

Developing a National Dementia Strategy for Ireland

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Introduction

Ireland's population whilst young by European standards is ageing. At present, about 11% of Irish people are aged 65 and over, but over the next 50 years this figure is expected to reach about 25% (Eurostat, 2008). In line with population ageing, over the next three decades, number of Irish people diagnosed with dementia will also increase, from current estimates of around 38 000 to future estimates of 50 000 by 2016, 70 000 by 2026 and to over 100 000 by the year 2036 (O'Shea, 2007). Like in other Western countries, in Ireland most people diagnosed with dementia live at home and are cared for by family members and by community support services (O'Shea and O'Reilly, 1999). About 4000 are aged less than 65 and this younger cohort places different and significant demands on the health and social care system and on family members.

There is also considerable regional variation in the prevalence of dementia across the country, with the West of Ireland because of its demographic profile, supporting the largest number of people (O'Shea and O'Reilly, 1999). Whilst undoubtedly home care may place strain on family members, Irish research has shown that overwhelmingly this is the type of care older people themselves prefer (Garavan *et al.*, 2001). Comparative cost estimates derived from an analysis of a number of European dementia studies reflect low per capita per annum costs of care for people with dementia in Ireland with other European countries such as Finland, Norway and Belgium spending a vast amount more per capita on dementia compared with Ireland (OECD, 2004).

Social policy ageing and dementia in Ireland

It has been recently argued that in Ireland, the overall level of awareness of ageing as a core issue for government policy is low (O'Neill *et al.*, 2009). There is also an absence of national statutory policies to govern the development of older peoples' services and health and social care provision for those diagnosed with dementia and some confusion about who is responsible for developing policy—whether this is a central governmental (Department of Health and Children (DoHC)) or a health service (Health Service Executive (HSE)) responsibility (Burke, 2009). When the former Irish Health Board system was abolished and replaced in 2005 with the HSE, policy development for older people and those with dementia was considered to fall within the remit of the DoHC but over the years, an *ad-hoc* approach to policy-making has evolved, with evidence of more senior HSE staff attempting to influence the policy process or policy changes emerging in response to controversial aged care issues being picked up by the media.

In this context the Leas Cross nursing home expose (Prime Time Investigates, RTE, 2005) is a useful example of the way in which reform in one sector of Irish Health and Social Policy has evolved. Here staff employed in a private nursing home in North Dublin, brought to public attention through an under-cover televised programme, the hazardous practices/institutional abuse, taking place in a facility responsible for the care of frail older people. Many of the residents in this same facility had Alzheimer's disease and were unable to advocate for themselves. The media coverage which followed this exposé, the subsequent inquiry and

report commissioned by the HSE (O'Neill, 2006), and the public and professional debate the programme generated, clearly sped up a major reform in aged care residential policy with the introduction of new national independent nursing home inspection procedures and new national standards for the care of people in long stay facilities (HIQA, 2007).

The recent new Nursing Home Act (House of the Oireachtas, 2009) reflects further significant change in Irish government policy on nursing home eligibility and funding arrangements for older people including those with dementia. Whilst much of what is embedded in this Act is informed by a report written by the Interdepartmental Working Group on Long-Term Care, (2005), the policy reform also results from work undertaken by an Expert Advisory Group on Services for Older People established by the HSE in 2006. Whilst lacking statutory power or authority, this Advisory Group has clearly helped to shape and inform reform in residential care policy (O'Neill *et al.*, 2009).

Evolution of dementia policy in Ireland

Whilst recommendations for the development of policy for dementia in Ireland feature in many of the earlier Care of the Elderly Irish government reports (Care of the Aged Report, 1968; The Years Ahead, 1988; Shaping a Healthier Future, 1994; A Review of the Years Ahead, 1997; Quality and Fairness Health Strategy, 2001; and the Mental Health Policy 'A Vision for Change', 2006), the main blueprint shaping Irish dementia care policy is the 1999 Action Plan on Dementia (O'Shea and O'Reilly, 1999). Written by a gerontological health economist and his colleague, the Action Plan emerged following extensive consultation with key stakeholders working in or affected by dementia. In it, the authors identified 'the need for the development of co-ordinated, multi-layered and well-resourced dementia services' (1999: 32) which provide person-centred care and maximised individual autonomy and independence.

