



THE ALZHEIMER
SOCIETY *of* IRELAND

**Submission to the Department of Jobs, Enterprise &
Innovation consultation on the European Pillar of Social Rights**

September 2016



1. Introduction

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to input to the Department of Jobs, Enterprise & Innovation consultation on the European Pillar of Social Rights.

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 living 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

The following questions have been taken from the online consultation and included here with answers to inform a Department submission.

What do you see as most pressing employment and social priorities?

The Alzheimer Society of Ireland wishes to draw attention to the increasing number of people living with dementia and the related impact that this will have for wider social and economic conditions.

There is a significant and rising number of people currently living with dementia in Ireland; approximately 55,000 individuals. If current trends continue, this number will increase to 77,460 people by 2026 (Pierce et al., 2014).

The World Health Organisation (WHO) has identified dementia as one of the major causes of disability among older people worldwide. The World Alzheimer Report in 2010 (Wimo et al., 2010) found that the total estimated worldwide costs of dementia are US\$604 billion in 2010. In Ireland it's estimated that the average annual cost per person with dementia in Ireland is €40,500.

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.

A significant number of employment and social priorities present for people living with dementia and their families and carers. For those living with younger onset dementia, there is a clear need for supported employment initiatives. As retirement ages increase worldwide beyond the age of 65 years, this will be an issue for late-onset dementia also. Carers, as well as people with dementia, would benefit from more flexible work arrangements.

Alzheimer Disease International (2015: 73) maintains that there are considerable challenges in achieving acceptable levels of coverage and access to care. Currently, far too few people with dementia receive a diagnosis, let alone treatment and support. The care sector as a growing employment sector needs to be given appropriate attention to ensure that people with dementia receive and access appropriate care in the right place at the right time.

In conclusion, people living with dementia also have needs, interests and rights beyond care, supported employment and social protection and these extend to inclusion and participation in all aspects of society.

How can we account for different employment and social situations across Europe?

The current outline of the Social Pillar focuses mainly on ensuring disabled people's access to employment. It is important that people with dementia and their specific cognitive needs are incorporated into this understanding of disability.

Is the EU "acquis" up to date and do you see scope for further EU action?

The European Parliament (EP) and the umbrella association Alzheimer Europe (AE) have assumed for some time now that dementia will become one of the greatest challenges facing health and social services in Europe (link http://www.sociopolitical-observatory.eu/uploads/tx_aebgppublications/Demenz_NL_Engl_01.pdf).

It is proposed that the EU 'acquis' are utilised to make active use of the Convention on the Rights of Persons with Disabilities (CRPD), which can enhance the suite of 'acquis' to ensure people with dementia are able to access their rights on an equal basis with others.

What trends would you see as most transformative?

- Demographic trends (e.g. ageing, migration)
- Changes in family structures
- New skills requirements
- Technological change

- Increasing global competition
- Participation of women in the labour market
- New ways of work
- Inequalities
- Other

What would be the main risks and opportunities linked to such trends?

Demographics:

As stated above, the increase in the number of people living with dementia will impact on economic and social conditions in terms of an increasing demand for a workforce that can provide care and support for people living with dementia as well as greater flexibility and innovation in supporting people living with dementia and carers to continue to engage in the workforce themselves.

Changes in Family Structure:

It is most common for family and friends to provide unpaid care to the person with dementia in their own home. In Ireland, the value of informal care for those with dementia is estimated to be €807 million per annum. Changing demographics of families means that women, who traditionally performed most caring roles, are now more likely to be working outside of the home and their incomes are often vital. The overall number of family carers in employment has increased from over one-third to over a half in the past ten years and this number is continuing to rise. In addition, in the current economic climate, financial demands on families are likely to grow, meaning that they will find it increasingly difficult to afford to provide care in the home (Care Alliance Ireland, 2015: 42). This trend is also linked to the participation of women in the labour market as well as wider civic society.

Inequalities:

Specific issues present for people living with younger onset dementia. 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.

Are there policies, institutions or firm practices – existing or emerging – which you would recommend as references?

The Alzheimer's Disease International report on Dementia Friendly Communities Global developments - [available at this link <http://www.alz.co.uk/adi/pdf/dfc-developments.pdf>] contains numerous examples of Government action on dementia at a level that recognises

that people with dementia can continue to contribute and engage in wider society outside of social care and social protection systems.

Do you agree with the approach outlined here for the establishment of a European Pillar of Social Rights?

The Social Pillar includes a focus on disability and long term care in the chapter on social protection but ASI would advocate for disability to be incorporated across all social pillars to ensure that people with dementia, included within the disability category, are viewed not just as recipients of social protection, but as active and engaged citizens who want to participate in all aspects of society.

Article 26 of the EU Charter for Fundamental Rights states that the Union recognises and respects the right of disabled people to benefit from measures to ensure their independence and participation in the life of the community. These rights of people with disabilities, including those living with dementia, should be strengthened by the social pillar.

Are there aspects which are not adequately expressed or covered so far?

Article 24 of the Convention on Rights of People with Disabilities states that all disabled people have the right to inclusive education. However, disabled people are not mentioned as a target group in the Social Pillar's chapter on skills, education and lifelong learning.

The chapter about long-term care should have a focus on transitioning from institutional care to community-based services instead of focusing on making the long-term care system financially sustainable.

The Pillar should adopt a human rights perspective on disability, as outlined in the CRPD. In this regard, the model of disability in the Social Pillar could be widened beyond care and benefits to include a focus on integrating people living with dementia, and other disabilities, throughout society.

What domains and principles would be most important as part of a renewed convergence for the euro area?

All of the areas listed are important in the lives of people living with dementia. However, access to essential services, long term care, housing and financial supports are priority areas from the proposed list.

Long term care and housing are inter-related for people living with dementia. There is growing consensus that home or community based care can be a cost-effective alternative to long-term residential care, yet there is a funding bias towards long term care. Funding and investment in long term care should not replace a focus on community and home based care. The EU social pillar needs to widen the disability focus beyond social protection in order to ensure developments in housing and long term care that are flexible and innovative to support people to live independently for as long as possible. The focus on housing does not mention disability or the role of housing in enabling people to live in their communities for as long as possible.

The section on access to essential services within the social pillar should explicitly mention, within the recommendations, the need to make essential services accessible to people with disabilities.

Finally, employment and social protection must be flexible to meet the needs of younger people living with dementia as well as carers. The social pillar acknowledges the role of informal carers, mainly women, as well as the need to ensure that they can “access leave arrangement” and “care services”. Research has pointed out that approximately 80% of care across the EU is provided by families (spouses and children) and friends, predominantly within the home environment. Even in countries with a well-developed supply of formal long term care, the number of informal carers is estimated to be at least twice as large as the formal care workforce. This needs to be integrated into all elements of the social pillar to ensure the needs of carers and a core part of a more caring and supportive European framework.

How should these be expressed and made operational? In particular, do you see the scope and added value of minimum standards or reference benchmarks in certain areas and if so, which ones?

The social pillar should take a rights-based approach and guarantee that those rights have a strong legal basis.

Social rights, as espoused in this pillar, can not be reliant on voluntary guidelines. Minimum standards and benchmarks can guide effectiveness but law is the only reliable way to ensure compliance.

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.