An Overview of Alzheimer’s Dementia or other Cognitive Decline Impacting Aging Adults with Intellectual Disability

Matthew P. Janicki, Ph.D.

University of Illinois at Chicago & National Task Group on Intellectual Disabilities and Dementia Practices

mjanicki@uic.edu

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Speaker Background

- *Research Associate Professor*, Department of Disability and Human Development, University of Illinois at Chicago
- *Co-President*, National Task Group on Intellectual Disabilities and Dementia Practices
- *Member,* Federal Advisory Council on Alzheimer’s Research, Care, and Services
- *Principal investigator*, Longitudinal study of specialized dementia-related care group homes designed for adults with intellectual disability
- *Formerly,* Director for Aging and Special Populations for the New York State Office for People with Developmental Disabilities

Content

- Risk factors, prevalence, and implications for services of different causes/types of dementia
- Issues faced by adults with intellectual disability as they grow older and their risk of older age neuropathologies, including Alzheimer's disease
- Prevalent service and support models helpful to maintaining community living of adults with dementia
- National Alzheimer’s Project Act and the National Plan to Address Alzheimer’s Disease

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Dementia & ID: Nutshell Version

Why important to consider?

- Dementia is the **result** of a brain disease or injury, such as Alzheimer's disease, Lewy body disease, or a brain injury or trauma
- With **progression**, an adult with dementia is increasingly less able to take care of him or herself … and requires supervision and someone to help him or her with basic necessities
- Dementia care **options** for most agencies are to support the person in place (whether at home or in their residential accommodation), refer to a long-term care facility, or admit to a specialty dementia-capable group home
- Dealing with dementia calls upon agencies to make some **critical decisions** about dementia care and developing support resources

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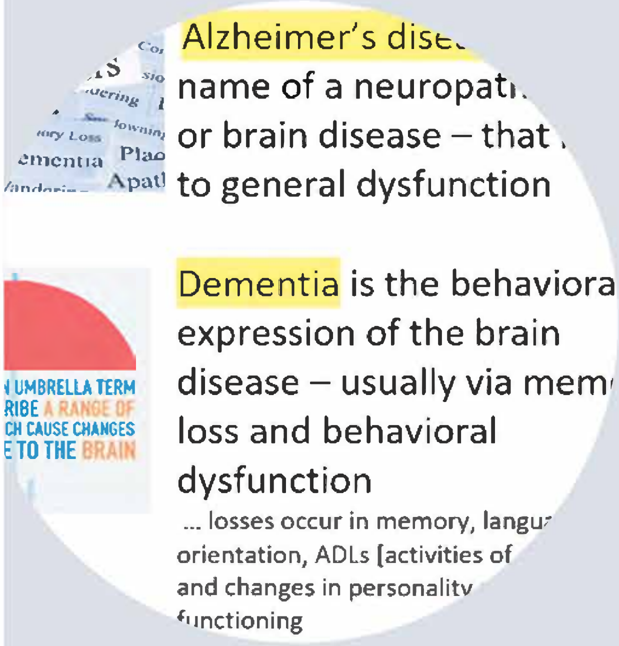


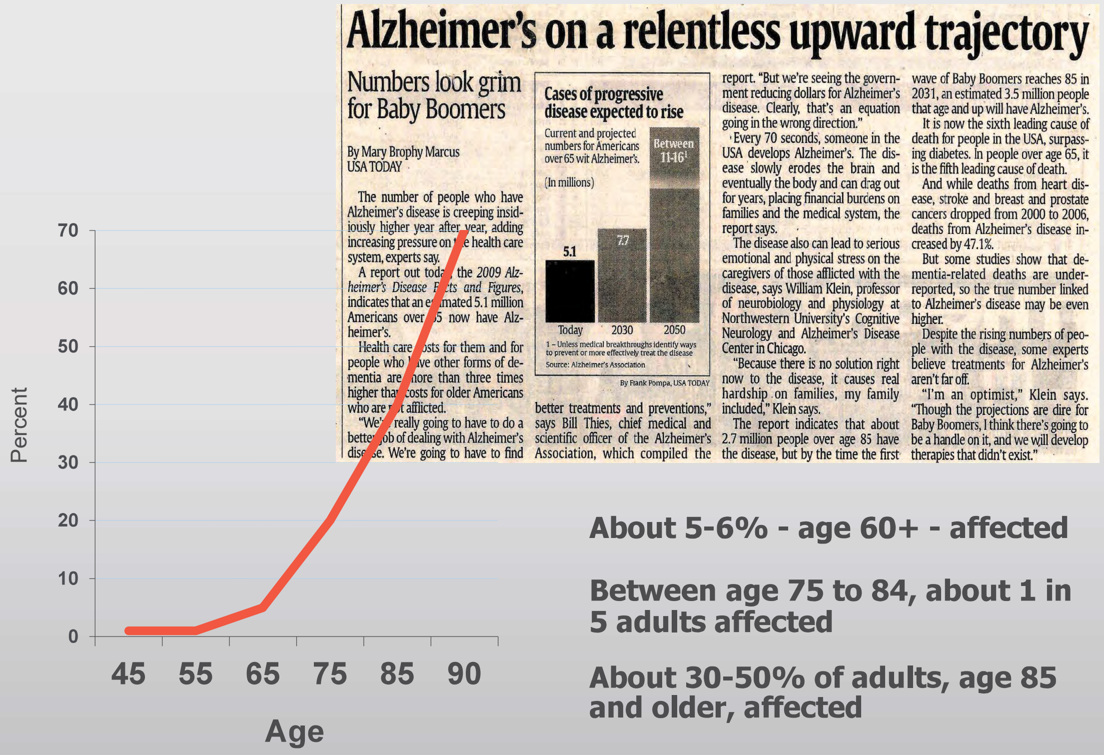
Alzheimer's dise
name of a neuropat
or brain disease – that
to general dysfunction

Dementia is the behaviora
expression of the brain
disease – usually via mem
loss and behavioral
dysfunction

… losses occur in memory, langu
orientation, ADLs [activities of
and changes in personality
functioning

Things to know about dementia

- **Dementia an umbrella term** for a range of changes in behavior and function affecting aging adults and usually linked to brain disease (e.g., Alzheimer's) or injury (e.g., stroke)
  - Alzheimer's is **a disease of the brain** – dementia describes the resulting behavior
  - Most adults with Down syndrome (DS) are at **risk of Alzheimer's disease** and consequently dementia; same risk as general population for adults with other ID
  - **Average age of 'onset'** in Down syndrome is about **52** and +60s/-70s for ID; Alzheimer's begins some 20 years before 'onset'
  - **Changes in memory** often signal dementia in ID; changes in personality often signal dementia in DS
  - After diagnosis **progressive decline in DS** can last for from 1 to 7+ years; up to 20 years in other ID
  - **Care** after the **early stage** can become more challenging as memory, self-care, communication, and walking become more difficult… eventually leads to advanced dementia



Alzheimer's on a relentless upward trajectory

Numbers look grim for Baby Boomers

By Mary Brophy Marcus
USA TODAY

The number of people who have Alzheimer's disease is creeping insidiously higher year after year, adding increasing pressure on the health care system, experts say.

