Aging, Dementia and Public Policy with Regard to People with Intellectual Disabilities

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Uppsala, Sweden ● 22 November 2010
A word about me...

• Career with the New York State Office of People with Developmental Disabilities... as director for planning and then as director for aging services

• Now with the Rehabilitation and Research Training Center on Aging and Developmental Disability – Lifespan Health and Function at the University of Illinois at Chicago
Why focus on this topic?
DEMOGRAPHICS, LONGEVITY, LIFE EXPECTANCY, RISK
Key Facts

- 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.
- Only 5% of Africa’s population will be 65 or older in 2050.
- Seniors will increase to 18% of Latin America’s population by 2050.
- The fastest growing age group – those 65+ - are now at 8% - and will triple to 24% by 2050.

Source: The Straits Times (Singapore), 25 June 2009, p. A26
Population Age Structure in Nordic Countries

High aging population is explained by low fertility levels, higher average life expectancy, and the out-migration of young people.

Brown color represents areas with higher than average older populations.

Age group 65+ as percent of the population in Nordic countries (2006)

Median ages 2010 2030

<table>
<thead>
<tr>
<th>Country</th>
<th>2010</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>40.7</td>
<td>42.7</td>
</tr>
<tr>
<td>Finland</td>
<td>42.1</td>
<td>44.8</td>
</tr>
<tr>
<td>Iceland</td>
<td>35.2</td>
<td>39.3</td>
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<tr>
<td>Norway</td>
<td>38.9</td>
<td>41.1</td>
</tr>
<tr>
<td>Sweden</td>
<td>41.0</td>
<td>42.8</td>
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</table>

Nordic average: 16.1%

Age group 65+ as percent of the population in Nordic countries (2006)

Median ages 2010 2030
Denmark 40.7 42.7
Finland 42.1 44.8
Iceland 35.2 39.3
Norway 38.9 41.1
Sweden 41.0 42.8

Nordic average: 16.1%

Percent population age 65+ for three years: 2010, 2020 and 2030: Nordic countries

<table>
<thead>
<tr>
<th>Country</th>
<th>2010</th>
<th>2020</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>16.5</td>
<td>20.4</td>
<td>23.2</td>
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<tr>
<td>Finland</td>
<td>17.1</td>
<td>22.7</td>
<td>26.1</td>
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<tr>
<td>Iceland</td>
<td>12.2</td>
<td>15.3</td>
<td>19.2</td>
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<tr>
<td>Norway</td>
<td>15.2</td>
<td>18.3</td>
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<tr>
<td>Sweden</td>
<td>18.3</td>
<td>21.5</td>
<td>23.6</td>
</tr>
</tbody>
</table>
Life Expectancy in Nordic Countries
# Life Expectancy in Nordic Countries

<table>
<thead>
<tr>
<th>Country</th>
<th>All</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>78.3</td>
<td>76.0</td>
<td>80.6</td>
</tr>
<tr>
<td>Finland</td>
<td>79.3</td>
<td>76.1</td>
<td>82.4</td>
</tr>
<tr>
<td>Sweden</td>
<td>81.8</td>
<td>80.2</td>
<td>83.3</td>
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<tr>
<td>Iceland</td>
<td>80.2</td>
<td>77.8</td>
<td>82.5</td>
</tr>
<tr>
<td>Norway</td>
<td>80.9</td>
<td>78.7</td>
<td>83.0</td>
</tr>
</tbody>
</table>
Comparative life expectancy in select countries

World: 67.2
Males: 65.0
Females: 69.5
Life Expectancy in Sweden

Men: 78
Women: 83

- Social and economic factors, such as family and education, affect the mortality rate in each county.

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

<table>
<thead>
<tr>
<th>Country</th>
<th># Jonas (est.)</th>
<th>ID# (est.)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>78,744</td>
<td>3,630</td>
</tr>
<tr>
<td>Finland</td>
<td>77,516</td>
<td>3,690</td>
</tr>
<tr>
<td>Iceland</td>
<td>3,319</td>
<td>150</td>
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<tr>
<td>Norway</td>
<td>71,447</td>
<td>2,980</td>
</tr>
<tr>
<td>Sweden</td>
<td>141,948</td>
<td>6,880</td>
</tr>
</tbody>
</table>

*4/1000 - 65+
**Alzheimer's on a relentless upward trajectory**

**Numbers look grim for Baby Boomers**

By Mary Brophy Marcus  
USA TODAY

The number of people who have Alzheimer’s disease is creeping insidiously higher year after year, adding increasing pressure on the health care system, experts say.

