

Creating Excellence in Dementia Care: Ireland in an International Comparative Perspective

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Overview

- Background and context
- Population ageing and prevalence of dementia
- Economic and social costs of dementia
- Community care
- Residential long-stay care
- Concluding remarks

A worldwide phenomenon

- **Worldwide** 35.6 million people over 60 years with dementia in 2010
- Numbers to **double every 20 years** to 65.7 million by 2030 and to 115.4 million by 2050 (Prince, 2009)
- **Worldwide** cost of dementia = US\$604bn (Wimo and Prince, 2010) greater than cancer, heart disease and stroke care combined
- **Western Europe has highest** number of people with dementia (Ferri *et al.*, 2005; Prince, 2009)
- Approx. **7 million** Western Europeans with dementia in 2010
- To increase to 10m in 2030 and 13.4m in 2050 (Prince, 2009)
- Costs of dementia in **Europe** = €160bn (Wimo et al., 2011)

Dementia is a stigmatizing condition

Despite the growing impact globally, a lack of understanding of dementia contributes to fears and to stigmatization. For those who are living with dementia (both the person and their family), the stigma contributes to social isolation and to delays in seeking diagnosis and help.

(WHO, 2012)

International policy backdrop

- **United Nations Declaration on Non-Communicable Disease** recognises dementia as an important cause of morbidity and need for provision of equitable access to effective programmes and health-care interventions (UN, 2011)
- **World Health Organization:** ‘Dementia should be considered a part of the public health agenda in all countries’ (WHO, 2012)
- **European Initiative on AD and other dementias (EC, 2009)**
 - Prevention and early diagnosis
 - Improve understanding of dementia (incl. JPND)
 - Exchange of good practices
 - Respecting the rights of people with dementia

National responses to dementia



Ireland's Response to Dementia

Ministerial
announcement of
Government
commitment to
develop a National
Dementia Strategy
(Apr 2010)



Programme for Government

“We will develop a national dementia strategy by 2013 to increase **awareness**, ensure **early diagnosis and intervention** and the development of **enhanced community-based services**. This Strategy will be implemented over five years.”

(Programme for Government 2011-2016)

Evidence-base to inform National Dementia Strategy for Ireland

Objectives:

- provide new estimates of current and future dementia prevalence rates
- specify the main costs of dementia
- review current service availability
- review best practice in dementia care locally and internationally

Collaboration between researchers:

Living with Dementia programme in TCD

Irish Centre for Social Gerontology in NUIG

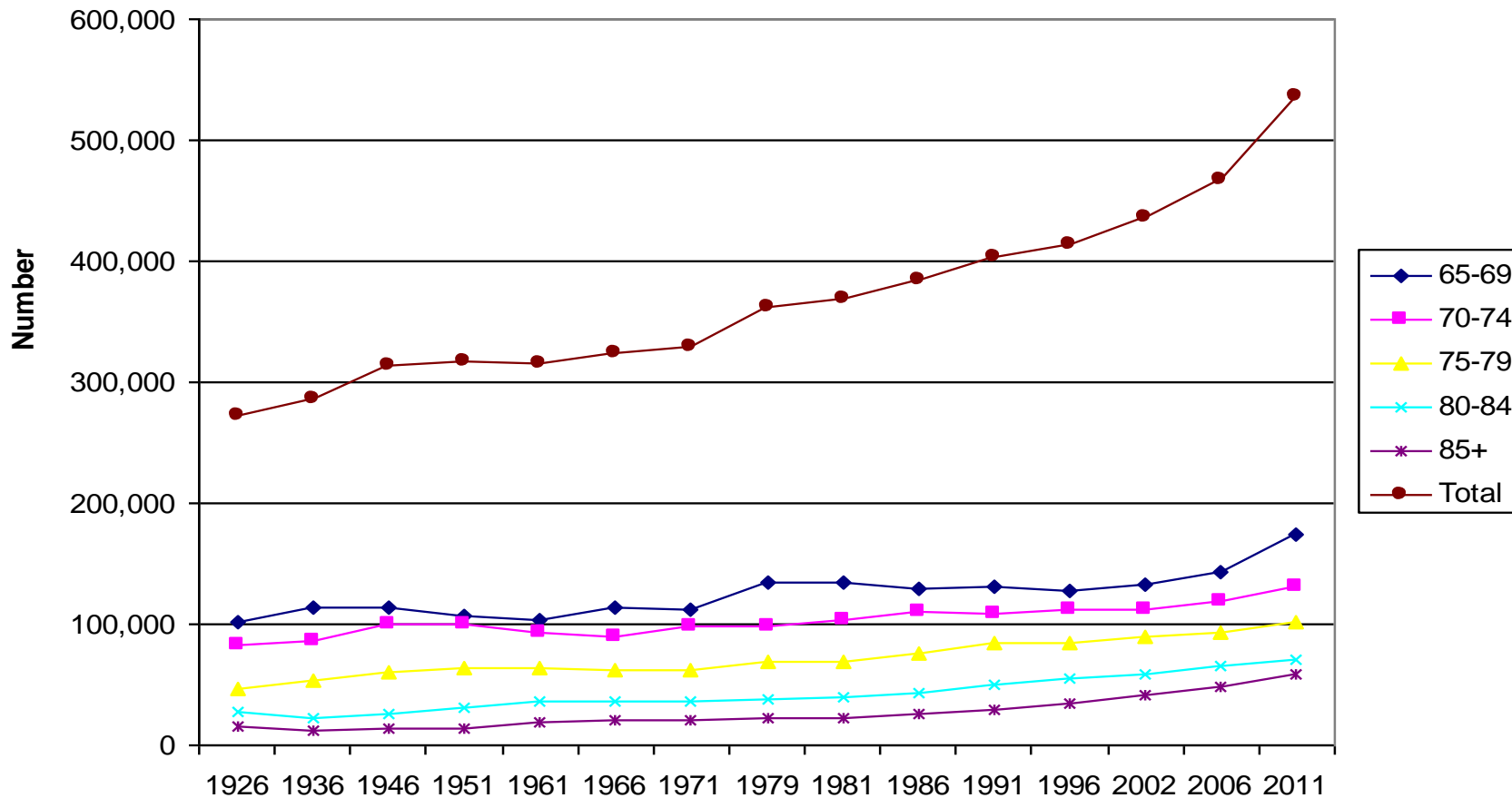


CREATING
EXCELLENCE IN
DEMENTIA CARE

A Research Review for Ireland's
