

## DEMENTIA AND AGE-RELATED DECLINE IN PEOPLE WITH LIFELONG DISABILITIES

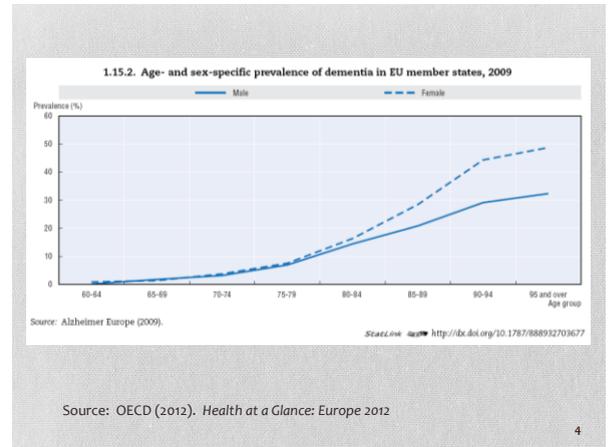
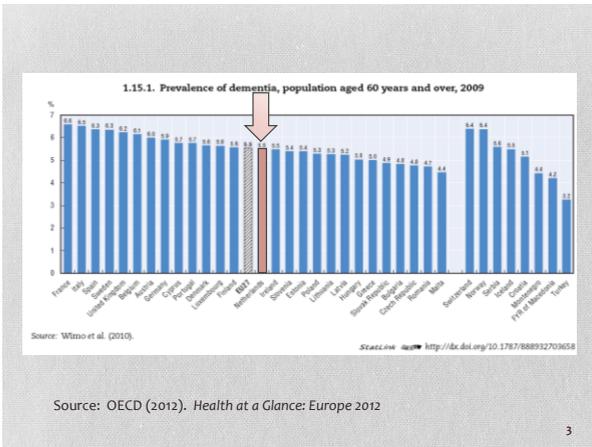
### PART 1: BACKGROUND

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### Percent of national populations age 65 and older

By 2018, 65-year-olds will outnumber children age 5 and under...



	EuroCoDe (2009)	EURODEM (1991)
Austria	126,296	111,294
Belgium	163,511	144,584
Bulgaria	99,291	90,584
Cyprus	8,024	7,295
Czech Republic	123,194	111,141
Denmark	78,744	70,108
Estonia	17,825	16,831
Finland	77,516	68,738
France	974,391	854,219
Germany	1,368,330	1,214,096
Greece	159,275	144,745
Hungary	131,995	118,159
Ireland	37,417	33,719
Italy	1,012,819	896,688
Latvia	29,846	26,583
Lithuania	40,619	36,423
Luxembourg	5,814	5,178
Malta	4,524	4,122
Netherlands	210,665	187,912
Poland	391,344	354,160
Portugal	153,386	137,403
Romania	227,036	207,789
Slovakia	51,622	46,607
Slovenia	25,380	22,822
Spain	690,992	611,734
Sweden	161,327	141,948
UK	931,134	822,679
<b>Total European Union</b>	<b>7,299,318</b>	<b>6,486,560</b>
Iceland	3,319	2,957
Norway	71,447	62,679
Switzerland	125,614	110,954
Turkey	253,367	242,771
	<b>7,753,065</b>	<b>6,905,631</b>

