THE ALZHEIMER SOCIETY of IRELAND

For the attention of the Joint Committee on Disability Matters,

On behalf of The Alzheimer Society of Ireland, I present a submission for the Joint Committee on Disability Matters.

It is imperative that people living with dementia are involved in a meaningful way in the development of policy and legislation in relation to disability. This joint Committee should consider the lived experiences of people with dementia as it develops a Terms of Reference. This will inform the work of the Committee as it strives to ensure the systematic change needed, change that will not only support people with disabilities to be included effectively in society, but that will also support society to continue to be included in the lives of people with disabilities, including those with dementia. People with dementia must not be treated differently or unfairly because of their disability, and the rights of this vulnerable cohort should always be upheld.

I would be willing to appear in public session at a committee meeting to discuss in greater detail the issues outlined below and the lived experiences of people with dementia on the issues that affect them. I would appreciate your consideration of the issues and concerns enclosed.

Yours sincerely,

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Submission to the Joint Committee on Disability Matters

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to make a submission to the Joint Committee on Disability Matters. Our position is informed by The ASI's Charter of Rights for People with Dementia[1], the UN Convention on the Rights of Persons with Disabilities, and the lived experiences of people living with dementia and family carers.

The ASI is keen to inform the Committee of these lived experiences through the Irish Dementia Working Group - an advocacy group of people diagnosed with dementia, and the Dementia Carers Campaign Network- a group of people who have experience caring for a loved one with dementia and who raise awareness of issues affecting families living with dementia.

Understanding Dementia

Before progressing to the issues of this Submission, it is important to understand the context of dementia in Ireland. The number of people living with dementia in Ireland is approximately 64,000, and this figure is expected to rise to 150,000 by 2041[2]. While dementia is not a normal part of the ageing process, age is the main risk factor. Accordingly, the prevalence of dementia is very much connected to Ireland's ageing population. Those with dementia are also very likely to be ageing with another chronic, sensory or physical disability. There is also a high prevalence of dementia among those who have an intellectual disability. Significantly for this Committee to be aware there is also a significant cohort of younger people living with dementia, those aged under 65 years, totalling approximately 4,200[3] people.

Dementia is not an illness in itself, rather an umbrella term used to describe a range of conditions that have similar symptoms, enough to interfere with activities of daily living, and are progressive in nature. Symptoms of dementia range from memory loss, to time and space disorientation, changes in reasoning and motivation, communication difficulties and sensory and functional difficulties. Symptoms differ from person to person and no two people will experience it in the same way. With this in mind, while mental capacity will be affected by dementia, it differs for each individual and the person's mental capacity can fluctuate across time.

In addition, a person's physical, social and emotional circumstances will affect the experience, also their personality and existing familial and friendship relationships have an impact. There is no cure for dementia and as a progressive condition, the supports and care people require change; requiring an increasing range of individually tailored and integrated responses (Department of Health, 2014)[4].

Increasingly, people with dementia are expressing a desire to avoid being defined solely in relation to dementia and to continue to be considered as valued members of society. This is particularly important as the term dementia can have negative connotations. Neurological impairment may interfere with people's day-to-day abilities, coping skills, financial resources, the emotional and psychological impact of dementia, and access to timely and good quality support. Reactions of relatives, friends and fellow citizens are also important, as well as society's response to dementia.

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[1] Irish Dementia Working Group and the Alzheimer Society of Ireland (2016) *A Charter of Rights for People with Dementia.* https://www.alzheimer.ie/getattachment/About-Us/Policy/Human-Rights/A-Charter-of-Rights-for-People-with-Dementia/Charter-of-Rights-for-People-with-Dementia.pdf.aspx

[2] Health Atlas Ireland, 2020.

[3] O'Shea, E. Cahill, S. and Pierce, M. (2017) Developing and Implementing Dementia Policy in Ireland. NUIGalway.

[4] Department of Health (2014) The Irish National Dementia Strategy. Dublin: DoH.

Dementia as a Disability

In Ireland, the dementia discourse has traditionally been influenced by a highly medicalised view of the condition. There is a focus on biomarkers, plaques and tangles, brain scans, cerebrospinal fluid, drugs, custodial care etc. This narrative has drawn extensively on medical, clinical and nihilistic language, often framing dementia in terms of atrophied brains, personal tragedy discourse and negativity.

Although this medical model still abounds, a shift in the tone of dementia discourse is underway. Dementia is beginning to be understood as a disability, with a human rights dimension. This is an important development considering that the myriad of diseases that cause dementia result in a series of difficulties or inabilities relating to, for example, planning, concentration, remembering and so on.

Factors likely to have contributed to an understanding of dementia as a disability include greater public awareness of dementia and the heterogeneity of the diseases causing it; the elevation of the voice of the individual previously silenced; the establishment and advocacy work of the Irish Dementia Working Group and the Dementia Carers Campaign Network; the launching by former president Mary Robinson of an Irish Charter on Human Rights and Dementia; and changes in our mental-health legislation, as reflected in the new Assisted Decision Making (Capacity) Act.

The magnitude and complexity of dementia is such that it requires multiple responses and a broad range of interpretative frameworks. Understanding dementia as a disability and through a human rights lens can ultimately help to create solutions and build a more humane and inclusive world those affected by dementia.

Relevant Legislation

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) provides the framework to promote, protect and ensure the rights of all people with disabilities and promotes equal rights in all areas of life. Ratified by Ireland in 2019, this legislation is extremely important for people with dementia as it refers to the person with disability as having legal capacity (decision-making ability) on an equal basis in all aspects of life. It also includes a section on supported decision making which respects the person’s autonomy, will and preferences.

