Public consultation on the updated National Standards for Residential Services for Disabled People

16 July 2026

Please provide your feedback on the standard statements and features set out under Principle 1: A Human Rights-based Approach

This public consultation response is submitted by The Alzheimer Society of Ireland (The ASI). The ASI is the largest dementia-specific service provider in Ireland, supporting people living with dementia, their families and carers through a wide range of community-based services and supports.

Dementia is a syndrome caused by a range of progressive brain diseases, the most common of which is Alzheimer's Disease. It is characterised by a progressive loss of cognitive and functional abilities, often impinging on quality of life and the ability to live independently. Alzheimer Europe estimates that 69,949 people are currently living with dementia in Ireland. AE also reports that there is currently an estimated 9,065,706 people with dementia in the EU, a figure which will increase to 14,335,788 by 2050. As the most significant risk factor for dementia is ageing, dementia mainly affects older people. However, there are growing numbers of people diagnosed with young-onset dementia (i.e. before age 65) who have a unique set of needs.

The ASI's vision is a society where people on the journey of dementia are valued, can realise their rights and exercise choice, and are living well where they choose. Dementia is a recognised disability under the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and in Irish equality laws. However, this recognition does not always translate in Ireland to service provision, including residential services. The ASI strongly welcomes the inclusion of a human rights-based approach as a key guiding principle of the Updated National Standards for Residential Services for Disabled People ("the Updated National Standards").

Living with Dementia and Residential Care Settings

While there has been an increasing focus on supporting people to age in place, some people living with dementia will, at different stages of their condition and for a variety of reasons, require or choose to move into nursing home care. Also, some people may develop dementia after moving to residential care. As highlighted in The ASI's 2022 Briefing Paper, *Adult safeguarding & People with Dementia in Nursing Homes* ("the 2022 Briefing Paper"), a significant number of people with dementia in Ireland are likely to live in nursing homes and other residential care settings.

People living with dementia in residential care settings should be supported to enjoy a good quality of life, maintain and develop relationships, and contribute to society. However, institutional and organisational practices within nursing homes can restrict residents' privacy, dignity, choice and independence, while also limiting opportunities for social engagement and participation in meaningful activities.

People living with dementia in nursing homes often have more complex care needs, may face difficulties communicating those needs, and can be particularly vulnerable to the effects of inadequate care. As a result, specific consideration must be given to ensuring their safety and protection. For a more in-depth discussion of human rights of people living with dementia in nursing homes and other residential care settings, please see the 2022 Briefing Paper: https://alzheimer.ie/wp-content/uploads/2023/09/Adult-Safeguarding-and-People-with-Dementia-in-Nursing-Homes-Final-Report-2.pdf

Impact of Living with Dementia on Human Rights

Living with dementia can impact a person's enjoyment of human rights in various and profound ways.

Impact on Daily Activities and Independence

The impact of dementia extends far beyond cognitive symptoms. Difficulties with everyday activities such as managing medications, organising oneself, preparing meals, handling finances, driving, attending appointments and navigating familiar environments can significantly reduce independence. Over time, people with dementia require assistance with personal care and other activities of daily living, increasing reliance on informal and formal care supports.

In 2023, The ASI conducted a national study, *The Experience of Dementia in Ireland* (https://alzheimer.ie/wp-content/uploads/2023/09/The-Experience-of-Dementia-in-Ireland-2023.pdf), which captured the perspectives of 72 people living with dementia and 597 family carers. One respondent outlined their experience of living with dementia as follows: *"I am no longer self-sufficient, can't remember how to do basic tasks."* For many people, the loss of independence associated with dementia is one of the most feared and distressing aspects of the condition. Activities and responsibilities that were once routine become increasingly challenging, resulting in a gradual loss of autonomy and confidence.

The provisions of the Updated National Standards under Standard 1.2 Autonomy are particularly welcome in this regard. People living with dementia in residential care settings should be supported to maintain their autonomy, including by completing everyday tasks and activities independently.

Impact on Social Participation

Social participation is deeply affected by dementia. People tend to withdraw from social activities due to cognitive difficulties, reduced confidence, practical barriers or stigma. Activities that once provided enjoyment, purpose and connection can become increasingly difficult to access or sustain. There are a number of reasons why a person living in a residential care setting would face difficulties in realising their right to social participation, such as reduced opportunities to participate in community life, and separation from established social networks.

