

# DIAGNOSIS AND MANAGEMENT OF DEMENTIA AMONG ADULTS WITH INTELLECTUAL DISABILITY

Matthew P. Janicki, Ph.D.

University of Illinois at Chicago

mjanicki@uic.edu

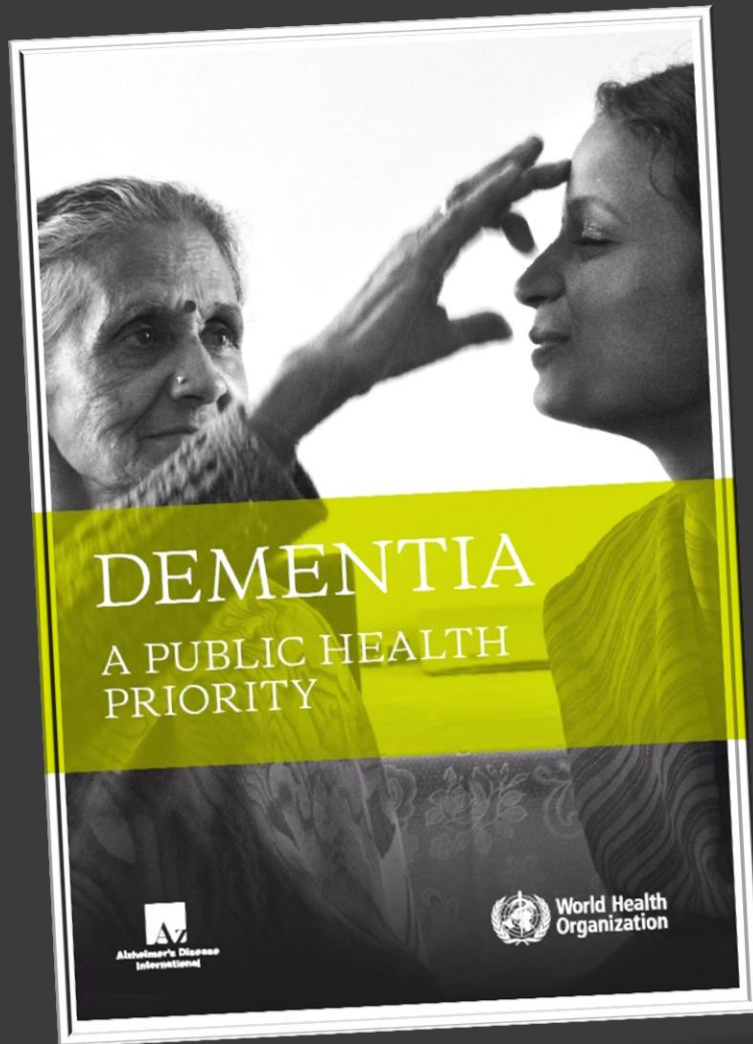
UNE's Geriatric Education Center Training Program

Preparing for the Future: Alzheimer's Disease and Related Dementias

Bar Harbor, Maine – June 14, 2014

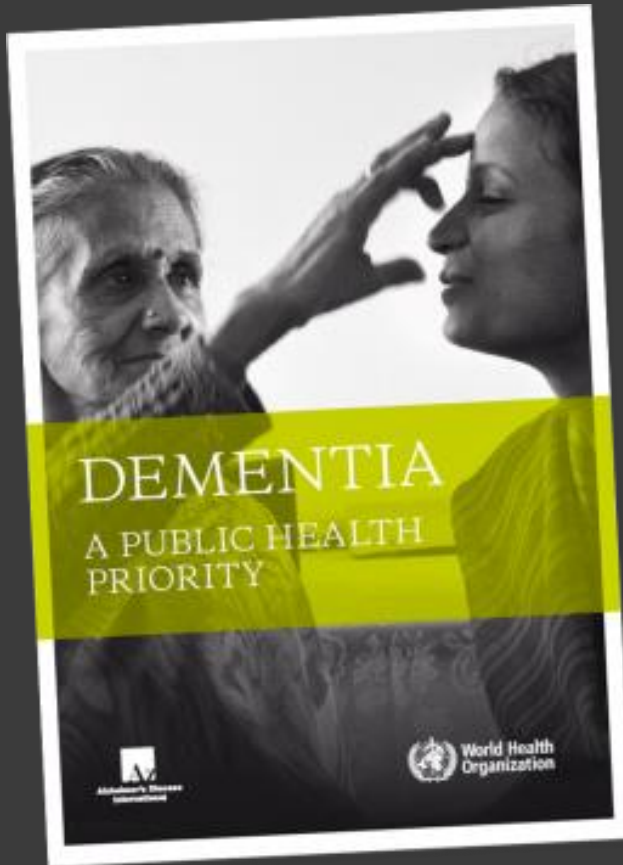


# WHO report on dementia



- Prevalence and incidence projections indicate that the **number of people with dementia will continue to grow**, particularly among the oldest old
- The total number of people with dementia worldwide in 2010 is estimated at 35.6 million and is **projected to nearly double every 20 years**, to 65.7 million in 2030 and 115.4 million in 2050
- Primary prevention should focus **countering risk factors** for vascular disease, including diabetes, midlife hypertension, midlife obesity, smoking, and physical inactivity

# Intellectual disabilities



## Care pathways for populations with specific needs

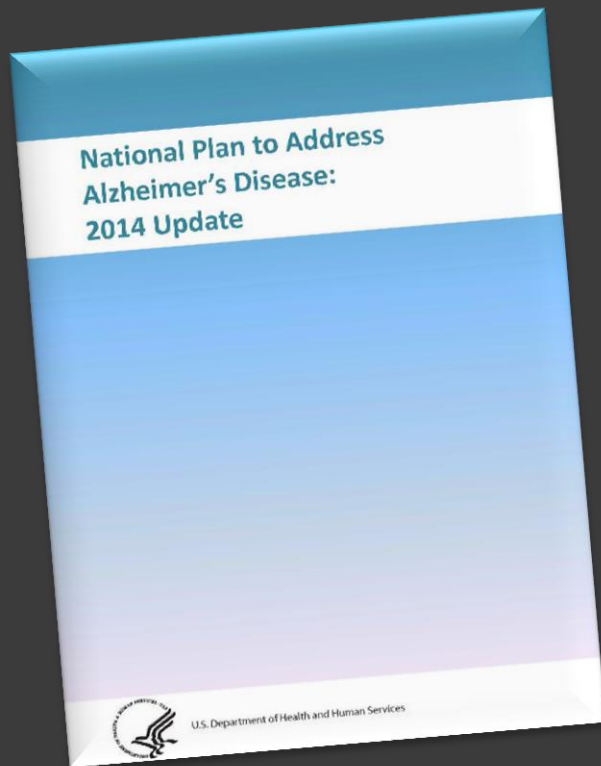
- 'Some groups have additional needs arising from having dementia or being a caregiver of a person with dementia. Examples of specific or minority groups include... **people with intellectual disabilities...**'
- 'Some of the barriers to access include a lack of understanding or recognition of the dementia in their population group, language or cultural barriers, and a lack of appropriate information resources and services.'

## Intellectual disability

- 'People with Down syndrome are at a significant risk of developing Alzheimer's disease. Studies suggest that 50–70% will be affected by dementia after the age of 60 years.
  - The onset of dementia in people with Down syndrome is likely to be younger than the sporadic form of dementia that generally affects older people.'
- 'In the USA, a national task force of experts on intellectual disabilities and Alzheimer's disease has developed a comprehensive report with policy and practice recommendations on detection, care and support for this population.\*
  - *The aim of the report is to enable adults with intellectual disabilities who are affected by dementia to remain living in the community with quality support.'*

## 2014 Update to the National Plan to Address Alzheimer's Disease

Activities – having implications for intellectual disabilities  
– directed toward...



- Developing targets, strategies, and milestones for dementia-capable primary and specialty care workforce
- Continuing work on measuring high-quality dementia care and identifying meaningful outcomes
- Exploring models of family support for people with intellectual disabilities as they age
- Developing a compendia of state policies on residential care and adult day health
- Enhancing public awareness and engagement (national education and outreach initiative)
- Producing a chartbook on characteristics of people with AD and their caregivers

