

Community Supports For Older Age Related Neuropathologies: Leveraging The National Plan To Address Alzheimer's Disease

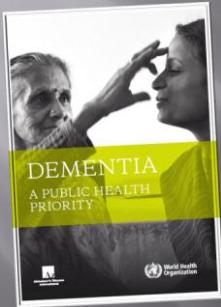
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AUCD Conference – Washington, DC
 December 2, 2012

The 'Big Picture'



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

http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html

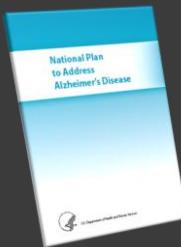
The ‘NAPA’

- National Alzheimer's Project Act (became law in early 2011)
 - Required 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 first convened in September 2011
 - Council composed of Presidential appointees and federal agency staff
 - Council (via staff) developed the first National Alzheimer's Plan in the US – 1 of 17 worldwide!

The National Alzheimer's Project Act requires 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.



U.S. National Plan to Address Alzheimer's Disease



- Calls 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 task groups on I/DD

Rationale for the effort

- ❑ No systemic and cross-cutting national-level plan existed in the United States that addressed the needs of adults with intellectual disabilities affected by dementia
 - ❑ Recognized need for attention to this issue and growing requests for information and policy direction
 - ❑ A new federal law that called for a 'national action plan' for dementia made it timely to ensure that intellectual disabilities were considered in this national plan
 - ❑ Thus, was formed the 'NTG'



The NTG



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What is the NTG?



The National Task Group is a collective composed of over 100 agency personnel, academics, government officials, family members, and persons affiliated with various associations and organizations.

It is associated with several organizations (*the American Academy of Developmental Medicine and Dentistry, the American Association on Intellectual and Developmental Disabilities, and the University of Illinois at Chicago's RRTC on Aging and Developmental Disabilities – Lifespan Health and Function*) as well as numerous other university centers and national organizations.

Janicki, MP

2012-13 NTG Activities

A national early detection screen

The NTG-EDSD undergoing field test to determine validity and usefulness of items

Will be completed in Winter 2012 and then issued nationally

Practice guidelines

Several variants as 'works-in-progress'
Health practices, social care, day-to-day services and practices

Program standards

Training and education activities

Training workshops

Meetings with professional groups

Family information promotion

Linkages

U.S. Administration on Community Living
State DD agency administrators
CARF National program standards group



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NTG Report

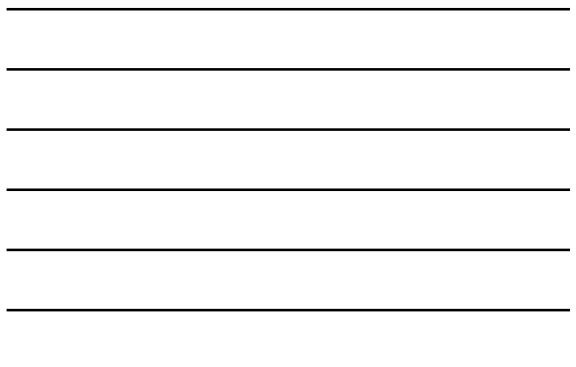
'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports

Available from: www.aadmd.org/ntg



- Population factors
 - Challenges facing people with dementia and ID
 - Community supports
 - Education and training
 - Financing
 - Possible solutions
 - National dementia and intellectual disabilities action plan (and recommendations)

Stakeholders



Dementia and UCEDs



Why focus on this topic?



- ❑ The 'age wave' is here... the US population is aging (increases in absolute numbers and %)
 - ❑ Number of at risk and affected adults is increasing
 - ❑ Many providers are becoming aware but many are not sure what to do
 - ❑ There is now a national strategy for addressing dementia care issues among people with ID and their families

NTG Action Plan recommendations attributed to universities' DD academic and research centers



- # 2: Conduct studies to identify and scientifically establish the risk factors associated with the occurrence of dementia among adults with an intellectual disability.
 - # 9: Conduct studies on the impact of aging of family caregivers on the support and care of adults with intellectual disabilities residing in at-home settings.
 - # 13: Conduct nationwide medico-economic studies on the financial impact of dementia among people with intellectual disabilities in various service provision settings.
 - # 16: Conduct an evaluation of a workable scoring scheme for the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities that would help identify individuals in decline.
 - # 17: Conduct studies on the nature and extent of health compromises, conditions, and diseases found among adults with an intellectual disability and affected by dementia.
 - # 19: Organize and deliver a national program of training using workshops and webinars, as well as other means, for staff and families.
 - # 20: Develop and produce an education and information package for adults with an intellectual disability to help them better understand dementia.

Activities that can contribute to the 'National Action Plan'...

- ❑ Aid local providers adopt 'best practice' models in community-based dementia-capable housing
 - ❑ Institute dementia care support services for families
 - ❑ Promote use of practice guidelines for health and social care settings
 - ❑ Organize and/or provide screening, assessment, and diagnostic services
 - ❑ Disseminate information on dementia and care/ support practices

Helping family caregivers...

