic conditions such as obesity
- High prevalence of vision and oral health conditions

Difficulty with

- Access to specialists
- Physical access to care
- Feeling welcomed and understood
- Knowledge, training and perception of medical staff
- Patient-provider communication
- Quality of care

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Healthcare & Older Adults with Developmental Disabilities

- Significant Challenges Accessing Specialty Care, especially in Rural Areas.
- Low awareness of age related issues

Developmental Services are not a great fit with the medical model

- Providers do not have a high level of clinical training
- Providers are not required to have clinical supervision
- The field does not have much experience with aging
- Rules may contraindicate commonly used dementia practices

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Stakeholder Feedback

Perceived Barriers to Accessing Healthcare

- Too few geriatricians
- Too few providers with expertise in developmental disability
- Lack of awareness of aging issues, including dementia
- Difficulty obtaining accurate diagnosis
- Difficulty obtaining differential diagnosis

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Stakeholder Feedback

Perceived Barriers to Accessing Adequate Services and Supports

Developmental Services

- Waitlists for Developmental Services
- Some regulatory barriers
- Lack of awareness of aging related issues
- Lack of awareness or utilization of existing resources
- Difficult to adapt existing services to be dementia capable
- Staff skills
- "Reinventing the wheel"
- Limited availability of family supports
- Institutional care

Elder Services

- Difficulty accessing in-home services
- Inconsistent experiences with utilization of services
- Belief that people receive comprehensive services elsewhere
- Staff skills

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Stakeholder Feedback

Perceived Barriers to Supporting Individuals and Families

- Difficult to reach families of persons who are “not in the system”
- Lack of flexible resources
- Need for immediate resources when caregiving families have a crisis
- Fear of the system
- Educating and supporting families
- Accessibility of programs and supports
- Age thresholds for eligibility

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Sharing Resources

In Action

- Training programs such as NTG, Savvy Caregiver and Direct Service Worker Online
- ADRC (Southern Maine Area Agency on Aging) Dementia Capable Service Network Grant
- Integration of Community Living programs at the state and federal level
- “No Wrong Door”
- Addressing Abuse, Neglect and Exploitation

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Sharing Resources

Opportunities

- Futures Planning
- Dealing with Risk
- Housing
- Transportation
- Reliable Home Care

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Next Steps

Increase Awareness

- Persons with disabilities and families
- DD service providers
- Health and long term care professionals

Increase Integration of Services and Supports

- State agencies
- DD & aging service providers
- Research & education entities

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Next Steps

Expand Systemic Capacity:

- Workforce development
- Enhance family support services

Adopt Evidence Based Screening Practices

Improve Data

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Questions & Answer Panel

- Q&A will begin once the recording has stopped
- Please submit your questions in the chat box
- You may also raise your virtual hand and we will facilitate Q&A

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NACDD

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Community and State

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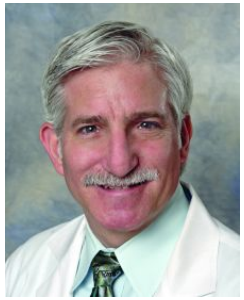

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