A report out today, the *2009 Alzheimer's Disease Facts and Figures*, indicates that an estimated 5.1 million Americans over 65 now have Alzheimer's.

Health care costs for them and for people who have other forms of dementia are more than three times higher than costs for older Americans who are not afflicted.

"We're really going to have to do a better job of dealing with Alzheimer's disease. We're going to have to find better treatments and preventions," says Bill Thies, chief medical and scientific officer of the Alzheimer's Association, which compiled the report. "But we're seeing the government reducing dollars for Alzheimer's disease. Clearly, that's an equation going in the wrong direction."

Every 70 seconds, someone in the USA develops Alzheimer's. The disease slowly erodes the brain and eventually the body and can drag out for years, placing financial burdens on families and the medical system, the report says.

The disease also can lead to serious emotional and physical stress on the caregivers of those afflicted with the disease, says William Klein, professor of neurobiology and physiology at Northwestern University's Cognitive Neurology and Alzheimer's Disease Center in Chicago.

"Because there is no solution right now to the disease, it causes real hardship on families, my family included," Klein says.

The report indicates that about 2.7 million people over age 85 have the disease, but by the time the first wave of Baby Boomers reaches 85 in 2031, an estimated 3.5 million people that age and up will have Alzheimer's.

It is now the sixth leading cause of death for people in the USA, surpassing diabetes. In people over age 65, it is the fifth leading cause of death.

And while deaths from heart disease, stroke and breast and prostate cancers dropped from 2000 to 2006, deaths from Alzheimer's disease increased by 47.1%.

But some studies show that dementia-related deaths are underreported, so the true number linked to Alzheimer's disease may be even higher.

Despite the rising numbers of people with the disease, some experts believe treatments for Alzheimer's aren't far off.

"I'm an optimist," Klein says. "Though the projections are dire for Baby Boomers, I think there's going to be a handle on it, and we will develop therapies that didn't exist."

1 – Unless medical breakthroughs identify ways to prevent or more effectively treat the disease

Source: Alzheimer's Association

By Frank Pompa, USA TODAY

About 5-6% - age 60+ - affected

Between age 75 to 84, about 1 in 5 adults affected

About 30-50% of adults, age 85 and older, affected

Source: Marcus, M.B., "Alzheimer's on a relentless upward trajectory", USA Today, 24 March 2009, p. 6D

Terminology

Mild cognitive impairment (MCI)

Early-stage dementia

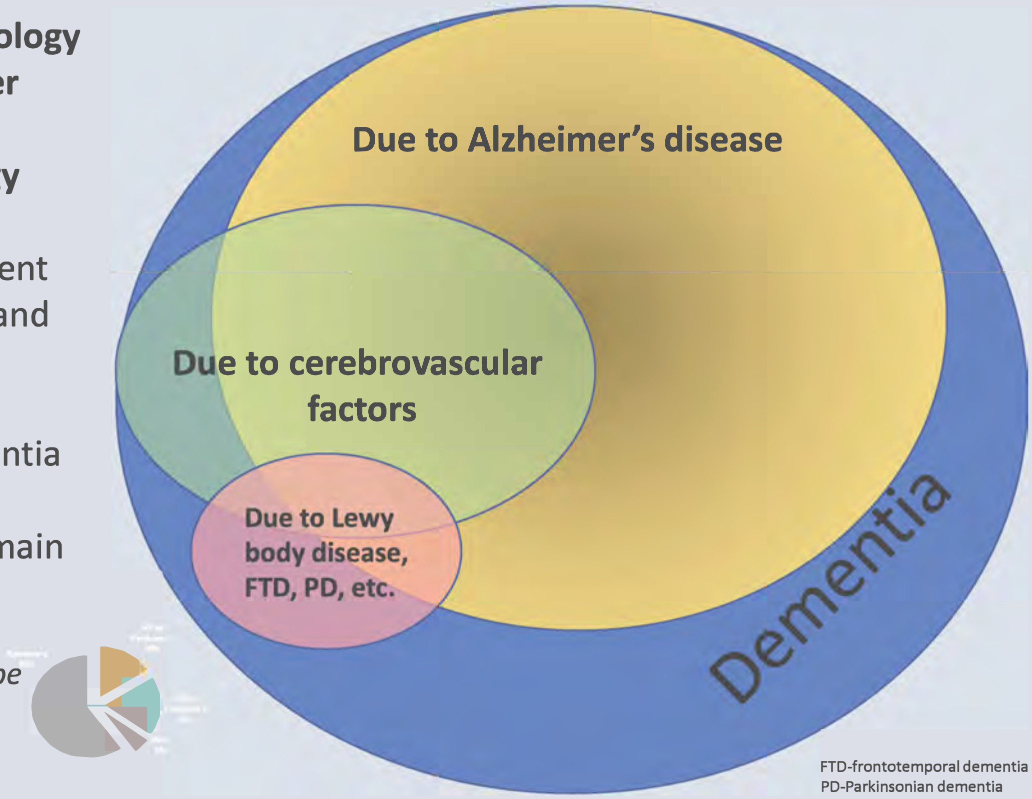
Mid-stage dementia

Late-stage or advanced dementia

Alzheimer's disease pathology often co-occurs with other pathologies, particularly cerebrovascular pathology

The effects of these different pathologies are additive, and may at least interact

At later ages, mixed dementia is very common, and additional pathologies remain to be identified



Pie chart illustrations can be misleading…

Source: Blacker, D. (2020) [graphic from Weuve, J.]

FTD-frontotemporal dementia
PD-Parkinsonian dementia

CLINICAL ASPECTS OF DEMENTIA AND INTELLECTUAL DISABILITY: IMPACT ON SERVICES

Onset

When change is first noticed

For DS: $\overline{X}$ = 52

For ID: $\overline{X}$ = late 60s - early 70s

Prevalence (DS ↗ 66%+

ID ⇄ 5 - 6%)

Progression

Patterns of change and decline

For DS: Some quick losses, other more normative (changes in personality before memory)

For ID: Varied trajectories; leading to progressive decline

Duration

Length of time persons are affected

For DS: Compressed duration

For ID: Similar to general pop

Why is ‘onset’ of importance?

