

Reframing Practice and Policy for People with Dementia in Ireland

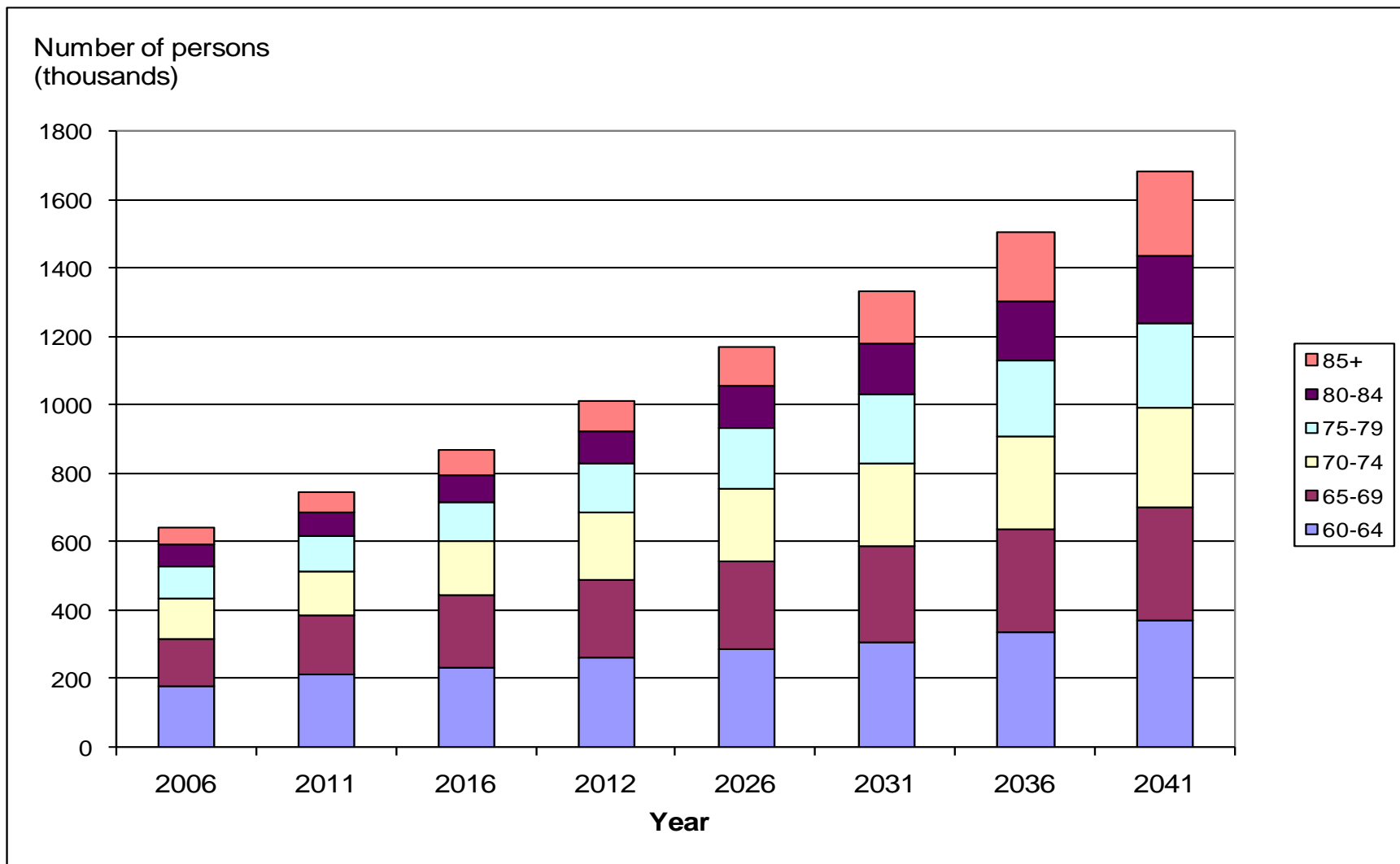
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Dementia in Ireland

- Dementia an ageing problem
- The predicted change in age structure of the population –particularly in the old old, - will significantly influence future dementia prevalence rates
- Great stigma still associated with diagnosis of dementia
- Financial, emotional and social costs of dementia are high
- Public knowledge improving, but attitudes remain largely negative pessimistic and nihilistic
- People with dementia are one of the most vulnerable and invisible groups in Irish society today
- Need for clinical, economic and social discourse

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



Actual number and projected growth in the number of people with dementia in Ireland by age group, 2006-2041 (M0F2) (n)

Age groups	2006	2011	2016	2021	2026	2031	2036	2041
30-59	2,576	2,803	2,967	2,982	2,930	2,869	2,791	2,686
60-64	983	1,193	1,303	1,449	1,592	1,696	1,853	2,024
65-69	2,258	2,734	3,334	3,649	4,069	4,488	4,842	5,304
70-74	4,130	4,542	5,575	6,868	7,576	8,495	9,397	10,141
75-79	6,716	7,378	8,328	10,421	12,992	14,467	16,323	18,178
80-84	10,096	10,924	12,504	14,543	18,632	23,568	26,554	30,301
85+	14,688	18,319	22,392	27,581	34,131	44,464	58,441	71,946
Total	41,447	47,893	56,404	67,493	81,922	100,047	120,201	140,580

Source: CSO (2008) *Population and Labour Force Projections, 2011-2041*, Stationary Office, Dublin, Table 5, p. 42; EuroCoDe (2009) estimates of age/gender-specific prevalence of dementia rates.



