INTELLECTUAL DISABILITY AND DEMENTIA PRACTICE

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TODAY’S SPEAKERS

Matthew P. Janicki, Ph.D. is the co-chair of the US National Task Group on Intellectual Disabilities and Dementia Practices, as well as a research associate professor in the Department of Disability and Human Development at the University of Illinois at Chicago. Formerly, he was director for aging and special populations for the New York State Office for People with Developmental Disabilities. Currently, he is leading a study of specialized group homes designed for dementia related care of adult with intellectual disabilities.

Seth M. Keller, MD is a neurologist and the co-President of the National Task Group in Intellectual Disabilities and Dementia Practices. He maintains a neurology practice in New Jersey and is a past-President of the American Academy of Developmental Medicine and Dentistry as well as the founding chair of the Intellectual Disabilities Interest Group within the American Academy of Neurology.

Thomas J. Buckley, Ed.D. serves as a consultant to several provider organizations, functions as an expert witness on disability discrimination suits, and serves on the Board of CARF. He was instrumental in aiding several organizations with setting up dementia-capable services for individuals with intellectual disabilities and is the author of numerous useful guides and products focusing on dementia care planning.
INTRODUCTION & OBJECTIVES

QUICK OVERVIEW OF DEMENTIA AND WHAT DOES IT MEAN
Basics – Dementia and Intellectual Disabilities
Federal and National Perspectives
Dementia Processes
Dementia Services and Supports
Medical and Health Factors
Individualized Care and Meeting Standards
Alzheimer’s disease is the name of a neuropathology – or brain disease – that leads to general dysfunction.

Dementia is the behavioral expression of the brain disease – usually via memory loss and behavioral dysfunction.

Causes of dementia among aging adults:
- Alzheimer’s disease
- Stroke and related vascular accidents
- Neurological diseases (Parkinson’s)
- Idiopathic changes in the brain (Lewy, FTD)
INTELLECTUAL DISABILITY (ID)

Characterized by

- Below normative intellectual functioning, due to cognitive impairment (organic or functional) present since birth or infancy
- Not a mental illness or psychiatric impairment
- Varies in degree and co-impairment
- Compensated by training, education, remediation, habilitation, supports for life activities

*Down syndrome* is a chromosomal abnormality present at birth (#21) associated with ID – In adults, age 40+, occurs in 10-12% of agency client pools

Developmental disabilities

- Neuro-developmental conditions leading to impairments in physical, learning, language, or behavior areas
- Originate in the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime
- Intellectual disability is one of the developmental disabilities

https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html
PROPORTION OF AGE GROUPS IDENTIFIED AS HAVING DEMENTIA OR ALZHEIMER'S DISEASE

THE ‘NAPA’ & NTG

NATIONAL ALZHEIMER’S PROJECT ACT
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 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

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

First released on May 15, 2012
Will be updated annually until 2025!
IMPLICATIONS OF NAPA FOR PROVIDERS?

- Tie-in to State Alzheimer’s Plans’ objectives
- GWEPs* – enhancing the capacity of the workforce (working in dementia-related areas)
- Potential implications of CMS’ Setting Rule – Dementia housing
- CDC’s Healthy Brain Initiative
- Alzheimer’s Disease Program Initiative – Annual funding call-out
  - http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/
  - ID-oriented grant projects funded in various states

*Geriatrics Workforce Enhancement Program
The **National Task Group** is a not-for-profit corporation charged to advocate, educate, provide technical assistance and program protocols, and guide public policy. Its members are composed of provider agency personnel, clinicians, academics, government officials, family members, and others.

The NTG is associated with the National Down Syndrome Society, is part of the LEAD Coalition in Washington, and has connections with university aging programs and community organizations.

✓ 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

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THE FUNCTIONS OF THE ‘NTG’

- Advocacy
- Education & training
- Family aids
- Policy
- Information dissemination
- Diagnostics and assessment
- National and international connections

www.the-ntg.org
NTG GUIDELINES

Health advocacy

Community living & supports

Diagnostics and medical care
KEY Features AND ISSUES

DEMENTIA PROCESSES AND INTELLECTUAL DISABILITY
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 necessities.

Main 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.
Dementia is 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 high 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 53 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.
Dementia is loss of memory and function, and behavioral changes caused by different brain conditions or diseases.

These problems must be notable and usually occur in a cluster.