- Knowing expected onset gives a head’s-up for surveillance
  - Look for changes
  - Introduce periodic screening
  - Alert staff/caregivers to be watchful
  - Provides for an ‘index of suspicion’
- Helps us to reformulate services and care practices
  - Creating safer environments
  - Signaling changes in demands for daily efforts
  - Planning ahead for eventualities
  - Setting goals for terms of service – adapting personal program plans

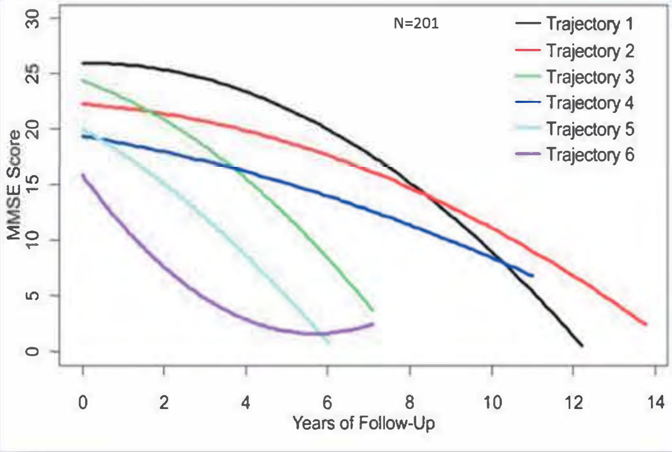
Intellectual disability and dementia

Rate of occurrence[1,3,5,8,14]	➢ Generally similar prevalence for adults with intellectual disability (~5-6% > age 60) ➢ Elevated prevalence in most adults with Down syndrome (60% >age 60)
Dementia type[2,9]	➢ Generally, ‘dementia of the Alzheimer’s type’ is prevalent in DS ➢ Similar ‘range of dementias’ found in other ID as in other people
Risk[15]	➢ DS and head trauma are significant risk factors in ID
Onset[1,2,3,10]	➢ Average onset age in early 50s for DS – late 60s for others ➢ Most DAT diagnosed within 3 years of “onset” in adults with DS
Behavioral changes[2,3,6,11,12,13,20]	➢ In DS - early change in personality more evident ➢ In other ID - initial memory loss more evident ➢ Notable behavioral changes: *apathy, sleep disturbance, agitation, incontinence, irritability, uncooperativeness, aggressiveness*
Neurological signs[1,2,4,7,16,17,18,19]	➢ Late onset seizures in 24%-53% of adults with DS ➢ Late onset seizures in DS indicator of life expectancy of less than 2 years ➢ Seizures more common at end-stage (84%) versus at mid-stage (39%) Alzheimer’s disease
Duration[2, 17]	➢ Aggressive Alzheimer’s disease can lead to death <2 years of onset in DS ➢ 2-7+ years mean duration in DS; probable death within 3-5 years of onset ➢ Same duration expected among ID in general as in other people with dementia

Sources: [1]Janicki, M.P. & Dalton, A.J. (2000). Prevalence of dementia and impact on intellectual disability services. Mental Retardation,38, 277-289. [2]Janicki, M.P., & Dalton, A.J. (1999). Dementia, Aging, and Intellectual Disabilities: A Handbook. Philadelphia: Brunner-Mazel; [3]Bush, A., & Beail, N. (2004). Risk factors for dementia and Down syndrome. AJMR, 109, 83-97. [4] Menendez M. (2005). Down syndrome, Alzheimer's disease and seizures. Brain Development, 27(4), 246-252. [5]Zigman, W.B., SchuPf, N., Devenny, D., et al. (2004). Incidence and prevalence of dementia in elderly adults with MR without DS, AJMR, 109, 126-141. [6]Ball, S.L., Holland, A.J., Hon, J., Huppert, F.A., Treppner, P., & Watson, P.C. Personality and behavior changes mark the early stages of Alzheimer's disease in adults with Down's syndrome: findings from a prospective population-based study. International Journal of Geriatric Psychiatry, 2006, [Jun 26]. [7]Crespel, A., Gonzalez, V., Coubes, P., & Gelisse, P. (2007). Senile myoclonic epilepsy of Genton: Two cases in Down syndrome with dementia and late onset epilepsy. Epilepsy Research, 77,165-168. [8]Evenhuis, H. (1997). The natural history of dementia in ageing people with intellectual disabilities. JIDR. 41(1), 92-96. [9]Strydom, A., Livingston, G., King, M., & Hassiotis, A. (2007).Prevalence of dementia in ID using different diagnostic criteria. Br. J. Psychiatry, 191, 150-157. [10] Margallo-Lana et al., (2007). Fifteen year follow-up of 92 hospitalized adults with DS. JIDR, 51, 463-477. [11]Giampietro, N. (2013). Research in dementia in Down syndrome. Presentation at the SR Congresso Internazionale sulla Sindrome di Down, Roma, Italy, November 9, 2013. [12]Deb S., Hare M., & Prior L. (2007). Symptoms of dementia among adults with Down's syndrome: a qualitative study. Journal of Intellectual disability Research, 51(9), 726-739. [13]Cooper, S-A. (1997). A population-based health survey of maladaptive behaviours associated with dementia in elderly people with learning disabilities. Journal of Intellectual Disability Research, 41(6), 481-487. [14] Torr, J., & Davis, R. (2007). Ageing and mental health problems in people with intellectual disability. Current Opinion in Psychiatry, 20(5), 467-471. [15]Moran J.A., Rafii, M.S., Keller, S.M., Singh, B.K., & Janicki, M.P., (2013). 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 Clinic Proceedings, 88(8), 831-840. [16] Esbenson, A.J., (2010). Health conditions associated with aging and end of life of adults with Down syndrome. Int Rev Res Ment Retard. 2010; 39(C): 107–126. [17] Prasher, V.P. & Corbett, J.A> (1993). Onset of seizures as a poor indicator of longevity in people with down syndrome and dementia. International Journal of Geriatric Psychiatry, 8(11), 923–927. [18] Robertson, Hatton, Emerson, & Baines. (2015). Prevalence of epilepsy among people with intellectual disabilities: A systematic review. Seizure, 29, 46–62. [19] McCarron M, Gill M, McCallion P, Begley C. (2005). Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia. J Intellect Disabil Res., 49, 560–566. 3/16. [20] Mascarenhas Fonseca et al. (2020). Amnestic and non-amnestic symptoms of dementia: An international study of Alzheimer's disease in people with Down's syndrome. International Journal of Geriatric Psychiatry, 35(6), 650-661.

