



THE ALZHEIMER
SOCIETY *of* IRELAND

**Submission to the WHO Global Action Plan on the Public
Health Response to Dementia.**

September 2016



1. Introduction

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to input into the WHO Global Action Plan on the Public Health Response to Dementia.

There is a significant and rising number of people currently living with dementia in Ireland; approximately 55,000 individuals¹. If current trends continue this will increase to 68,216 people by 2021 and to 132,000 people by 2041 (Cahill, S. & Pierce, M, 2013²). There is not a community in Ireland unaffected by dementia as the vast majority of people live at home (63%³). Although the main proportion of people who have dementia are over 65 years, as age is the main risk factor, there is a significant group aged under 65, an estimated 4,000 people, many of whom are in their 30's and 40's.

The following submission is informed by the direct work that The Alzheimer Society of Ireland undertakes in Ireland with people living with dementia and their families and carers.

2. Consultation Questions

2.1 General comments on vision, goals and cross-cutting principles

The ASI supports the vision, goals and principles, which present as strategic and wide-reaching. However, reference to adequate resourcing should be included. In addition, the language of rights and equity used throughout the principles should be reflected more in the detailed text on actions.

ASI also recommends that the action plan has a specific focus on the Convention on the Rights of People with Disabilities as many of the objectives in the WHO action plan can be met if member states implement the CRPD and apply a human rights based approach to policy and action on dementia.

2.2 Comments on strategic action areas

The following section provides comments on the action areas, global targets and indicators

¹ Department of Health (2014) *National Dementia Strategy*. Download from: <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

² Cahill, S. and Pierce, M (2013) *The Prevalence of Dementia in Ireland*. Genio Dementia Learning Event.

³ Ibid.

as well as the proposed actions.

2.2.1 Dementia as public health priority

The ASI welcomes the whole-of-government, broad multi-stakeholder public health approach outlined in this action area. In line with international evidence, the ASI would suggest that this public health approach is contextualised within a population health and life-course approach, which acknowledges that the development of dementia occurs across the life-course and infers action on the social determinants of dementia (ASI and IPH, 2015: 13).

In terms of specific actions for member states, with reference to the need for dementia strategies, the wording used refers to plans being independent documents or integrated across health and other sectors. The wording should be stronger, explicitly stating the need for independent documents which are also integrated, rather than an option for one or the other. Furthermore, the prerequisite for legislation should be stronger with a clear indication that a right to health and social care be made on a statutory basis to ensure the needs of people living with dementia are met.

Although information systems are included as a discreet action area, an additional action point should be included; a requirement to ensure compilation of accurate data and the production of registries to inform planning and service delivery.

There should be reference within the public health approach action to prevention. Stating that dementia prevention should be addressed as a public health issue in the same way as other chronic conditions. Measures to prevent dementia require embedding in chronic condition and broader public health policy.

Finally, member states should be required to report on how people with dementia in their respective countries are included in the implementation of the Convention.

2.2.2 Dementia awareness and friendliness

The ASI has successfully developed a Dementia Friendly Community model (ASI, 2016

available [here](#)). A key learning from this process was the importance of a community development approach and the need to identify key leaders and dementia champions at a local level. We recommend that this is incorporated into the actions for member states in developing dementia friendly societies.

The actions outlined for partners include reference to advocacy and seems to conflate advocacy with awareness and dementia friendliness. However, advocacy plays a wider role than influencing awareness-raising and is possibly a stand-alone action area. For this reason, ASI recommends using the term ‘engage all stakeholders in awareness-raising’ rather than introducing the term advocacy here with no background or context.

2.2.3 Dementia risk reduction

High quality longitudinal data on health behaviours and broader determinants of health linked to health outcomes is essential to inform dementia prevention policy (ASI and IPH, 2015). The requirement for research and longitudinal data collection should be incorporated into the actions for member states.

The paper on dementia prevention published by ASI and the Institute of Public Health (2015), recommended a brain health approach, embedded in a broader determinants and population health frame. We feel this should be the corner stone of public health action to address dementia prevention. It is important that research is shared among member states and that the infrastructure exists to support this.

2.2.4 Dementia diagnosis, treatment and care

The ASI particularly welcomes the actions for member states that shift the focus towards community-based care settings with integrated, community-based networks between social and health systems.

Evidence from many jurisdictions throughout the world shows that health promotion, proactive care and better outcome measures rely on incentivisation and resourcing of chronic disease management (Savage et al., 2015⁴). The Chronic Care Model (CCM) is widely

⁴ 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>

adopted and cited as a model on how to organize chronic care programmes in primary care. The CCM⁵ is an excellent resource to plan primary care services for dementia care.

