THE ALZHEIMER SOCIETY of IRELAND

Submission to the Committee on the Future of Healthcare

August 2016

Executive Summary

Key recommendations within this submission

Strategy:

1. ASI recommend three priority actions for the ten-year strategy:
    - Strategic policy and shared principles including a follow-on to the National Dementia Strategy.
    - Integrated policy and practice including case management and a collaborative approach to care.
    - Social care model and entitlement to community care to ensure that people can remain living in the community for as long as possible.
2. Providing adequate levels of funding for social and community care including home-based care.
3. Our ageing population and subsequent increase in number of people living with dementia needs to be factored into a ten-year strategy.
4. Adequate dementia data collection, recording and sharing needs to be developed.

Integrated Care:

1. ASI recommends five steps to an integrated care model, including (i) putting policy into practice; (ii) leadership; (iii) recognising the vital role of the community and voluntary sector; (iv) legislative change and (v) appropriate funding.
2. Many of the most effective management approaches are provided by primary level healthcare professionals from multiple disciplines.
3. Best practice examples includes Multidisciplinary Team approaches; the Alzheimer Scotland[1] Eight Pillar model for integrated health and social care; and the PREPARED project.

Funding:

1. Financing of care for people with dementia must be co-ordinated across the trajectory of the disease with adequate funding at each stage of progression.
2. Early diagnosis and early intervention, for example, can deliver cost savings to public services as well as delivering a better quality of care for people with dementia.
3. In recent years the financing of long-term residential care has increased, while investment in home care has gone down.
4. There is growing consensus that home or community-based care can be a cost-effective alternative to long-term residential care for some older people.

[1] http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf

1. Introduction

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to make this submission to the Committee. It is based on our experiences working with people with dementia and their family carers. There is growing public support for strategic action on dementia care with over 20,000 people signing our petition for increased Government investment into home-based care for people with dementia.

Dementia is one of the major causes of disability among older people worldwide (WHO, 2012[2]). It places a high demand on the health and social care system. People with dementia are extremely high users of services whilst experiencing high levels of unmet need (Cahill et al. 2012[3]), with services under-resourced and under-funded.

The majority of people with dementia would like to stay in their own homes for as long as possible, however our current system is failing to provide adequate home-based supports to enable this. This submission will present evidence and solutions to the on-going gaps in services[4]. Combined with an ageing population and a growing need for a strategic approach to dementia care, this means dementia must be a priority in a ten-year strategy for the health service.

2. Recommendations under Theme One: Strategy

2.1 Key priorities for the ten-year plan

We have identified three priorities which we feel must be included in the ten-year strategy, namely:

1. Strategic policy and shared principles
2. Integrated policy and practice
3. Social care model and entitlement to community care

Each will be addressed in turn below.

[2] World Health Organization (2015) Dementia: A Public Health Priority available via http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_executivesummary.pdf
[3] Cahill, S. O'Shea, E. and Pierce, M. (2012) Creating Excellence in Dementia Care report. Trinity College Dublin/NUIGalway.
[4] Please also see table in Appendix 3 which outlines gaps in services for people living with dementia.

2.1.1 Strategic policy and shared principles

The health system requires shared values and principles to underpin actions. Drawing on those outlined by the Health Reform Alliance[5], this includes a focus on equity, entitlement, adequate funding, integration and person-centredness.

In addition, planning must be underpinned by strategic policy. The implementation of the National Dementia Strategy (NDS[6]) (2014), it is hoped, will lead to systemic change including changes to Primary and Community Care, Mental Health, Acute and Long-Term Care; improving rates of diagnosis[7] and improving pathways to enable people to access care.

The lifespan of the current NDS is limited, coming to an end in 2017. The strategy too has limitations, namely:

- A lack of priority to the needs of people with younger onset dementia[8] and the maintenance of the discriminative age barrier to access some health and social care services.
- Little focus on residential care.
- Little priority given to a Dementia Friendly Community model as a measure to address social and community care.
- No attention given to dementia risk reduction and/or prevention.

These issues can be addressed in a follow-on Strategy and built into wider strategic reform of the healthcare system.

2.1.2 Integrated policy and practice

The NDS states that dementia policy, service delivery and development should be guided by the principles of chronic disease management as set out by the Department of Health (2014)[9]. However, dementia is not part of the chronic disease prevention and management programme. A gap arises as a result to enable GPs to give time and appropriate attention to pro-actively manage dementia.