In ID, similar signs but of varying presentation depending on level of ID.
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
KEY WARNING SIGNS OF DEMENTIA IN DOWN SYNDROME

- Adults with Down syndrome are at high risk for Alzheimer’s disease and dementia.
- Researchers are finding that the first signs of Alzheimer’s disease, some new changes to brain cells (the ‘plaques and tangles’), occur some 20 years before behavioral changes will be noticed.
- Researchers have also found that adults with Down syndrome show early symptoms in a different way...
  - Noticeable first are changes in personality and in general decision making, then in memory (in contrast memory is usually affected first in other people).

- Abrupt onset of seizures when there had been none in the past
- Incontinence when an individual has always been toileting appropriately
- Sleep/wake cycle changes or disruptions
- Loss of sociability – a noticeable change in personality
WHY IS THERE A FOCUS ON DOWN SYNDROME?

- The National Institute on Aging notes that “people with Down syndrome are born with an extra copy of chromosome 21, which carries a gene that produces a specific protein called amyloid precursor protein (APP). Too much APP protein leads to a buildup of protein clumps called beta-amyloid plaques in the brain. The presence of beta-amyloid plaques is one of the hallmarks of Alzheimer’s disease.”

- By age 40, most people with Down syndrome have these plaques, along with other protein deposits, called tau tangles, which cause problems with how brain cells function and increase the risk of developing Alzheimer’s symptoms.”

- The CDC notes that “As with all adults, advancing age increases the chances a person with Down syndrome will develop Alzheimer’s disease.”

A major analysis* of Down syndrome and dementia data articles showed that:

- Estimated age at onset: 53.8 years
- Estimated age at death: 58.4 years
- Estimated disease duration: 4.6 years

Some adults have early onset and shorter duration

- Younger-age (or early) onset is found in adults with Down syndrome and head injury
- Most adults with Down syndrome survive less than 7 years after the onset of dementia

Some differences in symptom presentation

- Most early symptoms are the same, except in Down syndrome where there are more notable early personality changes

Assessments are conducted differently

- Standard tests used with typical adults with dementia are not useful – With adults with intellectual disability need to use comparisons of the same individual over time
| **Rate of occurrence**<sup>1,2,5,8,14</sup> | - Age-cohort percent for adults with 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> | - Generally, dementia of the Alzheimer’s type is prevalent in DS  
- Similar range of dementias found in other ID as in other people |
| **Risk**<sup>15</sup> | - DS and head trauma are significant risk factors in ID |
| **Onset and duration**<sup>1,2,3,10</sup> | - 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**<sup>2,3,6,11,12,13</sup> | - In DS - early change in personality more evident  
- In other ID - initial memory loss more evident  
- Notable changes in behavior - apathy, sleep disturbance, agitation, incontinence, uncooperativeness, irritability, aggressiveness |
| **Neurological signs**<sup>1,2,4,7,16,17,18,19</sup> | - Late onset seizures in 24%-53% of adults w/DS  
- Late onset seizures in DS indicator of life expectancy of less than 2 years, probable death within 3 years, and death almost invariably within 5 years of onset  
- Seizures more common at end-stage (84.0%) versus at mid-stage Alzheimer’s disease (39.4%) |
| **Prognosis**<sup>2,17</sup> | - Aggressive AD can lead to death <2 years of onset in DS  
- 2+7 years mean duration in DS; probable death within 3 years, and death usually within 5 years of onset  
- Same duration expected among other ID as in other people |

**Sources:**  
WHY IS RECOGNITION OF ‘ONSET’ IMPORTANT?

- **Knowing expected onset gives a ‘head’s-up’ for initiating surveillance**
  - Look for changes
  - Introduce periodic screening
  - Alert staff to be watchful
  - Provides for an ‘index of suspicion’

- **Helps us to begin to reformulate services and care practices**
  - Creating safer environments
  - Introducing cues for movement and way-finding
  - Engaging in planning ahead for eventualities
  - Setting goals for terms of service – adapting personal program plans
TYPES OF DEMENTIA

Understanding Different Types of Dementia

As we age, it’s normal to lose some neurons in the brain. People living with dementia, however, experience the growth of abnormal proteins, loss of neurons, stop working, lose connections with other brain cells, and eventually die. At first, symptoms can be mild, but they get worse over time. Read on to learn more about four different types of dementia.

TYPES OF DEMENTIA

| Alzheimer’s Disease | Frontotemporal Dementia | Lewy Body Dementia | Vascular Dementia |

What Is Happening in the Brain?

- Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain.
- Abnormal amounts or forms of tau and TDP-43 proteins accumulate inside neurons in the frontal and temporal lobes.
- Abnormal deposits of the alpha-synuclein protein, called “Lewy bodies,” affect the brain’s chemical messengers.
- Conditions, such as blood clots, disrupt blood flow in the brain.

*These changes are just one piece of a complex puzzle that scientists are studying to understand the underlying causes of these forms of dementia and others.

Symptoms

- Administrative and organizational difficulties, impaired judgment
- Communication difficulties: word-finding difficulties, comprehension
- Cognitive decline: memory impairment, confusion, disorientation
- Emotional problems: depression, anxiety
- Gait and balance problems:
- Language problems
- Sleep disturbances
- Visual hallucinations

Typical Age of Diagnosis

- Alzheimer’s: 65 and above, with some cases in the 50s
- Frontotemporal: 5–10 years
- Lewy Body: 60–80 years
- Vascular: 60 years and above

Diagnosis

- There is currently no cure for these types of dementia, but some treatments are available. Speak with your doctor to find out what might work best for you.
# Symptoms by Type of Dementia

## Types of Dementia

<table>
<thead>
<tr>
<th>Type of Dementia</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frontotemporal Dementia</td>
<td>Behavioral and Emotional: Difficulty planning and organizing, Impulsive behaviors, Emotional flatness or excessive emotions. Movement Problems: Shaky hands, Problems with balance and walking. Language Problems: Difficulty making or understanding speech.</td>
</tr>
<tr>
<td>Lewy Body Dementia</td>
<td>Cognitive Decline: Inability to concentrate, pay attention, or stay alert. Disorganized or illogical ideas. Movement Problems: Muscle rigidity, Loss of coordination, Reduced facial expression. Sleep Disorders: Insomnia, Excessive daytime sleepiness. Visual Hallucinations:</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>Forgetting current or past events, Misplacing items, Trouble following instructions or learning new information, Hallucinations or delusions, Poor judgment.</td>
</tr>
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### Typical Age of Diagnosis

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Typical Age of Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's Disease</td>
<td>Mid 60s and above, with some cases in late 50s to 60s</td>
</tr>
<tr>
<td>Frontotemporal Dementia</td>
<td>Between 45 and 64</td>
</tr>
<tr>
<td>Lewy Body Dementia</td>
<td>50 or older</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>Over 65</td>
</tr>
</tbody>
</table>

*Symptoms can be similar among different types of dementia, and some people have more than one form of dementia. Treatment and care are also important factors. Consult with a doctor for a diagnosis. This information is for educational purposes only. For specific symptoms, consult with a healthcare professional.*
STEP-WISE PROGRESSION OF VASCULAR DEMENTIA
LEWY BODY DEMENTIA

Men more at risk

Caused by build-up of Lewy Body proteins in the brain
Signs and symptoms of frontotemporal dementia

- Changes in personality. The person may become quiet and withdrawn, or even unusually cheerful and outgoing
- Emotional changes, such as seeming cold and distant
- Difficulty understanding what is considered appropriate behavior, or seemingly having ‘no filter’
- Change in language, such as words coming out in the wrong order
- Becoming easily distracted or confused, they may feel easily overwhelmed when trying to process information from their senses
- Difficulty with movement
- Repetitive behavior, such as obsessive cleaning, collecting or exercising
- Not looking after themselves
- Binge eating. The person will recognize that they are full but not stop eating, because their brain doesn’t tell them to.
Most persons with **Down syndrome** will have **dementia of the Alzheimer’s type** – caused by Alzheimer’s disease

Persons with ID may have a **variety of dementias (in norm with the general population)**

- **Generally**, **dementia of the Alzheimer’s type** is linear and causes a slow, progressive decline of function and loss of cognitive abilities
- **Generally**, **vascular dementia** will affect specific parts of the brain damaged by a vascular accident and will cause a stepped diminution of function
- **Generally**, **fronto-temporal dementia** will first affect behavior and personality and then eventually all function

**Why is it important (or useful) to know type?**

- To determine ‘course of treatment’ and expectations of staging and rate of decline
- To help with determining best ways to handle ‘challenging behaviors’
- To help with organizing staffing patterns and clinical supports
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.
Is it “Possible, Probable, vs. Definite dementia”? 

