**Submission to The Special Rapporteur**

**on the Rights of Persons with Disabilities**

**in response to Call for Submissions**

**on the rights of older persons with disabilities**

I make this submission as an independent researcher with a keen interest in this area. I have selected a few key areas on which I am best placed to comment based on my research and other experience.

I have recently completed a PhD on disability and ageing (taking in the experience of first experiencing disability with ageing as well as that of ageing with long-standing disability, see Leahy 2018b, cited below). I have many years of experience of working within and NGO in the age-sector, and also experience as a researcher in a range of areas including healthcare. I am also a qualified lawyer (Solicitor).

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**Questionnaire on the rights of older persons with disabilities (English)**

1. Please provide information on the legislative and policy framework in place in your country to ensure the realization of the rights of older persons with disabilities, including both persons with disabilities who are ageing and older persons who acquire a disability.

In Ireland, there has been a large policy focus on disability and many explicit policies for many years, including a national strategy (from 2005). The UNCRPD has been ratified only since 2018. The Irish Human Rights and Equality Commission is Ireland’s national human rights institution and national equality body.

However, there are a number of issues around how policies are approached and implemented – both for disabled people generally and for older disabled people. I highlight three issues in this part of this submission:

* **Lack of Enforceable rights -** public policies do not generally confer rights of access to services and supports;
* **Separate Policy Frameworks on Ageing and Disability** - traditionally separate approaches to policy on ageing and on disability mean that older disabled people generally do not benefit from the approaches and models of disability that apply to disabled people more generally (and all of this occurs within a broader context in which community/home support in Ireland is not well-developed for either group); and
* **Underdeveloped Policies for those Ageing with long-standing disability -** the policy framework is not well developed for those ageing with long-standing disability.

**1.2 Lack of Enforceable Rights**

A seminal policy document from 1996, The *Report of the Commission on the Status of People with Disabilities, A Strategy for Equality*, articulated three informing principles:

* disability as a social issue not a medical one;
* a civil rights perspective; and
* equality as a key feature of the human rights approach.

This positions disability within social models and it promotes rights (Linehan *et al.* 2014). Legislation (the Disability Act 2005) and a series of measures introduced in 2005 amounted to a National Disability Strategy whose main objective was supporting disabled people to be active and contributing members of society and involving mainstreaming of disability issues across government departments. However, lacking a legal basis for its commitments, key aims have not been realised (Jenkins 2013) and a national review suggested that services do not meet stated policy objectives with little opportunity in practice for self-determination (Expert Reference Group on Disability Policy 2010).

In addition, older disabled people (or at least those first experiencing disability in older age) for the most part come within older people’s services which tend to be informed by different values and objectives, which I come to next.

**1.2 Separate Policy Frameworks**

Separate public policy frameworks operate for ageing and disability and, thus, they underscore difference between people with different timings of disability onset (using age 65 as the boundary). Separately funded ageing and disability sections operate within the Department of Health and within Ireland’s national health service, run by the Health Service Executive (where both are in the Social Care Directorate). Separate funding streams militate against boundary-crossing and create difficulties for some groups, such as those with early onset dementia (Conroy and Mangan 2006). Those who experience disability for the first time in later life may only encounter older people's services, and, thus, a small difference in timing of disability onset around one's 65th birthday may result in experiencing a different service model. The Disability Federation of Ireland (2009; 2014) highlights anomalies, including the fact that those experiencing disability after age 65 do not have access to the same range of services as those experiencing disability prior to age 65.

That the two frameworks operate out of separate values and with separate objectives can be illustrated by reference to key public policy documents. For example, the Health Service Executive national plan for 2019 articulates aims for disabled people that include ‘supporting and enabling people with disabilities to maximise their full potential, living ordinary lives in ordinary places, as independently as possible’ (Health Service Executive 2018: 49). Their voices are to influence planning and improving services. However, aims for older people more typically focus on efforts to ‘maintain’ them in their homes and communities, while also referencing the need for availability of residential care. For example, the same national plan for 2019 characterises its older persons’ services as ‘delivered through a community-based approach, supporting older people to live in their own homes and communities and, when necessary, ….avail[ing] of high quality residential care’ (Health Service Executive 2018: 58). Thus, for older people there is no reference to independence, participation in communities or for input into service planning or improvement.

Meanwhile, *the National Positive Ageing Strategy* (informed by an active ageing approach, although lacking much implementation) focuses on promoting a self-managed approach to maintenance of health and functioning, but does not address how active ageing is to be achieved by older disabled people (neither those first experiencing disability with ageing nor those ageing with long-standing disability).

Research which I conducted with Irish people working in social care in policy-making, service provision and activism on ageing and on disability in Ireland found there was often no concept of disability with ageing, and participants identified people acquiring impairment as they aged with terms like ‘just elderly’ (see Leahy 2018a). A ‘disabled older person’ was often understood to be someone who was ageing having lived with lifelong disability. At a fundamental level, the findings suggest the need to find ways in common across the two sectors of articulating what it is to experience disability in older age. I suggest that universal, biopsychosocial understandings of disability, associated with the U.N. Convention on the Rights of Persons with Disabilities, could facilitate the encompassing of people experiencing

disability with ageing within the category of ‘disabled people’ and provide a common language between the two sectors. This would be one step in a process that needs to interrogate the different informing philosophies and approaches of older people’s and disability policy and service frameworks – a prerequisite, I suggest, in relation to any integration or alignment between the two.