Evidence from other jurisdictions shows that health promotion, pro-active care and better outcome measures rely on incentivisation and resourcing of chronic disease management (Savage et al.,

[5] http://healthreformalliance.ie/wordpress/health-reform-alliance-principles/
[6] Department of Health (2014) National Dementia Strategy. Available via http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf
[7] In the UK, it is estimated that only about 40% of people with dementia have a diagnosis. Formal diagnosis of dementia in Ireland is not common place and there is no national register of people with dementia.
[8] There's an estimated 4,000 people under 65 years currently living with dementia in Ireland.
[9] This includes the development of a model of shared care that is integrated across organisational boundaries; planning care that is delivered in the appropriate setting; and using multidisciplinary teams in the provision of care.

2015[10]). The Chronic Care Model (CCM) is widely adopted and cited as a model on how to organize chronic care programmes in primary care. The CCM[11] is an excellent resource to plan primary care services for dementia care.

In addition, people with dementia, especially those under 65, would benefit from strategic developments arising from the neuro-rehabilitative strategy.

Integrated policy should, in turn, lead to more integrated working across the health and social care system. Case management and a collaborative approach to care are effective in organising care for people with dementia at home. This requires leadership and designated personnel to support people to navigate a care pathway (Trepel, 2015[12]).

Currently, people with dementia are one of a core group who are caught in the delayed discharge cycle. It's estimated 25% of all patients in a typical general hospital have dementia (Timmons et al, 2015[13]). Worryingly 51% of delayed discharges between May 2013 and February 2015 were a result of delayed access to appropriate community supports (HSE, 2016). Targeted approaches to reduce the length of time people with dementia stay in hospital must be a priority:

- Average length of hospital stay for a person with dementia admitted and discharged to and from their home is 22 days (de Suin and O'Shea, 2014[14])
- Average length of stay for the general population is 5.43 days and 12.3 days for someone aged over 65[15]

Evidence from the UK[16] shows that a strategic approach to dementia care saves money by reducing the need for unplanned admissions to long-term care and unnecessary admissions to hospital.

2.1.3 Social care model and entitlement to community care

A social model of care recognises that people living with dementia utilise social and community care in addition to health services. To meet the preferences of people living with dementia to live in the community, and recognising the broader societal impact of the condition such as that on family carers, a key priority in a ten-year strategy is entitlement to care, particularly entitlement to home-

[10] Savage et al (2015) Clinical and Economic Systematic Literature Review to Support the Development of an Integrated Care Programme for Chronic Disease Prevention and Management for the Irish Health System. UCC Available via https://www.hse.ie/eng/about/Who/clinical/SystematicLiteratureReviewSupportDevtofIntegratedCareChronicDiseases2015.pdf
[11] See: http://www.improvingchroniccare.org/index.php?p=The_Chronic_CareModel&s=2
[12] See: https://www.alzheimer.ie/getattachment/About-Us/Policy/Expert-Policy-Paper-Series/Trepel,-D-2015-An-Economic-Analysis-of-Home-Care-Services-Final.pdf.aspx
[13] Timmons, S. et al (2015) Dementia in older people admitted to hospital: a regional multi-hospital observational study of prevalence, associations and case recognition. Age and Ageing. September 28.
[14] de Suin, A. and O'Shea, E. (2014) Report of the National Audit of Dementia Care in Acute Hospitals 2014.
[15] Department of Health (2015) Review of the Nursing Home Support Scheme.
[16] See https://www.hsj.co.uk/Journals/2015/02/19/a/a/w/Dementia-Today-and-Tomorrow.pdf

based care such as home help, post-diagnostic (e.g. cognitive stimulation and rehabilitation therapies, counselling), information services, social clubs, befriending, respite, day care etc. with appropriate options for supported/assisted living.

The Report of the Seanad Public Consultation Committee on the Rights of Older People (2012[17]) identified (i) the rights of older people to be enshrined in a formal way and (ii) the need to support and encourage independent living at home for as long as possible.

A social care model and an entitlement to community and home-based care would place an obligation on Government to make certain choices about the use of existing resources within a ten-year strategy. This, in turn, will ensure that community care:

(i) meets needs by addressing current blockages in the delivery of care to people with dementia,
(ii) ensures care assessments takes account of needs arising from cognitive impairment as well as personal care requirements,
(iii) has regulations to ensure consistency of care and safeguards against risk,
(iv) greater integration of community care across all health and social care system.