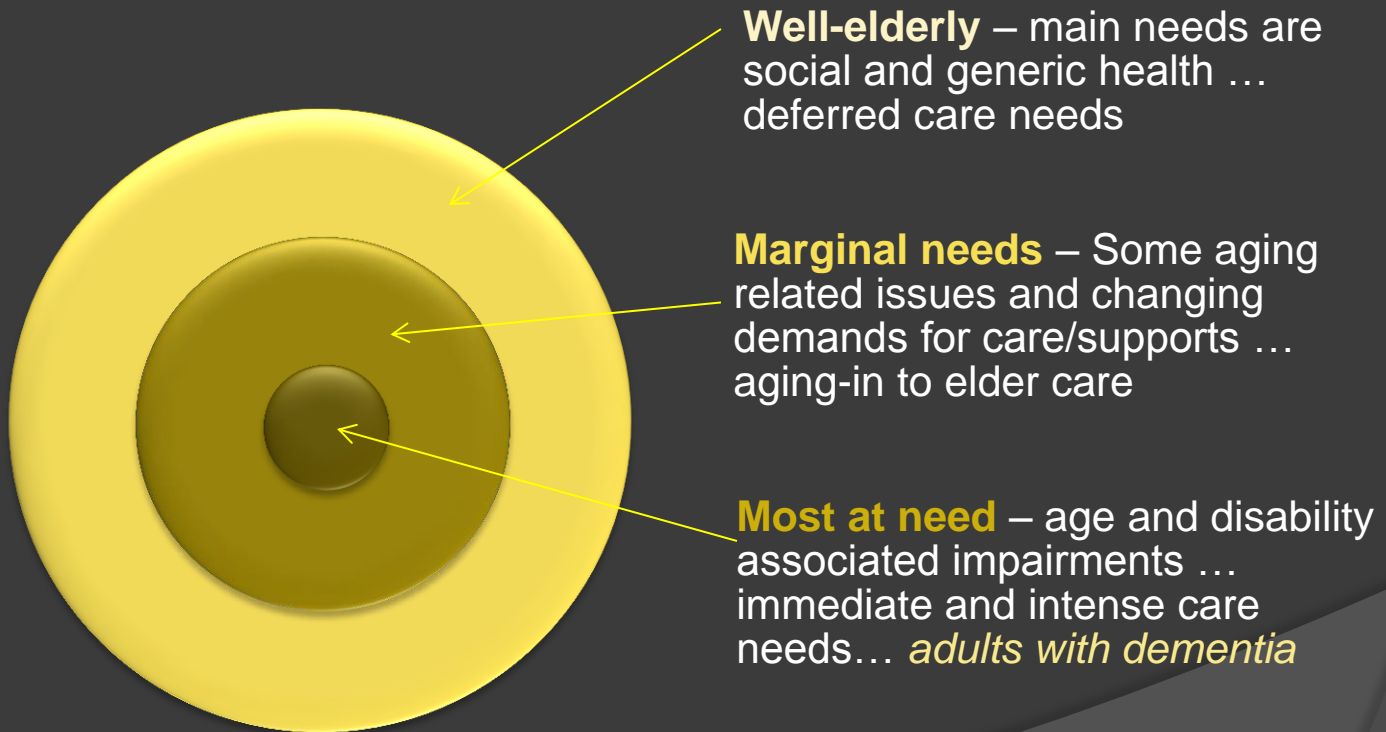
- ⦿ Demographics are trending upwards for a larger older population
- ⦿ Alzheimer's disease currently affects 5.2 million Americans (and 9 million by 2050)<sup>1</sup>
- ⦿ In more than 90% of adults with Alzheimer's disease, symptoms generally appear after age 60, and the incidence of the disease increases with age<sup>1</sup>
- ⦿ *The numbers of older adults with ID are growing as is the number affected by dementia*

<sup>1</sup> source: Alzheimer's Association

# Needs...

- ▣ Need for 'best practice' models in community based housing
- ▣ Need for supportive services when in family home
- ▣ Need for practice guidelines for medical and health care settings
- ▣ Need for screening, assessment, and diagnostic resources
- ▣ Need for more information on population and effects of dementia on long term care

# Diverse older population – by urgency of needs



# Dementia and Intellectual Disability



# Dementia & ID: the questions

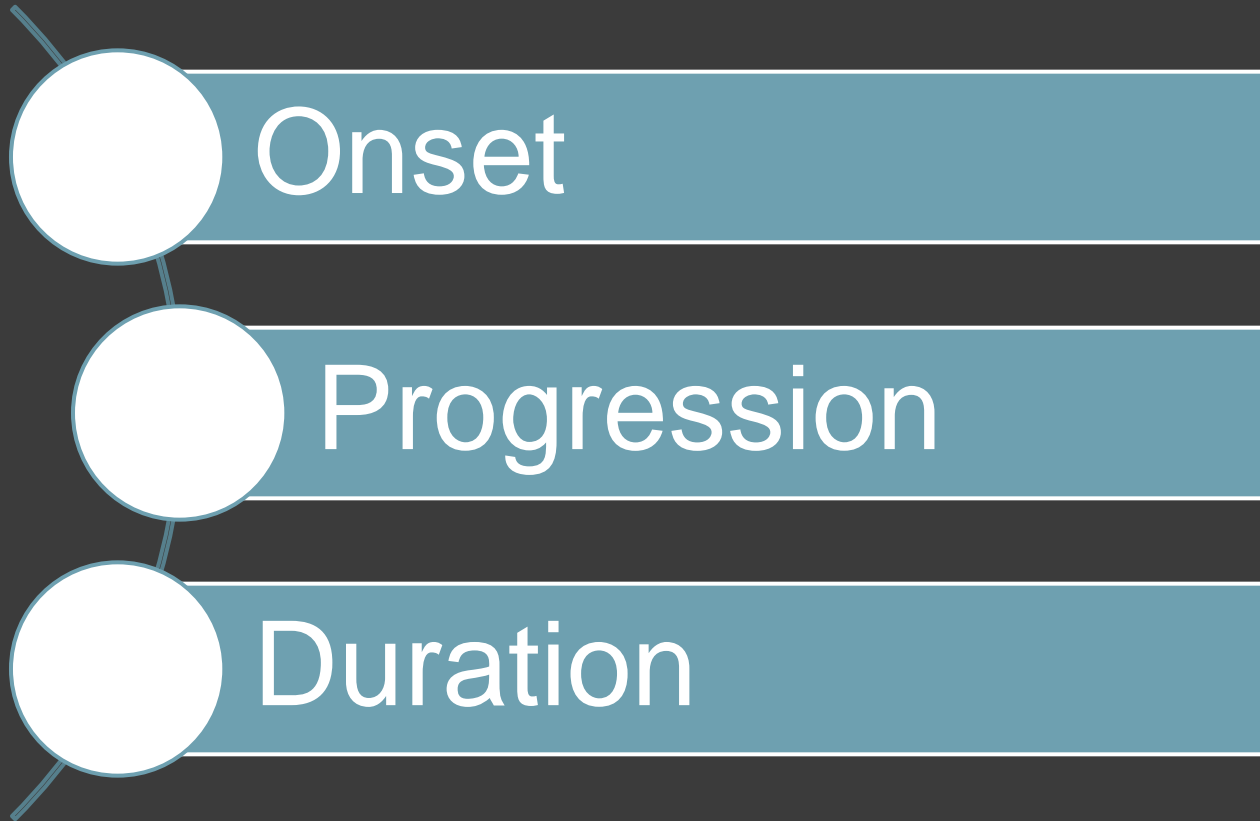
- ⦿ What is dementia? How does it differ from lifelong intellectual disability?
- ⦿ How does it impact people with intellectual disabilities? Is the impact different?
- ⦿ Will all persons with ID be affected in old age? Why and who will?
- ⦿ How can we respond? What services are needed? Who can help us?

# ID vs. Dementia

- ⦿ Intellectual disability involves undeveloped or underdeveloped mental or intellectual skills and abilities
- ⦿ Dementia is a widespread loss of mental or intellectual skills and abilities - Dementia related losses occur in memory, language skills, orientation, ADLs [activities of daily living], and changes evident in personality and global functioning

*Key:* behavioral presentation may be similar, but it's the loss from previous level of function that differentiates the two

# Dementia and ID



# Differences in ID?

## Early onset?

- Among some etiologies – e.g., Down syndrome, head injury

## Symptom presentation?

- Mostly the same, some variations due to etiology – e.g., Down syndrome... early personality losses

## Assessment?

- Standard measures not useful – comparisons by individual over time

## Services?

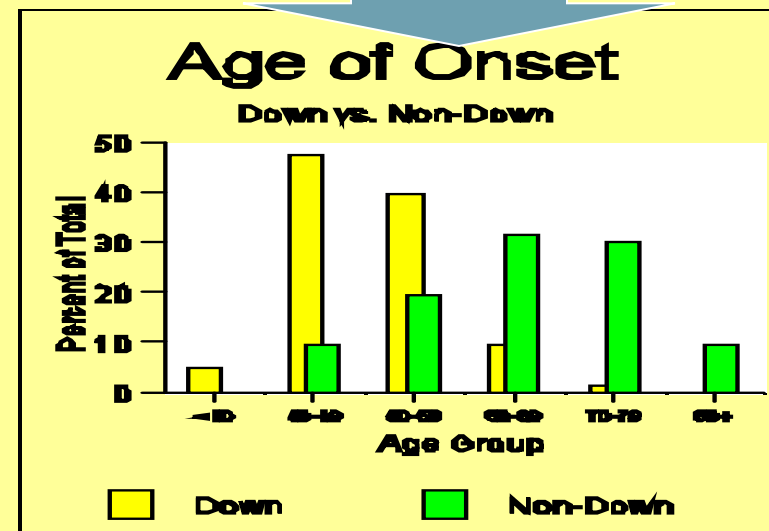
- More dementia care options as lifelong supports generally available

# When Does Onset Occur?

Onset is speculative . . .

