‘Building common approaches to the growing dementia concerns among people with intellectual disability as they age’

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‘Building a Picture of Ageing in Persons with Intellectual Disability: Future Directions for Ageing Well’

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Why focus on this topic?

- National populations are aging (absolute numbers are increasing)
- Numbers of at risk and affected adults are increasing
- Providers (NGOs) are becoming aware but many are not at front of this ‘age wave’
- National strategies for addressing dementia care issues among people with ID and their families are virtually non-existent
Impact of aging demographics

- General population growth among aged
- Increases in dementia as populations age
- Challenges for long-term care
- Planning – connecting the Alzheimer’s network with the intellectual disabilities services
Of the world’s estimated 9.3 billion people, 16% will be 65 and older in 2050. Europe will continue to be ‘greyest’ region, with 29% of the population projected to be 65 or older by 2050.
Aging Population by Country

- Nearly 25 percent of people in Europe in 2030 will be above age 65
  - up from about 17 percent in 2005
- About 20% of Europe's population could be above age 80 by 2050
About 5-6% - age 60+ - affected

Between age 75 to 84, about 1 in 5 adults affected

About 30-50% of adults, age 85 and older, affected

Source: Marcus, M.B., “Alzheimer’s on a relentless upward trajectory”, USA Today, 24 March 2009, p. 6D
Dementia and Intellectual Disabilities

- Dementia is an age-associated condition that affects more than 7 million Europeans and at least 30,000 adults with ID*
- Dementia – progressive behavioral dysfunction – results from brain disease or trauma
- Adults with some syndromes of ID – such as Down syndrome – are at high risk of Alzheimer’s dementia
- Community agencies and families are facing greater challenges in providing residential and general living supports for adults affected by dementia

*Estimate based on N=124,431,000 Europeans age 65+ x 4/1000 = 497,724 older adults with ID x 5% est. prevalence of dementia age 65+.
Implications of growing number of older adults with ID

- Service populations are aging
  - Richmond BC Canada example
- Risk factors
  - Down syndrome most at risk
  - Many adults with DS still at home
  - Earlier onset of dementia and shorter duration
- If in service, then potential for adapted care
- If not in service, more difficult to get specialized care
Changes in agency service population (%)

Increased Average Life Expectancy - DS


Source: Torr (2009)
Prevalence of dementia in adults with intellectual disabilities

- Dementia found in adults with ID
  - 3% > 40 years of age and older
  - 6% > 60 years of age and older
  - 12% > 80 years of age and older
- Dementia found in adults with DS
  - 25% > 40 years of age and older
  - 66% > 60 years of age and older

Dementia is found in 5-6% of adults age 60 and older in the general population.

Except for DS, the 60+ ID data correspond with the data reported for the 60+ general population.

NGO awareness

- Growing concerns among providers over how to best accommodate dementia
  - Usually case-by-case response
  - Some forward and purposive planning and service development
  - Difficulties with integrated services
  - Lack of financial incentives or reimbursements for added costs
  - Low access for training of staff
Public policy deficits

- Little governmental attention due to
  - Not yet enough noise to stimulate national level planning
  - Potentially costly services to ‘do right thing’
  - Lack of national integration of concerns (ID and AD planning)
- No litigation
- No advocacy by parents (‘ostrich’ effect)
Preparing for 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

Unknowns...

- Who will be affected
- How long will person live after dx
- What other diseases or medical conditions may be co-incident
- What particular dementia-related behaviors will become more prominent
Transitions and Life Focal Points for People with Intellectual Disabilities

- **Childhood**
  - Living with family
  - Help for families
  - Schooling
  - Medical care
  - Recreation

- **Young adult**
  - School leaver
  - Possible living on own
  - Independent of family

- **Middle age**
  - Changes in health
  - Lifestyle changes
  - Family/carer aging

- **Old age**
  - Pensioning
  - Physical & mental decline
  - Loss of carers

- **Living on own or with group**
  - Retirement
  - Health care
  - Community involvement