Death from Dementia

- Dementia and Alzheimer disease has replaced ischaemic heart diseases as the leading cause of death in England and Wales, accounting for 11.6% of all deaths registered in 2015.
- People are living longer plus improved detection and diagnosis. An updating of the international rules for determining the underlying cause of death is also a factor, accompanied by falls in other causes.



Main costs of dementia

- **Burden of illness estimate has been produced for dementia in Ireland : 1.9 billion**
- **Families bear most of the cost of caring for people with dementia > 50%**
- **Residential care costs also high**
- **Primary care and community care low in comparison**
- **Irish burden has been analysed in comparative context- burden significant relative to other diseases like cancer and heart disease**



Current Realities

- Lack of focus on prevention
- Diagnosis – absence of timely diagnosis
- Many people unaware they have disease
- Too few memory clinics
- Primary care – knowledge, information, pathways
- Community care – fragmented and incomplete
- Acute care – awareness, training, education
- Residential care – focus on instrumental care - weak on personhood and quality of life
- Poor support systems for family carers
- Weak palliative care support

Government Policy

- Stated objective of government policy for people with dementia is to facilitate their continued living at home for as long as possible and practicable



(The Years Ahead, 1988; Shaping a Healthier Future, 1994; A Review of the Years Ahead, 1997; Action Plan on Dementia, 1999; A National Health Strategy, 2001; Dementia Manifesto, 2007; HSE Report on Dementia, 2007; National Dementia Strategy, 2014)



National Dementia Strategy

- Principles – personhood and citizenship
- Intensive home care packages for people with dementia – 500 up to 2018
- Public awareness – Dementia Understand Together Campaign - HSE
- Education and training – GP's and Primary Care system

Other Countries

- *Living Well with Dementia (England)*: comprehensive, address continuum of care from diagnosis to death,— (i) public and professional understandings; (ii) early diagnosis, (iii) treatment and support; (iv) quality care in community, hospital and residential settings
- **France**: ambitious: making dementia a priority, commitment to ring-fenced resources, detailed implementation plan; focuses on a broad range of areas including raising awareness of dementia
- *Making the Most of the Good Days (Norway)*: Focus on 3 areas – Day care, Developing and adapting Nursing Homes; Increased knowledge and skills for all
- **Scotland**: key services delivery areas – Improved post-diagnostic information and support; Improved care in general hospital settings, including alternatives to admission
- **Australia/Canada**: Incorporate a focus on prevention - research, risk reduction, delaying onset of dementia
- **European**: Emerging European themes: origins of ND disease; disease mechanisms and models; disease definitions and diagnosis; developing therapies, preventive strategies and interventions; health care and social care



Current Policy Frame

- Individual
- Biological
- Residential
- Risk
- Deficits
- Exclusion



Counter Policy Frames

- Collective
- Social
- Home
- Capabilities
- Assets
- Inclusion



Practice Implications: Collective

- Making dementia public
- Knowledge for people with dementia
- Knowledge for health professionals
- Combating ageism and prejudice
- Policy and planning
- Prioritising dementia



Practice Implications: Social

- Maintaining identity
- Enabling relationships
- Securing attachments to people and places
- Challenging communities
- Sustaining care relationships
- Replicating good practice



Practice Implications: Home

- Self and identity
- Biography and personality
- Care services
- Autonomy and empowerment
- Giving and receiving
- Funding models



Capabilities

- Stages of the disease
- Younger people with dementia
- Relationships
- Physicality
- Personhood explained



Assets

- Person with dementia as active citizen
- Being and doing
- Time
- Whole families and communities
- Networks, friendships, dignity, respect
- Memory and relationships



Inclusion

- Citizenship
- Rights
- Home
- Visibility
- Acceptance
- Protection
- Resource allocation



Conclusion

- Dementia is the most important ageing question
- Need to mobilise intellectual resources in support of a liberating dementia strategy
- Create awareness and understanding of dementia among the public
- Agree key priorities for resource allocation
- Support the practice of personhood



The Challenge

- Do we have the vision, courage and capacity to imagine and initiate a new paradigm for people with dementia and to recalibrate the National Dementia Strategy to support that new paradigm?