Preparing Minnesota for Alzheimer’s: Budgetary, Social and Personal Impacts

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Presented at American Society on Aging Conference
March 31, 2012
• Project is sponsored by MN Department of Human Services in partnership with
  – Minnesota Board on Aging
  – MN Department of Health
  – Several other state agencies
• Purpose is to prepare Minnesota for the age wave of baby boomers and a permanent shift in the age of our state’s population
Outline of Presentation

Minnesota’s Plan for Alzheimer’s

• Process used for development of plan
• Issues related to Alzheimer’s
• Policy directions and recommendations
• Next steps for implementing recommendations
• National Alzheimer’s Association encouraged state legislatures to create state plans
• Alzheimer’s Association Minnesota—North Dakota led successful effort for legislation calling for a state plan
• Once enacted, the Minnesota Board on Aging and the Association partnered to meet legislative requirements
• Created the Alzheimer’s Disease Working Group
• Worked from August 2009 through 2010
• Group included many national experts
State Role in Alzheimer’s

• Minnesota Board on Aging (state unit on aging) is the state agency with greatest role in services for persons with Alzheimer’s in the community

• Department of Human Services is the largest funder of nursing facility and assisted living care for persons with dementia including Alzheimer’s
Vision of Person-Centered Care

Prepared communities

High quality health and long-term care

Early detection and diagnosis

Persons with Alzheimer’s and their caregivers receive support and care
Definitions and Risks

• Most common symptom is gradual decline in the ability to remember new information.

• Risk factors include:
  – Age
  – Genetics
  – Mild cognitive impairment
  – Other chronic conditions
Projected Number of Older Persons in Minnesota with Alzheimer’s Disease by Age Group: 2000 - 2050

2000: 88,000
2010: 90,000
2020: 102,000
2030: 142,000
2040: 197,700
2050: 219,500

65 - 74
75 - 84
85+
Total
Who are the Caregivers?

- In 2009, there were 200,000 individuals out of a total population of 5,270,000 that provided care for an adult with dementia including Alzheimer’s.
- They provide 223 million hours of unpaid care each year.
- These hours are valued at $2.6 billion per year.
- Growing numbers of those with dementia are living alone in the community without caregivers nearby.
- The number of caregivers is on the rise, as more boomers care for their frail elderly parents.
Characteristics of Caregivers in Minnesota (in percents)

- Parental caregiver: 5.8%, 23.9%
- Spousal caregiver: 5.9%, 21.8%
- Retired: 11.5%, 27.4%
- Living with recipient: 13.4%, 56.1%
- 60+: 16.7%, 33.6%
- Long-term (6+ years): 19.6%, 26%
- Physically limited: 26%, 31.4%
- Female: 57.3%, 75.6%
- Employed: 59.3%, 79.3%
Economic Effects of Caregiving

• A recent Evercare survey reported that caregivers spent an average of $5,531 per year on “out-of-pocket” expenses for the care recipient, such as food, prescription drugs, co-pays, and other similar expenses.

• Nationally, 27% of caregivers report feeling a strong financial hardship (defined as a rating of 4 to 5 on a 5-point scale), as a result of caregiving.

• 51% said the economic downturn had increased their stress about being able to care for their relative or close friend.
### Impact of Parental Caregiving on Wages

This does not include loss of private pensions or private savings.

**Women**

<table>
<thead>
<tr>
<th></th>
<th>Reduced Hours Working</th>
<th>Labor Force Exit</th>
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</thead>
<tbody>
<tr>
<td>Lost wages</td>
<td>$120,616</td>
<td>$142,693</td>
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<tr>
<td>Lost Social Security Benefits</td>
<td>$64,433</td>
<td>$131,351</td>
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<tr>
<td>Total Impact</td>
<td>$185,049</td>
<td>$274,044</td>
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</table>

**Men**

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<tr>
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<th>Reduced Hours Working</th>
<th>Labor Force Exit</th>
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<tbody>
<tr>
<td>Lost wages</td>
<td>$126,934</td>
<td>$89,107</td>
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<tr>
<td>Lost Social Security Benefits</td>
<td>$37,923</td>
<td>$144,609</td>
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<tr>
<td>Total Impact</td>
<td>$164,857</td>
<td>$233,716</td>
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Source: MetLife Study on Effects of Caregiving
## Health and Social Effects of Caregiving in Minnesota

