



THE ALZHEIMER  
SOCIETY *of* IRELAND

**Submission to Department on Health on  
implementation of the Madrid International Plan  
of Action on Ageing**

*June 2016*



## **1. Introduction**

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to input into **Department on Health on implementation of the Madrid International Plan of Action on Ageing**

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 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.

We also operates the Alzheimer National Helpline offering information and support to anyone affected by dementia at 1800 341 341.

## **2. Implementation of the Vienna Declaration or is the Madrid International Plan of Action on Ageing**

All activities undertaken by ASI support people living with dementia and their carers to live well with dementia. In this way, all of our services and supports serve the four goals of the Vienna Declaration. It follows that underfunding of ASI services is a barrier to effective implementation of the Vienna Declaration as this impacts significantly on the capacity of ASI to meet the level of need in the community. In the last seven years the ASI has experienced a decrease in funding from the HSE. In 2008, the HSE grant covered 74.5% of ASI services and in 2014 this grant covered just 67%.

For the purpose of this report, the following provides a summary of three key activities that progress the Vienna Declaration related to human rights, creating Dementia Friendly Communities and information provision.

### **Goal 2: Participation, non-discrimination and social inclusion of older persons are promoted**

#### **1. Name of Programme - Charter of Human Rights for People with Dementia**

##### **Activities and Outcomes**

The Irish Dementia Working Group developed a Charter of Rights in collaboration with the Alzheimer Society of Ireland.

The process involved workshops with people with dementia, surveys of carers and wider stakeholders and consultation with ASI staff around the topic of living with dementia and human rights.

The findings from these workshops, surveys and consultation were collated and informed the production of a Charter of Human Rights for People Living with Dementia.

The Charter was officially launched by former UN High Commissioner for Human Rights, Mary Robinson, in Dublin in April 2016.

The Charter took a PANEL approach to human rights and centred the rights of people living with dementia according to the right to participation, accountability, non-discrimination, empowerment and legality.

The Charter was disseminated widely and is available as a document for consultation by policy makers, carers, and people with dementia and health and social care professionals.

### **Plans for Further Activity**

There are plans to further disseminate the Charter to schools and wider stakeholders.

### **Areas where Future Action Needed**

The rights outlined in the Charter can only be fully realised when Ireland ratifies the UN Convention of the Rights of People with Disabilities.

### **Goal 3: Dignity, health and independence in older age are promoted and safeguarded**

- 1. Name of Programme** Provision of information materials for people with dementia developed in collaboration with the Irish Dementia Working Group

## **Activities and Outcomes**

The Information Manager with the ASI facilitated a workshop with The Irish Dementia Working Group to ascertain their comments and ideas on material for a series of booklets about living well with dementia, including:

- I have dementia...First steps after diagnosis
- Practical tips for Living Well with Dementia
- Driving and dementia
- Helpcard [to support people when out and about in their community]

## **Plans for Further Activity**

Continue to develop resources that are accessible and useful to people living with dementia and serves to empower them to participate in society and live well with dementia.

### **1. Name of Programme - Dementia Friendly Communities**

## **Activities and Outcomes**

The aim was to build the capacity of communities across Ireland to become more dementia friendly

The outcomes included:

- The lives of people with dementia and their loved ones will be improved and they will remain involved and included in their communities for longer
- Key stakeholders in the community will be more dementia aware and better able to respond to the needs of people with dementia and their loved ones
- The ASI will play a significant role in providing and demonstrating thought leadership in the development of DFC

To achieve these outcomes, key activities were undertaken. Each DFC project set out their key activities with clearly stated expected outcomes for the person with dementia, their family and/or the community. Each project was different but a number had overarching themes that can be grouped as follows:

1. Dementia awareness for the general community
2. Dementia awareness for service providers
3. Volunteer engagement
4. Intergenerational learning
5. Improvements to the physical environment
6. Supporting people with dementia to stay active in their community
7. Supporting families and enabling them to empower their loved ones

### **Plans for Further Activity**

Many of the projects across Ireland will continue to develop their work raising awareness in their local community and supporting people with dementia living in them. The ASI is developing a toolkit for multiple stakeholders on how to ensure their community is more dementia friendly. A complete guide on how to create a DFC is also being developed using the learning from each of the seven projects. The guide incorporated the key elements required for creating a DFC, case study examples of activities undertaken and an outline of the project's challenges and learnings. This toolkit will be widely disseminated across Ireland.

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Ends.