Critical factors in dementia care planning

- Degree of retention of function
- Expected trajectory of progressive dysfunction
- Duration (remaining life years)
- Type of dementia
- Health status
- Environmental accommodations



Varying trajectories have implications for continual assessment and adaptations to care management

Source: Figure 2 from Wilkosz et al., (2009). Trajectories of cognitive decline in Alzheimer's disease. *International Psychogeriatrics*, 28,1-10

Ruby

Ruby at age 62

Courtesy: A.J. Dalton (2000)

Sign or Symptom	Age
Early	
Impaired memory function	54.7
Impaired learning abilities	56.7
Hearing loss	57.0
Disorientation	58.0
Hypothyroidism	59.0
Middle	
Personality changes	60.5
Deterioration of ADL skills	63.0
Abnormal reflexes	64.5
Late	
Hallucinations	64.5
Seizures	65.0
Incontinence	65.4
Has to be fed	65.4
Apathy	65.4
Complete care required	65.4
Death	65.5

Ruby spent most of her life in a large congregate care institution … back in the 80s.

Contemporary practices would have offered her a different life and opportunities… specially when dealing with her decline and eventual succumbing to dementia.

Ruby's decline illustrates a typical progression of stage associated losses of function, onset of comorbidities, and aging

Janicki, 2022

What to do when dementia is suspected - ID?

Start with an administrative screen

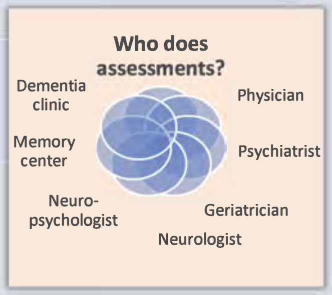
- Capture visuals on functioning (preferably ‘personal best’)
  - *digital recording of behavior*
  - Screening instrument
- Observe if screen provides ‘hits’ on ‘warning signs’

Refer for clinical assessment and diagnosis

- Clinicians reapply ID-specific measures to look for longitudinal patterns
- If evidence points to dementia-like symptoms, refers for full diagnostic evaluation (for differential dx)

Post-diagnosis support

- Post-dx – decide on value of pharmacological tx
- Implement non-pharmacological strategies
- Support through stage changes



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Possible risks or threats to brain health

- Improper use of some medicines
- Smoking
- Excessive use of alcohol
- Heart disease, diabetes, and other health problems
- Poor diet
- Insufficient sleep
- Lack of physical activity
- Little social activity and being alone most of the time

Source: "Brain Health As You Age: You Can Make a Difference!" Web presentation by the Administration for Community Living (2015) – Brain Health Initiative [http://www.acl.gov/Get_Help/BrainHealth/Index.aspx]

Community Dementia Care Models

EXPECTATION OF CHANGE AND FACTORS IN ID AND DEMENTIA UNDERLYING HOUSING AND CARE PRACTICES

Expectations of change

- Cognitive skills will decline
- Support needs will increase
- Increase risks of falls, injuries
- Swallowing dysfunction, clots, pneumonia, bladder infections, nutritional deficiencies, seizures

Care factors

- Watch for signs of abuse and neglect (including self-neglect)
- Watch for signs of caregiver burn-out and stress at home … affected on adult's behavior
- Watch for advanced dementia and needs for end-of-life care (palliative care and hospice)

ID associated issues that extenuate these factors:

- Co-incident conditions that may affect gait, sensory faculties, and cognition
- Co-morbidities or diseases that may affect physiological functions
- Previously identified 'mental health' issue
- Late-onset seizures
- Precocious (early) aging effects
- Expressive language difficulties
- Nutritional deficiencies & diet inadequacies
- Presence of polypharmacy

Options for dementia care

Staying

Staying at home

- Continued care by family members until eventual advanced dementia and end-of-life
- *Considerations*: home adaptation, close supervision for safety and avoiding self-harm or neglect 24/7, possible wheelchair use, palliative and/or hospice aid

Agency focus
Outreach and community supports (HCBS)
Helping support family caregivers

Leaving

Leaving home

- Admission to a nursing facility after non-ambulatory care is necessary
  - *Consideration*: SNF capability & understanding of DS?
- Looking for an agency run specialty dementia care group home
- Other options – perhaps memory care centers, assisted living programs?

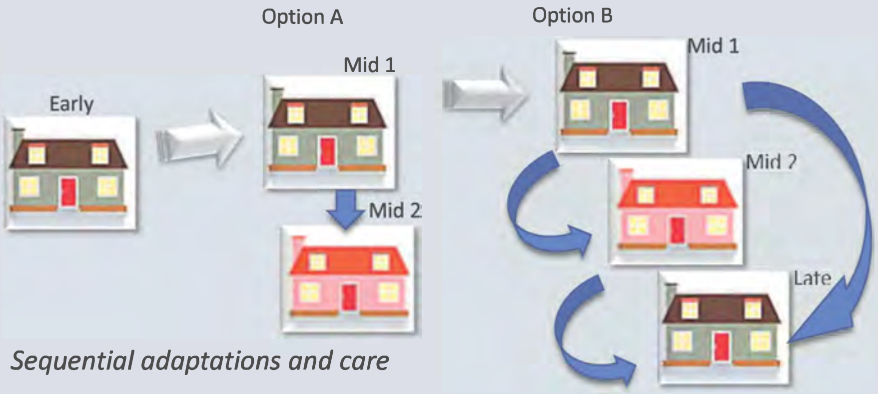
Agency Focus
Securing housing with dementia specialty care
Clinical team supports
Training for staff

Prevalent models of group home-based dementia care

AGING-IN-PLACE
- *single care home and stable stay*

Linear adaptations and care

IN-PLACE-PROGRESSION
- *multiple care homes & movement with progression*



Sequential adaptations and care

Mid = mid-level

Source: JANICKI (2010)

Study

- Since 2011, we have been following a cohort of 15 legacy adults with ID (w/15 replacements) who lived in **3 purpose-built, 5-resident, dementia-capable GHs**
  - along with 15 community-dwelling (non-dementia) adults with ID as age-matched controls
- Data collected include resident function, demographics, health, and other related information as well as staff/home administrative factors

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What have we found?

