Submission to the Aras Attracta Review Group National Consultation Process on the Rights, Health and Wellbeing of Adults with an Intellectual Disability in Ireland

*September 2015*
1. Introduction
The Alzheimer Society of Ireland welcomes the opportunity to input into the Aras Attracta Review Group National Consultation Process on the Rights, Health and Wellbeing of Adults with an Intellectual Disability in Ireland.

There are approximately 48,000 people currently living with dementia in Ireland. This number is expected to increase significantly in the coming years; rising to 68,216 people by 2021 and to 132,000 people by 2041 (Pierce et al., 2015).

However, as Cahill et al (2012: 33) highlight, the Irish dementia prevalence rates exclude data on people with intellectual disability (ID) including those with Down syndrome and dementia. People with an ID have no excess risk of developing a dementia but they do face particularly issues with diagnosis, assessment and management of dementia. However, those with Down syndrome (DS) are at a heightened risk and there is a large body of research evidence which provides convincing evidence that rates of Alzheimer’s type dementia are significantly higher in persons with Down syndrome compared with the general population (Stanton, 2004).

McCarron et al (2010:286) suggest that current estimates are that 15–40% of persons with DS over the age of 35 present with symptoms of dementia and that their related declines are precipitous. The onset is also earlier, the mean age of dementia in persons with Down syndrome is estimated to be 51.3 years (ibid: 286). Recent data from IDS-TILDA\(^1\), the Intellectual Disability Supplement to TILDA (The Irish Longitudinal Study on Ageing) found that in the three-year period since the first wave of data collection was conducted in 2010, the prevalence of dementia among people with Down syndrome over the age of 40 had almost doubled from 15.8 per cent to 29.9 per cent.

The National Dementia Strategy (2014) refers to the need to ensure that available resources are deployed on the basis of need and as effectively as possible to provide services for all people

\(^1\) Accessed via http://www.idstilda.tcd.ie/info/
with dementia, including those with an intellectual disability (NDS: 13). In addition, Cahill et al (2012:86) maintain that people with intellectual disabilities, who develop a dementia, are a particularly disadvantaged group in Irish society at risk of being overlooked by mainstream and specialist service providers.

For all of these reasons, ASI are making this submission on the basis that it is critical to consider dementia when consulting on the rights, health and wellbeing of adults with an intellectual disability in Ireland.

2. **About The Alzheimer Society of Ireland**

The Alzheimer Society of Ireland 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 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.

3. **Dementia policy and people with intellectual disabilities**

Cahill et al (ibid: 86) state that there is a dearth of published literature available to inform the development of services for people with an intellectual disability who have a dementia (Jokinen, 2005; Llwellyn, 2011). In this regard, there is little evidence for policymakers and services providers to inform and develop dementia care services for people with intellectual disability who are living with dementia (Jokinen, 2005).
People with intellectual disability and dementia often fall between the cracks of different service delivery structures, including intellectual disability services, generic community care services for older people and those specifically for people with dementia (ibid: 86). Like older people, the social care services required by people with an intellectual disability and dementia include in-home supports, day care services and respite services. However, they also have specific needs related to dementia as highlighted in the National Dementia Strategy (NDS) which identifies people with intellectual disabilities as an important target group for better awareness and understanding of dementia. The NDS also mentions people with intellectual disabilities in the context of diagnosis and management of dementia. The following submission expands of these issues in more detail.

4. Better awareness and understanding of dementia

Intellectual disability services are encouraged to proactively prepare for dementia care (Janicki and Dalton, 2000). Different and useful service models have been identified (Janicki et al. 2002; Kerr et al., 2006), including ‘ageing in place’, ‘in place progression’ and ‘referral out’ models (Cahill et al., 2012:86). However, recent research results show that there is an absence of an adequate skill-base in relation to dementia assessment in Intellectual Disability services (De Siún and Manning, 2010; McCarron et al., 2011). Research shows specifically a lack of preparedness and understanding among staff in the intellectual disability services on the course of dementia, issues relating to advanced dementia and end-of-life issues (McCarron & Lawlor, 2003; McCallion & McCarron 2004).