There is a growing imperative that policy considers optimal arrangements of the limited societal resources to mitigate the impact of dementia on people with dementia, their families, health and social systems and wider society (Trepel, 2015⁶).

Sustaining people with dementia at home is their stated preference and makes rational economic sense. In community research finds that increasing demands for care are often borne by family and friends, however formal provisions are often required to augment care and any provision must be cost-effective (Quentin et al. 2010).

ASI also supports the action on ensuring care pathways involving a continuum of flexible innovative care and person-centred approaches, which are appropriate to changing and complex needs arising. The ASI would add that care pathways need to engage case management. 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).

2.2.5 Support for dementia carers and families

People with dementia and their carers are experts in relation to the lived experience of dementia and they need formal recognition as care partners and primary stakeholders in dementia care.

In addition to direct supports for carers, there must be adequate services available for the people with dementia for whom they care. Adequate resourcing of home care and other community services compliments the care role carried out by families but also ensures that family carers have time and capacity to engage in activities outside their care role. The importance of adequate levels of services for the person with dementia must be incorporated into any discussion of supports for carers.

Trepel (2015: 4) in his analysis of the economics of home care states that professionals

⁵ See: http://www.improvingchroniccare.org/index.php?p=The_Chronic_CareModel&s=2

⁶ 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>

involved in care vary over the spectrum of dementia care. The action plan should include reference to further research to establish the quality and cost of how professionals are complementing family carers (Hallberg et al. 2014). For Trepel the goal for people with dementia and for wider society is to provide an optimal arrangement of care - that is, maximising overall welfare given scarce available resources. Trepel has built the argument that case management, collaborative care and information systems are all necessary to ensure effective community care for people living with dementia. Supports for family carers, therefore, must be contextualised within a framework that recognises the need for greater information and case management for those for whom they care.

2.2.6 Information systems for dementia

The Irish National Dementia Strategy (2014) states that there is no reliable epidemiological study in Ireland providing accurate numbers on the prevalence of dementia in the Irish population, the characteristics and needs of those with dementia or their carers, and the full range of services and treatments that people with dementia are receiving (NDS, 2015: 33). The NDS contains a number of actions pertaining to data collection and information systems to address this gap. It is important that the WHO action plan recommends that member states prioritise actions on information systems being driven from national strategy documents.

As stated earlier, the requirement for research and longitudinal data collection should also be incorporated into the actions for member states. This recommendation also applies in the development of information systems.

2.2.7 Dementia research and innovation

The ASI welcomes the statement in this action area on increased investment in research and the need for member states to develop national dementia research agendas. However, it is imperative that investment in research needs to strike a balance between research into treatment, care and cure on the one hand and pharmacological and psychosocial intervention approaches on the other.

In addition, ASI recommends the need to encourage greater collaboration across members states on research through mechanisms such as priority funding for collaborative research.

3. Conclusion and general comments

The ASI welcomes the WHO action plan. The seven priority areas are comprehensive and focused and have the potential to greatly enhance the lives of people living with dementia. The language of rights and equity presented in the principles underpinning the action plan should be incorporated throughout the plan and the rationale for each action area. This submission has made a number of recommendations to improve the action areas including the need to introduce a life-course approach; the need to identify key leaders and dementia champions; the need to be specific about resource allocation; the importance of information and case management to support a person's journey and a number of additional suggestions across the seven action areas.

In conclusion, ASI asks that the action plan requires member states to report on how people with dementia are included in the implementation of the Convention by Member States. This is significant as many of the objectives in the WHO action plan can be met if member states implement the CRPD and apply a human rights based approach to policy and action on dementia.

Ends.

About the Alzheimer Society of Ireland

The ASI is the leading dementia specific service provider in Ireland. We work across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their family carers.

In 2014 the ASI provided over 1 million hours of care to approximately 9,500 people with dementia. In addition, our national helpline assisted 4,000 people in 2014. Our range of supports and services include a National Helpline, Dementia Adviser Service, Social Clubs, Alzheimer Cafes, Home Care, Day Centres, Respite Care, Family Support Groups, Family Education Programmes and Cognitive Stimulation Therapy Programmes. We are also the only national advocacy organisation for people with dementia and their carers.

Our vision is an Ireland where no one goes through dementia alone and where policies and services respond appropriately to the person with dementia and their carers, at the times they need support. A national non-profit organisation, The ASI is person centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core.

References

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Pierce, M, Cahill, S. and O'Shea, E. (2014) Prevalence and Projections of Dementia in Ireland, 2011-2046. Dublin: Trinity College Dublin/NUIG/Genio.

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