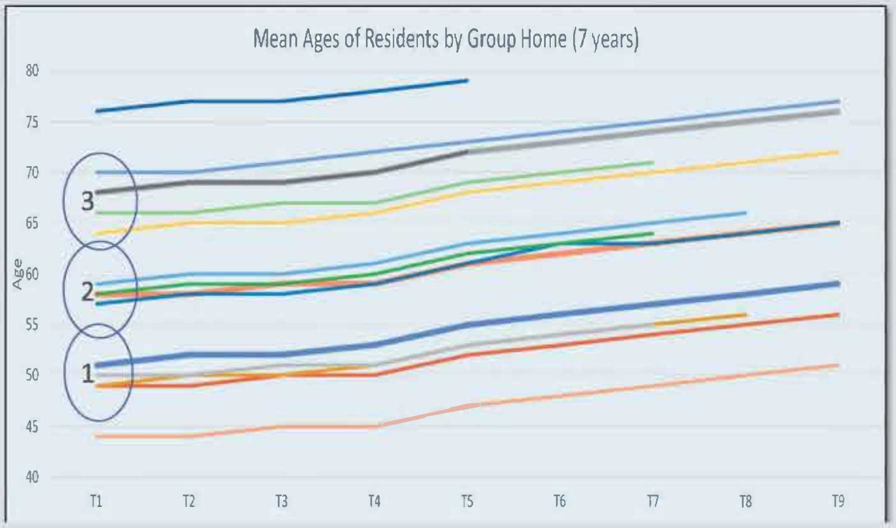
√ Admission trends

√ LOS

√ Mortality

√ Care patterns

√ Staffing



Admission age clusters

Janicki

Admissions based on dementia and age showed a tri-modal pattern

- Admit Age Group #1 entry: ± age 50 [X=50.5] [range: 49-53] *– generally DS*
- Admit Age Group #2 entry: ± age 57 [X=57.1] [range: 56-59] *– some DS and ID*
- Admit Age Group #3 entry: ± age 67 [X=66.8] [range: 64-70] *– generally ID*

Outliers were either

- much older [76, 79] or
- much younger [40, 44]

Length of stay patterns by home

Janicki

Average LOS over 10 years for 3 group homes was 4.9 years (58.5 months)

includes transfers, deaths, and new admissions

Average LOS for 15 'legacy' residents over 10 years was 8.3 years (99.6 months)

Implication

home compositions may change over time

Lighter shade of color = DS

Mortality

Original residents n=15

Survivor residents n=4 (27%)

11/15 (73.3%) died over 10 years

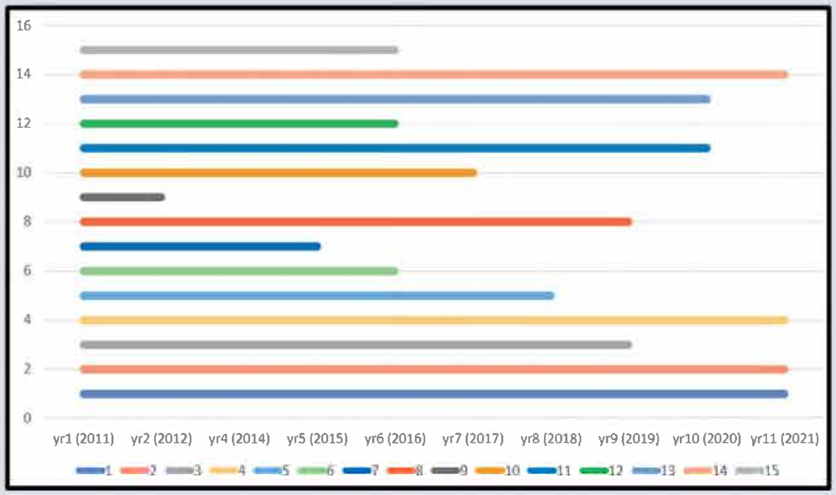
- *Mean age at entry: 59.1*
    - *[ID: 66.2; DS: 53.5]*
- *Mean* age at death = 67.5
    - *[DS: 58.8; ID: 72.4]*
    - *Males = 66.3 yrs; Females = 69.5 yrs*
- Mean years from entry to death: 5.4 yrs

Mean age at entry of original residents who

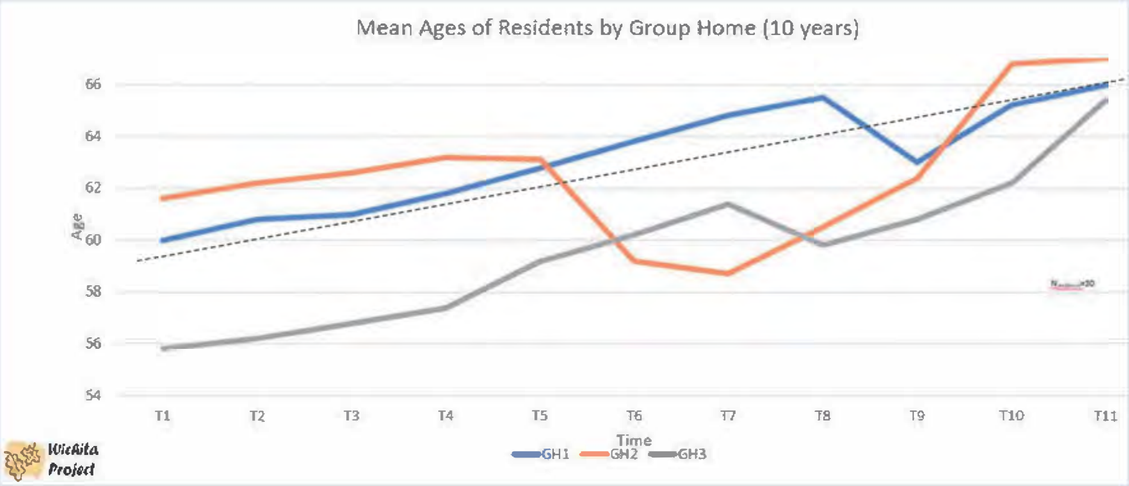
> died = 60.9

> are survivors = 54.4

- Deaths began 2 years following admission
- Average age of death for controls: 71.4 yrs
    - 5/15 (33%) deaths among controls