National Dementia Strategy

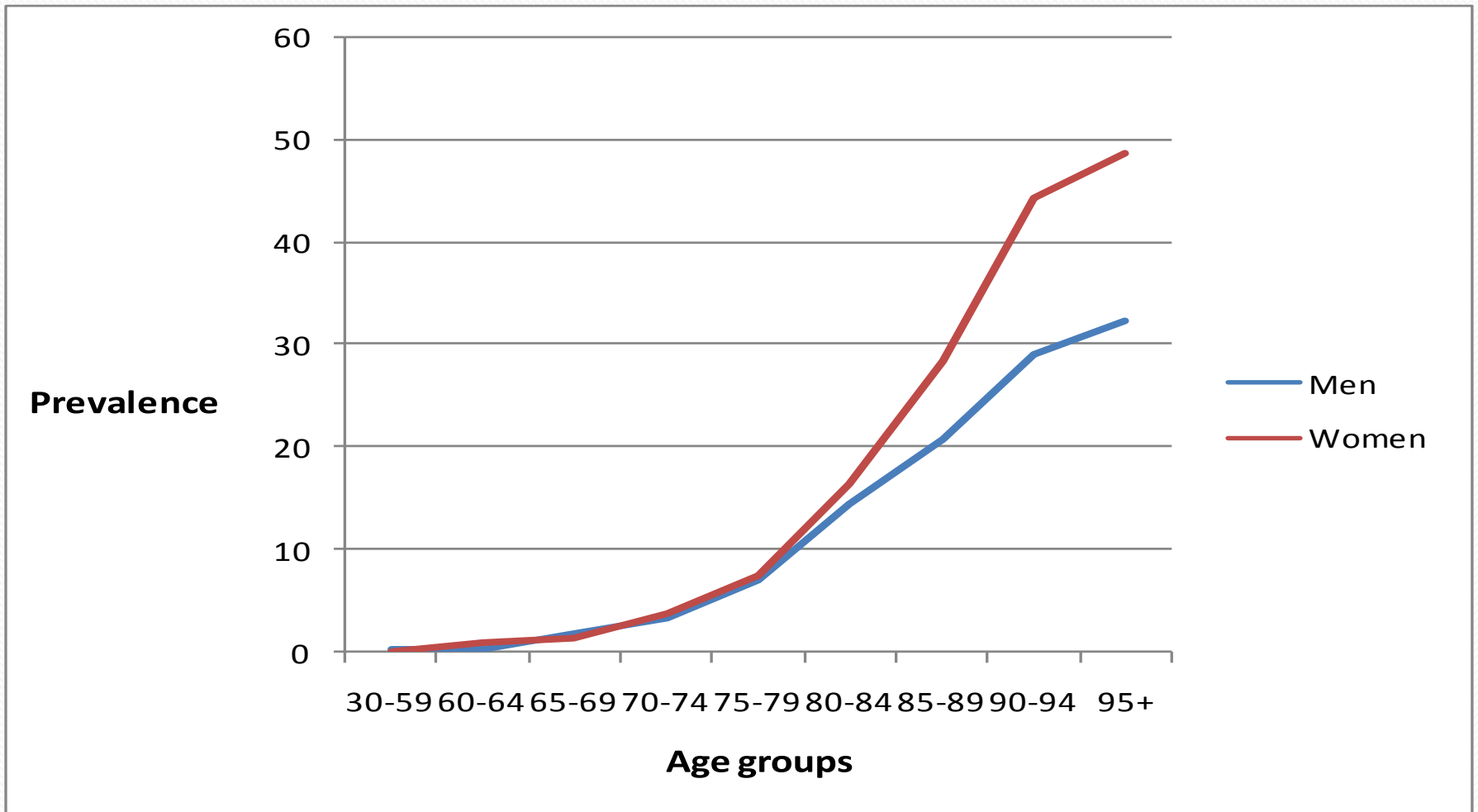
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Persons aged 65 years and over in Ireland (1926-2011)



