

# Intellectual Disabilities and Alzheimer's Disease

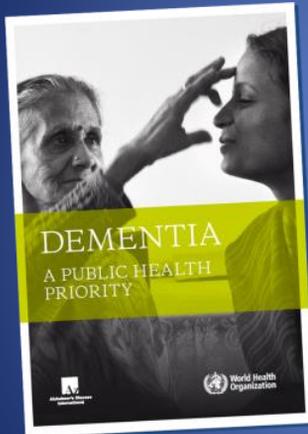
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North Carolina Task Force on Alzheimer's Disease and  
Related Dementia  
Morrisville, North Carolina - July 24, 2015

## Developmental disabilities

- Many conditions may originate prior to birth, in early infancy or during childhood, or before brain maturation (usually in the late teens)
  - Some impair senses, cognition, mobility, or severely compromise health and function
- An **intellectual disability** impairs cognitive and personal function (self-direction and self-care) over a lifetime
- A **developmental disability** (which may include an intellectual disability, but does not always imply intellectual impairment) impairs normal growth, development, and function over a lifetime
  - Categorical vs. functional -- neurodevelopmental conditions
- In some jurisdictions these terms are used interchangeably. In some, only specific conditions are included under the terms
- Definitions provide for eligibility... eligibility provides for funding
  - Those that fund provide the definitions - state vs. federal

## Long term care

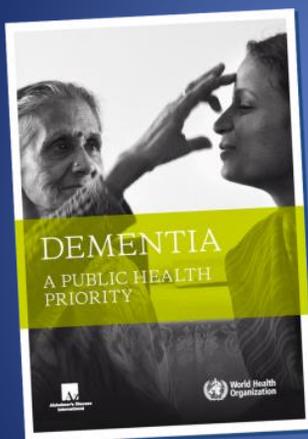


The term "long-term care" is often used to describe the range of services which help meet both the medical and nonmedical need of people with a chronic illness or disability who cannot care for themselves.

Long-term care includes:

- **post-diagnostic services:** planning for the future; offering support, advice and information as needed; and helping maintain independence;
- **community services:** helping people with dementia to remain at home as long as they wish and until it is no longer possible, and providing short breaks / respite care to support caregivers and providing an opportunity for social engagement for the recipient.
- **continuing care:** caring for people who can no longer stay at home (e.g. in different kinds of supported or institutional living arrangements such as group homes and residential care), and providing for the end stages of dementia.

## Intellectual disabilities



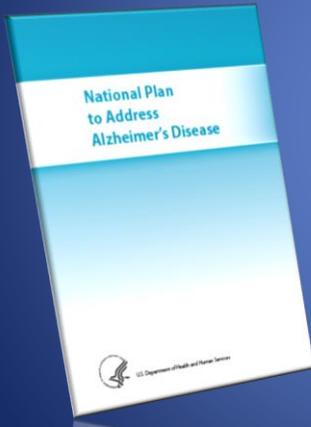
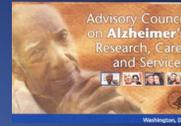
### Care pathways for populations with specific needs

- '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.'

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



Calls for -- among other things....

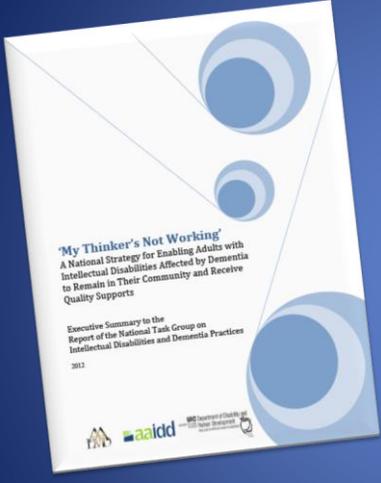
- ☑ Issuance of practice guidelines for care and supports and expanded public education
- ☑ Promotion of assessment tool for detection of cognitive impairment as part of the annual wellness visit
- ☑ Enhanced supports for caregivers
- ☑ Expanded research
- ☑ **Special task groups on I/DD**

Released on May 15, 2012  
Will continue to be updated annually until 2025!

## National Plan updates with relevance to ID



- Action 1.A.9: Convene a workshop to examine the special needs of people with Down syndrome, who are at high risk for developing Alzheimer's disease
- Action 2.A.5: Strengthen state aging, public health, and intellectual and developmental disability workforces
- Action 2.B.3: Educate family and service providers of persons with intellectual disabilities about changes that may indicate the onset of dementia
- Action 2.H.4: Enhance understanding of models of family support for people with intellectual disabilities as they age
- Action 3.B.8: Provide education about respite care for caregivers of people with Alzheimer's disease
- Action 3.B.13: Improve the dementia capability of the long-term services and supports systems so they can better meet the needs of people with Alzheimer's disease and their caregivers
- Action 3.D.3: Enhance training to address the needs of individuals living in long-term care settings