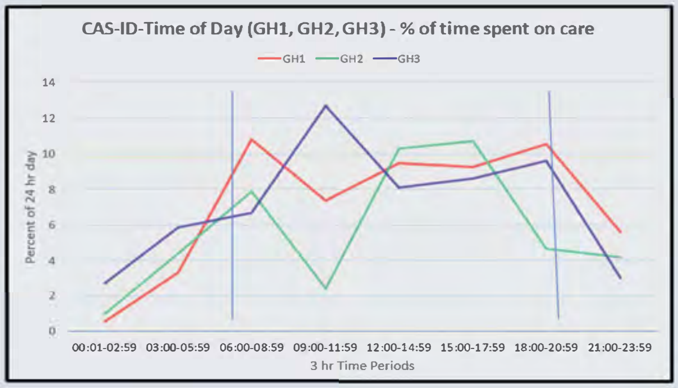
Legacy residents



Aging in place

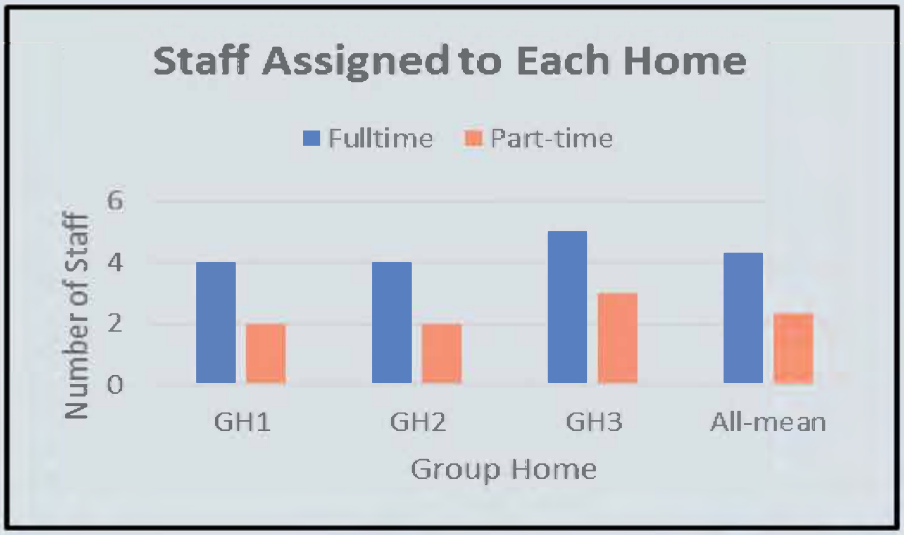
- Long-term residents age in place and mean age of residents progressively rises
- New entry residents, if younger, lead to lower mean age, but eventually also show aging-in-place
- Implications – with aging, comorbidities increase need for health and medical services

Staff time care patterns by home



- Staff care time patterns varied by homes as well as the caregiving focus
- Most time was spent on
  - **toileting aid** (GH1/GH3)
  - **eating/drinking assistance** (GH1/GH2)
  - **behavior management** (GH2)
- *Chart shows 3hr block pattern variations by home (averaged over 3 times – T1, T5 & T8)*

Janicki



Staff assignments by home

Janicki

- More staff were assigned to GH3 – the advanced dementia home
- Mean staffing: 4.3 full-time and 2.3 part-time
- Implication – consider staffing patterns at home
  - Need more staff during times of peak activities and care
  - Need specialized staff
  - Plan for turn-overs

Findings

- Of the 15 legacy residents 11 died and were replaced by 15 others (*greater mortality was noted among legacy residents with ID compared to DS*)
- All 30 residents (legacy and replacements) – exhibited features related to decline (*increasing problems, more comorbidities with age, and lessened function with dementia progression*)
- With multiple homes, over time there were inter-home transfers and new admissions, and the GHs trended toward stage/level specialty care
- There was an ebb and flow of movement related to stage of dementia and changes in character among the 3 dementia GHs, as well as variations in staffing patterns and periods of focused staff care and intensity during the day
- Costs and staffing patterns varied among the homes

Implications for dementia care housing

Location	Safety	Utility	Design
* Normative appearance and siting * Ease of access to off-housing resources and amenities	* Control egress and facilitate outdoor use * Evacuation factors * Wandering paths * Minimizing risk	* Single story * Ambulation ease * Wheelchair use * Privacy vs public spaces	* Planful transitions with decline * Functionality (bathing, common areas, colors, lighting, etc.)

What to think about…

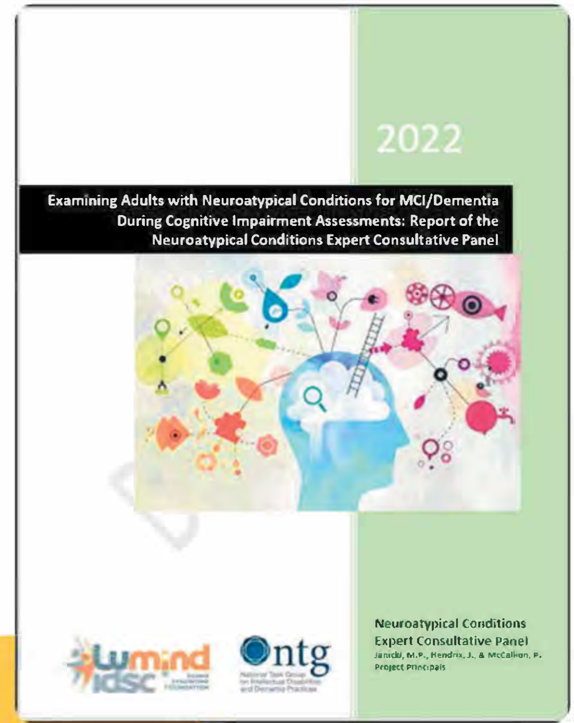
- Is the **building** set up for dementia care? (single level, lighting, barrier free, enclosed yard)
- Have **staff** received specialized training?
- At what point does the agency **‘admit**’ to the home? Criteria? Matching to level of other residents?
- At what point does the agency **‘terminate’** care? What are the policies? End-of-life options?
- How is the daily **support program** individualized? Involvement in community? How adapted to change in functions? How long do people **stay** at the home? Adaptable for advanced dementia?
- What are the attitudes and **capabilities** of staff? Is there comfort with dementia-capable care? Comfort with skills?
- What are the training and **clinical supports**?

Last thoughts

- Dementia care expectations
  - **varied trajectories of decline**
  - **mortality linked to** complexity of **pre-existing conditions** and **progression of dementia**
  - **changes in the focus of care needs over time** (including advanced dementia and end-of-life care)

- Effective in-community dementia care is contingent on understanding
  - **what dementia does** to behavior and function
  - how well **staff are trained**
  - how agencies **provide supports** – *such as*
    - clinicians who can consult on care issues
    - help with planning when changes occur
    - staffing levels based on needs for care

Background and Key Findings RE: ‘Dementia Assessment Challenges with Adults with Neuroatypical Conditions’



2022

Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments: Report of the Neuroatypical Conditions Expert Consultative Panel

Neuroatypical Conditions
Expert Consultative Panel
Janicki, M.P., Hendrix, J., & McCallion, P.
Project Principals

www.the-ntg-org/screening-assessment

The Neuroatypical Conditions Expert Consultative Panel

Assembled by the Lumind IDSC Foundation and the National Task Group on Intellectual Disabilities and Dementia Practices

- Composed of academic and clinical experts familiar with each of the neuroatypical conditions included

Charged with **examining** what **barriers** existed to effective screening, detection, and assessment of adults with neuroatypical conditions and with **identifying** the special **adaptations** that may be employed when examining adults with these conditions

What is this about?

- People with certain disabilities and conditions lack equity with respect to access for early detection of MCI and dementia…
  - *Why* are there barriers and *what* are they?
  - *What* can be done to achieve equity?