Source: Table 1A, CSO (2012) *Census 2011 Profile 2: Younger and Older*, Stationary Office, Dublin.

EuroCoDe age/gender-specific prevalence rates for dementia



Estimated number of people with dementia by age groups and gender in Ireland, 2006

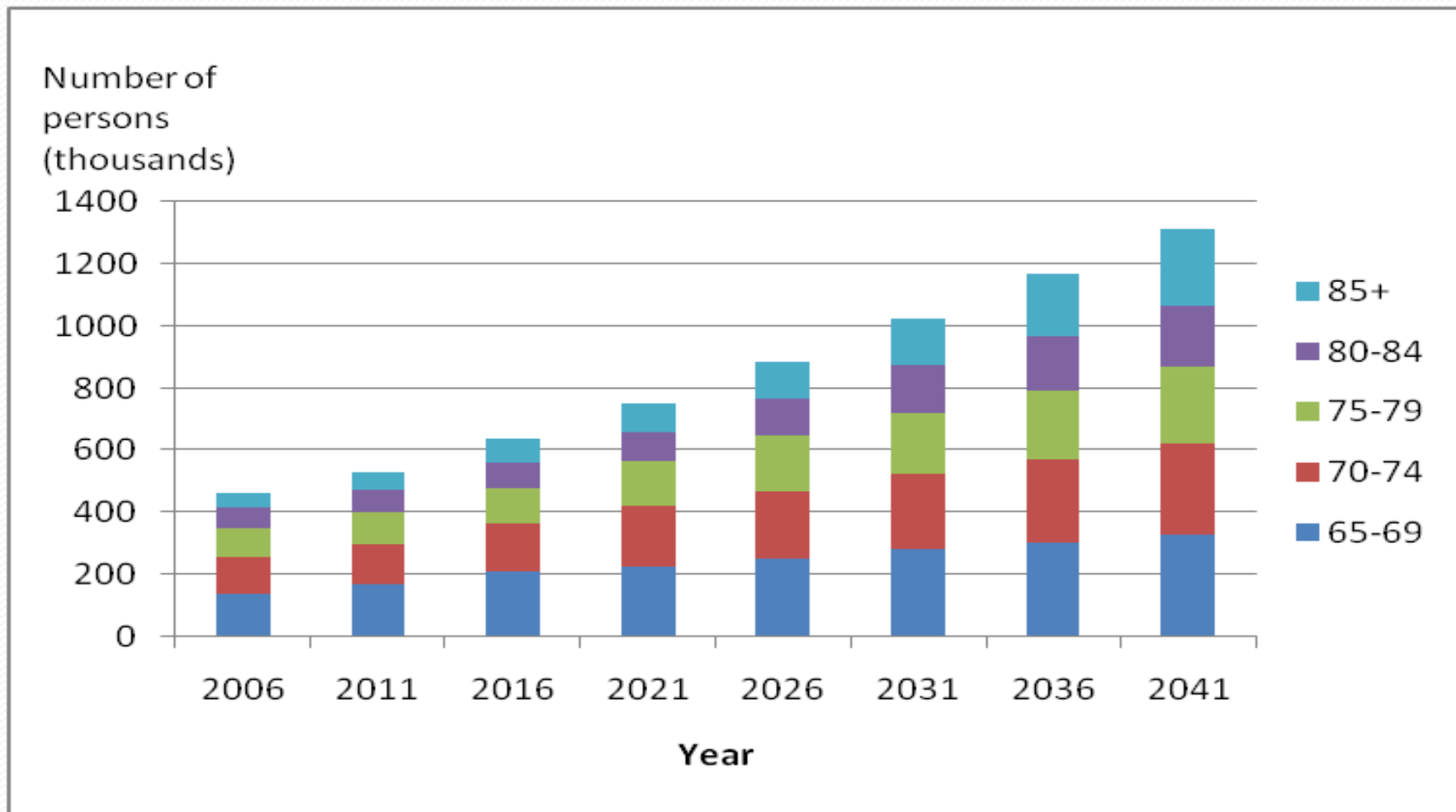
| Age range | Population† | | | Estimated persons with dementia? | | |
|-----------|-------------|-----------|-----------|----------------------------------|------------------|--------|
| | Men | Women | Total | Men | Women | Total |
| 30-59^ | 869,212 | 850,724 | 1,719,936 | 1,738 ¹ | 851 ¹ | 2,589 |
| 60-64 | 91,561 | 90,166 | 181,727 | 183 | 811 | 994 |
| 65-69 | 70,895 | 72,501 | 143,396 | 1,276 | 1,015 | 2,291 |
| 70-74 | 56,540 | 62,612 | 119,152 | 1,809 | 2,379 | 4,188 |
| 75-79 | 40,121 | 52,345 | 92,466 | 2,808 | 3,978 | 6,786 |
| 80-84 | 24,694 | 40,190 | 64,884 | 3,581 | 6,591 | 10,172 |
| 85-89 | 11,021 | 22,281 | 33,302 | 2,303 | 6,350 | 8,653 |
| 90-94 | 3,231 | 8,814 | 12,045 | 943 | 3,913 | 4,856 |
| 95+ | 593 | 2,088 | 2,681 | 192 | 1,019 | 1,211 |
| Total | 1,167,868 | 1,201,721 | 2,369,589 | 14,833 | 26,907 | 41,740 |

Source:

† CSO,¹³ Tables 2B and 2C, pp. 16-17 and Table 5, p. 28.

? New prevalence figures generated by applying EuroCoDe age-related prevalence rates¹⁰ applied to Census 2006 data. Note: ^ As EuroCoDe does not specify prevalence rates for 30-59 age group, EURODEM dementia prevalence rates for this age group by gender as reported by Hofman et al.¹⁵ were used instead.

Actual and Projected Population of Older People in Ireland by Age Group, 2006-2041 (MOF2) (Source: CSO, 2008)



Projections of dementia

- **Expected increase** in numbers of people with dementia over next 30 years
- Numbers estimated to almost **double every 20 years** (from 42,000 in 2006 to 82,000 in 2026)
- By **2041**, it is estimated that there will be over 140,000 people with dementia in Ireland
- Projections of dementia do have **limitations!!**

Prevalence of dementia: Ireland in comparative perspective

| | Ireland | Norway | UK |
|------------------------|----------------|---------------|-----------|
| Population size | 4.5million | 4.8million | 62million |
| 65 and over (%) | 11.7% | 14.9% | 16.4% |
| PwD | 42,000 | 66,000 | 750,000 |

Ireland is now and is expected to remain a country with one of the youngest populations in Europe

The current economic constraints makes it unlikely that a population-based epidemiological study will be undertaken in Ireland in the foreseeable future

People with dementia across care settings in Ireland

| Care Setting | Number of people with dementia | Proportion of people with dementia |
|----------------------------|--------------------------------|------------------------------------|
| Community | 26,104 | 63% |
| Acute Care | 644 | 2% |
| Psychiatric care | 456 | 1% |
| Residential long-stay care | 14,266 | 34% |
| All | 41,470 | 100% |