The Action Plan called for the 'development of new and expanded psychosocial approaches to complement existing medical models. It detailed how Irish dementia services should be developed, the costs of service provision and the timeframe (3 years) during which action should be taken. Importantly, a person-centred philosophy of care underpinned all key practice, policy and research recommendations detailed in the Action Plan. Securing additional resources was seen as a key pre-requisite to the implementation of this Action Plan and at the time of its publication (now some 10 years

ago), recommendations were costed at €45 million (O'Shea and O'Reilly, 1999). Such recommendations centred around (i) community care, (ii) long-term care, (iii) training, (iv) case management, (v) geriatric medicine and Psychiatry of Old Age services. An important point made in this policy document was that often in Ireland people with a dementia fall between the cracks of different service provision, including Geriatric medicine, Old Age Psychiatry, Neurology and Primary Care. The Plan recommended more visionary purpose-built long-term care services and for more dementia-specific training of health service professionals. Whilst establishing an Implementation Committee was considered critical to the success of the Action Plan and whilst a commitment to rolling out the recommendations was later enshrined in government policy documents (Quality and Fairness Health Strategy, Department of Health and Children, 2001) regrettably neither an implementation committee nor any real concerted effort has been made since then to implement this now 10 year old strategy.

Dementia as a National Health Priority and the need for a National Dementia Strategy

Since the Action Plan, further work (Dementia Manifesto) commissioned by the Alzheimer Society of Ireland (ASI), and by a HSE National Working Group on dementia have highlighted the changes required to better plan and deliver future Irish dementia services, (Working Group on Residential Services for Persons with Dementia, 2007; O'Shea, 2007). The Dementia Manifesto, pointed to the importance of making dementia a national health priority, beginning with the full and accelerated implementation of the 1999 Action Plan. As a national health priority, dementia would have four key service priorities namely, (i) early intervention, education and training, (ii) enhanced community based services for people with dementia and their caregivers, (iii) co-ordination and integration of multi-disciplinary care provision and (iv) person-centred quality residential care. The Manifesto argued that support structures must be collective and public if the full potential of older people with dementia and their carers is to be realised. The HSE Working Group report reiterated the need for dementia to be made a national health priority and called for the appointment of more service providers including, dementia-specific Case Managers and dedicated dementia care teams in the community. It recommended that comprehensive multi-disciplinary assessments should take place prior to nursing

home placement, that palliative care services for people with end stage dementia should be developed. It called for the better recognition of the social, economic and emotional needs of family caregivers.

Despite the Action Plan, the Dementia Manifesto and the HSE Working Group report, Alzheimer's Disease/dementia remains a neglected, under-funded and under prioritized health issue in the Irish health and social care system. Some of this is common to other services for age-related diseases, and some of the systemic inertia is reflected in the fact that the potentially important position of National Director of Services for Older People in the HSE has not been held by a permanent post-holder for most of the time that the post has existed, and the only HSE advisory group on services for older people terminated its work without any noticeable impact on development of services and support for those with dementia. The fact that a carefully compiled evidence-based Action Plan has not been implemented, that a second national Working Group on dementia has since 2008 been disbanded and that Alzheimer's Disease/dementia has failed to feature in the HSE's 2009 Service plans, reflects the lack of current focus on dementia as a policy and service area in Ireland. Accordingly, while Ireland is currently developing a Positive Ageing Strategy¹, the country has no coherent up-to-date national dementia strategy. So, in the absence of having a national strategy how are services to people with dementia currently delivered in Ireland?

Current dementia services in Ireland

Ireland has a mixed welfare economy and recent years have witnessed a shift in the provision of older peoples' services away from what was traditionally viewed as the voluntary and informal sector towards a more blended form of service provision including the involvement of the formal (statutory) and private sector (Timonen *et al.*, 2005). Despite the involvement of the statutory sector, unlike the UK and other Scandinavian countries, in Ireland older people including those with dementia have no legislative right to community care services. Key providers of dementia services in Ireland include family members, formal health and social care services, voluntary organizations and private for profit organizations such as domiciliary services and private nursing home providers. Like in other Western countries, however, the main bulk of

service provision is undertaken by family caregivers. The GP is a pivotal health professional contact for the majority of people with dementia (Begley, 2009) although it has been noted that some Irish GPs lack confidence in making diagnoses, would welcome more training in this area and both rural and urban GPs experience time delays in accessing diagnostic services (Cahill *et al.*, 2006; Cahill *et al.*, 2008). If diagnosis is made however, generally this is done through primary care services or in more unusual cases (early onset dementia or where a differential diagnosis is required) by Medical staff at Memory Clinics, or in community-based Old Age Psychiatry services. At the time of writing there are seven fully operational Memory clinics across Ireland, most of which are committed to providing diagnostic, treatment and referral services. Recent years have also seen a significant expansion in medical and psychiatric services for people with dementia. For example, there are now over 60 geriatrician appointments and over 25 old age psychiatrists employed across the country. Such services are also often used in the diagnosis and follow up of people with dementia.