**TERMINOLOGY**

- Mild cognitive impairment (MCI)
- Early onset dementia
- Early-stage dementia
- Mid-stage dementia
- Late-stage or advanced dementia
For adults with Down syndrome there is compressed staging of Alzheimer’s dementia.
<table>
<thead>
<tr>
<th>Early Stage</th>
<th>Middle Stage</th>
<th>Late Stage</th>
</tr>
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<tbody>
<tr>
<td>Confusion and memory loss</td>
<td>Difficulties with ADLs [“activities of daily living”]</td>
<td>Loss of speech</td>
</tr>
<tr>
<td>Disorientation in space</td>
<td>Anxiety, paranoia, agitation and other compromising behaviors</td>
<td>Loss of appetite, weight loss</td>
</tr>
<tr>
<td>Problems with routine tasks</td>
<td>Sleep difficulties</td>
<td>Loss of bladder and bowel control</td>
</tr>
<tr>
<td>Changes in personality and judgment</td>
<td>Sleep difficulties</td>
<td>Loss of mobility</td>
</tr>
<tr>
<td></td>
<td>Difficulty recognizing familiar people</td>
<td>Total dependence on others</td>
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<tr>
<td></td>
<td></td>
<td>~Death</td>
</tr>
</tbody>
</table>
Varying trajectories have implications for continual assessment and adaptations to care management.

Source: Figure 1 from Wilkosz et al., (2009). Trajectories of cognitive decline in Alzheimer’s disease. International Psychogeriatrics, 28,1-10
IMPLICATIONS OF TRAJECTORIES AND DURATION

- Knowing something about variations in trajectories
  - Anchors around potential duration of ‘stay’ at same level of functioning
  - Provides ideas about potential changes and their nature
  - Creates a schedule for timing changes in service orientation – planning care, evaluating patterns of care, and organizing staffing and environmental modification
  - Provides an empirical basis for expectations of co-morbidities
  - Gives staff information about anticipating changes
  - Helps with introducing ameliorative interventions or aids for day-to-day functioning
  - Long-term planning for care financing (budgeting for shifts in staff and housing)
Older adults with Down syndrome are at high risk of Alzheimer’s disease

Not every adult will show signs of dementia as he or she ages

Age-associate decline may be due to aging and not dementia

Institute baseline for (‘personal best’) functioning at age ~40 for Down and at ~60 for other ID

Useful to know the signs of MCI* and dementia and keep track of capabilities after age 40

Early detection screening useful to identify possible progression into MCI or dementia

Early referral for assessment or diagnosis if signs present is advised (to rule out alternative bases for physical or cognitive changes)

*Mild Cognitive Impairment
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

Who does assessments?

- **Physician**
- **Psychiatrist**
- **Geriatrician**
- **Neuro-psychologist**
- Dementia clinic
- Memory center

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SCREENING-ASSESSMENT-DIAGNOSIS PROCESS

**Screening**
Done by carers or staff
- **Picks up key problem areas** — some associated with MCI or dementia
- Confirms suspicions
- Signals areas for further surveillance by carers or staff
- 'The starting point'

**Assessment**
Form used by carers or staff to begin discussion about concerns with clinician
- Clinician uses noted items for more in-depth assessment and tracking
- Suspicions can be confirmed or revisited periodically
- Neurological scans can be ordered

**Diagnosis**
Clinic or clinicians ascertain whether dementia dx is viable
- Eventual review of symptoms and application of range of general dementia ascertainment measures
- Designation of possible or probable dementia and potentially clinical etiology
WHAT IS THE FUTURE IN DIAGNOSTICS

- The National Institute on Health has funded numerous studies of biomarkers, both within the general population and of adults with Down syndrome.

- Biomarkers provide detailed measures of abnormal changes in the brain, which can aid in early detection of possible disease in people with very mild or unusual symptoms.

- People with Alzheimer's disease and related dementias progress at different rates, and biomarkers may help predict and monitor their progression.

- Given the difficulty of using traditional office-methods of diagnosing dementia in adults with intellectual disability, biomarkers will offer a means of confirming a clinician’s suspicions or diagnostic outcomes.