Economic and social costs of dementia in Ireland

Dementia in Ireland (2010) is costly: €1.69bn

Includes:

| | | |
|---------------------------------|--------------|-----|
| • Informal care | €807 million | 48% |
| • Formal health/social services | €88 million | 9% |
| • Hospitalisation | €21 million | 1% |
| • Residential long-stay care | €731 million | 43% |

Average cost estimated at €40,500 per person per annum

Costs in Ireland comparable to other countries

- Costs of dementia in Ireland broadly in line with those from other international studies, e.g. €40,500 (Ireland), €36,000 (Europe), over £25,000 (UK) per person per annum
- Distribution of dementia-related costs across sectors also in line with those reported in other studies, e.g. informal costs accounted for 48% (Ireland), 55% (UK) and 56% (Europe) of total costs

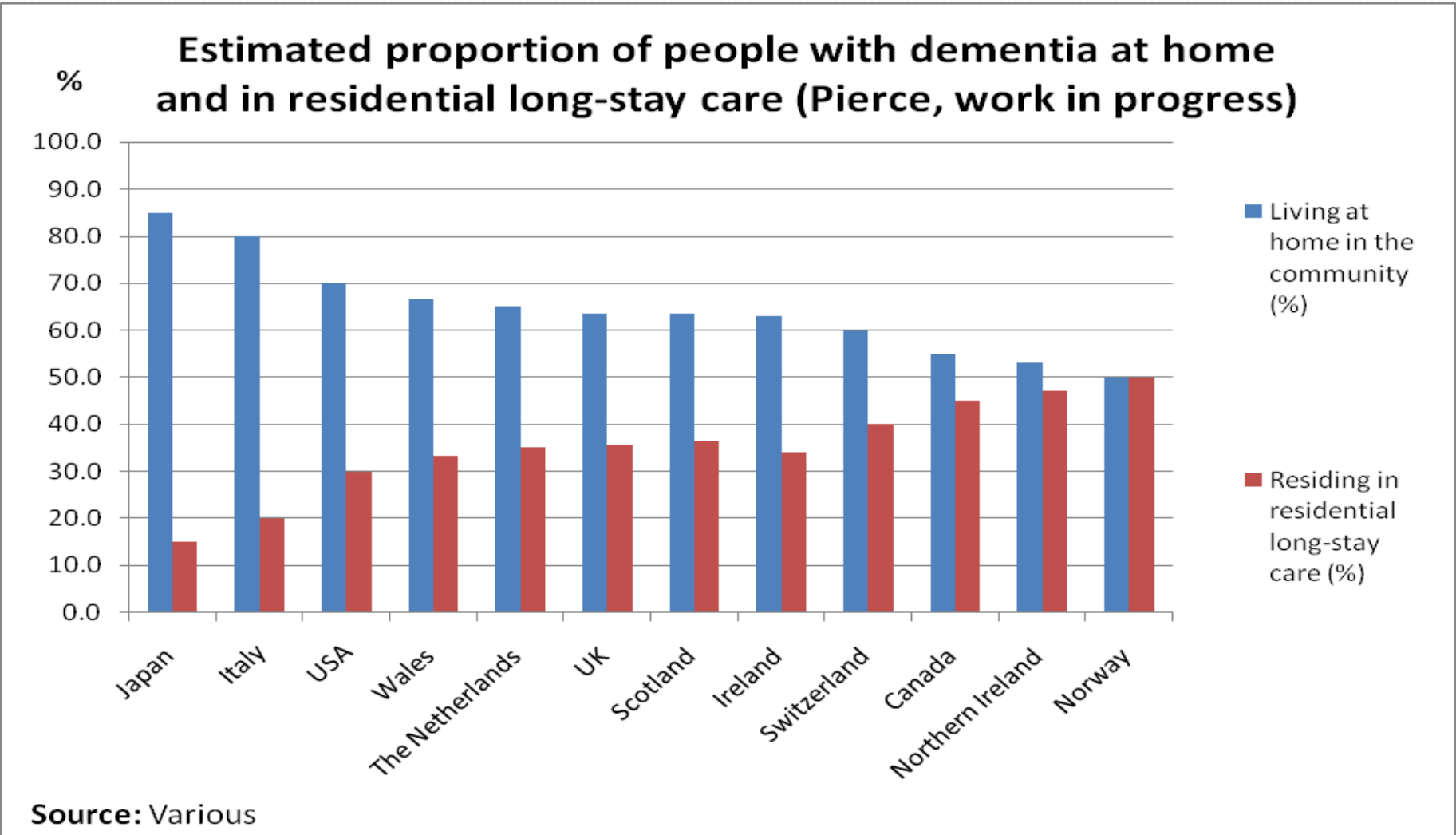
Government Policy

Stated over-riding objective of government policy in Ireland for older people and for people with dementia is to facilitate them to remain in their own home for as long as possible and practicable (Working Party on Services for the Elderly, 1998)



