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 development 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.


Janicki (7’24’15)

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 50 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…’

Janicki (7’24’15)
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!

Janicki (7/24/15)

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

Exceptional Parent, June 2014, 44(6), 15-16

Janicki (7/24/15)
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

http://www.alzheimer.ca/~/media/Files/national/Advocacy/ASC_Rising%20Tide_Full%20Report_Eng.ashx
Features of dementia in adults with ID

<table>
<thead>
<tr>
<th>Rate of occurrence</th>
<th>Age-cohort percent for adults with intellectual disability (ID) is same as in general population (~5-6% over 60)</th>
<th>Much higher prevalence (60% age 60) and neuropathology indicative of AD in most adults with Down syndrome (DS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia type</td>
<td>Generally dementia of the Alzheimer’s type is prevalent in DS</td>
<td>Similar range of dementias found in other ID as in other people</td>
</tr>
<tr>
<td>Risk</td>
<td>DS and head trauma are significant risk factors in ID</td>
<td></td>
</tr>
<tr>
<td>Onset and duration</td>
<td>Average onset age in early 50s for DS – late 60s for others</td>
<td>Most DAT diagnosed &lt;3 years of “onset” in adults with DS</td>
</tr>
<tr>
<td>Behavioral changes</td>
<td>More evident early change in personality in DS</td>
<td>More initial memory loss in other ID</td>
</tr>
<tr>
<td>Neurological signs</td>
<td>Late onset seizures in 24%-46% of adults w/DS</td>
<td>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</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Aggressive AD can lead to death &lt;2 years of onset in DS</td>
<td>2-7+ years mean duration in DS</td>
</tr>
</tbody>
</table>

Differences in ID?

Early onset?
- Yes, 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 changes

Assessment?
- Significant difference ... Standard measures not useful – have to use comparisons by individual over time

Services?
- Infrastructure in place... More dementia care options for ID as lifelong supports generally available
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...

• 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
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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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

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
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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