1.2 Challenges in achieving a universal single tier health service

People with dementia require a continuum of flexible innovative care, individual needs-led approaches; appropriate to changing and complex needs arising from the condition. This means providing lower levels of care and support in the earlier stages and high levels of care as the condition progresses.

In the majority of cases, dementia can be addressed at the level of primary and community care provision (Cahill et al, 2012[18]). There is growing consensus that home or community-based care can be a cost-effective alternative to long-term residential care for some older people (Review of the Nursing Home Support Scheme, 2015[19]; OECD, 2005[20])[21].

A key challenge then is the provision of adequate levels of funding for social and community care including home-based care. Recent research (Donnelly et al., 2016[22]) shows that Ireland is slipping

[17] Available via http://www.oireachtas.ie/parliament/media/committees/seanadpublicconsultationcommittee/reports/FinalReport.pdf
[18] Ibid
[19] Ibid.
[20] OECD (2005) Ensuring Quality Long-term Care for Older People.
[21] European analysis of average costs in dementia care for example found that residential long-term care costs €4,491 per month compared to €2,491 for aggregate costs from home care (Wübker et al, 2014).
[22] Donnelly, S. O'Brien, M. Begley, E. and Brenna, J. (2016) Older People's Preference for Care: Policy but what about practice. University College Dublin/Age Action/Alzheimer Society of Ireland/Irish Association of Social Workers.

below international standards for the proportion of the population aged 65 and older receiving home help as recommended by the OECD (HSE, 2016 in Donnelly et al., ibid).

Due to the financial cost of dementia and the health benefits of having a medical card for people with the condition, the ASI maintains that it is critically important that people living with dementia have access to a medical card or system of care that allows them to access care based on their needs regardless of income.

1.3 Future demographic pressures

2.3.1 Ageing population

There is a significant and rising number of people currently living with dementia in Ireland; approximately 55,000 individuals[23]. If current trends continue, and within the lifetime of a ten-year strategy, this number will increase to 77,460 people by 2026 (Pierce et al., 2014[24]). Although the majority of people with dementia are over 65, as age is the main risk factor, there is a significant proportion under 65, an estimated 4,000 people.

Many of those caring for people with dementia are older people; 84% of those in a caring role are over 45 and 37% are over 65 (ASI, 2007[25]). Changing demographics of families mean that women, traditionally the main carer, are now more likely to work outside the home. We need to respond with strategic planning to appropriately address this demographic change.

2.3.2 Data collection and evidence based service planning

Reliable information on dementia is largely absent in Ireland. Information is not currently being recorded on national databases. This has implications for policy and the provision and planning of evidence-based services and supports and for ensuring that resources are targeted effectively.

2. Integrated Primary and Community Care

A strategic approach to dementia care within the health system must include integrated and multi-disciplinary care across primary, secondary and long-term care.

[23] Department of Health (2014) National Dementia Strategy. Download from: http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf
[24] Pierce, M, Cahill, S. and O'Shea, E. (2014) Prevalence and Projections of Dementia in Ireland, 2011-2046. Dublin: Trinity College Dublin/NUIGalway/Genio.
[25] The Alzheimer Society of Ireland (2007) Living with Dementia – The Experience of Carers with Dementia (unpublished)

The ASI advocates for community/home-based care and the need for an integrated care pathway with a multi-disciplinary case management approach to dementia. This is against the current backdrop of a home care service, often experienced as impersonal, inflexible, underfunded and poorly integrated with other health and social care services (SCIE, 2014[26]).

People living with dementia and their carers find it increasingly difficult to negotiate complex pathways of care (Pratt et al., 2006[27]). The delivery of integrated care for people with dementia has challenges across a range of areas, including:

- Lack of an integrated IT systems;
- Lack of appropriate data collection and sharing;
- Poor dementia education and training;
- Lack of leadership;
- Inappropriate legislation for community/home-based care;
- Inadequate levels of funding for community/home-based care.