A report out today, the 2009 Alzheimer’s Disease Facts and Figures, indicates that an estimated 5.1 million Americans over 65 now have Alzheimer’s.

Health care costs for them and for people who have other forms of dementia are more than three times higher than costs for older Americans who are not afflicted.

“We’re really going to have to do a better job of dealing with Alzheimer’s disease. We’re going to have to find better treatments and preventions,” says Bill Thies, chief medical and scientific officer of the Alzheimer’s Association, which compiled the report. “But we’re seeing the government reducing dollars for Alzheimer’s disease. Clearly, that’s an equation going in the wrong direction.”

Every 70 seconds, someone in the USA develops Alzheimer’s. The disease slowly erodes the brain and eventually the body and can drag out for years, placing financial burdens on families and the medical system, the report says.

The disease also can lead to serious emotional and physical stress on the caregivers of those afflicted with the disease, says William Klein, professor of neurobiology and physiology at Northwestern University’s Cognitive Neurology and Alzheimer’s Disease Center in Chicago.

“Because there is no solution right now to the disease, it causes real hardship on families, my family included,” Klein says.

The report indicates that about 2.7 million people over age 85 have the disease, but by the time the first wave of Baby Boomers reaches 85 in 2031, an estimated 3.5 million people that age and up will have Alzheimer’s.

It is now the sixth leading cause of death for people in the USA, surpassing diabetes. In people over age 65, it is the fifth leading cause of death.

And while deaths from heart disease, stroke and breast and prostate cancers dropped from 2000 to 2006, deaths from Alzheimer’s disease increased by 47.1%.

But some studies show that dementia-related deaths are under-reported, so the true number linked to Alzheimer’s disease may be even higher.

Despite the rising numbers of people with the disease, some experts believe treatments for Alzheimer’s aren’t far off.

“I’m an optimist,” Klein says. “Though the projections are dire for Baby Boomers, I think there’s going to be a handle on it, and we will develop therapies that didn’t exist.”

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**Cases of progressive disease expected to rise**

Current and projected numbers for Americans over 65 with Alzheimer’s.

<table>
<thead>
<tr>
<th></th>
<th>2030</th>
<th>2050</th>
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<tbody>
<tr>
<td>Current</td>
<td>5.1</td>
<td>7.7</td>
</tr>
</tbody>
</table>

1 – Unless medical breakthroughs identify ways to prevent or more effectively treat the disease.

Source: Alzheimer’s Association

By Frank Pompa, USA TODAY

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Source: Marcus, M.B., “Alzheimer’s on a relentless upward trajectory”, USA Today, 24 March 2009, p. 6D
Prevalence of Dementia by World Regions

‘The Age of Alzheimer’s’

Author: Sandra Day O’Connor¹, Stanley Prusiner² & Ken Dychtwald³

¹Former US Supreme Court Justice
²Nobel Prize winner
³Gerontologist

- For every one cent spent on research in AD, $3.50 is spent on caregiving for AD
- The likelihood of AD doubles every 5 years after age 65
- Postponing onset of AD for 5 years, would mean that a large share of nursing beds would remain empty
- US spends $172B/year on care – by 2020 it will be $2T and by 2050 it will be 20T

**Intent:** Written with eye to encouraging the US Congress to increase funding for Alzheimer’s research


B: billion dollars  T: trillion dollars
Alzheimer’s disease and adults with intellectual disabilities

• Increasing risk of Alzheimer’s disease (an age-associated condition) due to population aging
• Greater risk of Alzheimer’s disease among adults with Down syndrome and with serious head injuries
• Many carers or care provision agencies not prepared for occurrence of dementia as adults with disabilities age
Demographers and researchers tell us

- The older ID population will increase dramatically in the next 10-20 years
- Current and future older adults will be healthier and better educated than previous generations
- There is a low expectation that families will be able to absorb all the older persons who will need care at home
- Although older adults will be healthier, those adults with disabilities will still need health and social services and some will be affected by age-associated pathologies — such as dementia
What is contributing to longevity?