- the best we can do is identify that point when significant change or impairment has become noticeable
- in some people noticeable changes have been preceded by MCI – “mild cognitive impairment”
- early 50s for DS – late 60s for ID

Note difference between DS (yellow) and other ID (green)

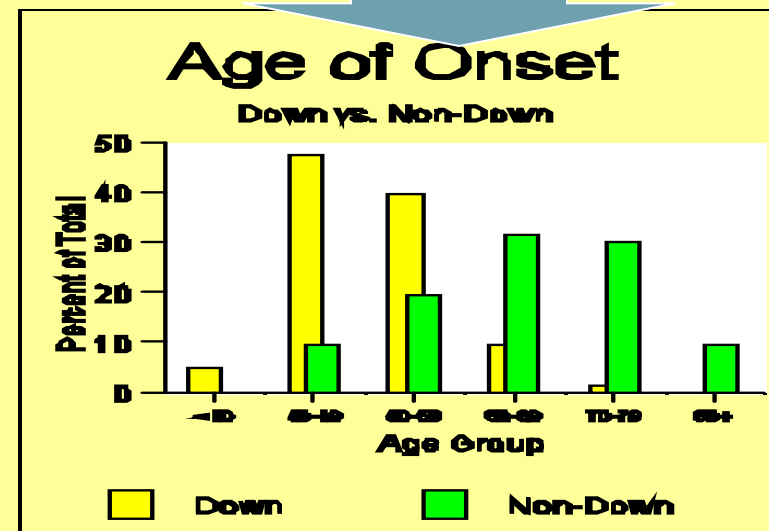


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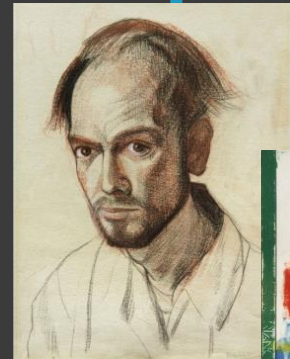


~20 years before ... the pathogenesis of Alzheimer's disease

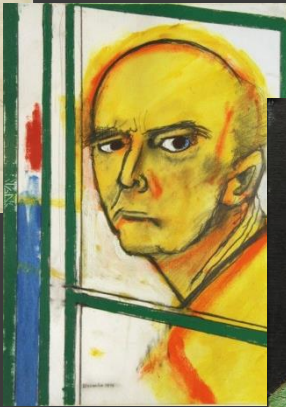
Symptoms become pronounced enough to warrant concern ... thus 'onset'... Application of biomarkers

Progressive mental decline and physical debilitation (from 2 to ~20 years) to death

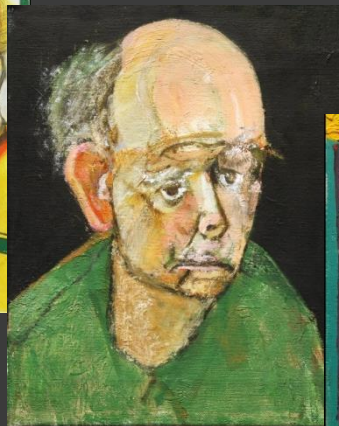
# Progressive cognitive deterioration due to Alzheimer's disease



1967



1996



1997



1998



1999



2000

Functional capacity

William Utermohlen's Self-Portraits Of His Decline From Alzheimer's Disease

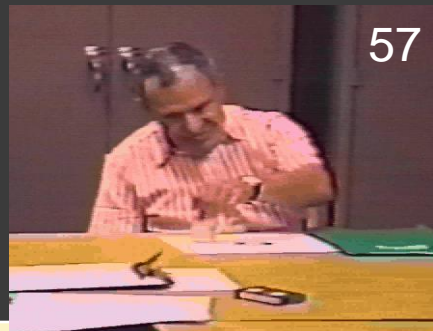


Time

# Stages of Alzheimer's Disease

## EARLY or MILD STAGE

2 to 4 years or longer



## MID- or MODERATE STAGE

2 to 10 years

## LATE or SEVERE STAGE

1 to 3 years of longer

Compressed staging for adults with Down syndrome

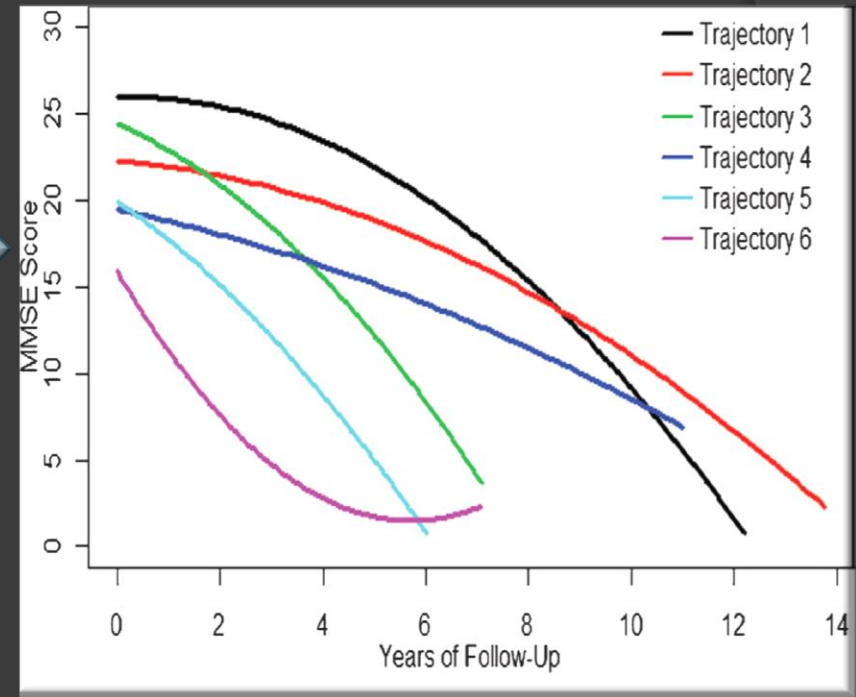


# Critical factors

- 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

# Dementia & ID Findings

## Rate of Occurrence<sup>1, 3, 5, 8</sup>

- Age-cohort percent for adults with intellectual disability (ID) is same as in general population (~5-6% over 60)
- Much higher prevalence (60% >age 60) and neuropathology indicative of AD in most adults with Down syndrome (DS)

## Dementia Type<sup>2,9</sup>

- Type of dementia differs between DS and other types of ID
- Generally dementia of the Alzheimer's type is prevalent in DS
- Similar range of dementias found in ID as in other people
- Problem of 'diagnostic overshadowing' in DS

## Onset and Duration<sup>1,2,3,10</sup>

- Average onset age in early 50s for DS – late 60s for others
- Most DAT diagnosed <3 years of "onset" in adults with DS

## Behavioral Changes<sup>2,3,6,11</sup>

- More evident change in personality in DS
- More initial memory loss in other ID

## Neurological Signs<sup>1,2,4,7</sup>

- Late onset seizures found in 12%-84% of adults w/DS

## Prognosis<sup>2</sup>

- Aggressive AD can lead to death <2 years of onset in DS
- 2-7 years mean duration in DS
- Same duration expected among other ID as in other people

Sources: <sup>1</sup>Janicki, M.P. & Dalton, A.J. (2000). Prevalence of dementia and impact on intellectual disability services. *Mental Retardation*, 38, 277-289. <sup>2</sup>Janicki, M.P., & Dalton, A.J. (1999). Dementia, Aging, and Intellectual Disabilities: A Handbook. Philadelphia: Brunner-Mazel; <sup>3</sup>Bush, A., & Beall, N. (2004). Risk factors for dementia and Down syndrome. *AJMR*, 109, 83-97. <sup>4</sup>Menendez M. (2005). Down syndrome, Alzheimer's disease and seizures. *Brain Development*, 27(4), 246-252. <sup>5</sup>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. <sup>6</sup>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, 1 Jun 26]. <sup>7</sup>Crespo, A., Gonzalez, V., Coubes, P., & Gellise, P. (2007). Senile myoclonic epilepsy of Genton: Two cases in Down syndrome with dementia and late onset epilepsy. *Epilepsy Research*, 77,165-168. <sup>8</sup>Evenhuis, H. (1997). The natural history of dementia in ageing people with intellectual disabilities. *JIDR*. 41(1), 92-96. <sup>9</sup> Strydom, A., Livingston, G., King, M., & Hassiotis, A. (2007).Prevalence of dementia in ID using different diagnostic criteria. *Br. J. Psychiatry*, 191, 150-157. <sup>10</sup> Margallo-Lana et al., (2007). Fifteen year follow-up of 92 hospitalized adults with DS. *JIDR*. 51, 463-477. <sup>11</sup> Gianpietro, N. (2013). Research in dementia in Down syndrome. Presentation at the SR Congresso Internazionale sulla Sindrome di Down, Roma, Italy, November 9, 2013.

