Are people with dementia equal in Finnish social security system?

2 October 2010 Luxemburg

Henna Nikumaa
Alzheimer Society of Finland

henna.nikumaa@muistiliitto.fi
Alzheimer Society of Finland

- Established in 1988 to provide help and assistance for people with dementing illness and their caregivers
- A non-profit organization which is mainly funded by the Finnish Slot Machine Association
- In Finland 120,000 persons with dementia
  - 7,000 – 10,000 working age people with dementia
  - 13,000 new cases every year
The Society and the local associations

• Central Office in Helsinki, the capital city of Finland
• 3 District Offices
  • Northern Finland
  • Eastern Finland
  • Western Finland
• Central Society for 42 member associations around the country
  • 10,000 members
  • approximately 140 employees
The Study

The primary aim was to clarify how and if equality is achieved in the availability of Finnish social security

- 157 professionals interviewed using a questionnaire
- 8 people with dementing illness interviewed individually
- 4 caregivers interviewed individually to give supplement information
Finnish Social Security System

- The Finnish Constitution guarantees the right to social security and necessary income security for all people living in Finland
- Public and very extensive system
- Funded primarily by taxation
- Mainly responsibility of government and municipalities – nowadays also the private and the third sector play an important role
Various forms of support

“It is almost like a jungle”
“I didn’t understand anything about those application forms”
“It is almost easier to not apply”

→ very difficult to master even for professionals

Eloniemi-Sulkava et al. 2006
Applying social security (N=157)

- Very difficult: 9%
- Difficult: 36%
- Neither easy nor difficult: 37%
- Easy: 16%
- Very easy: 2%
Person's possibility to express his/her will when applying social security (N=157)

Person's opinion or will is taken into consideration when applying social security (N=156)
How equality is achieved in availability of social security when people with dementing illness and other diagnostic groups are compared?
Certain forms of social security are not equally available.

<table>
<thead>
<tr>
<th>FORM OF SOCIAL SECURITY</th>
<th>Badly/very badly</th>
<th>Well/very well</th>
</tr>
</thead>
<tbody>
<tr>
<td>transportation service</td>
<td>46 %</td>
<td>22 %</td>
</tr>
<tr>
<td>adaptation training</td>
<td>43 %</td>
<td>17 %</td>
</tr>
<tr>
<td>other rehabilitative support</td>
<td>46 %</td>
<td>9 %</td>
</tr>
</tbody>
</table>
Why?

1. Social security legislation is interpreted mostly through the applicant’s physical ability
   
   cognitive impairment ↔ physical disability
   
   dementia ↔ invalidity

2. Dementia is still too often considered a part of normal aging – lack of knowledge

   “It is almost if you had any other disease than my Alzheimer’s, you’ll get the social security you need”
Conclusions

• People with dementia are not completely equal in the availability of public social security
• Finnish social security legislation is interpreted too narrowly through a person’s physical ability
• Dementia is not seen as caused by neurological disease
• People with dementia feel they are considered unworthy of services given to people with physical disability or visible condition
Thank you for your attention!