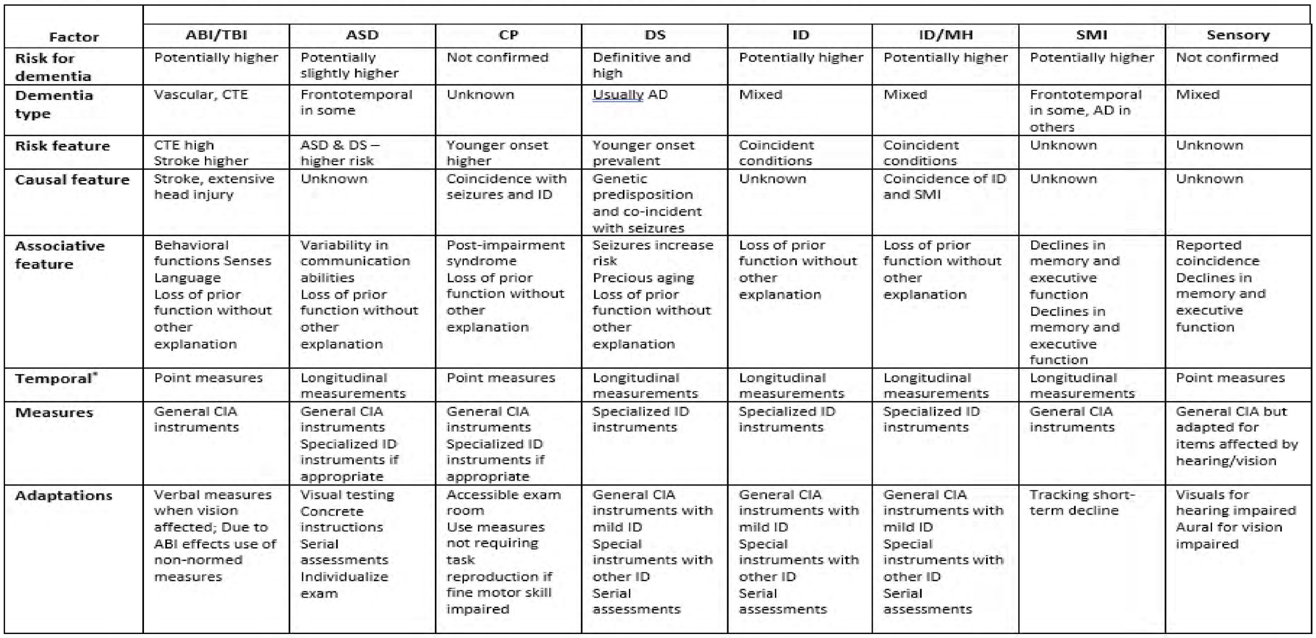
Which groups of adults may face special challenges when being assessed?

- **Neuroatypical conditions** include:
  - Acquired and traumatic brain injury
  - Autism spectrum disorder
  - Cerebral palsy
  - Intellectual disability
    - Down syndrome
    - Intellectual disability with severe behavioral/mental health issues
  - Serious mental illness
  - Significant vision/hearing impairment

> *"Each of these conditions has a range of prevalence in the adult population in the US, but in aggregate they represent a considerable number of Americans – probably between* ***10 and 25%*** *of all older adults who may initially present with MCI or dementia at their annual wellness visit or other older-age screening."*

Factor associated with dementia

Table 2: ***Summary of Factors Related to Dementia in Select Neuroatypical Conditions***



Factor	ABI/TBI	ASD	CP	DS	ID	ID/MH	SMI	Sensory
Risk for dementia	Potentially higher	Potentially slightly higher	Not confirmed	Definitive and high	Potentially higher	Potentially higher	Potentially higher	Not confirmed
Dementia type	Vascular, CTE	Frontotemporal in some	Unknown	Usually AD	Mixed	Mixed	Frontotemporal in some, AD in others	Mixed
Risk feature	CTE high Stroke higher	ASD & DS – higher risk	Younger onset higher	Younger onset prevalent	Coincident conditions	Coincident conditions	Unknown	Unknown
Causal feature	Stroke, extensive head injury	Unknown	Coincidence with seizures and ID	Genetic predisposition and co-incident with seizures	Unknown	Coincidence of ID and SMI	Unknown	Unknown
Associative feature	Behavioral functions Senses Language Loss of prior function without other explanation	Variability in communication abilities Loss of prior function without other explanation	Post-impairment syndrome Loss of prior function without other explanation	Seizures increase risk Precious aging Loss of prior function without other explanation	Loss of prior function without other explanation	Loss of prior function without other explanation	Declines in memory and executive function Declines in memory and executive function	Reported coincidence Declines in memory and executive function
Temporal*	Point measures	Longitudinal measurements	Point measures	Longitudinal measurements	Longitudinal measurements	Longitudinal measurements	Longitudinal measurements	Point measures
Measures	General CIA instruments	General CIA instruments Specialized ID instruments if appropriate	General CIA instruments Specialized ID instruments if appropriate	Specialized ID instruments	Specialized ID instruments	Specialized ID instruments	General CIA instruments	General CIA but adapted for items affected by hearing/vision
Adaptations	Verbal measures when vision affected; Due to ABI effects use of non-normed measures	Visual testing Concrete instructions Serial assessments Individualize exam	Accessible exam room Use measures not requiring task reproduction if fine motor skill impaired	General CIA instruments with mild ID Special instruments with other ID Serial assessments	General CIA instruments with mild ID Special instruments with other ID Serial assessments	General CIA instruments with mild ID Special instruments with other ID Serial assessments	Tracking short-term decline	Visuals for hearing impaired Aural for vision impaired

Risk for dementia among adults with neuroatypical conditions

Diagnostic condition	Risk factors	Dementia
Acquired and traumatic brain injury	Potentially higher in some circumstances – depending upon extent and location of injuries. Penetrative injuries (e.g., bullets, shrapnel), repetitive contact brain injuries (concussions)	Vascular, CTE*
Autism spectrum disorder	Potentially higher, but not certain	Frontotemporal
Cerebral palsy	Not confirmed; potential higher if ID and seizures present	Unknown
Intellectual disability	At norm, general factors, head injuries	Alzheimer's disease, mixed dementias
Down syndrome	Predisposition to Alzheimer's due to abnormal accumulation of amyloid	Alzheimer's disease
Serious mental illness	Potentially higher, depending upon dx	Frontotemporal, Alzheimer's disease
Significant vision/hearing impairment	Not confirmed, may be higher if coincident condition present	Mixed types when present

*Chronic traumatic encephalopathy

NAPA and the National Plan to Address Alzheimer's Disease

The ‘NAPA

- **National Alzheimer’s Project Act** (became law in early 2011)
  - Requires DHHS to submit an annual Alzheimer’s plan to Congress – from 2012 to 2025
- Administered by federal **Department on Health Human Services** (DHHS)
- **Advisory Council on Alzheimer's Research, Care, and Services**
  - Council composed of Presidential appointees and federal agency staff
  - Creates the National Plan to Address Alzheimer’s Disease with annual updates

The National Alzheimer's Project Act required the creation of a national strategic plan to address the rapidly escalating Alzheimer's disease crisis and calls for coordination of Alzheimer's disease research and caregiver support efforts by the federal government

National Plan called for -- among other things….