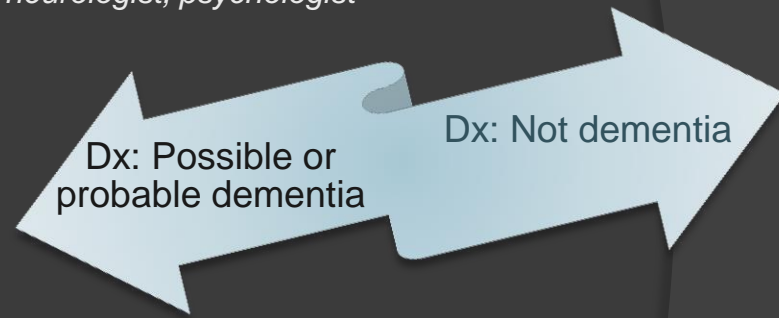
# What's important to know

- ⦿ The difference between normal aging changes and pathological aging changes
- ⦿ Early signs of functional change associated with dementia
- ⦿ Types of dementia and their main characteristics, what will be the behavioral/functional changes, and their duration
- ⦿ When is it best to refer for assessment and to whom
- ⦿ What options exist for early dementia-related supports
- ⦿ What options exist (or need to be put in place) for long-term dementia capable care/supports

# Dementia Detection and Adaptation Model



*Assessment by psychiatrist, neurologist, psychologist*



## Program/services adaptations



- Dietary changes – hydration, nutrition, weight
- Changes in staff – staff paired to dementia stages
- Adaptations of living environment – sounds, lighting, way-finding, safety
- Adaptions to routines and activities – lower stimulation, but engaging activities
- Specialized attention to ADLs, health, mental health, incontinence, memory cues

- Examples...
- Short term memory loss
  - Confusion
  - Decline in abilities
  - Challenging behaviors
  - Personality changes
  - Wandering
  - Falling



# What to do when dementia is suspected?

- ⊙ Apply a detection/screening instrument to look for signs
  - if comes up positive
- ⊙ Refer for assessment...
  - To whom?
    - Agency MD, local MD, psychologist, nurse, other person who may do formal assessment to validate suspicions
  - If outcome comes up positive
- ⊙ Refer for diagnostic work-up
  - Ask for confirmatory information and determination that it is dementia (*by exclusion of other causes*)

# Ascertaining dementia

- ◎ Start with an administrative screen (e.g., NTG-EDSD)
  - Capture visuals on functioning (preferably ‘personal best’)
    - *digital recording of behavior*
  - Observe if screen provides ‘hits’ on ‘warning signs’
- ◎ Refer for clinical assessment
  - 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)
- ◎ Obtain diagnosis and track function

# Benefits of differentiating types of dementia as part of the dx process

- Diagnostic precision
- Potential medication treatment variations
- Developing expectations of residual life years
- Setting up care management plans on expected behavioral presentations and progression
- Communication and interaction variations
- Projecting expectations for change in care needs

# Challenges to ID diagnosis and care

- ⦿ Individuals with ID 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 ID
- ⦿ Difficulty of measuring change from previous level of functioning
- ⦿ Challenges with assessing change in adults with severe and profound ID
- ⦿ Conditions associated with ID maybe mistaken for symptoms of dementia
- ⦿ Diagnostic overshadowing
- ⦿ Aging parents and siblings (informants or carers)
- ⦿ Dearth of research and training on differential Dx



Screening

Administrative [NTG-EDSD]  
Clinical (DSDS, DLD, AADS)

Assessment

Dementia Assessment Scales  
Neuro-psych evals  
CT - MRI

Diagnosis

Possible  
Probable  
Definitive

# If you are concerned as to whether it is dementia...

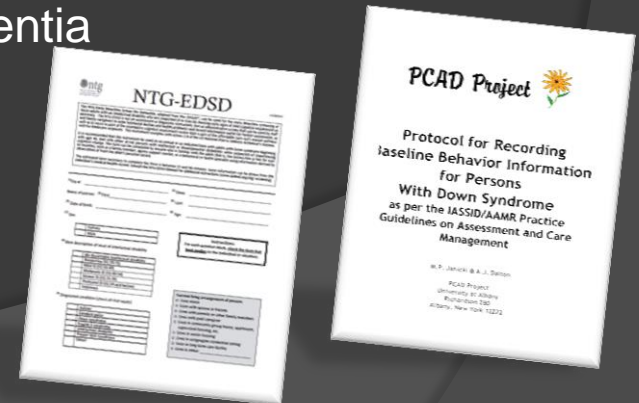
- ◎ Keep track of the behavior
  - Use a digital recording device
  - Use a screen/early detection instrument
  - Seek advice from another clinician
  - Gather as much information as you can
    - Speak with other program staff
    - Speak with housemates, etc.
    - Speak with family
  - Review record for previous status
    - History
    - Mention of decline

# Need for a early detection/screening tool

- ◎ Clinicians report individuals often have problems well in advance of significant signs of dementia
- ◎ Why screening?
  - Screening tools capture information about early changes in behavior and function
  - Caregivers can be good observers and reporters of relevant signs and symptoms of changes
  - Screening tools provide a common format for sharing information
- ◎ Cognitive and functional status are not usually included in periodic health exam visits
  - Relevance to ACA cognitive assessment as part of the annual wellness visit

# Early & Periodic Screening

- Applying screening/detection and assessment measures
    - Controversy as to whether this is intrusive
    - Balance privacy vs. risk
  - Benefits
    - Pick up on early warning signs
    - Helpful with early differential dx
    - Associate with data from biomarkers
  - Easy ways to collect quick impressionistic data
- Protocol for recording a set of signal performance tasks and behaviors linked to potential early expression of dementia
  - Can be used as part of the individual's permanent record or program plan to periodically track changes in behaviors that might indicate cognitive and motor changes associated with dementia



# 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 several languages

Use: to provide information to physician or diagnostician on function and begin the conversation leading to possible assessment/diagnosis

**ntg**  
National Task Force  
on Alzheimer Disease  
and Memory Care

## NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID<sup>®</sup>, 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](http://www.aadmd.org/ntg/screening)).

(1) File #: \_\_\_\_\_ (2) Date: \_\_\_\_\_

Name of person: (3) First: \_\_\_\_\_ (4) Last: \_\_\_\_\_

(5) Date of birth: \_\_\_\_\_ (6) Age: \_\_\_\_\_

(7) Sex:

<input type="checkbox"/>	Female
<input type="checkbox"/>	Male

(8) Best description of level of intellectual disability

<input type="checkbox"/>	No discernible intellectual disability
<input type="checkbox"/>	Borderline (IQ 70-75)
<input type="checkbox"/>	Mild ID (IQ 55-69)
<input type="checkbox"/>	Moderate ID (IQ 40-54)
<input type="checkbox"/>	Severe ID (IQ 25-39)
<input type="checkbox"/>	Profound ID (IQ 24 and below)
<input type="checkbox"/>	Unknown

(9) Diagnosed condition (check all that apply)

<input type="checkbox"/>	Autism
<input type="checkbox"/>	Cerebral palsy
<input type="checkbox"/>	Down syndrome
<input type="checkbox"/>	Fragile X syndrome
<input type="checkbox"/>	Intellectual disability
<input type="checkbox"/>	Prader-Willi syndrome
<input type="checkbox"/>	Other: _____

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

**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: \_\_\_\_\_

<http://aadmd.org/ntg/screening>



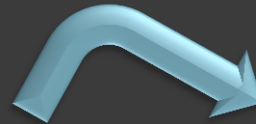
# Assessment

## ◎ Function

- To examine adults due to suspicion of cognitive or functional decline that may result from Alzheimer's or other conditions

## ◎ Process

- Collect informant information (family, staff, friends, etc.)
- Apply detailed measures assessing function, and physiological and neurological factors
- Conduct collateral examinations (neurological, CT/MRI)



### **Diagnostics...**

Focused medical and family history  
Physical exam and laboratory tests  
Functional status exam  
Mental status exam  
Assessment for delirium/depression  
Brain scans (CT or MRI)  
Neuropsychological tests

# Barriers to effective assessments

- Absence of specialized training among clinicians
- Poor knowledge of assessment protocols to assess dementia
- Dearth of assessment services
- Lack of familiarity with identifying dementia in adults with ID among primary care medical practitioners
- Confusion by symptoms and misdiagnosis

Reversible/treatable causes of dementia-like behaviors

- Adverse drug reaction
- Depression
- Metabolic changes
- Nutritional deficiencies
- Head injuries





# Program options

# Dementia and ID



# What is optimal dementia care?

## ◎ Foundation –

- Settings need to be ‘dementia friendly’ and ‘dementia capable’
- Avoiding institutionalization or re-institutionalization in large congregate settings irrespective of auspice (aging, disability, health)