Yet the information needs of particular vulnerable groups such as young people with dementia and those with an intellectual disability and dementia are likely to be different from those of the majority population and may require specifically tailored approaches. Notably, the National Dementia Strategy has identified people with intellectual disabilities as a target population, particularly at risk, and in need of better awareness and understanding of dementia (NDS: 14). The NDS (ibid: 24) also states that staff in all care settings should have the necessary training for treating and supporting a person with dementia, including training in palliative approaches that are appropriate for people with dementia.
5. Diagnosis, interventions and integrated care

Many Irish people with early onset dementia and people with an Intellectual Disability are either misdiagnosed or their dementia remains undetected (Haase, 2005; McCarron et al., 2011: 120). A Guidance Document by the Faculty of Learning Disability Psychiatry of the College of Psychiatrists of Ireland maintains that the assessment of dementia in persons with intellectual disabilities (ID) should be multidisciplinary. The Guidance Document (2014) also suggests that in the management of dementia in persons with ID, once the diagnosis has been made, the multidisciplinary team should communicate the diagnosis to carers and family as soon as is practical. Members of the multidisciplinary team should include a consultant psychiatrist in intellectual disability, a clinical psychologist, a social worker and specialist nurses with access to occupational therapy, physiotherapy, and speech and language therapy.

The NDS has a priority action on timely diagnosis and intervention. Specific mention is made to intellectual disability services:

*The Health Service Executive will review existing service arrangements so as to maximise the access that GPs and acute hospital clinicians have to specialist assessment and diagnosis of dementia, including Old Age Psychiatry, intellectual disability services, geriatric medicine, neurology services and memory clinics (NDS: 14).*

An additional action within this priority area on diagnosis and intervention states that the Health Service Executive will examine the issues arising regarding the assessment of those with Down Syndrome and other types of intellectual disability given the early age of onset of dementia for these groups and the value of establishing a reliable baseline (NDS: 23).

Post diagnostic supports and the need for an integrated approach to care are central to managing dementia for people with intellectual disabilities. Cahill et al (ibid: 86) maintain that the health and social care needs of people living with intellectual disabilities and dementia has received much less attention compared with topics relating to their assessment and diagnostic needs (Strydom et al., 2009). In this context, the importance of cross agency and interdisciplinary liaison is often highlighted (Lwellyn, 2011). There is a need for intellectual
disability services to network effectively with primary care health services and generic and
dementia-specific community care services.

Cahill et al (ibid: 86) also explain that current thinking suggests that people with intellectual
disability who acquire a dementia are best cared for by service providers who have specific
intellectual disability expertise (Dodd, 2003; Kerr et al., 2006; McCarron and Lawlor, 2003;
Watchman 2003). However, professionals working in this specialist field lack knowledge and
skills in dementia care (De Siún and Manning, 2010). This highlights the need for better
dementia training and support for staff working in intellectual disability services. However,
Cahill et al (ibid:86) point out that there is general agreement that people with intellectual
disabilities and dementia should have the same access to specialist dementia services as those
without learning disabilities (Llwellyn, 2011).

From diagnosis to post diagnostic care, it is important to ensure that the individual and his/ her
family are consulted and involved in the process and the development of any care plans. The
Guidance Document (2014: 8) by the Faculty of Learning Disability Psychiatry of the College of
Psychiatrists of Ireland states that

*The individual also has a right to be informed as much as possible about their illness. There
are some useful books for people with ID that deal with growing older and dementia
published by the British Institute for Learning Disabilities (Dodd et al, 2005). The individual’s
GP and family should be informed of the diagnosis and management plan as they may be
increasingly involved as the disease progresses.*

6. Conclusion

Supporting persons with intellectual disabilities and dementia is a concern for health and social
care policy particularly as the population of people with intellectual disabilities ages. The
National Dementia Strategy (2014) has identified the need for an integrated and multi-
disciplinary response by community services, primary care and secondary care as a way to
support people with dementia and their carers. This means an integrated approach across the
dementia journey, from information to diagnosis and care. The rights, health and well-being of
people with intellectual disabilities must be placed within a life course approach that acknowledges how dementia may present as they age and live for longer.

References


**Further information:**

Further information on this submission is available from The Alzheimer Society of Ireland, Temple Road, Blackrock, Co. Dublin.