Two separate - and potentially overlapping - initiatives on social care started in Ireland during 2017 from the disability and older people's sections of the Department of Health, respectively. Mirroring developments that have already taken place in other countries (see Anand et al., 2012), the first involves moves towards a widespread personalised approach designed to facilitate increased levels of choice and control for ‘people with disabilities’ (Department of Health, 2016). Simultaneously, the second involved a consultation process relative to homecare – concerning proposals for a new statutory scheme and system of regulation (Department of Health, 2017). Advocacy groups responded in the context of the latter by pointing out the need to address homecare delivery across the lifecourse (Active Ageing Partnership et al., 2017). The first process (involving a Taskforce on Personalised Budgets) has resulted in a recommendation that demonstration projects be initiated to test the delivery of personalised budgets with a view to identifying the best approach to the wider roll-out of these payment models. No report or recommendations have issued yet from the consultation process on establishing a statutory homecare scheme. How these two processes are to be linked to ensure that people with disabilities of all ages receive high quality, appropriate support at home needs to be clarified[[1]](#footnote-1).

One final point I wish to make here is that, unfortunately, it is obvious why advocacy for

disabled people often attempts to link rights for disabled people to those aimed at children and adults below retirement age so as to be considered entitled to the full participation and activity afforded to adults (Jönson & Larsson, 2009). I would suggest that there is the need for more linkages between the two policy and service frameworks, and that this should be approached in a way that subjects their underlying assumptions and philosophies to scrutiny (see Leahy 2018a).

**1.3 Policies for those Ageing with long-standing disability**

Those ageing with lifelong disability have not been a significant focus of Irish public policies, and the policy framework for them has received little attention and is not well developed (Anand et al., 2012), something that mirrors the position in other countries (see Bigby, 2002; Raymond et al., 2014).

In the Irish context, this can be illustrated by reference to the fact that while some iterations of national disability policy suggest that older people's services are responsible for

life-long disabled people after age 65 (see Expert Reference Group on Disability Policy, 2010; Working Group Report, 2012), the sole reference to disability within the goals and objectives of the National Positive Ageing strategy (published in 2013), is to its *prevention* (objective 2.1) and policies on ageing do not generally have any specific focus on this group (that is, people ageing with long-standing disability). In my study (Leahy 2018a, b), I found instances of those ageing with disability experiencing (on reaching age 65) continuity in social care provision (that is, staying within disability services and sometimes benefitting from its values/approaches) and others experiencing disruption and diminution of services by being transferred to older people’s services at age 65 – the latter appeared to be operating in some geographical areas or on a discretionary basis.

The position of older people with longstanding disability requires a specific policy focus. The likelihood of their experiencing exclusion or marginalisation over a long period of time (which means that many will be ageing with cumulative disadvantages) requires, I suggest, development of a particular focus and skills within public policies and greater linkages and learning across the two sectors, which has often been absent so far. It may also be the case that those first experiencing disability with ageing might benefit from approaches that inform disability services if they were more available to them.

1. Please provide information on discrimination against older persons with disabilities in law and practice.

There has been much research on disability in Ireland over the last decade – but most of it does not focus on *older* disabled people. Much of this work has focussed on attitudes to disability, the experiences of (younger) disabled people and the issue of disability and labour market and service-related discrimination. One such recent research study comes from the Irish Human Rights and Equality Commission and the Economic and Social Research Institute (Banks *et al,* 2018). Its specific focus was not older disabled people but it included older disabled people and it acknowledges that disabled people are more likely to be older. The report found that disabled people:

* experienced discrimination mostly in health services and in private businesses;
* when they experience discrimination, it has a more serious effect on their lives (than on the lives of non-disabled people).

The report suggests that the experience of any type of discrimination falls with age. However, as the report acknowledges, the equality module on which the report is based provides a subjective measure of discrimination. It does not tell us whether individuals have experienced discrimination but rather whether individuals have reported to have experienced discrimination. As the report states, “Some groups might therefore over- and others under-report discrimination depending on characteristics such as gender and levels of education for example”.

I would suggest that these issues would bear further examination. For example, Irish older people have lower educational levels relative to other age groups (according to the Central Statistics Office analysis of the 2016 Census). Furthermore, it is possible that perceptions of less discrimination with ageing may be associated with the fact that those first experiencing disability in later-life tend *not* to identify with a disability identity, thought to relate to their perception that their functioning is normal for their age (Langlois *et al*.1996; Kelley-Moore *et al.* 2006; World Health Organization and World Bank 2011). It is also likely that those first experiencing disability with ageing do not identify discrimination because they do not have a ‘disability’ consciousness – not generally coming within ‘disability’ services, and separate policy frameworks likely contribute to this (see Leahy 2018b).