## National Task Group on Intellectual Disabilities and Dementia Practices

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


  
 National Task Group on Intellectual Disabilities and Dementia Practices

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

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## Common elements of *national* dementia policies

- Delaying institutionalization, enabling individuals to remain at home as long as possible
- Supporting caregivers in order to delay the move of individuals living with dementia to long-term care
- Giving individuals living with dementia as much control over their care as possible... while recognizing limitations due to cognitive impairment (e.g., in relation to having the capacity to make informed choices)
- Equating service provision with need
- Promoting early diagnosis
- Coordinating services at the local level, where possible
- Making long-term care, when required, as home-like as possible

Source: Source: Rising Tide: The Impact of Dementia on Canadian Society (Alzheimer Society of Canada, 2010, p. 39) [[http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC\\_Rising%20Tide\\_Full%20Report\\_Eng.ashx](http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC_Rising%20Tide_Full%20Report_Eng.ashx)]

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# Focal Preparations for dementia

- **Short term planning**
  - Institute behavior screening to capture baseline & determine if changes warrant further study
  - Conduct periodic re-screenings among those at risk or who staff suspect have experiencing change or decline
  - Training and orientation of staff on 'warning signs' and basics of early dementia recognition and interventions
  - Maintain surveillance of those adults considered at risk
    - **KNOW WHO IS AT RISK OR WHO HAS DEMENTIA...**

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# Focal Preparations for dementia

- **Long range planning**
  - Some 5-6% of adult client population may be affected by dementia; more if people with DS involved – *anticipate demand for services & aid family carers*
  - Possible specialized housing and care programs for those progressing to 'middle-stage' and beyond
  - Cost factors a consideration; budgeting for increased staffing and supervision – and housing
  - Staffing for nursing-type care to those in late or end stage

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## Planning considerations

**Change of care focus**

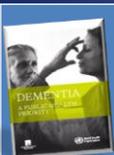
Going from making gains to that of maintaining function and dealing with eventual loss and decline

**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 AD neuropathology in older adults w/Down syndrome (DS)
- ✓ Mixed causal neuropathologies in adults with ID – with implications for course and duration
- ✓ 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
- ✓ Missed cases due to inadequate diagnostic resources

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**WHO report**



**NAPA Alzheimer's Plan**



**NTG report on ID and Dementia**

### Workforce Development

<p><b>Training needs</b></p> <p>There is a need for training in the basic medical, nursing and therapy curricula regarding diagnostic and needs-based assessments, and to move beyond the current preoccupation with simple curative interventions to encompass long-term support and chronic disease management. <b>Given the frailty of many older people with chronic health conditions, there is also a need for training in outreach care, and in assessing and managing patients in their own homes.</b></p>	<p><b>Strategy 2.A:</b></p> <p><b>Build a workforce with the skills to provide high-quality care</b></p> <p>Physicians and other health care providers need information on how to implement the “detection of any cognitive impairment” requirement in the Medicare Annual Wellness Visit included in the Affordable Care Act. Major efforts ... [should] include expanded training opportunities created in the Affordable Care Act, [to] support geriatric training for physicians, nurses, and other health workers. Enhanced specialist training is also needed to prepare these practitioners for the unique challenges faced by people with Alzheimer’s disease.</p> <p><b>In addition, work is needed to expand the capacity of the primary care community to serve people with Alzheimer’s disease. Dementia-specific capabilities within the direct-care workforce need to be expanded and enhanced.</b></p>	<p><b>Goal E: To produce a capable workforce and produce education and training materials.</b></p> <p>Recommendation #7: Establish undergraduate, graduate, and continuing education programs, using various modalities, to enhance the diagnostic skills of community practitioners.</p> <p><b>Recommendation #18: Develop a universal curriculum, applicable nationwide, on dementia and intellectual disabilities geared toward direct care staff, families, and other primary workers.</b></p> <p><b>Recommendation #19: Organize and deliver a national program of training using workshops and webinars, as well as other means, for staff and families.</b></p>
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## Building capacity via workforce development

- Dementia orientation and competency among direct care workers
- Enhanced skill development among clinical support staff
- Policy and program competencies among administrative personnel
- Skill enhancement among medical / health assessment and provider personnel

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## Plan inclusion topics

- Census / estimates of population
- Caregiver support
- Early detection and screening
- Capable dementia diagnostic services
- Community housing / care settings
- Accommodations for advanced dementia
- General workforce development
- Practitioner / clinician skill enhancement
- State long range planning for impacted population

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# What needs to be in place?

- Improving understanding of dementia
- Alerting to risk and early signs - onset
- Adapting living environments
- Helping with futures planning (health and social care)
- Aiding families who are carers
- Enhancing staff skills – training with respect to dementia
- Considering trajectories and duration
- Quality checks in services
- Providing stage related services
- Getting State government to invest resources
- Including Down/ID issues in State Alzheimer's plan

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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



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