The ASI's research consistently demonstrates the importance that people living with dementia place on maintaining meaningful activities, social connection and maintaining their sense of identity following diagnosis. However, many individuals report barriers to participation and a lack of appropriate opportunities and supports. For example, in The ASI's national research in 2023, one person living with dementia reported *"I used to be very actively engaged with all local groups GAA, active retirement, community alert, historical committee… But when I was diagnosed with dementia, all that stopped because I thought it was the end."* This withdrawal from social participation can contribute to loneliness and isolation for the person living with dementia. This is also deeply concerning as social participation is essential for brain health according to 2024 report of the Lancet standing Commission (https://pubmed.ncbi.nlm.nih.gov/39096926/). In the case of people living with young-onset dementia (YOD), it is important that activities and social connection appropriate for their age be considered. As dementia primarily affects older people, often residential nursing homes and dementia-specific units are set up for this cohort, and people with YOD are not catered to.

While there are several references in the Updated National Standards that relate to participation, inclusion, relationships or engagement, The ASI would welcome an explicit reference to the importance of social participation and how this can be promoted in residential care settings in Ireland.

Impact on Family and Personal Relationships

It is estimated that for every one person diagnosed with dementia, three people in their close circle are significantly impacted. Family members frequently assume caregiving responsibilities, often resulting in changes to established roles and dynamics within families. Family members often continue to provide practical, physical, and psychological care to their relative in the nursing home and act as an important care partner. Caring responsibilities place significant demands on spouses, partners, children and other relatives, affecting family life, social participation and overall wellbeing. Findings from our national research demonstrate that both people living with dementia and family carers experience unmet support needs and challenges accessing appropriate services. Family carers report balancing caregiving responsibilities alongside employment, parenting, financial commitments and their own health needs. The

progressive nature of dementia places considerable and growing emotional and practical strain on family relationships over many years.

The ASI welcomes the provisions of the Updated National Standards under Standard 1.4 Relationships and Intimacy which highlight the importance of supporting the right to relationships, family life, friendships and intimacy.

Recommendations

A series of recommendations were set out in the 2022 Briefing Paper to support the human rights of people living in nursing homes with dementia, including:

- Promoting a human rights-based approach
- Supported decision-making
- Promoting agency and identity
- Creating dementia-friendly environments
- Ensuring meaningful participation
- Supporting relationships and family life
- Using restraint-free and person-centred care

Charter of Rights for People with Dementia

The ASI has worked consistently to advance the rights of people living with dementia by championing their lived experience to achieve rights-based policy and law reform. A key element of this was the publication of a **Charter of Rights for People with Dementia** ("the Charter") in April 2016 with the IDWG. The Charter calls for greater participation, accountability, equality, empowerment, and legal recognition of the rights of people with dementia.

Assisted Decision-Making (Capacity) Act 2015

Supported decision-making is an important step in respecting the autonomy, participation and human dignity of older persons with cognitive impairment, including people living with dementia. A number of the principles underlying the Assisted Decision-Making (Capacity) Act 2015 (ADMCA) merit highlighting here as important examples of good practice, including:

- A person is presumed to have capacity unless it is shown otherwise.
- A decision is only made for a person when it is necessary.
- A decision made for a person must be the least restrictive of their rights and freedom.
- A decision must respect the person's right to dignity, bodily integrity, privacy, autonomy and control over their own affairs.

- A person should be permitted, encouraged and facilitated to participate in any action/intervention taken for them.

Capacity is assessed using a functional test, which recognises that a person may communicate their decision through a range of methods, including speech, writing, sign language, assistive technology, or any other means.

Conclusion

People living with dementia in residential care settings retain the same rights to autonomy, dignity, participation and self-determination as all other citizens. While dementia may affect a person's ability to communicate, make decisions independently, or advocate for their preferences, it should never diminish their rights, voice or value. The ASI believes that residential care services must actively support people living with dementia to exercise choice, participate in decisions affecting their care and everyday lives, maintain meaningful relationships, and remain connected to their communities. This requires a human rights-based approach, dementia-specific expertise and supports, robust supported decision-making practices, and the meaningful involvement of people living with dementia in policy and service development.