☑ Issuance of practice guidelines for care and supports and expanded public education

☑ Promotion of assessment tool for detection of cognitive impairment as part of the annual wellness visit

☑ Enhanced supports for caregivers

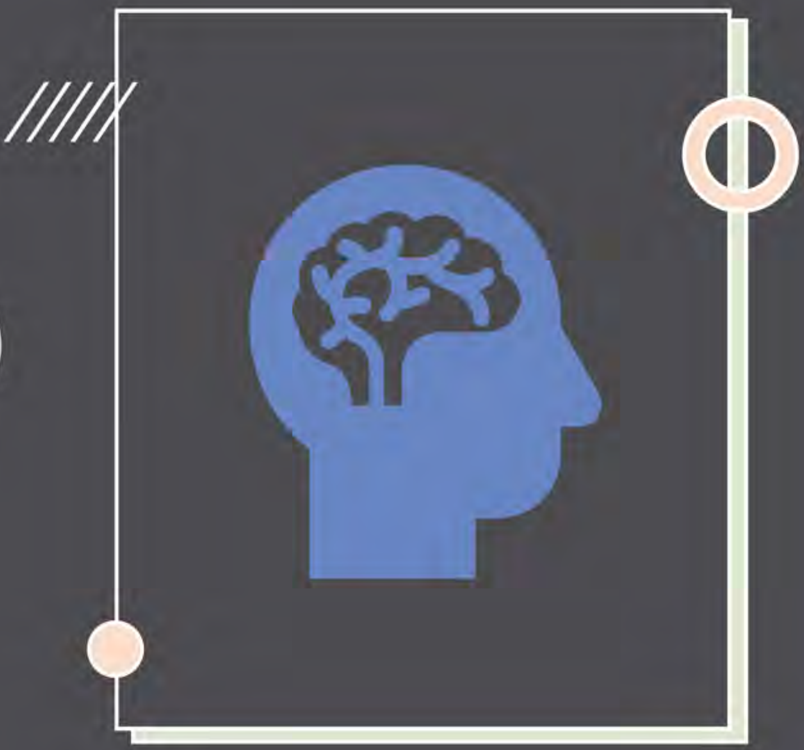
☑ Expanded research

☑ Special population focus - I/DD

National Plan
to Address
Alzheimer's Disease

First released on May 15, 2012
Continues to be updated annually until 2025!

The National Task Group (NTG)



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ntg
National Task Group
on Intellectual Disabilities
and Dementia Practices

The **National Task Group** is a non-profit organization charged with creating quality lives for adults with intellectual disability at-risk of or living with dementia and ensuring that their interests and those of their families are taken into account as part of the *National Plan to Address Alzheimer’s Disease*.

The NTG’s mission is to advocate for services and supports for people with intellectual disability and their families who are affected by Alzheimer's disease and dementias.

‘My Thinker’s Not Working’

‘My Thinker’s Not Working’
A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports

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

2012

- ✓ To define best practices that can be used by agencies in delivering supports and services to adults with intellectual disabilities affected the various dementias
- ✓ To identify a workable national a ‘first-instance’ early detection / screening instrument
- ✓ To produce educational materials of use to families, people with ID, and providers of services
- ✓ To further public policy with respect to dementia as it affects adults with intellectual disabilities

www.the-ntg.org

NTG Activities

Early detection-screening instrument (NTG-EDSD)

- Various language versions available
- Access at www.the-ntg.org

Practice guidelines

- Community supports guidelines
- Health advocacy guidelines
- Assessment guidelines

Training and education activities

- National education curriculum on dementia & ID
- Training workshops & webinars
- Meetings with professional groups
- Family information promotion & support group

Linkages

- Administration on Community Living, NIH Summits, HRSA
- NASDDDS, N4A, NACDD & state activities
- CARF & national program standards
- NDSS, Dementia Connect, Biomarkers Research Consortium
- The Arc, Alzheimer's Association, LEAD, Down Syndrome Coalition

NTG-EDSD

'My Thinker's Not Working'
A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports

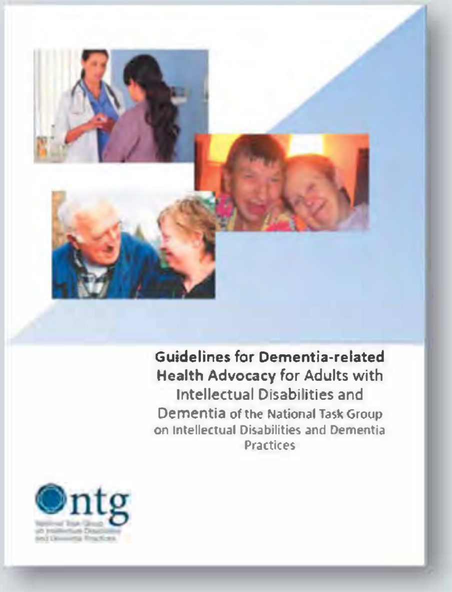
Executive Summary to the Report of the National Task Group on Intellectual Disabilities and Dementia Practices

2022

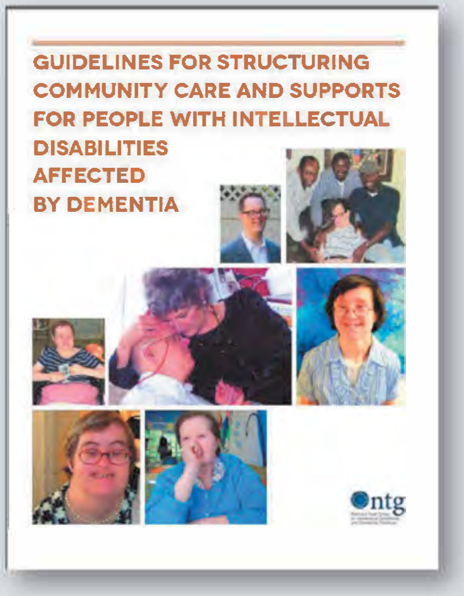
Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia of the National Task Group on Intellectual Disabilities and Dementia Practices

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

NTG Guidelines



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



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

DIAGNOSIS AND TREATMENT GUIDELINES
Consensus Recommendations

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

www.the-ntg.org

mjanicki@uic.edu

Matthew P. Janicki, Ph.D.
University of Illinois at Chicago
Chicago, Illinois USA

mjanicki@uic.edu

www.the-ntg.org

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