- **Deinstitutionalization** (improved quality of life via community living)

- **Available and effective health care** (medical training in disabilities, better nutrition, disease prevention)

- **Research about growing older** (richer medical and social science literature enabling better services)

- **Cohort differences** (40-year-olds born in the 1960s – different life experiences)

- **Public policy attention** (governmental financing of services, laws, regulations)
People with intellectual disabilities*

Characterized by

– Below normative intellectual functioning, due to cognitive impairment (organic or functional) present since birth or infancy
– Not a mental illness or psychiatric impairment
– Varies in degree and co-impairment
– Compensated by training, education, remediation, habilitation, supports for life activities

Down syndrome is a chromosomal abnormality present at birth (#21) associated with ID – In adults, age 40+, occurs in 10-12%

*Some may refer to ID as “mental retardation”
Some comments about intellectual disabilities & Down syndrome
ID vs. Dementia

- Intellectual disabilities involve undeveloped or underdeveloped mental or intellectual skills and abilities.
- Dementia is a widespread loss of mental or intellectual skills and abilities - Dementia related losses occur in memory, language skills, orientation, ADLs [activities of daily living], and changes evident in personality and global functioning.

*Key:* behavioral presentation may be similar, but it’s the loss from previous level of function that differentiates the two.
Why focus on Down syndrome?

• Adults with Down syndrome represent a significant number of cases of dementia among people with ID
• People with Down syndrome are at elevated risk of Alzheimer’s disease and experience onset at earlier chronological ages
• In many places, adults with Down syndrome represent at least 10% of people with ID over age 40

A caution: Early studies which used adults with Down syndrome who had dementia as Ss left the impression that all people with ID were at elevated risk

1 Stancliffe, R.J., et al., (2010), Adults with Down syndrome who use the US developmental disabilities service system. JARID, 23(5), 482.
• 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.
Increased Average Life Expectancy


Source: Torr (2009)
Percent Persons with Down Syndrome Showing Evidence of Neurofibrillary Tangles (NFT) and Senile Plaques (SP) at Autopsy

Source: Mann (1993) – [based on 39 published studies $n=434$]
Down syndrome and dementia

• 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
• Useful to know the signs and keep track of capabilities after age 40
• Early referral for assessment or diagnosis
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

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


Janicki
<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage with clinical signs of dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>30’s</td>
<td>2%</td>
</tr>
<tr>
<td>40’s</td>
<td>10-15%</td>
</tr>
<tr>
<td>50’s</td>
<td>33%</td>
</tr>
<tr>
<td>60’s</td>
<td>50-70%</td>
</tr>
</tbody>
</table>

The average age at which people are dying in the United States is
- 68.5 for men
- 76.1 for women
- 72.3 for both

(This is not a life expectancy figure)

Average age of death of adults with ID age 40+
Adults with ID 66.1 years
Adults with DS 55.8 years
Adults in Population 70.4 years


Low heritability
The ages at which one’s parents die has a mere 3% effect on age of death...

Examples of heritable traits:
- Height (85%)
- Attention-deficit hyperactivity disorder (75%)
- Weight (70%)
- Intelligence (52%)
- Personality (50%)
- Alzheimer's disease (50%)
- Vocational interests (42%)
- Scholastic achievements (38%)
- Memory (22%)
- Hypertension (20%)
- Life span (3%)
Some Background on Dementia & ID

► Rate of occurrence\textsuperscript{1, 3, 5, 8}
  – Age-cohort percent is same as in general population for adults with ID
  – Much higher prevalence & neuropathology indicative of AD in most adults with Down syndrome (DS)
    ▶ Adults w/DS make up about 10-12\% of adult ID population

► Dementia type\textsuperscript{2, 9}
  – Type of dementia differs between DS and other types of intellectual disability
    ▶ Generally dementia of the Alzheimer’s type is prevalent in DS
    ▶ Range of dementias found in other people with ID
  – Problem of ‘diagnostic overshadowing’

► Onset and duration\textsuperscript{1, 2, 3, 10}
  – Average onset age in early 50s for DS
  – late 60s for others
  – Most DAT diagnosed within 3 years of “onset” in adults w/DS

► Behavioral changes\textsuperscript{2, 3, 6}
  – More personality change in DS
  – More initial memory loss in other ID

► Neurological signs\textsuperscript{1, 2, 4, 7}
  – Late onset seizures found in 12\%-84\% of adults w/DS

► Prognosis\textsuperscript{2}
  – Aggressive forms of AD can lead to death <2 years of onset in DS
    ▶ 2-7 years mean duration in DS
  – Same longevity expected for other ID


12/1/2010
Normal aging to MCI to dementia progression goes through stages or transitions (T) – the differences between these can be measured.

