

# Reframing Practice and Policy for People with Dementia in Ireland

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# Centre for Economic and Social Research on Dementia

- Building on 30 years of ageing research
- HRB Leader Award in Dementia
- HRB Applied Partnership Award with HSE
- Research Programme - economics, social care, family care, psychosocial care, personhood, public policy
- Dementia Observatory
- Leadership and capacity-building
- Stakeholder engagement



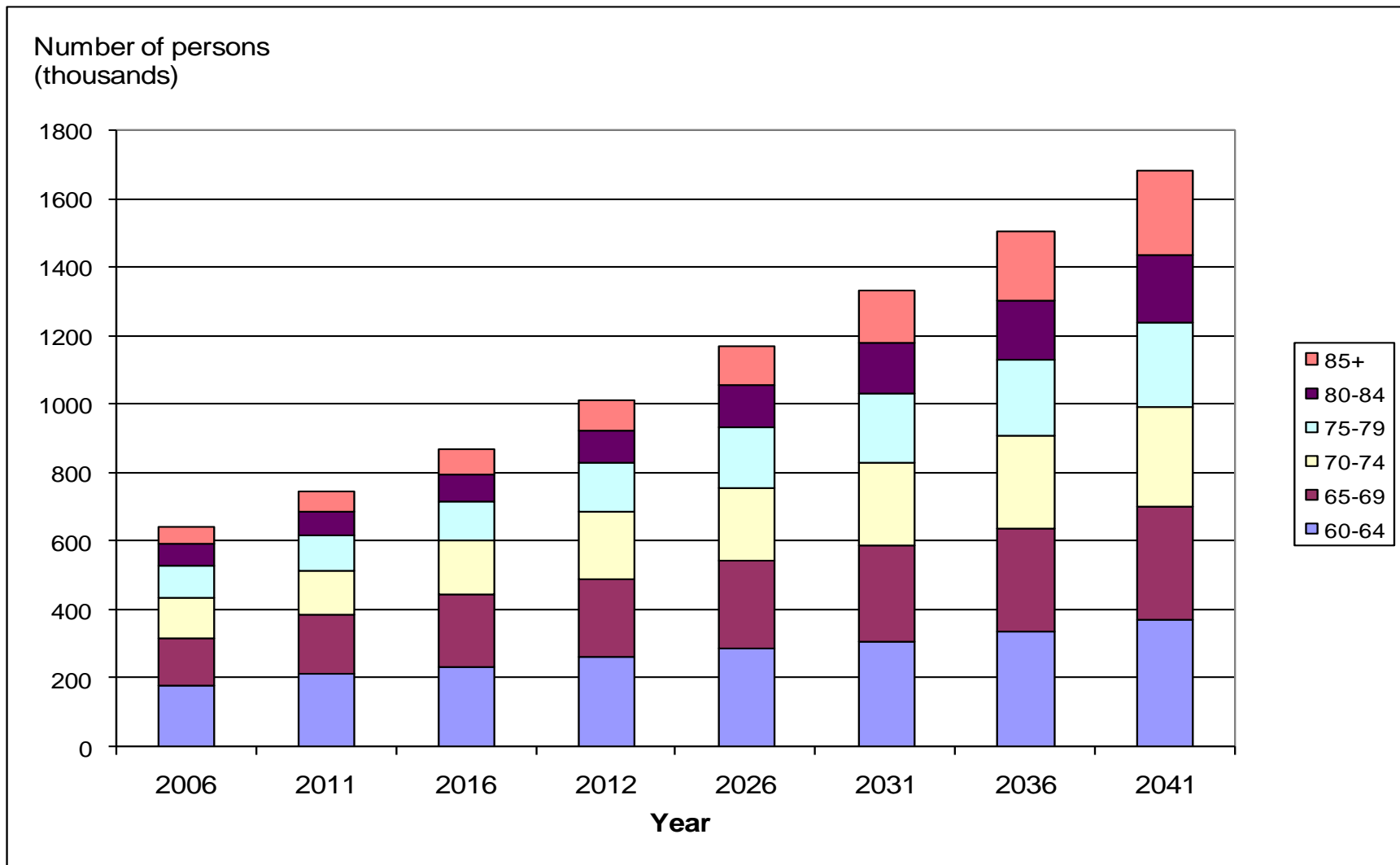
# Introduction

- Dementia is chronic progressive condition largely affecting older people
- Cognitive impairment, memory loss, confusion, disorientation, language difficulties, behaviour
- 47 million people with dementia worldwide; 132 million by 2050; 10 million new cases annually
- 55,000 people with dementia in Ireland
- €2 billion annual cost

# Background

- Dementia an ageing problem
- Stigma still associated with diagnosis of dementia
- Economic and social costs of dementia are high
- Public knowledge improving, but attitudes remain largely negative, pessimistic and nihilistic
- 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)



# Number of People with Dementia

YEAR	Number
2016	55,000
2031	100,000
2041	140,000



# Death from Dementia

- Dementia and Alzheimer disease has replaced ischaemic heart diseases as the leading cause of death in England and Wales - 11.6% of all deaths registered in 2015
- 2,115 Irish deaths from dementia in 2015 – 7% of all deaths – many more die with dementia
- 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

- Cost of Dementia is €2 billion
- Families bear most of the cost - around 50%
- Residential care costs also high
- Primary care and community care low in comparison
- Cost significant relative to other diseases like cancer and heart disease





# Current Realities

- Lack of focus on prevention
- Diagnosis – absence of timely diagnosis
- Community care is patchy
- Co-ordination of care is weak
- Acute care – awareness and training
- Residential care – overly instrumental
- Support weak for family carers e.g. PDS
- End-of-life care needs not being met



# What Do Older People Want?

- Good information
- Choice
- Individualisation of care
- Integrated care
- Family involvement
- Opportunity to live well at home



# 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



# Policy Frames

## Current

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

## Counter

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



## Practice Implications: Collective

- Making dementia public
- Knowledge for people with dementia
- Knowledge for carers
- Knowledge for health professionals
- Combating ageism, stigma and prejudice
- Public financing model
- Prioritising dementia



# Practice Implications: Social

- Maintaining self and identity
- Enabling familial and social relationships
- Securing attachments to people and places
- Challenging communities to care
- Psycho-social interventions



## Practice Implications: Home

- Expanding care supports and services
- New funding model
- Individualising care
- Involving communities
- Autonomy and empowerment
- Vulnerable groups: younger people with dementia; ID and dementia



# Capabilities

- Biography and personality
- Stages of the disease
- Relationships
- Physicality
- Personhood
- Psychosocial interventions





# Assets

- Person with dementia as active citizen
- Participation in decision-making
- Whole families and communities
- Networks, friendships, dignity, respect
- Memory and relationships



# Inclusion

- Citizenship
- Rights
- Visibility
- Protection
- Resource allocation

# Conclusion

- Dementia is the most important ageing question
- Spending nearly 3 times more on residential care than home care
- Need individualised home care solutions
- Personhood costs money
- Carers need more support e.g. PDS
- Need to talk about private/public/family responsibilities
- Need new funding model for enhanced home care provision in Ireland