



THE ALZHEIMER
SOCIETY *of* IRELAND

**Submission to the Department of Justice and Equality on the National
Disability Inclusion Strategy 2016-2019**

November 2016



1. Introduction

The Alzheimer Society of Ireland welcomes the opportunity to input into the National Disability Inclusion Strategy 2016-2019.

There are approximately 55,000 people living with dementia in Ireland. If current trends continue this number will increase to 77,460 people by 2026 (Pierce et al., 2014¹).

Dementia is an umbrella term which describes a range of progressive conditions which cause changes and damage to the brain. These changes can affect memory, thinking, language and a person's ability to perform everyday tasks. It is not a normal part of the ageing process and each individual's experience of dementia is different, dependent on the type of dementia they have, the stage of dementia they are in and factors relating to their personality, their social and psychological responses, their support networks and the physical environment in which they live.

Dementia is a disability under Irish equality law² and under the United Nations (UN) Convention on the Rights of Persons with Disabilities³ and like other disabilities, dementia is stigmatised.

People with dementia are socially isolated, marginalised and voiceless because of their disability. Including dementia within the disability framework and altering the responses using a social model of disability is a key way to shift the policy emphasis towards enabling, empowering and supporting people with dementia to live well. Yet, disability discourse rarely, if ever, reference dementia.

For all these reasons, it is important that disability policy on social inclusion addresses the barriers to social inclusion that present for people with dementia.

2. The National Disability Inclusion Strategy: Objectives and themes

The National Disability Inclusion Strategy has 8 broad themes and a wide range of associated actions, to which ASI would suggest the following edits and additions:

¹ Pierce, M, Cahill, S. and O'Shea, E. (2014) Prevalence and Projections of Dementia in Ireland, 2011-2046. Dublin: Trinity College Dublin/NUIGalway/Genio.

² There are two main equality laws in Ireland, which include the Equal Status Acts 2000-2011 and the Employment Equality Acts 1998-2011.

³ The convention defines disability as an evolving concept and results from the interaction between a person's impairment and obstacles such as physical barriers and prevailing attitudes that prevent their participation in society. The more obstacles there are the more disabled a person becomes. Persons with disabilities have long-term physical, mental, intellectual, or sensory impairments such as blindness, deafness, impaired mobility, and developmental impairments. Some people may have more than one form of disability and many, if not most people, will acquire a disability at some time in their life due to physical injury, disease or aging.

3.1 Education

In 2015, the ASI suggested the need to focus on lifelong learning, as the elements of this objective in the original strategy document had too narrow a focus, centred on children and younger people. The ASI, therefore, welcomes the objective to ensure that people with disabilities are supported to transition successfully from one stage of education or training to the next throughout the lifecourse. Specific mention, however, should be made to lifelong learning.

3.2 Employment

The actions under this theme are substantially more developed than in 2015. The ASI welcomes the focus on training employers, which was part of our submission made in 2015.

3.3 Health & Well-being

The ASI suggests that this objective is edited to include 'Health, Well-being and Social Care' as the majority of people with dementia live in the community and use social care services in addition to health services. There is a need for greater integration between health and social care systems to enhance well-being.

Staff in all health and social care services must be fully trained to work with diverse groups including those with a cognitive disability such as dementia. Particularly as the condition is progressive, has unique characteristics and requires a tailored individual response. In addition, appropriate responses are required by trained staff as the population of people with dementia increases alongside population ageing, age being the main risk factor.

3.4 Person-centred disability services

Stigma and ageism are major barriers to accessing services for people with dementia. Disability services must be trained to work with people with dementia. ASI suggests that reference is made in the person-centred care theme to a life-course approach to disability services. This would recognise disabilities acquired with age and acknowledge additional social exclusion issues posed by ageism.

3.5 Housing

There is a need to include an objective that recognises the situation in which independent living may be communal or may include higher levels of intervention and supports. Ageing in place must underpin housing developments.

There is specific mention to people with early onset dementia within this theme but ASI would argue that housing and supports for people with dementia does not have an age limit or marker and instead matters for all people living with dementia.

3.6 Transport and accessible places

People living in rural areas face specific barriers to inclusion regarding lack of transport. Transport must be viewed as a journey and not just a task. It supports social engagement and participation in communities, helping people to stay independent. The process of travelling includes planning around finance, involving other people and arranging pick-up and drop off times.

Living with a disability can mean extra reliance on private transport and this should be a theme.

3.7 Equality and choice

The actions outlined under this theme are welcome.

The ASI suggests that full equality and choice for people with disabilities requires legislative change to how supports in the community are provided. Providing community care on a statutory basis would ensure greater equity and choice for people with disabilities, such as dementia, living in the community.

3.8 Joined-up policies and services

The Government published the National Dementia Strategy in 2014, which has six priority action areas and 14 priority actions. This Strategy must be implemented in order for people with dementia to live well in their communities and play an active role as citizens. There is also a need to ensure that the Disability Strategy on Social Inclusion is integrated with other key Strategies such as the National Dementia Strategy, National Carers Strategy and the National Positive Ageing Strategy. There is also the National Housing Strategy for People with Disabilities, Healthy Ireland and the National Spatial Strategy to address specific issues for people in rural Ireland.

In addition, the Strategy on Social Inclusion must be aligned with the Age Friendly Ireland programmes. The key purpose of Age Friendly Ireland is to manage the now five year old national Age Friendly Cities and Counties Programme. Likewise, the ASI's Dementia Friendly Community project aims to ensure that people with dementia have a voice and are included in their local communities. It is essential that Government policy on social inclusion takes note of these programmes that are already addressing social inclusion.

4 The National Disability Inclusion Strategy: Additional objectives suggested

The ASI suggests that two more themes are included in the Strategy.

The first of these is Social Protection in an effort to acknowledge the extra costs of living with a disability. This must include a theme on entitlements and financial support to utilise the gains offered by assisted technology. The theme on employment is welcome but there needs to be an acknowledgment within the Strategy that not all people with disabilities will be in work or of working age. In this regard, a robust social protection system is necessary to safeguard against poverty and socio-economic inequality when not in employment.

The second is Active citizenship, which recognises that people with disabilities are not just service users but also active citizens. People can be viewed as mainly service users in the process of exclusion rather than stakeholders in ordinary social life. Under this objective is the need to address the disabling aspects of the environment and communities in which people live. In this regard, awareness-raising and education regarding disability, including dementia, is crucial to addressing stigma and enabling people with disabilities to engage fully as active citizens.

6. Conclusion

The opportunity to make a submission on disability policy is welcome by the ASI. It provides the opportunity to highlight the fact that dementia is a disability and people with dementia can benefit from disability policy that supports social inclusion. People with dementia want to remain independent, live at home, be included in their community and make their own choices. Yet, people with dementia experience social exclusion in many aspects of their lives including where they live, what services they can access and what say they have in the services they use. To live well with dementia, people must be enabled to engage in their wider communities and in society and the barriers to that inclusion must be addressed.

References

- Cahill et al (2012) Creating Excellence in Dementia Care.
- Department of Health (2014) National Dementia Strategy.

About The Alzheimer Society of Ireland

The Alzheimer Society of Ireland is the leading dementia specific service provider in Ireland. The Alzheimer Society of Ireland works 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 Alzheimer Society of Ireland is person centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core.

The Alzheimer Society of Ireland also operates the Alzheimer National Helpline offering information and support to anyone affected by dementia at 1800 341 341.