- Silverman et al. (2010) found that measures of change in function were more pronounced in the MCI to dementia group scores.

- Four or more measures of change produce strong indications and assurance of the progression from MCI to dementia.

- Once MCI is present, difficult to determine what predicts subsequent progression to dementia.

MCI defined as -1 to -1.5 σ below X in episodic memory (attention, memory, language, visuo-spatial skills, impaired IADLs [global behaviors]).

MCI related neurological symptoms in adults with Down syndrome

- MCI [mild cognitive impairment] → Dementia conversion rate in adults with DS is about 33% over a 18 month period
- DS adults with MCI
  - exhibit more complaints of body aches and pains, confused thoughts, crying spells, and destructive behavior
  - are more inattentive and demonstrate object attachment and regression in ADLs, sadness and sleep problems & tiredness and more inappropriate anger and temper tantrums
- Aggressive behavior and physical and behavioral depression shows up more among adults with DS with MCI compared to other DS adults
- More neuropsychiatric symptoms evident when MCI is present
- Such behavioral markers are helpful when screening adults with DS for dementia

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 be more evident
A focus on carers
Place of residence for adults with intellectual disabilities

Age range of carers by place of residence (at home vs. away)

Carers

Findings...

• The majority of the primary carers are over the age of 50 years and continue to provide medium to high levels of support to adults with intellectual disability

• As carers and adults with intellectual disability get older, the crisis of care will have double the impact as services will need to respond to both the person with intellectual disability and their carer

Dementia care Options

- **Institutional care** – long term care facilities, nursing homes, old age homes, dementia special care units

- **Neighborhood group care** – generic group homes, specialized ID group homes
  - “in-place progression” model
  - “aging-in-place” model

- **Family care** – living with family, other relatives, or other family members or carers
Dementia care settings

At home

+: Live in familiar setting
  - Participate in family activities
  - Around familiar things

-: Burden of care in later stages
  - Impact on family
  - Lack of respite & other aid for families

Group care

+: Care provided by trained staff
  - Long term stay
  - Financing aid
  - Small, personal care

-: Unavailability of group homes
  - Risk of losing contact with family
  - Needs good oversight to ensure quality
Dementia & families

• Persons with DS & ID who live with parents – and develop dementia – pose severe challenges for 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
Concerns Cited by Families

- Incidents raising parental/carer concerns:
  - Falling
  - Difficulty eating
  - No longer talking
  - Increased aggression
  - Short-term memory loss
  - Throwing self on the floor
  - Decline in general abilities
  - Undressing inappropriately
  - Difficulty getting out of bed
  - Increased conflict with peers
  - Becoming disinterested in activities
  - Medical problems (e.g., seizures, incontinence)
  - Other problems (such as ‘trying to make guests leave house’)

Recent studies have shown that carer concerns may be as good as clinical assessment in identifying dementia...

Early stage caregiving

• Parents may need help to recognize onset of dementia in their son or daughter

• Their home may have to be adapted for dementia care

• They can benefit from support groups that share information about dementia and behavior management and supports

• Problems will arise later as dementia progresses and care may change from ambulatory (walking) to nursing care (bed care)
Helping family carers...

• Providing physical and social care
• Information about Alzheimer’s disease, medical needs, behavior management, nutrition, and personal care
• Knowing dementia-related behaviors and its progression
• Communicating with people affected by dementia
• Accessing help from outside family
How can families get help?

- By getting respite from caregiving to alleviate stress
- By joining a support group
- By getting help from Alzheimer’s organizations
- By getting involved with parents’ groups
- By deciding about where their son or daughter will live if they can’t care for him or her – or who will care for him or her
Group home care for adults with intellectual disabilities and Alzheimer's disease

Matthew F. Macek
Anthony J. Dayton
Philip McCallion
Diana S.B. Barnes
Anna Tendall

Abstract. The growing numbers of individuals with intellectual disabilities and Alzheimer's disease require innovative approaches to care. Home-based care settings offer a range of options that may include group homes, residential care, and assisted living facilities. These settings provide a supportive environment for individuals with Alzheimer's disease and intellectual disabilities, offering a sense of community and companionship. Group homes can be an effective and cost-effective option for providing care to individuals with Alzheimer's disease and intellectual disabilities. They offer a structured environment that is familiar and safe, with staff who are trained to provide specialized care.