- **Dementia impact zone**

- **Transitions**
Areas of focus

- Screening, Assessment and Diagnostics
- Prevention of institutionalization
- Specialized programs
- Clinical teams
- Specialized program plans
Regional and national planning

- NGO level planning – DDA in British Columbia
- Regional planning – The Reena Initiative in Ontario
- National Task Group on Intellectual Disabilities and Dementia Practices in the USA
- IDS-TILDA
Building capacity – an example

• ‘Reena’ – a large ID service agency in the Greater Toronto, Ontario Canada area – started by identifying its current adult service population - They identified current population and projected its character 10 years hence

• Recognized that the “social services” and “health and senior services” systems needed to be brought together

• Was instrumental in forming the **Ontario Forum on Aging and Developmental Disabilities**, which brought together the province’s services providers, government agencies, and planning bodies in both disability and aging
The Reena example...

How did they do it?

- Saw the need and worked with health, aging and social services agencies to identify and frame the issue.
- Got cooperation of Health Canada to underwrite early development.
- Held regional (provincial) workshops to educate and excite participation.
- Worked to develop and nurture local partnerships in aging and developmental disabilities.
- Involved a whole host of people, agencies, consumers and others – to gain support and consensus.
The National Task Group on Intellectual Disabilities and Dementia Practices

- Supported by AAIDD and AADMD – 90+ members from various organizations and agencies
- Collaborative effort to define a strategic plan for providing more effective services to adults with disabilities affected by dementia
- Involves US organizations and federal agencies from both the aging and disabilities sectors
- End plan/report will feed into the National Alzheimer’s Project Act – enacted by the US Congress to establish a strategic national planning process for dealing with the insidious effects of dementia in the population

www.aadmd.org/ntg
• Cooperative planning initiative...
• ‘The National Task Group’

www.aadmd.org/ntg
International dementia care options

Traditional 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

Innovative 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
Prevalent models of group home care provision

**Aging-in-place**
- Single care home and stable stay

**In-place-progression**
- Multiple care homes & movement with progression

**Linear adaptations and care**
- Early → Mid 1 → Mid 2 → Late

**Sequential adaptations and care**
- Early → Mid 1 → Mid 2 → Late

Mid = mid-level
Group homes and community dementia housing and services

**Model:** Dementia group homes follow an “in-place progression” approach to care for persons with dementia

**Residents:** Homes average 7 residents; age ranges - 50 to 94 years; both men and women

**Staffing:** Average staff to resident ratio is approximately 1.3:1

**Costs:** Average per annum approx. cost of care at ID homes is €37,177

**Admission:** Most homes use the presence or diagnosis of dementia or aging-associated frailty as a key criterion for admission – but leaving criteria are fluid
### ‘What if’ scenarios

<table>
<thead>
<tr>
<th>What would we do... if we knew exactly who would show dementia and when?</th>
<th>Biomarkers would tell us who had the precursors to clinical dementia</th>
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<tbody>
<tr>
<td>How would we maximize cooperation among different sectors?</td>
<td>In a perfect world, there would be synergy among government and NGOs re: dementia care</td>
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<td>How would we construct our housing and activity settings?</td>
<td>Housing would use universal design and be dementia capable</td>
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<td>How would we train and equip staff to maximize resources and efforts?</td>
<td>NGOs would have full levels of staff and supports to sustain dementia-affected persons with ID at home</td>
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<td>How would we change diets and risk exposure to minimize chance of dementia?</td>
<td>Prevention efforts could be incorporated into lifespan activities (nutrition &amp; wellness)</td>
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Preventing, addressing, helping, dementia and adults with ID

- Knowing what happens with advancing age and knowing the symptoms of dementia
- Planning ahead for care options and financial supports
- Setting up ‘specialized dementia care’ programs
- Linking with helpful resources, like the Alzheimer’s organizations
- Advocating for a government focus
- Ensuring that quality measures are in place
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