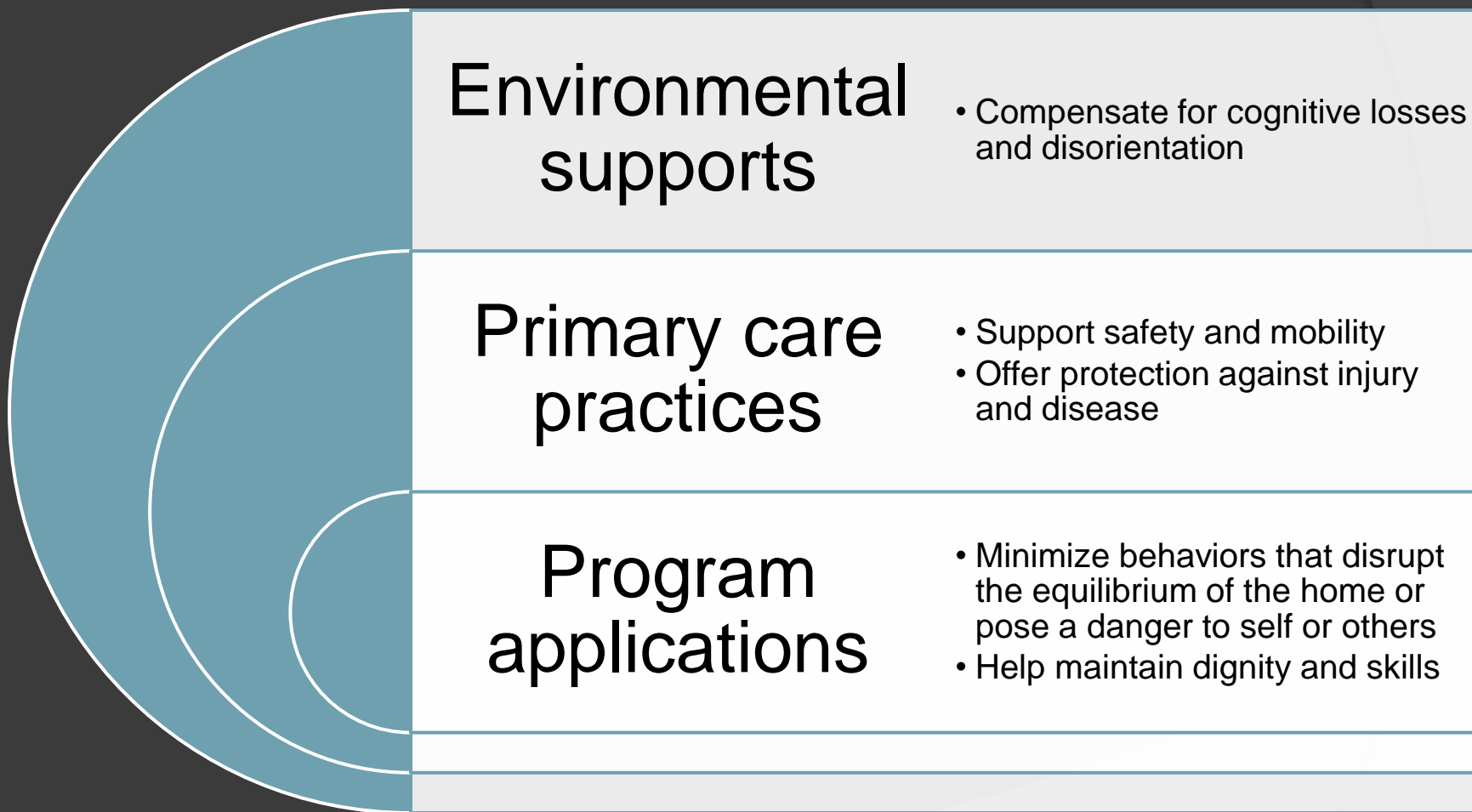
## ◎ Structure –

- Individualized, personalized care
- Comfortable settings, offering long term commitment to care, with family or small number of co-residents, capable staff, educated caregivers, adapted environment
- Protection from abuse, harm and neglect, safety

# Community Supportive Care

- ⦿ Dementia lessens an individual's ability to be left alone – thus eventual 'living without supervision' is not an option
- ⦿ What are the supports needed?
  - Help for carers and the person
  - Advanced planning for alternative care
  - Diagnostic and intervention assistance
  - Support groups for carers (family or staff)
  - Dementia capable community housing (group homes)
  - Respite for carers
  - Health care and social supports

# Dementia Care Focus



# Program Adaptations

Contextual

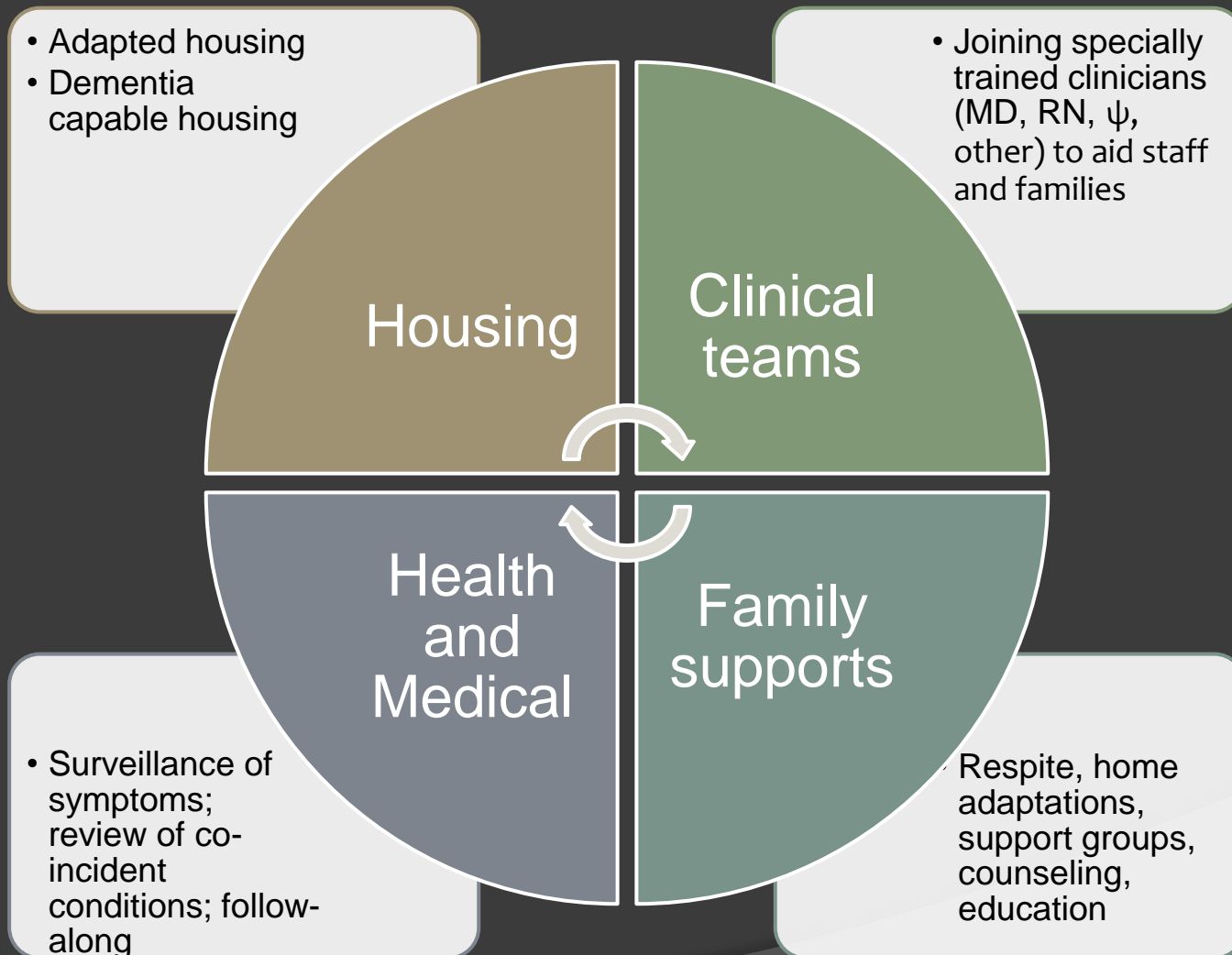
Rethinking  
how daily life  
and regular  
activities are  
approached

Lessening  
stimulation,  
while  
promoting  
involvement  
and challenge

Modifications  
in  
communication  
methods

Supporting  
residual skills

# Coordinated dementia-related supports/services



# Factors aggravating care decision-making

## Change of care focus

Going from making gains to that of maintaining function and dealing with eventual loss and decline

## Implications

- Care staff trained in developmental and growth techniques have to be reoriented to think in terms of maintaining capabilities
- Care situation planning has to consider progressive decline and greater inadequacies
- Care environments have to offer structure, comfort and familiarity

- ✓ Much higher prevalence of neuropathology indicative of AD in most older adults w/Down syndrome (DS)
- ✓ Alzheimer's type dementia is most prevalent among adults w/DS – with implications for course and duration
- ✓ Studies show average onset age in early 50s for DS and late 60s for other ID
- ✓ Dementia presents with variable rates of decline
- ✓ Duration may range from 1-2 years to 10-20 depending on type and other confounding factors
- ✓ If living alone, self-care not a viable possibility with progressing loss of function
- ✓ If living at home, long-term care may not always be possible (caregiver burden, home inadequacies, etc.)
- ✓ If living in group quarters, staff may not be prepared to provide long-term care
- ✓ Communities may not have viable in-community care resources



# Prevalent dementia care options and their intent

## Institutional care

[long term care facilities, nursing homes, old age homes, dementia special care units]

## Family care

[living with family, other relatives, or other family members of carers]

## Neighborhood group homes

[generic group homes, specialized group homes]

Group homes for persons with ID who age in the homes

Group homes for specialized dementia care

Sheltered dementia care  
[assisted living, dementia care homes]

Carer supports

Small personalized care settings

# Value of family home care

- Care at home enables continuity with familiar setting and people
- Family commitment to supporting aging and problems associated with decline
- Value enabled if family gets supports for continued home care (respite, home modifications, aides to help primary caregiver, financial assistance)
- Usually provides safety and security

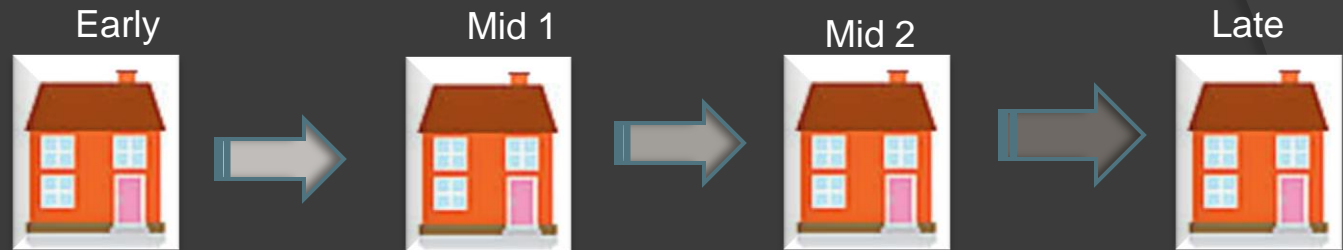
# Value of small group home care

- In lieu of care at home, next best option of comfort for families
- Many countries are adopting small group living as alternative to institutional care for persons in general population
- Intuitively and empirically viable – provide personalized care, in-community living, and connections with familiar settings
- Significant research base on structuring quality settings
- In ID field, readily available and adaptable for age-associated community care when dementia threatens independence
- Models exist for transitioning homes as dementia-capable living arrangements