Persons with I/DD who live with parents – and develop dementia – pose new challenges for aging parents

- > Behavior will deteriorate
- > Person may remain ambulatory
- > Physical needs will become more prominent

Aging parents may less capable of continuing to provide care at home

Situation may lead to crisis at home and request for out-of-home care

What activities/initiatives can help...

- Target older caregivers to help them with providing physical and social care
- Assist in adapting homes for dementia care
- Provide information about Alzheimer's disease and related dementias, and means of behavior management, nutrition, and personal care
- Teach about dementia, behavior, expectations of progression, and other issues to health and social welfare discipline workers
- Collaborate with Alzheimer's care groups to ensure inclusion of families with relative with I/DD

Preemptive caregiver assistance initiatives

- Providing education on older-age conditions
- Helping carers understand behavioral changes related to aging and dementia
- Developing useful materials on older age and dementia
- Organizing or helping with support groups for caregivers
- Helping adapt current housing to be dementia-capable
- Aiding families with futures-planning for inevitable demands of later stage dementia care

Basic content for 'dementia related trainings'

- 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

- ✓ Much higher prevalence of neuropathology indicative of AD in most adults w/ Down syndrome (DS)
 - ✓ Generally dementia of the Alzheimer's type is prevalent in adults w/ DS
 - ✓ Average onset age in early 50s for DS (late 60s for others)
 - ✓ Most DAD diagnosed within 3 years of "onset" in adults w/ DS
 - ✓ More initial personality change in DS (rather than memory loss)
 - ✓ Late onset seizures found in large number of adults w/ DS
 - ✓ Duration generally is from 2 to 7 years
 - ✓ Aggressive forms of AD can lead to death < 3 years of onset in adults w/ DS.

- Older adults with Down 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)
 - 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

Understanding dementia

- 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
 - Effects of dementia will be progressive and eventually lead to death
 - Early interventions can aid in adapting to changes and prolonging lucid periods

- 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 coincident?
 - What particular dementia-related behaviors will be more evident?

Dementia care options

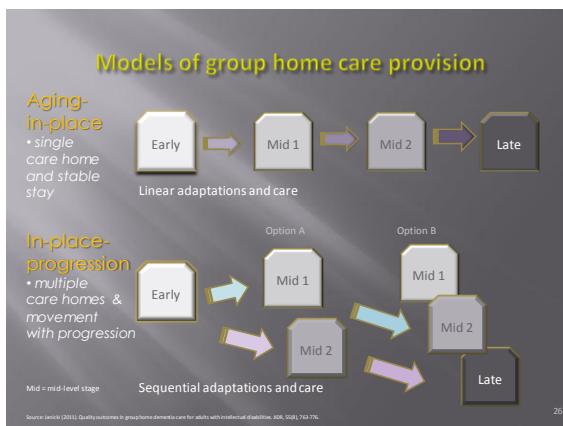
- **Institutional care** – long term care facilities, nursing homes, old age homes, dementia special care units
 - **Family care** – living with family, other relatives, or other family members or carers

Contemporary options

- ☐ **Neighborhood group care** – generic group homes, specialized ID group homes
 - Group homes for persons with ID who age in the homes
 - Group homes for specialized dementia care

Dementia care settings

At Home		Group Living	
Plusses	Minuses	Plusses	Minuses
Live in familiar setting	Burden of care in later stages	Care provided by trained staff	Unavailability of group homes
<ul style="list-style-type: none"> ●Participate in family activities ●Live around familiar things ●Family/kin supports 	<ul style="list-style-type: none"> ● Impact on family ● Lack of respite and other aid for families ● Possible financial insecurity 	<ul style="list-style-type: none"> ●Long-term stay ●Financing ●Small, personal care; help when frail ●In community 	<ul style="list-style-type: none"> ●Risk of losing contact with family ●Needs good oversight to ensure quality



Long term care

It is the position of the National Dementia and Intellectual Disabilities Action Plan to support and promote community-based models of dementia-capable care and applications of individualized supports

- #10: **Enhance family support services** to include efforts to help caregivers to identify and receive assistance for aiding adults with an intellectual disability affected by dementia.
 - #12: Plan for and **develop more specialized group homes** for dementia care as well as develop support capacities for helping adults affected by dementia still living on their own or with their family.
 - #13: Plan and **develop community-based 'dementia-capable' supports** to address the needs of those persons at-risk or affected by dementia.

UCEDs and dementia

- ❑ Adopt a life span perspective so that aging related needs are part of the package of activities
 - ❑ Partner with university centers on aging to tackle community needs related to aging and dementia
 - ❑ Promote inclusion of issues related to normal aging and aging-neuropathologies in training of students and community professionals
 - ❑ Provide clinical assistance and resources to local providers so they can more adequately provide for clientele affected by dementia
 - ❑ Undertake research related to dementia



Sourcing the 'Thinker' document

- <http://rtcadd.org/resources/NTG-Thinker-Report.pdf>
 - <http://aaidm.org/ntg>
 - <http://www.aaid.org/media/Publications/NTGThinkerReport.pdf>
 - <http://thenadd.org/wp-content/uploads/executivesummarywcover.pdf>
 - <http://autismnow.org/resources/my-thinkers-not-working/>

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