Translating Dementia Research Findings to Policy and Service Development

CARDI Dementia Colloquium

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A Global Phenomenon

- **Worldwide.** 44 million people with dementia (ADI, 2013). Numbers set to triple by 2050- expected to reach 135 million.


- **Worldwide Dementia** attracts far less funding than cancer stroke and heart disease combined
An Irish Phenomenon

- **In Ireland**, 48,000 people with dementia (Pierce et al, 2014). Numbers set to triple by 2050

- **In Ireland** cost of dementia = Ireland: €1.69billion per annum, equivalent €40,500 per person (Connolly et al, 2013).

- **In Ireland we suspect that dementia** attracts far less funding than cancer stroke and heart disease combined.
UK Number of Researchers compared to Cost to UK Economy by Disease

Data and Analysis Evidence, Thomson Reuters and Dementia, 2010
The status of national dementia strategies in Europe

- Red: Countries with national dementia strategy in place
- Dark red: Countries with government commitment to develop a dementia strategy
- Orange: Countries with other political support to develop a dementia strategy
- Light pink: Countries with no support to develop a dementia strategy

Alzheimer Europe, June 2014
What is the International Policy context for an Irish National Dementia Strategy?
2008: **EC** commitment to combat Neurodegenerative diseases, especially AD

2009: **EP** adopts Written Declaration in fight against AD. Same year European Initiative on AD and other dementias (EC, 2009)

2011: **UN** Declaration on Non-Communicable Disease

2012: **WHO** make dementia part of PH agenda

2013: **G8 Summit** with commitment to finding a cure for AD by 2025

2014: **Glasgow declaration on Dementia** – creation of European Dementia Strategy signed by 26 Alz Europe organisations.
What is the Irish Policy context & how is it informed by research?
A National Dementia Strategy for Ireland

“We will develop a national Alzheimer’s and other dementias strategy by 2013 to increase awareness, ensure early diagnosis and intervention, and development of enhanced community based services. This strategy will be implemented over five years” (p. 38)

Programme for Government 2011-2016
Evidence-base required to inform Dementia Strategy

To:

- provide new estimates of current and future dementia prevalence rates
- estimate the main costs of dementia
- review current service availability
- Report on best practice in dementia care locally and internationally
Evidence base for the Public
Time Lag has meant that new prevalence rates based on 2011 Census Data and estimated future prevalence rates have had to be generated. 

(Pierce, Cahill & O’Shea, 2013: Planning Services for People with Dementia in Ireland: Prevalence and Future Projections of dementia)
47,744 people are currently living with dementia in Ireland.

30,359 women

17,385 men
The number of people with the condition will double in the next 20 years and treble in the next 35 years.

Simple Linear Relationship between Research, Policy and Service Development

Good Quality Research → Creates Awareness → Shapes Policy → Governs Service Development
But linear relationship not a reality in the busy world of policy making

Context
Policy Makers
political structures/processes, institutional pressures, prevailing concepts, policy streams and windows etc.

Evidence
Researchers
credibility, methods, relevance, use, how the message is packaged and communicated, etc.

Stakeholder Links
Links between policy makers and other stakeholders, relationships, voice trust, networks, the media and other intermediaries including practitioners.

External Influences
International factors, economic and cultural influences; donor policies etc.

(Crewe & Young, 2002)
Consumer Advocacy
Making the Personal Political

#LivingWithDementia
The Role of the Media
How research findings are packaged

- Create a simple and compelling message which is clear concise, consistent and takes account of existing knowledge (Abernathy et al, 2001; Choi, 2005)

- Fight Alzheimer’s Disease and Save Australia
Facilitators to the uptake of Research findings in Policy

- Researchers and policy makers sharing common networks, building trusting relationships and honestly and openly representing interests of all stakeholders.

- Awareness that research and policy formulation is a two way process and both are significantly shaped by political processes.

- Making research work available in variety of formats.

- When research fits with the political and institutional limits and pressures of policy makers and resonates with policy makers own ideological assumptions.
Barriers to the uptake of research findings in policy

- Assumption that dementia policy-making occurs at one level (Manthorpe & Adams 2003)
- Poor quality research, which highlights problems not solutions
- Inability to acknowledge Policy makers may “march to a distant drum and policy may only be remotely related to research” (Marshall, 1999)
- Policy makers are influenced by evidence generated from a wide range of learning processes especially what they see with own eyes
Future Research Challenges

- Balancing types of research & different research methodologies
- Difficult decisions to be made on broad research priorities - cause, cure, care, prevention
- Shift from state patronage model to investment model (Hammersley, 2014)
- Investigating the views and attitudes of those with a more severe dementia
- Small country/ may soon reach saturation point in terms of including PwD in the process and including perspectives of HSPs
- Incorporating into National Policy new and recent research findings
Recent Irish dementia related research
Reports to be launched early 2015
Concluding remarks

- Relationship between policy making, service development and research is complex and non-linear
- Policy making can take years and implementation even longer
- The dementia care landscape is rapidly changing in Ireland the time is right now to reconceptualise both dementia, policy responses, and frameworks underpinning understandings
- Thinking about policy research and dementia calls for links to be made between the individual, family, local experiences and the broader global scene
€30m funding boost for dementia care

PAUL CULLEN
Health Correspondent

A €30 million boost in funding for the care of people with dementia has been announced arising from one of billionaire Chuck Feeney’s final grants before he winds up his philanthropy operation.

Mr Feeney’s Atlantic Philanthropies is making grants totalling €14.7 million to improve the wellbeing of people with dementia in the Republic, and this sum is being matched by the Department of Health and the Health Service Executive (HSE).

The HSE is getting €12 million from Atlantic, with the remaining €2.7 million going to

€12m

Amount Chuck Feeney’s Atlantic Philanthropies will give the HSE

“A very few significant investments are being made in initiatives that are at or building toward a tipping point, where catalytic efforts are most likely to expand and sustain opportunity and create more equitable outcomes,” said Christopher Oechsli, president and chief executive of Atlantic.

“These culminating Atlantic grants, therefore, will be especially important for those, like people suffering from d-
Thank You!

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References