# Prevalent models of group home-based dementia care

## AGING-IN-PLACE

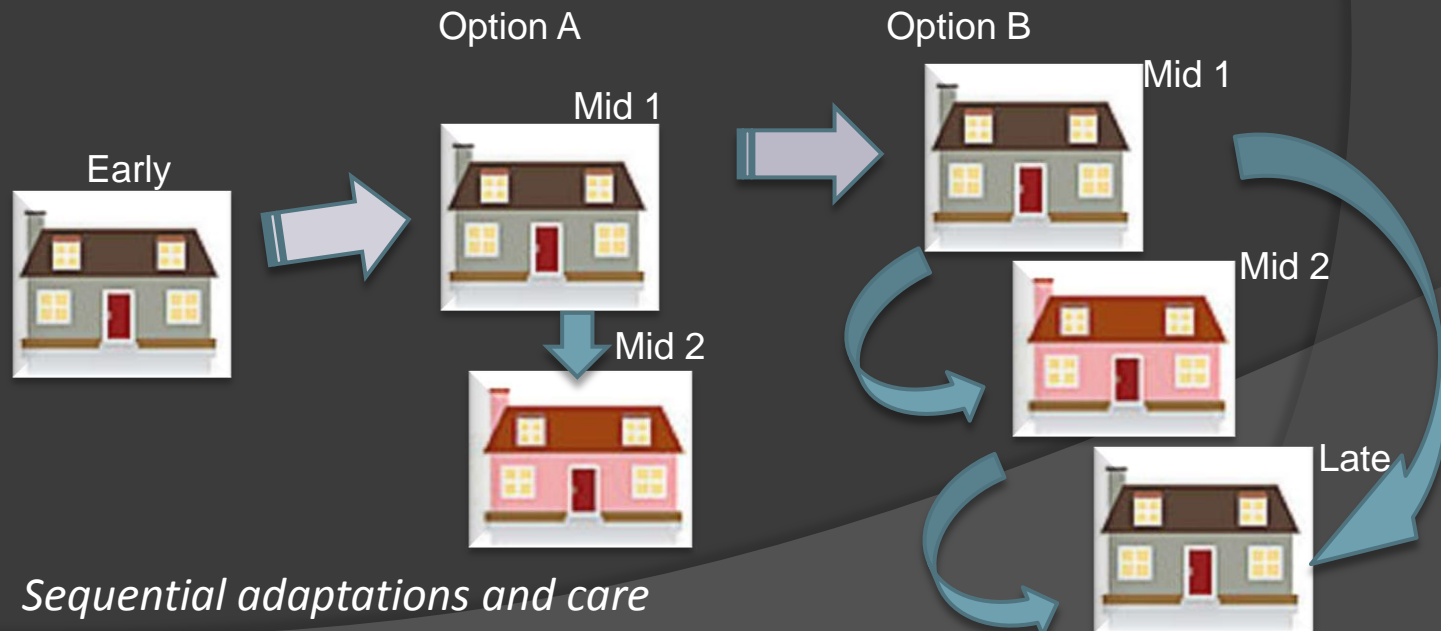
- single care home and stable stay



*Linear adaptations and care*

## IN-PLACE-PROGRESSION

- multiple care homes & movement with progression



*Sequential adaptations and care*

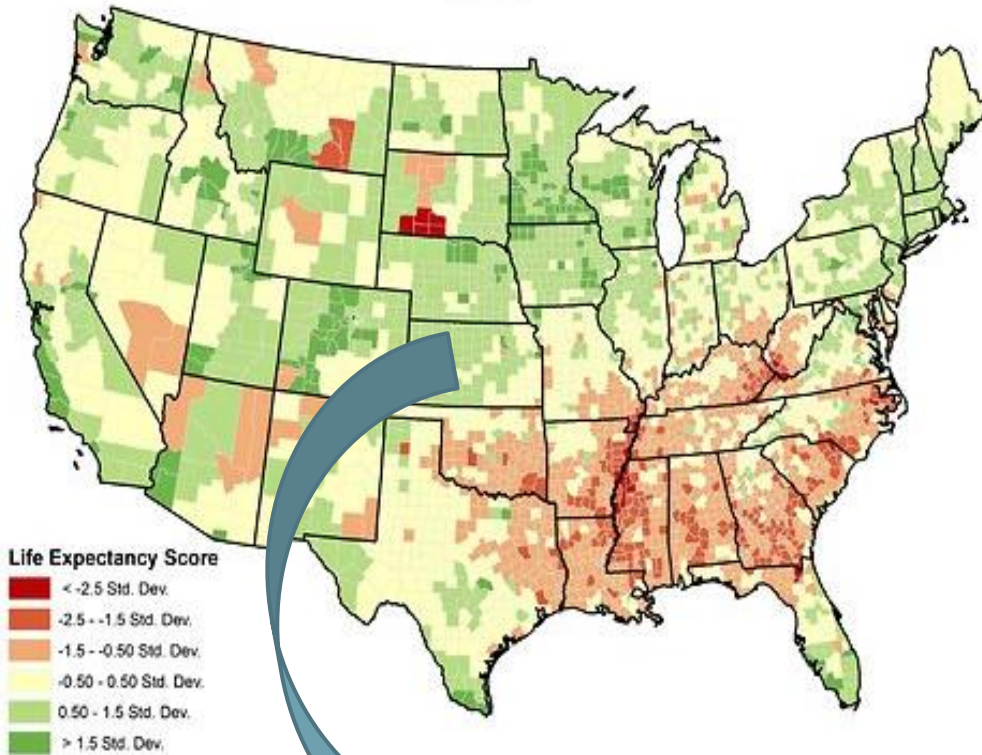
# Construct of small home-oriented dementia capable care

- ⦿ *Fixed staffing* – familiarity, mutual comfort, person focus
- ⦿ *Unregimented care* – personalized attention and schedules, ‘being at home’
- ⦿ *Familiar surroundings* – easily navigable, fixed personal space, intimate public spaces, adapted fixtures, lessens confusion
- ⦿ *Small resident size* – familiarity of others, friendships, home feel, high comfort level
- ⦿ *Care practices* – tailored to individual, attention to needs, easy pick-up on change indicators, group problem solving

Starkey's Goebel LIGHTHouse Project consists of **three specialized homes** for 15 people with intellectual disabilities and dementia

The three 3,700 square foot (343.7 sq m) homes have five bedrooms each, bathrooms, and shared dining and living spaces

The homes were designed to provide a supportive community living experience for people with disabilities and dementia with specialized staff support until skilled nursing care is required



*Phase I Study tracked 15 residents and 15 controls (who lived in other settings), as well as examined staff and administrative factors over a three-year period*

Study principals: M. Janicki, P. McCallion, L. Force



GH1 = Diana House; GH2 = WOW House; GH3 = Latimer House

# Two years later ...

- Evidence of change in function and increasing health problems or less 'wellness'
- Residents in homes 2 & 3 showed the greatest impact of dementia over the two years
- Higher number of co-morbidities among dementia residents compared to controls
- Staff time spent on caregiving much more than that for 'the controls'
- Trending toward individual home specialization as to level of care

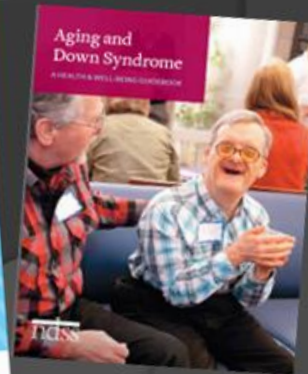
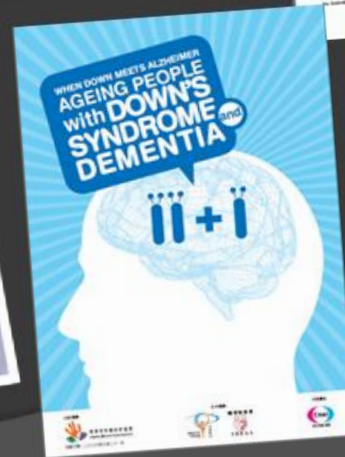
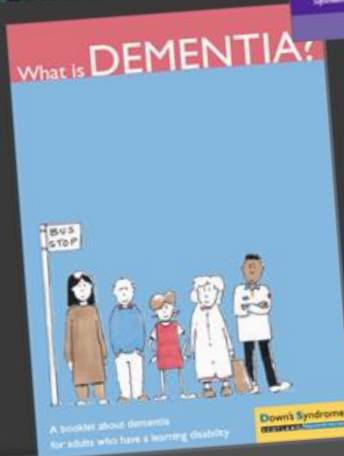
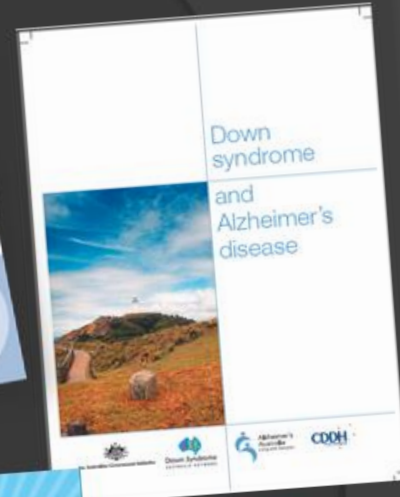
Phase II: Longitudinal study [2014-2018] of agency experience with the three community based dementia care group homes