3.1 Steps to an integrated model of primary, secondary and community care

Step 1	**Putting Policy into practice**	National policy is underpinned by a commitment to support people to age-in-place, in their own homes[28]. Yet, research shows that this policy is not being implemented (Donnelly et al, ibid). There is no official policy framework for integrated home-based care service and supports for older people (Timonen, Doyle and O'Dwyer, 2012 in Donnelly et al. ibid).
Step 2	**Leadership**	Good dementia care involves multi-disciplinary working and case management (Trepel, 2015[29]), requiring designated personnel at different levels in the health and social care system and effective inter-agency and interdisciplinary communication. The National Dementia Office has been established as part of the NDS implementation plan. There is a need to build and

[26] Social Care Institute for Excellence (2014) Commissioning Home Care for Older People. Available at: www.scie.org.uk/publications/guides/guide54/files/guide54.pdf
[27] Pratt, R., Clare, L. and Kirchner, V. (2006) '"It's like a revolving door syndrome": Professional perspective models of access to services for people with early-stage dementia', Aging and Mental Health, 10(1), 55-62.
[28] National Positive Ageing Strategy, 2013; Irish National Dementia Strategy, 2014; Future Health: A Strategic Framework for Reform of the Health Service 2012-2015
[29] Ibid

		further develop this infrastructure to embed clinical and policy leadership for dementia into the Department of Health and HSE.
Step 3	**Vital role of the community and voluntary sector**	The community and voluntary sector must also be considered critical in supporting the success of an integrated model. The wider strategic policy context of building towards a sustainable health system is complimented by a model that recognises the innovative and cost-effective role that the community and voluntary sector play in responding to emerging needs and community/home-based care for people.
Step 4	**Legislation**	The need for a statutory basis for community care has been outlined above. Overall, all developments relating to dementia care and support should be underpinned by a human rights legislative framework, to which providers should be accountable. People who use services should be involved in the decisions that affect their lives and they should be empowered to exercise choice and control over the care and support they receive.
Step 5	**Funding**	Funding for community/home-based care should be a priority step moving to an integrated system with a social model of disability. In recent years the financing of long-term residential care has increased, while investment in home care has gone down. Home-based community supports should be equal in status to clinical care. This requires an increased level of professionalisation of staff in the social care sector with a focus on career paths and accreditation. Factoring in a social care model will also involve putting a value on family care. The current system relies heavily on family members to provide care, which means that burdensome aspects of care are extremely significant in

		terms of balancing the provision of care for people with dementia (Trépel, 2012[30]). One of the main reasons people with dementia enter long-term care is due to family carer burnout (Brodaty and Donkin, 2009[31]).

3.2 How to achieve these steps

With respect to dementia, many of the most effective management approaches are provided by primary level healthcare professionals from multiple disciplines[32] (Grand et al., 2011[33]). Primary care is the point of first medical contact and hence the cornerstone of ensuring early detection, timely intervention, and effective ongoing management of care for people with dementia (UK Department of Health, 2001[34]).

3.3 Ensuring buy-in from health care professionals

There is an international evidence-base that points to the cost effectiveness and efficiency offered by a more integrated system.

Active involvement of key professional groups and clinicians and other health and social care professionals from the beginning of the process can also ensure buy-in. Providing space to communicate and discuss issues can enable different disciplines to identify common gaps and possible solutions. The ASI used a roundtable model[35] of consultation to bring health and social care professionals together in the lead-up to the National Dementia Strategy and in efforts since its publication to monitor the implementation of the Strategy; this has proved beneficial.

3.4 Example of best practice for consideration by the committee

Multidisciplinary Team approaches are good practice in responding to the care needs, required supports and preferences of older people (Donnelly et al, ibid).

Alzheimer Scotland[36] has produced an Eight Pillar model for integrated health and social care. This model addresses the social implications of dementia, demonstrating how these can be tackled most

[30] Trepel, D (2012) Financing Dementia: What money is available, what does dementia need and will the required resources be received? The Alzheimer Society of Ireland Expert Policy Paper Series.
[31] Brodaty, H. and Donkin, M. (2009) family Carers of People with Dementia. Dialogues in Clinical Neuroscience 11(2).
[32] General Practitioners, Public Health Nurses, Occupational Therapists (OT), Speech and Language Therapists, Mental Health Nurses and other key healthcare professional play a significant and frequent role in the management of dementia care.
[33] Grand et al (2011) Clinical features and multidisciplinary approaches to dementia care. J Multidiscip Healthc. 4: 125–147.
[34] Department of Health. National service framework for older people. London: Stationery Office, 2001.
[35] Reports available from this link http://alzheimer.ie/Alzheimer/media/SiteMedia/Living-with-Dementia_NDS-Roundtable-report_September-2013_The-Alzheimer-Society-of-Ireland.pdf
[36] http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf

effectively by coordinating the full range of health and social care interventions to meet individual needs.