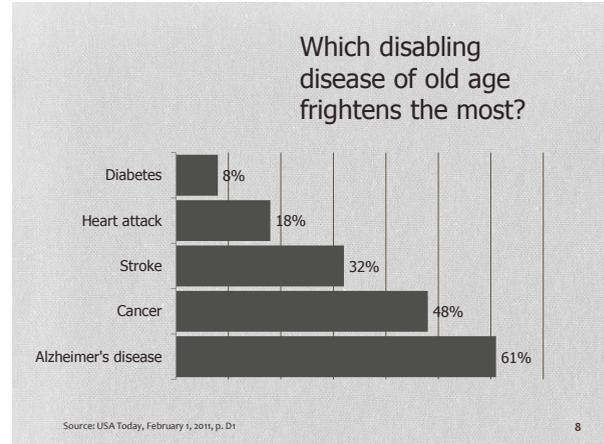
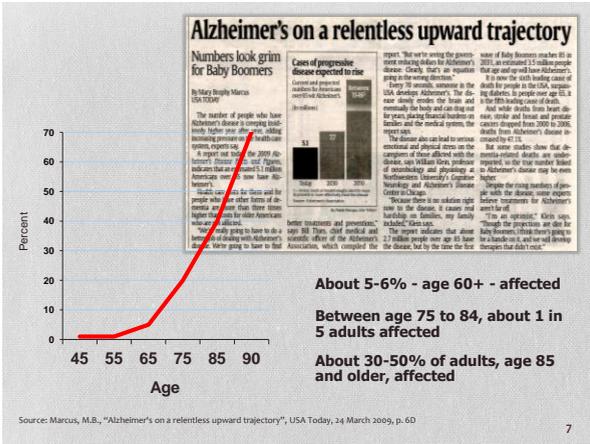
Numbers of People with Dementia In Europe  
(as calculated by Alzheimer's Europe)

- There are currently over 6 million people with dementia in the European Union
- It is predicted that this number will double in the next 20 years
- The cost per person with dementia is ~ € 21,000/yr
- Total cost for EU-27 is 130B/yr
- Some 5-6% of people with ID age 60+ will have dementia

### Dementia prevalence-Europe

Age Group	Males	Females
30-59	0.2%	0.1%
60-64	1.6%	0.5%
65-69	2.2%	1.1%
70-74	4.6%	3.9%
75-79	5.0%	6.7%
80-84	12.1%	13.5%
85-89	18.5%	22.8%
90-94	32.1%	32.4%
95-99	31.6%	36.0%

Source: Alzheimer Europe



## 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 on 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](http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html)

## Key points

- Dementia is not a normal part of ageing.
- The huge cost of the disease will challenge health systems to deal with the predicted future increase of prevalence.
- People live for many years after the onset of symptoms of dementia. With appropriate support, many can and should be enabled to continue to engage and contribute within society and have a good quality of life.
- Dementia is overwhelming for the caregivers and adequate support is required for them from the health, social, financial and legal systems.
- Countries must include dementia on their public health agendas. Sustained action and coordination is required across multiple levels and with all stakeholders – at international, national, regional and local levels.
- People with dementia and their caregivers often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them.

[http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/index.html](http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html)

## Care guidelines

Guidelines should provide clear steps for supporting physical and mental functioning and well-being for as long as possible... They should include guidance on the provision of:

- social engagement and recreational activities
- cognitive stimulation and rehabilitation, where appropriate
- physiological support, including identification and management of comorbid symptoms such as pain and delirium
- environments that are both safe and stimulating
- recognition of behavioral and psychological change and potential causes
- least restrictive management of behavioral and psychological symptoms (e.g. nonpharmacological approaches), including monitoring the effectiveness of the management approach
- palliative support which is timely and ethically based
- psychosocial support for the family.

[http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/index.html](http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html)

## 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.

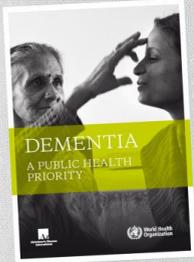
**Intellectual disability**

- 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.

*\*My Thinker's Not Working...\**

[http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/index.html](http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html)

## Awareness raising



- raising public awareness and understanding of dementia
- reducing the stigma of dementia
- recognizing the early signs of dementia to aid early diagnosis
- promoting quality of life
- providing information about risk factors

[http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/index.html](http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html)

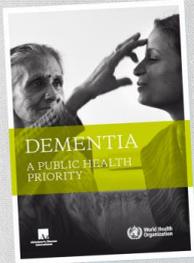
## Overcoming stigma and preconceived notions for people with Down syndrome



Ms. Scott, 55, was born with Down syndrome but is slowly dying from Alzheimer's disease, a progressive, degenerative illness that is destroying her brain. The two conditions are tragically linked; most people with Down syndrome are afflicted with Alzheimer's in middle age, and their final years are marked by a profound intellectual, emotional and physical decline.