<table>
<thead>
<tr>
<th>Reported Concern</th>
<th>Caregivers</th>
<th>Non-Caregivers</th>
</tr>
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<tbody>
<tr>
<td>Self-reported health status is fair or poor</td>
<td>12.0%</td>
<td>11.2%</td>
</tr>
<tr>
<td>Limitations in activity</td>
<td>26.7%</td>
<td>21.5%</td>
</tr>
<tr>
<td>Creates stress</td>
<td>27.0%</td>
<td>NA</td>
</tr>
<tr>
<td>Not enough time for self and family</td>
<td>23.0%</td>
<td>NA</td>
</tr>
<tr>
<td>Financial burdens</td>
<td>7.0%</td>
<td>NA</td>
</tr>
<tr>
<td>Interferes with work</td>
<td>6.0%</td>
<td>NA</td>
</tr>
<tr>
<td>Interferes with family relationships</td>
<td>5.0%</td>
<td>NA</td>
</tr>
<tr>
<td>Aggravates health problems</td>
<td>2.0%</td>
<td>NA</td>
</tr>
</tbody>
</table>

(Stresses of caring for someone with dementia are greater across these and other concerns)

Source: Minnesota BBRFSS, 2009
When family caregiving decreases, public costs increase.

For every 1% decline in family caregiving, it costs the public sector an additional $30 million annually.

Supporting families makes sense for social and fiscal reasons.
Capacity of Long-Term Care System

• Minnesota has a wealth of programs to serve older persons, including those with Alzheimer’s and their caregivers
• Most are funded through MA or Older Americans Act

Gaps
• Affordable respite, escorted transportation
• Affordable housing with health services and supervision
• Nursing facilities that provide dementia units
• Geriatric psychiatry units that serve as a short-term crisis inpatient unit for individuals with difficult behaviors
• Minnesota has many programs but they are fragmented, and hard for consumers to navigate
Alzheimer's Disease Working Group

RECOMMENDATIONS
Insights from Policy Work

• Legislative language focused on the assessing adequacy of the long-term care system to provide care for those with Alzheimer's.

• Assessment found that Minnesota was doing a relatively good job in provision of good care and a range of options for those with Alzheimer's.

• Thus, working group focused on medical care improvements in its recommendations.
1. Identify Alzheimer's early

- Lack of diagnosis of early stage Alzheimer's
- Providers unaware of benefits of early identification
- Individuals with the disease and their families appreciate the extra time to plan and spend time together

Assess the cognitive health of all Medicare patients at the annual wellness visit beginning in 2011
2. Use “health care home” for Alzheimer’s care

• Best practice for Alzheimer's care is now emerging
• Lack of funding stream for effective care models
• Lack of attention to patient needs across the whole care and life spectrum

Once identified, cognitive impairment should become an organizing principles for all other preventive and medical care of the patient
3. Achieve quality and competence in dementia care

- Few quality standards for dementia care in the medical system
- No specific quality standards for dementia care in long-term care
- Families don’t get enough help of the right kind to access quality of services needed

Evaluation/report card information for families and more training of formal caregivers in dementia care
4. Prepare our communities and the public

- Communities need guidance in how to prepare for Alzheimer’s and impact on their residents
- Need for community level supports for caregivers is critical

Create list of elements of a “dementia competent” community and action kits for communities to use to raise public awareness
5. Train medical providers in dementia care

• Inadequate dementia training of medical providers who serve older persons
• For example, University of Minnesota medical school provides two hours of training on dementia in four-year curriculum for all future physicians

Mandate inclusion of dementia training in all training and continuing education requirements
6. Pursue cost-savings policies

- Need to publicize the true and total cost of Alzheimer’s disease
- Need to intensify our search for strategies that save money

Replicate and expand evidence-based models that are proven and save money in treatment of persons with Alzheimer’s
7. Intensify research and surveillance

- Need for more volunteers to participate in Alzheimer’s research
- Need for more accurate prevalence data in Minnesota
- Need to expand and sustain research

Create web-based dementia clearing house and resource center to serve persons concerned about Alzheimer’s and other dementias
PMA 2020 – Next Steps

• Prepare Minnesota for Alzheimer’s 2020 (PMA 2020) is a state-wide, collaborative initiative seeking transformative change in the State’s medical and long-term care systems and communities to better support individuals with Alzheimer’s disease and their families

• http://collectiveactionlab.com/?q=node/61
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https://edocs.dhs.state.mn.us/lfsserver/Public/DHS-6254C-ENG