Irving and McGarrigle (2012[37]) as part of the ASI's expert policy series, conclude that a move towards more integrated working in terms of planning and service delivery could help achieve better outcomes for those with dementia and make the best use of current resources. Achieved through close integrated working across health and social care systems, the delivery of GP-led memory clinics in association with specialised support from community mental health teams, proactive case management as well as strengthening community networks and support.

The PREPARED[38] project, a primary care focused national research and service development initiative run by the Department of General Practice at UCC, funded under the National Dementia Strategy, aims to develop, deliver and evaluate training and education interventions for primary care clinicians. Key elements include multidisciplinary management, registries to collect data and appropriate resourcing of primary care, which are in line with the core aspects of the Chronic Care Model referenced earlier.

3. Funding Model: Which health service funding model would be best suited to Ireland?

Financing of care for people with dementia must be co-ordinated across the trajectory of the disease with adequate funding at each stage of progression. State spending on dementia to date has been low and inadequate. Dementia continues to lag behind other chronic diseases in terms of budget allocation in most countries, particularly relative to the disease burden (Cahill et al, 2012). The initial joint investment by Atlantic Philanthropies and the Government to support the implementation of the NDS has limited lifespan. Longer-term thinking and investment is required.

4.1 Financing, payment methods and service delivery (purchaser and provider)

Equality of access and outcome should be a guiding principle for any funding model. Refocusing policy on quality of care rather than solely cost-effectiveness. There is also a need to ensure that financial reform in the healthcare sector[39] does not negatively impact on health service users such as people with dementia. The National Economic and Social Council (2013)[40] found that cuts to health spending resulted in reductions in grants to outside agencies, which affect service provision on the frontline.

[37] Available at this link https://www.alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/Integrated-Care-Pathways.pdf
[38] More information available here
[39] European Commission. Europe 2020: A strategy for smart, sustainable and inclusive growth, COM(2010). Available at: http:// eur-lex.europa.eu/LexUriServ/LexUriServ. do?uri=COM:2010:2020:FIN:EN:PD
[40] NES (2013) *The Social Dimensions of the Crisis*

A concern for the NGO sector is that quantitative measurements of financial savings do not take into account the effect on service provision at a ground/micro level. NGOs can make an important contribution to health system reform in Ireland. They provide an input that is complementary to political forces, and they have interests primarily for society rather than commerce.

3.2 Best practice, or estimated costs of funding models

There is underinvestment in dementia research and care infrastructure, relative to its social and economic impact. Given the demographics of an ageing population, this gap will only increase. Evidence from the UK also shows that achieving better outcomes for people with dementia and achieving greater value for money in dementia care is possibly through changes to service provision or adopting new ways of working (House of Commons, 2011[41]). Early diagnosis and early intervention, for example, can deliver cost savings to public services as well as delivering a better quality of care for people with dementia (House of Commons, ibid).

4. Conclusion

Under the current health and social care system, people with dementia and their carers face serious barriers in equity of access and outcomes from the point of diagnosis to end of life. A key challenge in establishing an integrated health service based on need rather than ability to pay is ensuring that the service is person-centred, integrated and based on quality of life outcomes within a wider human rights and social model framework.

A ten-year plan for the health service must be informed by strategic policy and shared principles, integrated policy and practice on the ground, and a social model of care that ensures a right to community/home-based care.

Moving to an integrated health and social care system requires leadership, policy implementation, legislative change, appropriate levels of funding and a recognised role for the NGO sector. Funding must be underpinned by equality of access and outcomes and rebalanced in a way that recognises the need to resource primary and community care to provide a foundation for more integrated and strategic healthcare.

[41] House of Commons (2011) The £20 billion question An inquiry into improving lives through cost-effective dementia services. All-Party Parliamentary Group on Dementia. available via file:///C:/Users/MCrean/Downloads/The_%C2%A320_Billion_Question_-_an_inquiry_into_improving_lives_through_cost_effective_dementia_services_from_the_All-Party_Parliamentary_Group_on_Dementia_310811.pdf