Framing dementia as a disability confers rights on people as embedded in the UN CRPD. This includes the right to the highest attainable standard of health including with respect to a diagnosis, its ethical disclosure, access to rehabilitation services and to post-diagnostic services including drug treatments and non-pharmacological supports. And people with dementia have the same legal rights as others throughout all stages of their life: these legal rights are inviolable and can never be removed no matter how advanced the dementia.

The ASI’s Charter of Rights for People with Dementia calls for greater participation, accountability, equality, empowerment, and legal recognition for the rights of people with dementia. The voice of the person with dementia and their carers should be strengthened, and dignity and person-centredness should be respected at all times. In line with CRPD, emphasis must be on assisting the person with dementia to exercise their legal capacity, making every attempt to ascertain their wishes and preferences.

It is of concern that most people with dementia and their family members are unaware of their rights and many countries, even those that have ratified the CRPD, like Ireland, continue in part to operate out-dated legislation whereby people’s rights are often breached. This situation must change to ensure that where new legislation has been introduced, it is now fully implemented.

Dementia Care Pathway

People with dementia often experience discrimination and marginalisation and there is a need for more equitable health and social care policies. Currently there is no clear formal care pathway for people with dementia and there is a need for investment in post-diagnostic support from diagnosis disclosure and access to an accurate diagnosis to palliative care.

The 2017 national mapping exercise[5] of dementia-specific services points to serious geographical inequity and black spots where there are inadequate or non-existent services. It highlights that no county in Ireland has even a minimum standard of dementia services, and shows a lack of services to meet the overall need. The level of services available across area/ counties differs significantly, and clients in areas with fewer resources available locally find this immensely frustrating. Systemic discrimination and stigma can bring additional isolation, and lack of support leaves many carers with no option to take time out from their sustained workload and full-time role of caring.

Integrated Service

Many people with dementia and family carers experience services that are fragmented and disjointed and this can compound anxiety and concern during an already difficult time, and it can hinder families from accessing appropriate services.

There should be a strategic approach to dementia care within the health care system, and this should include an integrated and multi-disciplinary response by community services, primary and acute care to support people with dementia and their carers. Home care support and Dementia Advisers need to be allied closely with primary, acute and long-term care and have a strong working relationship within HSE structures, whilst a ‘whole community’ approach mobilises support and understanding for dementia care.

Young Onset Dementia (YOD)

Although people with YOD (under 65) represent a relatively small number of all those living with dementia (4,200), the impact of having this disease at this time in their lives is so huge that it reverberates and causes immense hardship and heart break, not only to the person with YOD, but also to their whole family. People who are affected by YOD can face different challenges to people who are affected by dementia at an older age, and may need different supports.

Many people with YOD experience difficulties accessing relevant services because most services are available only to people over the age of 65. However, upon reaching the age of 65 their condition is often perceived as an older person’s issue. There is no defined path for them to follow to access care and no one service that takes ownership to care for them.

In the earlier stages of symptom onset, timely diagnosis is the most pressing problem confronting people with YOD and their families. Delays in diagnosis and misdiagnoses with symptoms attributed to other causes, are very stressful for all affected. Essential elements of timely diagnostic services should include clear pathways to assessment, good diagnosis and disclosure patterns and referral to both specialist and generalist post-diagnostic services.

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[5] Dementia Specific Services in the Community: Mapping Public and Voluntary Services (2018) The Alzheimer Society of Ireland and the National Dementia Office in the Health Service Executive.

Impact of COVID-19

Living with dementia at any time brings everyday challenges for the person and those around them. The challenges from the impact of COVID-19 have made daily life considerably more difficult and are exacerbating the vulnerability of this group. People with dementia are disproportionately affected by COVID-19. Data from the UK Office for National Statistics reveals dementia to be the main underlying condition for 1 in 4 Covid-19 deaths.

A recent ASI research[6] report uncovered the extent of the plight and predicament facing people living with dementia and those who support them, as they struggle to cope with increased care workloads and decreased supports. Stress, exhaustion, loneliness and anxiety have intensified as many COVID-19 restrictions imposed on dementia services continue with no end in sight. Many fear they have been forgotten and abandoned. COVID-19 has not caused this plight, rather it has brought into sharp focus how people with dementia and their carers are routinely neglected and overlooked.

A targeted response is urgently needed to support people with dementia and their carers during COVID-19, particularly as many vital services remain closed. Many carers report that their loved ones are declining and dementia symptoms are accelerating as they struggle without services. There is an urgent need to put safe and appropriate community services in place for this cohort. Public policy should focus on supporting family carers who have shouldered a disproportionate burden during this global pandemic. Supports for carers need to be put in place immediately to address both the short and long-term needs of carers arising from COVID-19. This should include crisis prevention care, and therapeutic services including counselling should be made available to address the rise in mental health challenges.

Summary recommendations for the Committee

1. Ensure that the lived experience of people impacted by dementia is heard in the Committee's work. The ASI can support and facilitate access to people with the lived experience through our work with the Irish Dementia Working Group and Dementia Carers Campaign Network.

2. Dementia must be seen as a disability so that the same rights are conferred on people as embedded in the UN CRPD.

3. People with dementia need a care pathway, currently there is no clear formal journey for them. There is a need for investment in post-diagnostic support from diagnosis to palliative care.

4. People impacted by dementia experience services that are fragmented and disjointed and this hinder family from accessing appropriate services at the right time.

5. Special attention needs to be brought to people living with Younger Onset Dementia as this group in particular experience difficulties accessing relevant services because most services are available only to people over the age of 65.

6. Recognise and understand some of the unique challenges facing people impacted by dementia as a result of COVID-19.

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[6] The Alzheimer Society of Ireland, (2020) Caring and Coping with Dementia during COVID-19.

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