Keywords: dementia, Alzheimer’s disease, group homes

Group home care
Dementia Group Home Models

<table>
<thead>
<tr>
<th>“Aging-in-place”</th>
<th>“In-place Progression”</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Often only one person affected in home</td>
<td>• Cluster of persons with dementia in GH</td>
</tr>
<tr>
<td>• Person progresses at home through stages of disease (or dementia)</td>
<td>• Specialized staff and environment geared for long term care</td>
</tr>
<tr>
<td>• Supports adapted at each stage</td>
<td>• Tilted toward care in latter stages of Alzheimer’s disease (or other dementias)</td>
</tr>
</tbody>
</table>

**General Findings**

<table>
<thead>
<tr>
<th>“Aging-in-place”</th>
<th>“In-place Progression”</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Most prevalent</td>
<td>• Mostly occurs in agencies with multiple homes</td>
</tr>
<tr>
<td>• Case-by-case approaches - agencies test how they can cope with presentation of dementia</td>
<td>• Agencies use both “purpose built housing” and “adapted housing” with dementia capable designs – development reactive</td>
</tr>
<tr>
<td>• Minimal additional resources as dementia progresses - commitment to continued care</td>
<td>• Special staff preparation or training variable</td>
</tr>
<tr>
<td>• Unfocussed staff training and program &amp; environmental accommodations</td>
<td>• No long-term tests of model</td>
</tr>
<tr>
<td>• Ripple effect on housemates w/o DAT</td>
<td>• Easier to cost out and secure resources</td>
</tr>
</tbody>
</table>

International Sample of Group Homes for People with Dementia
**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 SEK398,712

**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
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

Mid = mid-level
What to do to provide feasible and quality “dementia capable” care in small group homes?

• Staff need to be trained and aware of warning signs for changing capabilities and possess an elevated “index of suspicion”
• Buildings should consider the special conditions and needs of residents with dementia (e.g., control for problems resulting from memory loss, disorientation, & wandering, while incorporating cues & familiarity)
• Individual home planning needs to account for stage-specific changes in decline of skills and presentation of aggravating behaviors
• Long-term planning needs to accommodate changes in character of home from ambulatory care to non-ambulatory care as disease progresses
Some concluding points with regard to generic dementia community care

• Small group homes seem like practical solutions to the desire of health officials and families for affordable neighborhood care
• Staff-to-resident ratios need to be stage dependent – e.g., more staff assigned with mid-stage ambulatory residents
• Staff expertise needs to be associated with stage of care
  • With ambulatory residents – staff capable of engaging residual memories and capabilities, providing socialization and diversionary activities
  • With non-ambulatory, late-stage residents – staff capable of providing basic nursing care and careful attention to personal needs
Planning and preparing for assistance to carers and people with ID
‘What if’ scenarios

• What would we do... if we knew exactly who would show dementia and when?
• How would we maximize cooperation among different sectors?
• How would we construct our housing and activity settings?
• How would we train and equip staff to maximize resources and efforts?
• How would we change diets and risk exposure to minimize chance of dementia?

1. Biomarkers would tell us who had the precursors to clinical dementia
2. In a perfect world, there would be synergy among government and NGOs re: dementia care
3. Housing would use universal design and be dementia capable
4. NGOs would have full levels of staff and supports to sustain dementia-affected persons with ID at home
5. Prevention efforts could be incorporated into lifespan activities (nutrition & wellness)
Potential New Findings

“...biomarker changes do seem to occur at least 10 years, maybe 20 years before the age of onset of symptoms”

“In medications are to be effective they must be taken many years earlier than currently – before symptoms even begin to appear...”

“.... If drugs could be given sooner, tailored to specific biological changes, or biomarkers, in the brain, treatment, or even prevention, might be more successful”
Early Detection of Alzheimer's

Scientists are making steady gains toward developing tests that can predict whether patients with mild cognitive difficulties or even no symptoms at all are likely to progress to full-blown Alzheimer's disease. The latest research, published this week in the Archives of Neurology, a journal of the American Medical Association, found that a test of spinal fluid performed exceptionally well in identifying patients with Alzheimer's or on the way to developing it.