In Ireland most (about two-thirds) people with dementia living in their own homes in the community (Cahill et al., 2012)

Comparable to several other countries

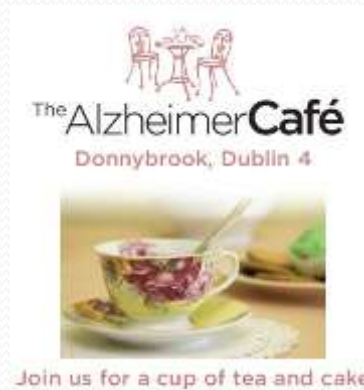


Community care

- In practice, policy and financing of care for older people/dementia biased towards residential care
- Bulk of community care for people with dementia provided by family caregivers with few receiving financial compensation
- No legislative basis for community care services
- Home help, HCPs, day care, in-home respite fragmented, inequitable and under-developed
- Mixed economy of care provision (public, private and voluntary sector)

Innovative and exciting initiatives

- First Alzheimer Café in Ireland



- Reminiscence project



- Genio Dementia Project - Demonstrator Site programme with projects in 4 locations across Ireland (1 in East, 1 In West, 2 in South) Will they change the landscape of community care for people with dementia?

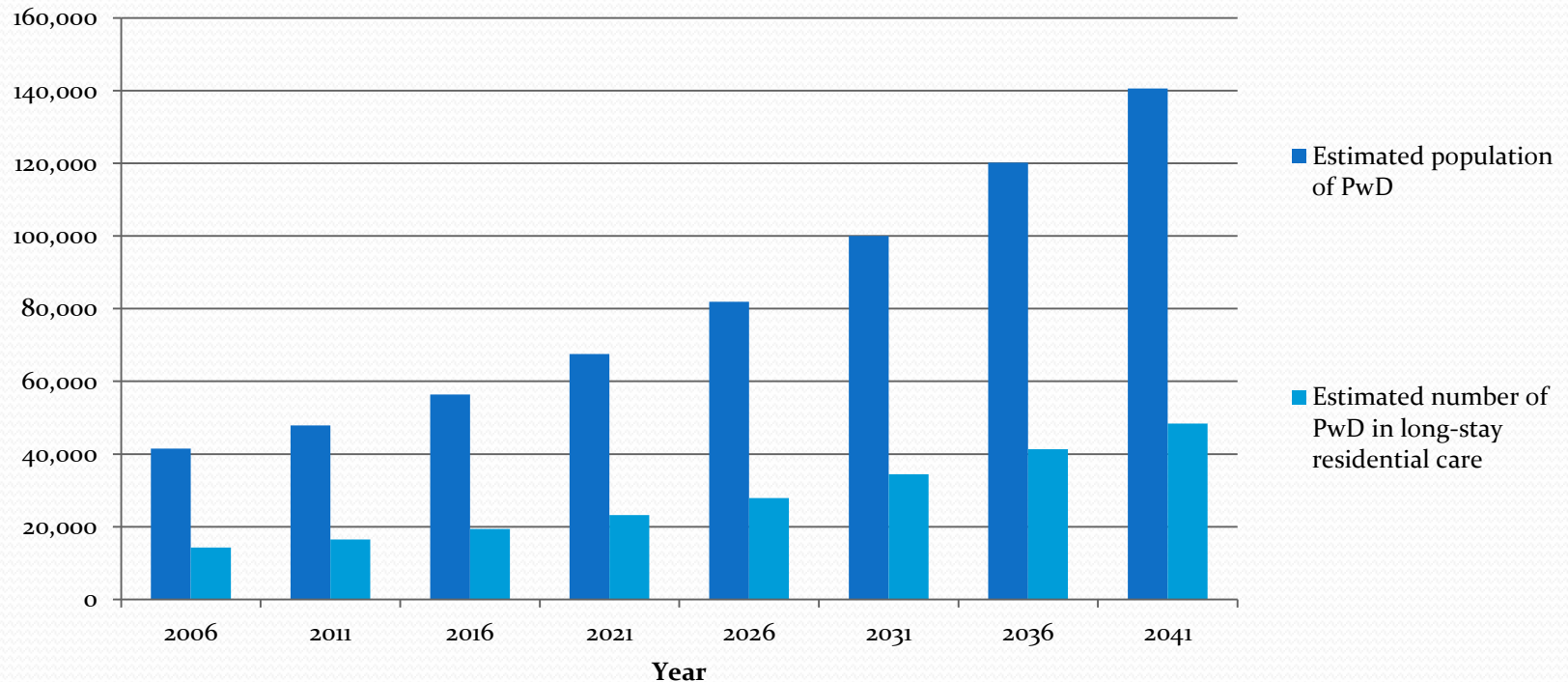
Responses in other countries

- Dementia advisors/co-ordinators, case management (England, Scotland, Wales, France, The Netherlands)
- Specialist interdisciplinary home care teams (France)
- Traditional and innovative short break provision (NI)
- Community care alternatives to hospital admission (Scotland)
- Telecare development (Scotland, France)
- Develop and offer a variety of day programmes (Norway)
- Supplement to HCPs for people with dementia (Australia)

Projections of PwD in Residential Long-Stay Care

Estimated population of people with dementia in long-stay residential care, 2006-2041 (Pierce, 2012)

Number



Policy on long-stay residential care

- Common stated policy objective is to delay admission to residential long-stay care
- Ireland comparable to other countries in this respect

But ...

- Reliable official data on residents with dementia in long-stay care is not available in Ireland
- Estimates for the dementia research review suggest that about 63% of residents of residential long-stay care settings have a dementia (Cahill et al., 2012)
- This is in line with Irish (Cahill et al., 2010) and international research, which suggests that over 50% of residents of long-stay care facilities are people with dementia

Irish Nursing Homes and Dementia



Very few alternative models to the traditional or hotel model across Ireland



Proportion of public and private residential long-stay care units* with SCUs



Source: Cahill et al., 2012

Note: *The majority (approx. 75%) of residential long stay units in Ireland are private (for-profit and not-for-profit).

SCUs for PwD in Ireland