# Building capacity and understanding....

## Resources



# Community care

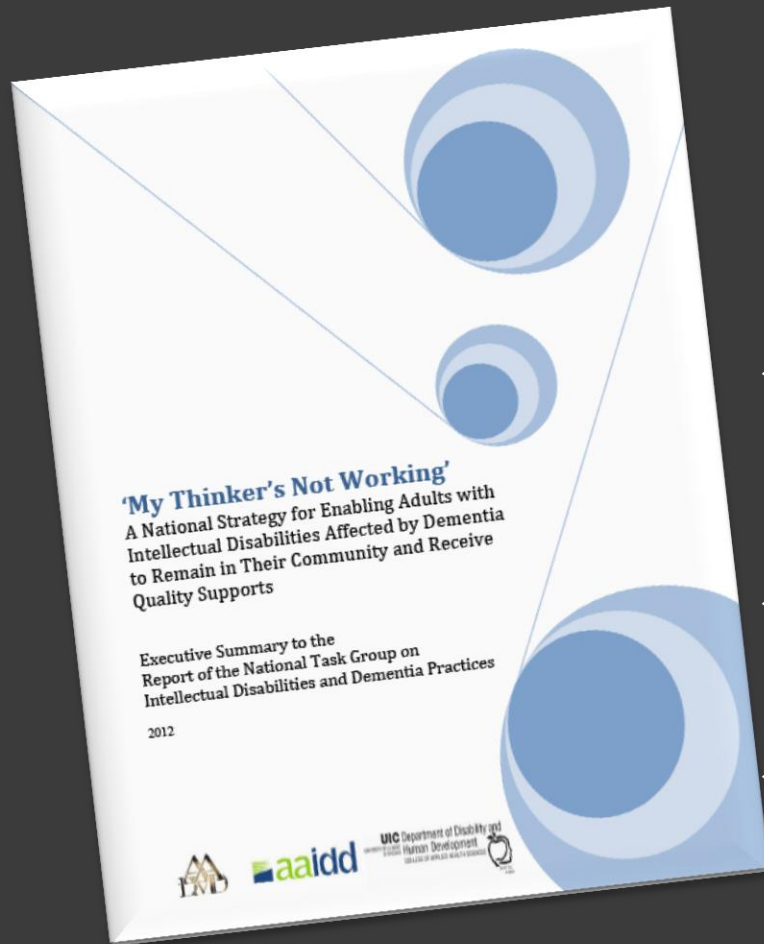
- ◎ What needs to be considered?
  - Where the person is with respect to dementia progression
    - Can he or she stay where they currently live?
    - Should a specialty dementia-care home be considered?
      - If so, what is the most appropriate pairing?
  - What are their wishes (or the wishes of the family)?
  - What options exist in agencies or in the community?
  - Are current services geared up for long term care?
    - Have a dementia-capable residence?
    - Have direct support and clinical staff knowledgeable of dementia and long-term dementia-related care?

# Community care

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# Social advocacy

# National Task Group on Intellectual Disabilities and Dementia Practices



- ✓ 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



# NTG Activities

- **An early detection-screening instrument (NTG-EDSD) & manual**

- Various language versions available
- Access at [www.aadmd.org/ntg](http://www.aadmd.org/ntg)

- **Practice guidelines**

- Community supports and health practitioner assessment guidelines issued
- Several others pending
  - Administrative practices, day-to-day care
- Program standards pending

- **Training and education activities**

- Training workshops
- Meetings with professional groups
- Information for families (FAQ)

- **Linkages**

- US Administration on Community Living
- NASDDDS, N4A, NACDD & state activities
- CARF & national program standards



## Need for practice guidelines

- Practice guidelines are a formulary – they structure approaches to care – offering guidance on what, where, and when
- Help define how to approach challenges in care, from individual interactions, to program practices, to assessment and interventions
- Stem from consensus and experience as well as evidence-base
- Form basis for regulatory compliance

# Guidelines for Community Care and Supports for People with Intellectual Disabilities Affected by Dementia

The guidelines suggest what actions should be undertaken to optimize community-based care and supports.

They follow reflect the progressive nature of prevalent dementias and use a staging model generally accepted for practice among generic dementia services...

... from a pre-diagnosis stage – when early recognition of symptoms associated with cognitive decline are recognized -- through to early, mid, and late stages of dementia

... and characterize the expected changes in behavior and function

**Use:** to help providers organize and deliver quality care and supports to people with ID affected by dementia

[www.aadmd.org/ntg/guidelines](http://www.aadmd.org/ntg/guidelines)





# NTG Practice Guidelines for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities



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. Jacicki, PhD

### Abstract

Adults with intellectual and developmental disabilities (ID/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 ID/DD, a question that most physicians feel ill-prepared to assess. 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 routinely with adults with ID/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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The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed as a response to the National Alzheimer's Project Act. Legislation signed into law by President Barack Obama. One objective of the NTG is to highlight the additional needs of individuals with intellectual and developmental disabilities (ID/DD) who are affected or will be affected by Alzheimer's disease and related disorders. The American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging With Developmental Disabilities—Lifelong Health and Function at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities combined their efforts to form the NTG to ensure that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are and continue to be considered as part of the National Plan to Address Alzheimer's Disease<sup>1</sup> issued to

address the requirements of the National Alzheimer's Project Act. Among the NTG's changes were (1) the creation of a newly designated team to help document suspected dementia-related decline in adults with intellectual disabilities, (2) the development of practice guidelines for health care and supports related to dementia in adults with intellectual disabilities, and (3) the identification of models of community-based support and interventions of persons with intellectual disability affected by dementia. In 2012, the NTG's "My Thinker's Not Working: A Manual for Enabling Adults With Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports." A subgroup of the NTG was formed specifically on health practices. The goals and recommendations outlined in it most represent the consensus reached upon at 2 planetary meetings, ongoing discussions that followed, and a review of the current literature as



From the Division of Geriatrics, Ball and Gerstein Medical Center, Harvard Medical Center, Harvard Medical School, Boston, MA (JAG); Department of Neurosciences, University of Colorado, San Diego, CA (MSR); Department of Psychiatry, Johns Hopkins University, Baltimore, MD (SK); Department of Neurology, Mayo Clinic, Rochester, MN (SK); Department of Neurology, Mayo Clinic, Rochester, MN (SK); Department of Neurology, Mayo Clinic, Rochester, MN (SK); Department of Neurology, Mayo Clinic, Rochester, MN (SK); Department of Neurology, Mayo Clinic, Rochester, MN (SK).

**Sanjay Gupta, MD, Editor**  
**The Gupta Guide**

**Dementia in Mentally Disabled Hard to Identify**

Published: Aug 26, 2013 | Updated: Aug 26, 2013  
Download Complimentary Article PDF

By Chris Cahlon, Cardiothoracic, MedPage Today  
Reviewed by Peter Hirsch, MD, MSc, Director of Geriatric Psychiatry, Harborview Medical Center at the University of Washington and Harborview Medical Center, Seattle, WA; and  
Reviewed by Michael C. Jensen, MD, MSc, Director of Geriatric Psychiatry, Harborview Medical Center at the University of Washington and Harborview Medical Center, Seattle, WA.

A new consensus statement addresses the challenges of recognizing and managing dementia in older adults with "intellectual and developmental disabilities," such as Down syndrome or brain injury. These patients have an increased risk of poorer outcomes, compared with the general population, in part because healthcare professionals often lack training and preparation to adequately respond to their special needs. A group of experts from the University of Washington Medical Center in Seattle, Washington, met recently with health care professionals from the University of Wisconsin Hospital in Tetons, Idaho, to discuss ways to improve care. Even trying to establish a baseline decline in cognitive abilities in adults with intellectual disabilities can be challenging because cognitive functioning is highly individualistic, and also because of external factors such as poor access, language and contact with insurance. Healthcare professionals who often "assume that the patient's current level of ability represents his or her baseline level of functioning and, then, miss signs of early decline," says a representative of the Alzheimer's Association. "It's a relatively new phenomenon to have a large number of people with intellectual disabilities living long lives. We, like and beyond," Moran told MedPage Today in an interview. "Primary care and other general physicians typically don't receive medical training specific to the needs of this patient population, particularly in terms of assessing their cognitive function. They need to be educated." To address the needs of these patients and their caregivers, the National Task Group on Intellectual Disabilities and Dementia Practices was formed. Its creation was a direct response to the National Alzheimer's Project Act that was signed into law in January 2013 by President Obama. The recommendations for assessing patients with intellectual disabilities are intended to help provide healthcare professionals the information they need for the "detection of any cognitive impairment"—a requirement that appears in the Medicare Annual Wellness Visit component of the Affordable Care Act. Researchers recommend a nine-step approach for assessing health and function. These include:

- ✓ The NTG's recommended nine-step approach for assessing health and function.
- ✓ Taking thorough history, with particular attention to "red flags" that potentially indicate premature dementia such as history of cerebrovascular disease or head injury, sleep disorders, or vitamin B12 deficiency
- ✓ Documenting a historical baseline of function from family members of caregivers
- ✓ Comparing current functional level with baseline
- ✓ Noting dysfunctions that are common with age and also with possible emerging dementia
- ✓ Reviewing medications and noting those that could impair cognition
- ✓ Obtaining family history, with particular attention to a history of dementia in first-degree relative
- ✓ Noting other destabilizing influences in patient's life such as leaving family, death of a loved one, or constant turnover of caregivers, which could trigger mood disorders
- ✓ Reviewing the level of patient safety gleaned from social history, living environment, and outside support
- ✓ Continually "cross-referencing the information with the criteria for a dementia diagnosis"

## Mayo Clinic Proceedings

Sources: 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.mcpagelibrary.com/TheGuptaGuide/Neurology/41094>

# Health advocacy guidelines

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

Kathleen M. Bishop<sup>1</sup>, Mary Hogan<sup>2</sup>, Matthew P. Janicki<sup>1</sup>, Seth M. Koller<sup>1</sup>, Ronald Lucchini<sup>1</sup>, Devona T. Mugha<sup>1</sup>, Elizabeth A. Perkins<sup>1</sup>, Baldevit K. Singh<sup>1</sup>, Kathy Service<sup>1</sup>, Sarah Wolfson<sup>1</sup>, and the Health Planning Work Group of the National Task Group on Intellectual Disabilities and Dementia Practices

### Abstract

Increasing numbers of adults with intellectual disabilities (ID) are living into old age. While this indicates the positive effects of improved health care and quality of life, the end result is that more adults with ID are and will be experiencing age-related health problems and also exhibiting symptoms of cognitive impairment and decline, some attributable to dementia. Early symptoms of dementia can be subtle and in adults with ID are often masked by their lifelong cognitive impairment symptoms, as well as find appropriate practitioners familiar with the medical issues presented by aging adults with lifelong disabilities. Noting changes in behavior and function and raising suspicions with a health care practitioner, during routine or ad hoc visits, can help focus the examination and potentially indicate that the decline is the result of the onset or progression of dementia. It can also help in ruling out reversible conditions that may have similar presentation of symptoms typical for Alzheimer's disease and related dementias. To enable caregivers, whether family members or paid staff, to prepare for and advocate during health visits, the National Task Group on Intellectual Disabilities and Dementia Practices has developed guidelines for dementia-related health advocacy preparation and assistance that can be undertaken by provider and advocacy organizations.

### Introduction

An emerging public health concern is the increasing prevalence of adults with intellectual disabilities (ID) diagnosed with Alzheimer's disease and affected by related dementias (Bishop et al., 2013; Janicki & Dalton, 1999; Johnson et al., 2013; NTG, 2012a; WHO, 2012). As a result of this increase, questions have been raised as to how formal (paid staff) and informal (family or friends) caregivers could best obtain help with accessing appropriate diagnostic and post-diagnostic supportive health services (Bishop & Lucchini, 2010; Bishop et al., 2013; Johnson et al., 2013). In 2010, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed and charged to work in correspondence with activities emanating from the government's implementation of the National Plan to Address Alzheimer's Disease (DHSS, 2012), as the nation lacked a coherent policy on enabling adults with ID to receive appropriate community-based diagnostic and dementia care services. As part of the NTG's activities, enabling family and paid staff caregivers to undertake dementia-related health advocacy was designated as a priority (NTG, 2012a). This was to be accomplished by an awareness campaign targeting caregivers who needed to access

diagnostic services and health care providers (NTG, 2012a), by providing increased information to primary health care personnel (Moran et al., 2013), and developing a training curricula for providers (Johnson et al., 2013; NTG, 2014).

These efforts stemmed from the growing realization that increasing numbers of adults with intellectual and developmental disabilities<sup>1</sup> in the United States were living into old age, paralleling the extended longevity of age peers in the general population (Heller et al., 2002). Population estimates have indicated the presence of over 650,000 adults age sixty and older with intellectual and developmental disabilities in the United States; projections further note this number is expected to double by 2030 (Heller & Caldwell, 2006; Tyler & Monte, 2009). Further, it is estimated that approximately 8% of this number of persons that may be affected by Alzheimer's disease and related dementias (NTG, 2012a). Many of these older adults live at home with aging caregivers or other family members, who are also experiencing age-

<sup>1</sup>Although the term "intellectual and developmental disabilities" is used generically, the guidelines applies more specifically to those adults with intellectual disabilities, who experience intellectual and comprehension abilities that are below norm.

- These NTG guidelines are designed to help family members or paid staff prepare for and advocate during health visits and enable provider and advocacy organizations undertake dementia-related health advocacy preparation and assistance
  - They define how family caregivers recognize and communicate symptoms, as well as find appropriate practitioners familiar with the medical issues presented by aging adults with lifelong disabilities.
- What's important in health advocacy?
  - Noting changes in behavior and function
  - Being prepared with items to discuss
  - Raising suspicions with a health care practitioner, during routine or ad hoc visits
  - Helping focus the examination and potentially validate that the decline is the result of the onset or progression of dementia.
  - Following-through on post-exam recommendations

## Need for standardized training curriculum

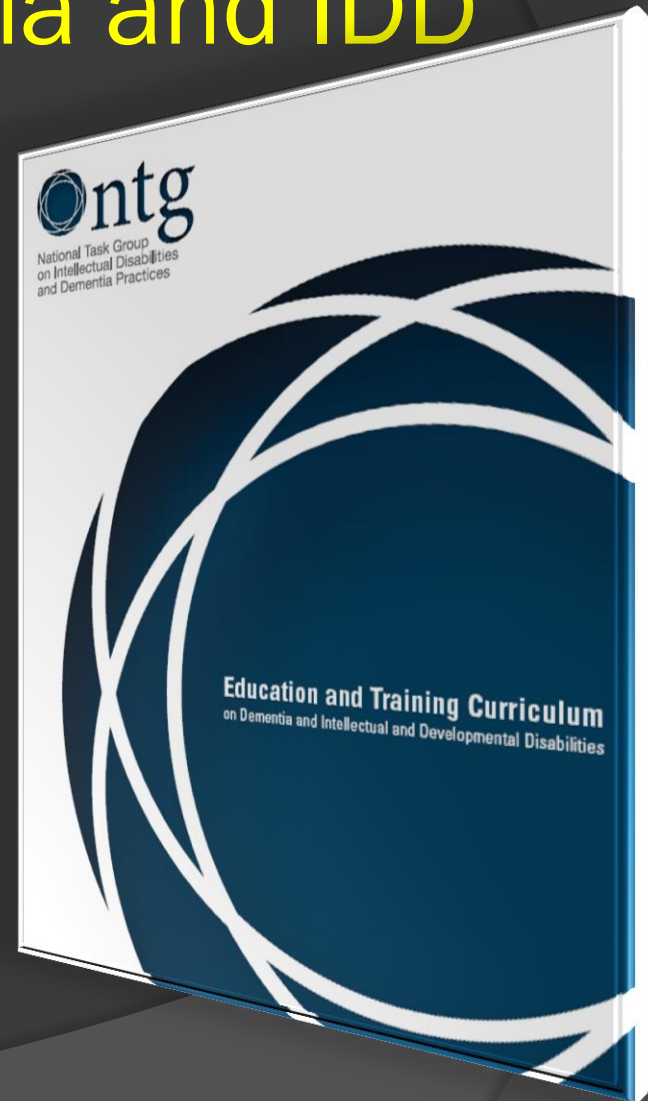
- Curriculum models help standardize what and how critical information is conveyed
- Consensus-based content as to what should be included and what would be most helpful to caregivers
- Training enhances competencies in staff and quality care environments
- Subject to measures of knowledge and basis for evaluation of quality of care

# NTG Education & Training Curriculum on Dementia and IDD

**New national curriculum currently in development**

*Curriculum will have several levels*

- **Level 3:** Core curriculum for staff employed in programs directly serving adults with ID and dementia
  - extensive content on in-depth knowledge of dementia and dementia capable care
- **Level 2:** Content for staff employed and participating in a continuing education program
  - content on basic knowledge of aging and dementia
- **Level 1:** Content for new hires participating in orientation and in-service training
  - content on basics of aging, touching on awareness of dementia symptoms; limited time



# Where are efforts going?

- Improving understanding of dementia
  - Alerting to risk and early signs
  - Adapting living environments
  - Helping with futures planning (health and social care)
  - Aiding families who are carers
  - Enhancing staff skills – training with respect to dementia
  - Quality checks in services
  - Providing stage related services
  - Getting federal government to invest resources
- Our experience... All begun as workable endeavors, are works in progress, or are on the planning table



# Impact....

- ⦿ **Have lives been improved?**
- ⦿ **Have agencies been able to deliver more appropriate and worthy services?**
- ⦿ **Are families better off?**
- ⦿ **Have we set a standard for how people with ID affected by dementia should be seen and treated?**
- ⦿ **Has there been a shift in thinking... and in actual program changes?**
- ⦿ **Has there been more attention paid to ID issues within the Alzheimer's communities (researchers, advocates, public policy people, etc.)?**

The NTG is supported by the American Academy of Developmental Medicine and Dentistry and the University of Illinois at Chicago's RRTC on Developmental Disabilities and Health

[www.aadmd.org/ntg](http://www.aadmd.org/ntg)



Matthew P. Janicki, Ph.D.  
mjanicki@uic.edu