New FDA approved Alzheimer’s therapeutics

EFFECTS OF DEMENTIA

SOME INFORMATION FOR SUPPORT SERVICES
UNDERSTANDING DEMENTIA

Knowns...
- People with ID have same rate of dementia as general population
- Some people with ID have higher rates (e.g., Down syndrome, head injury)
- Some % of any adult client pool will be affected
- Early interventions can aid in adapting to changes and prolonging lucid periods
- Effects of dementia will be progressive and eventually lead to death

Unknowns...
- Who will be affected?
- How pronounced will be early changes?
- How dramatic will be the changes in function?
- How long will person live after diagnosis?
- What other diseases or medical conditions may be co-incident?
- Which particular dementia-related behaviors will be more evident?
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
WHAT ARE NEEDED SUPPORTS?

- Help for caregivers and the person
- Advanced planning for alternative care
- Diagnostic and intervention assistance
- Support groups for caregivers (family or staff)
- Dementia capable community housing (group homes)
- Respite for caregivers
- Health care and social supports

“… people have, on average, six years of living independently once mild cognitive impairment starts.”*

Dementia is a condition that lessens an adult’s ability to be left alone – thus, living without supervision is not an option as the condition progresses.

OPTIONS FOR DEMENTIA CARE SETTINGS

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

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
Outreach and community supports (HCBS)
Helping support family caregivers

Agency Focus
Securing housing with dementia specialty care
Clinical team supports Training for staff
AGING-IN-PLACE
• single care home and stable stay

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

PREVALENT MODELS OF GROUP HOME-BASED DEMENTIA CARE

Linear adaptations and care
Option A

Sequential adaptations and care
Option B

Mid = mid-level

Source: JANICKI (2010)
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
WHAT SERVICES ARE NEEDED FOR AGING PEOPLE WITH ID AND DEMENTIA?

- **Pre-clinical symptom phase**
  - Periodic screening

- **Assessment & diagnostic phase**
  - Referrals for assessment and diagnosis

- **Post-diagnostic support phase**
  - Supports for continued living with families - when available and appropriate
  - Interventions to help with *Behavioral and Psychological Symptoms of Dementia*
  - Health reviews and surveillance
  - Appropriate screening and assessments for co-incident aging-related conditions
  - Health maintenance – nutrition and exercise
  - Supports for ‘dementia-capable’ care in community care settings that can change as the disease progresses; including education and training
  - Supports for caregivers
**EARLY STAGE**

<table>
<thead>
<tr>
<th>Engage</th>
<th>Engage the individual and their family, and/or other carers or guardians in advance care planning (and prepare advance directives) consistent with state or other requirements.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify and plan</td>
<td>Identify and plan to remediate the environmental challenges to help maintain community living</td>
</tr>
<tr>
<td>Establish</td>
<td>Establish a daily regime that provides for purposeful engagement based on individual needs and preferences, yet is organized so as not to cause anxiety and confusion</td>
</tr>
<tr>
<td>Provide</td>
<td>Provide ongoing clinical supports to address behavioral and psychological symptoms associated with dementia</td>
</tr>
<tr>
<td>Redesign</td>
<td>Redesign day activities and programs so that participation in valued activities and opportunities for interaction with others continues and respite for families and other caregivers is possible</td>
</tr>
</tbody>
</table>
Provide increased assistance with **personal care and hygiene** when needed.

Secure appropriate residential supports and consider housing options to **accommodate increasing losses** in independent functioning.

Continue surveillance and periodic **assessments** to determine extent of change and progressive dysfunction as well as the possible development of comorbid conditions.

Monitor any **medications** being taken to prevent ADRs.

Enhance **training of staff and family** as well as consultation to carers around coping with behaviors and adapting routines.

Institute planning for **long-term services** and supports.

Ensure **protections are in place** to preclude abuse or harm in both formal and informal settings.

(Source: Jokinen et al., 2013)
LATE / END STAGE

- Reorganize care management toward nonambulatory care
- Reassign staff to activities more structured around nursing and personal care including the support of family carers who wish to maintain the person at home
- Obtain support from palliative care or hospice specialists
- Institute procedures to maintain dignity, comfort, and address pain and symptom management
- Organize end-of-life supports and post-death arrangements
WHAT CAN YOU DO?

- Improve understanding of aging and dementia
- Be alert to risk and early signs decline
- Adapt living environments to minimize risk
- Help with futures planning (health and social care)
- Aid families who are carers
- Enhance staff skills – training with respect to dementia
- Quality checks on services
- Provide stage-related services
- Plan for future growth of aging segment of population
- Matthew Janicki
- mjanicki@uic.edu
- www.the-ngt.org
MEDICAL AND HEALTH FACTORS IN ID AND DEMENTIA

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NEW JERSEY
DISCUSSION AND Q&A