The study, led by Belgian and American researchers, found that certain biological markers in spinal fluid provided a "signature" that was able to identify 94 percent of a group of Alzheimer's patients whose disease was confirmed by autopsies.

It also identified every single patient in a group with mild cognitive impairment who went on to develop Alzheimer's within five years.

Although there is no cure as yet, knowing who has Alzheimer's or is destined to get it would be highly useful. An accurate test could distinguish patients with advanced illness who were wrongly diagnosed with Alzheimer's and whose disease might actually be treatable.

And it might identify patients at the very earliest stages of Alzheimer's before it becomes symptomatic, allowing scientists to study how the disease progresses and perhaps find drugs to slow or halt the process.

Spinal taps, which require inserting a needle into the spinal area and withdrawing a small amount of fluid, have drawbacks.

Many doctors and patients are nervous about the procedure, which they fear will be painful and cause headaches or infections. Many are expected to prefer brain scans that can show the telltale plaques that are characteristic of Alzheimer's and have shown much promise in recent studies. The long-term goal, assuming effective drugs can be developed to prevent or slow the disease, would be screening programs that can identify those likely to be helped as early as possible.

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<thead>
<tr>
<th></th>
<th>Early stage</th>
<th>Mid stage</th>
<th>Late stage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Administrative</strong></td>
<td>Plan forward for more focused care with progression; lock in funding to cover extended care</td>
<td>Set up specialty care programs or support teams for in-home care; augment staffing</td>
<td>Adjustments to staff and physical features of home</td>
</tr>
<tr>
<td><strong>Clinical</strong></td>
<td>Early screening and diagnostics; medical oversight</td>
<td>Periodic reassessments and follow-up; check for coincident conditions</td>
<td>Nursing care evaluations; medical oversight</td>
</tr>
<tr>
<td><strong>Programmatic</strong></td>
<td>Introduce memory aids; watch for changes in function; reduce options</td>
<td>Closer supervision; specialized care; wandering controls; memory exercise; move to specialty homes</td>
<td>Careful attention to avoid dehydration and malnutrition; avoid ‘bed sores’; introduce hospice care</td>
</tr>
</tbody>
</table>
Preparing for dementia

• Short term planning
  – Institute behavior screening to capture baseline
  – 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
Preparing 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
  – Need specialized housing and care programs for those progressing to ‘middle-stage’ and beyond
  – Cost factors a consideration; budgeting for increased staffing and supervision
  – Staffing for nursing type care to those in late or end stage
Training/staff education

- Aging
- Diseases and conditions of older age
- Medications
- Dementias
  - Alzheimer's, vascular, fronto-temporal, Lewy body
- Care management
- Communication & activities
- Environmental adaptations
Need for Geriatricians

Basic geriatric knowledge is preventive medicine

Need for medical students to become acquainted with minimum understanding of differences of patients in older age...

The ‘Don’t kill Granny’ list... know how to:
- Prescribe medications
- Assess patients’ abilities to care for themselves
- Recognize atypical presentations of common diseases
- Prevent falls
- Recognize hazards of hospitalization
- Decide on treatments based on elderly patients’ prognosis and personal preferences

The 2008 Report of the Institute of Medicine – recommended that all licensed health care professionals demonstrate such competencies in the care of older adults

Preventing, addressing, helping, attacking dementia and adults with ID/DS

• Knowing what happens with advancing age
• Knowing the symptoms of dementia
• Planning ahead for care options and financial supports
• Setting up ‘specialized dementia care’ group homes
• Using helpful resources, like the Alzheimer’s organizations
• Increasing our research effort in this area, both in the biological basis and in psycho-social supports
Conclusions: Helping people with ID who are aging and at risk of dementia

• Know what happens with advancing age
• Know the symptoms of dementia
• Plan ahead for care options and financial supports
• Best bet can be ‘specialized dementia care’ group home
• Use helpful resources like the Alzheimer’s Association
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For information on ID and dementia:
http://www.rrtcadd.org/TA/Dementia_Care/Resources/Info.html

For access to our University website:
http://www.rrtcadd.org/index.html