Toronto (Canada) Globe & Mail, May 4, 2007

## 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.

[http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/index.html](http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html)



Currently, there are an estimated 250,000 people in the Netherlands with dementia. This number is expected to double to more than 500,000 by 2040 (Alzheimer Nederland).

The Deltaplan Dementia 2012-2020 is built on three pillars:

- 1) the development of an **e-health portal**;
- 2) the establishment of a **national dementia registry**, and
- 3) the investment and implementation of new programs for **scientific research**.

The Deltaplan Dementia 2012-2020 aims to reduce loss of productivity

- 1) by **slowing** down the **progression** of disease and reducing symptoms (especially for early onset dementias) allowing patients to **work longer**,
- 2) by enabling patients to **stay at home** as long as possible, hence reducing the need for inpatient care, and
- 3) by reducing the time dedicated to care giving, enabling carers to provide **care in a more efficient way** through e-health and other kind of innovations.

Deltaplan Dementia 2012-2020

## 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. 30) ([http://www.alzheimer.ca/~media/1/en/national/AdvocacyASC\\_RisingTide\\_PublicReport\\_English](http://www.alzheimer.ca/~media/1/en/national/AdvocacyASC_RisingTide_PublicReport_English))

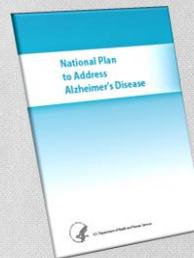
## U.S. National Plan to Address Alzheimer's Disease



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
- Recognizes I/DD as special group

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



## What is the NTG?



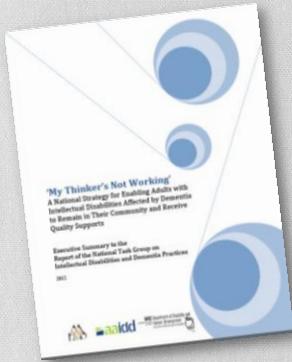
The National Task Group is composed of over 100 agency personnel, academics, government officials, family members, and persons affiliated with various associations and organizations.

It is derived from a collaboration of the **American Academy of Developmental Medicine and Dentistry**, and the **University of Illinois at Chicago's** RRTC on Aging and Developmental Disabilities as well as other university centers and national associations.

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

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## National Task Group on Intellectual Disabilities and Dementia Practices



● Create a national plan on dementia and ID

● Identify a workable administrative screening instrument

● Produce health/screening practice guidelines for the medical and allied health community

● Define 'best practices' for community social care of adults with ID and dementia

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

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 WHO report	 US NAPA Alzheimer's Plan	 NTG report on ID and dementia
<b>Workforce Development</b>		
<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: 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>Recommendation #18: <b>Develop a universal curriculum, applicable nationwide, on dementia and intellectual disabilities geared toward direct care staff, families, and other primary workers.</b></p> <p>Recommendation #19: Organize and deliver a national program of training using workshops and webinars, as well as other means, for staff and families.</p>

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## National Task Group on Intellectual Disabilities and Dementia Practices

**Aim:** To have the National Task Group (NTG) feed into the NAPA effort and ensure that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are considered as part of the U.S. national strategy.

**Goals:**

- 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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## Method

The NTG used a 'voluntary involvement model'

- 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
- There were no such documents at the state level as well
- As new federal law [National Alzheimer Project Act – NAPA] called for a 'national action plan' for dementia, it was timely to ensure that intellectual disabilities were considered in that national plan
- Thus, was formed the 'NTG'

The model employed 4 steps:

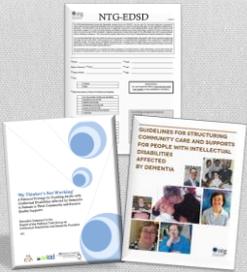
- Obtained support for the formation of a national working group
- Drew on volunteer-based membership from across the country and from various constituencies
- Got support from pro-bono work and other contributions for its working group's efforts
- Drew in key governmental and national organizational officials to support its efforts and implement its recommendations.



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## 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




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