After diagnosis, persons with dementia and their families may be referred to statutory community services (public health nursing, occupational therapy, meals on wheels) or to the ASI for more specialist dementia-specific services. Across the country, each community care area has its own entitlement policy, type and quantity of service provision, service mix and the cost of care varies from one area to another depending on how the services are structured and who provides the care required (Brennan, 2008). Dedicated dementia-specific services are sparse in Ireland. For example, dementia-specific day care is not in general available through the statutory care services and there is evidence of a paucity of community based dementia-specific services with long wait periods especially for services such as occupational therapy (Begley, 2009). Accordingly, use of services remain limited with family caregivers often reporting that they would like to use more services but find it difficult due to lack of information and barriers to access including transport and stigma (Begley, 2009).

It is also well known that gaining access to nursing home care for people with dementia can be very difficult. There are few dedicated specialist care units across the country, purposefully designed to cater for the unique and complex needs of people diagnosed, despite very preliminary evidence pointing to the benefits derived from such care (Myers, 2007). The main dementia-specific service provider in Ireland is the ASI which offers in-home respite care, day care and

¹Given the nature of submissions received, the Positive Ageing Strategy is likely to contain several recommendations about policies and services for people with dementia.

residential respite. The Society also provides a telephone help-line, social clubs, carer support groups and undertakes advocacy work. Its mission is to advocate for the rights and meet the needs of people with dementia and all those who care for them. The Society is a member of Alzheimer's Europe and has recently received large external philanthropic funding to undertake concerted advocacy work designed to raise professional and public awareness about dementia. In addition, the Neurological Alliance of Ireland, (www.nai.ie) an advocacy platform for a range of neurological illnesses of which the ASI is a member, has given increasing prominence to dementia in its advocacy activities, in particular during its annual Brain Awareness Week.

In 1999, a Dementia Services Information and Development Centre (www.dementia.ie) funded by the DOHC was first established at St James's Hospital in Dublin. This is a national service dedicated to best practice in dementia care. Its remit is to expand and improve services, to provide information and education to health service professionals around the country and to commission and undertake research on dementia. Since its establishment, a large network of national and international contacts have been developed and extensive educational and training services are now being provided across the country. In 2007, the DSIDC received a large external philanthropic grant to set up the Living with Dementia Research programme (www.socialwork-socialpolicy.tcd.ie/livingwithdementia). The key objective of this programme is to support psycho-social research contributing to the development of timely responsive and accessible interventions to support the individual diagnosed with dementia and his or her family caregiver.

In Spring, 2009, the DSIDC hosted a large, well attended forum, lobbying for the development of an Irish national dementia strategy. The forum involved a UK speaker who brought to an Irish audience's attention, England's recent experience in developing and launching a national dementia strategy. There is no doubt but that this event has helped to create a momentum for the development of an Irish dementia strategy as despite the country's current economic downturn, a very recent commitment has been made on the part of senior civil servants at the DOHC, to make dementia a key priority in 2010 and a scoping exercise for the development of a national dementia strategy has already got underway. Whilst this is encouraging, it remains unclear whether or not a focused, sustained and strategic coalition exists between the main advocacy foci and the professional groupings for dementia care to the same extent that has

been seen with some effect in the development of the case for better services for stroke, (Horgan *et al.*, 2008) and palliative care services (<http://www.endoflife.ie>) in Ireland. The development of such a focus is likely to represent a necessary condition to ensuring that health and societal policy truly does develop a greater priority to supporting those affected by dementia in Ireland, and would draw wide support from the professionals (O'Neill, 1998).

Summary

This paper has argued that in Ireland, the baseline profile of services for people with dementia is low and despite its ageing population, dementia remains a neglected, under-funded and under prioritized health issue in the Irish health and social care system. At a time when countries across Europe including France, Norway, Malta, England, Scotland, Wales and Northern Ireland are each facing up to the global challenge of Alzheimer's Disease by developing national dementia strategies, Ireland currently has no national dementia strategy. The political process which has led to the development of national dementia strategies being developed in other European countries, their implementation programmes, including funding arrangements and the key dementia service priorities identified for the next 5 years, may be useful for countries like Ireland to now reflect on. We can learn from the experiences of other European countries with a longer history of population ageing and dementia, nations considerably more advanced in their policy development. The impact of demographic ageing is as important in the Republic of Ireland as in the UK and other European countries and the significance of Alzheimer's Disease and dementia in overall health and social care costs is huge and must now be given high priority in Ireland's national health and social care agenda.

Conflict of interest

None declared.

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