- Few Specialist Care Units in private (21%) and fewer in public (14%) residential long-stay care units
- Units often attached to general hospitals, not always located in close proximity to local community and not usually purposely designed or built
- A minority of PwD with dementia in long-stay care reside in SCUs, facilities that are often two to three times larger than recommended average size (6-8) (Cahill et al., 2012)

Best practice in other countries

- A range of options offered when residential care is required



In small-scale homelike settings



Normalization of daily life with person-centered care as central



Emphasize respect for residents' autonomy and choice
Recognize that challenging behaviours may be an expression of unmet needs
International consensus regarding the features and principles of good design for dementia (Judd, Phippen, Marshall, 1999)

What are other countries doing?

- **Norway:** the principle for residential facilities is 'small is beautiful'
- **The Netherlands:** Emphasis on small-scale, home-like living
- **France:** Adapting residential care for people with dementia and creating specialised care units for people with dementia and challenging behaviours; allocation of ring-fenced resources to achieve this
- **England:** specialist assessment; services to reach into residential care; creating a more therapeutic environment reducing anti-psychotic medication and developing non-pharmacological approaches for managing behavioural problems
- **Scotland:** Common standards of care for dementia



Concluding remarks

- Ireland likely to remain one of the youngest countries in Europe, but rapid population ageing will mean an increase in the future numbers of people with dementia, which is a costly and often stigmatising condition
- Government policy on dementia care requires a stronger commitment to community care and to supporting family caregivers
- Recent announcement of cutbacks to home help services and home care packages is counteractive and makes no economic sense

Concluding remarks (contd)

Challenges for residential long-stay care in Ireland are many.

The **landscape** of residential long-stay care needs to be changed through:

- development of **‘Teaghlach’** or household model of care
- **alternative models of care** along the line of extra care housing
(Convery, 2011)

Need to **create incentives** to appropriately reward the hard work and dedication of many professional staff working with people with dementia across long-term care settings

Ireland does not yet have a national strategy on dementia, although it is promised – lessons can be learned from models and best practices in other countries

Thank you



Acknowledgements