As mentioned, I conducted a PhD thesis addressing the experience of ageing with disability as well that of first experiencing disability with ageing (focusing on physical and sensory disability) and comparing the two experiences (see Leahy 2018b). Amongst its findings are that while older disabled people are often not considered ‘disabled’ as younger people might be, the subjective experience of disability in older age is consistent with a biopsychosocial model of disability (where disability is the outcome of the interaction between individual and contextual factors), and, thus, to a model, applied within the field of disability (including in human rights instruments) but not of ageing – where, by contrast, ‘disability’ tends to be understood as a predominantly individual or biological process. It also shows how separate frameworks for policy on ageing and disability contribute to keeping in place medicalised, reductionist notions about the nature of disability in older age (see Leahy 2018a, b).

Some participants in this study who first experienced disability in older age *did* identify with a disability identity – and that, I suggested, was related to their (somewhat anomalously) benefitting from the support of a mainstream disability organisation (that is, disability organisations operating out of a social model informed by human rights principles and that more typically support younger disabled people or at least people first experiencing disability before age 65). Furthermore, while many participants first experiencing disability in older age did not describe themselves as ‘disabled’ or wish to be so identified, what they experienced in their contexts (physical environments etc) and in daily interactions with others was often consistent with how disabilty scholars discuss the experience of marginalisation or exclusion from the mainstream of social interaction that is the experience of disabled people generally (Watson 2003: 40). I conclude that their own tendency (reflecting a broader societal tendency) not to consider themselves as ‘disabled’ does not protect them from disablism[[2]](#footnote-2) but that it does mean they do not benefit from a sense of solidarity with other disabled people (see Leahy 2018b).

Disability scholars like Wendell (1996:27), suggest that connecting with other disabled people helps to build solidarity. For Wendell, she said it helped her to feel no longer ‘struggling alone’. My study evidences that those first experiencing disability with ageing could experience the prejudice and exclusion of disablism without the sense of support or solidarity from identifying or connecting with other disabled people, something kept in place by the separate models used in disability and ageing frameworks.

1. Please provide information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the realization of the rights of older persons with disabilities in general, as well as with particular focus in the following areas:
* Exercise of legal capacity;
* Admission procedures to social or healthcare services, including involuntary admissions;
* Older persons with disabilities living in institutions;
* Access to support to live independently in the community;
* Access to free or affordable healthcare:
* Access to free or affordable rehabilitation goods and services;
* Access to social protection schemes; and
* End of life and palliative care.

Here I have opted to focus on a few issues:

* Legal Capacity,
* Access to Support to Live Independently in the Community,
* Access to free or affordable healthcare
* End of life or Palliative Care

I will deal with the issue of residential care, below, in answer to question 4.

**3.1 Legal Capacity**

Anticipating ratification of the UNCRPD, the Assisted Decision Making (Capacity) Act was enacted at the end of 2015 but key provisions have not yet been implemented. When implemented,

* it will place a legal requirement on service providers to enable a person make a decision through the provision of a range of supports and information appropriate to their condition,
* it will abolish the Wards of Court system and provide for a review of all existing wards to either discharge them fully or to transition those who still need assistance to the new structures.

Thus, under the Assisted Decision-Making (Capacity) Act, the wardship system is to be gradually wound up and will be replaced by the new assisted decision-making scheme (a Ward is someone deemed by the court to lack capacity to make decisions). In the interim, however, the number of applications for wardship is rising. There are almost 3,000 Wards, with total assets of over €1 billion (National Safeguarding Committee 2017). Adults who are made Wards of Court are predominantly older people - in 2016, of the 289 adult declarations of wardship 81% (234 people) were admitted to wardship due to dementia and age-related illness (National Safeguarding Committee 2017).

A range of issues have been identified with the system of wardship by Safeguarding Ireland (a not‐for‐profit formed with the support from the Irish Government). Issues they highlight include:

* Procedures of the Ward of Court system rely excessively on the integrity of families and professionals acting in the best interests of vulnerable adults and there are concerns that there are insufficient checks to ensure that the interests of a proposed Ward are independently considered and possible conflicts identified.
* There is no system of review of Wards; there is no system of unannounced visits or otherwise, although (at the time of the report) there were plans to introduce this on a random basis.
* There is no automatic system of providing prospective Wards in an application for wardship with independent legal or non-legal advocacy.
* There is no recognition by the court that a Ward may have capacity to make particular decisions (apart from the exception of where the court may decide that the Ward has capacity to execute a will) (National Safeguarding Committee 2017).

Pending commencement of the provisions of the 2015 Act, the Safeguarding Committee has made a number of findings and recommendations to ensure the human rights of the individuals are respected. Included amongst them is the recommendation that all prospective Wards should have independent legal or non-legal representation (National Safeguarding Committee 2017).

Another issue they have highlighted is the need for adult safeguarding legislation, which they highlight by reference to Article 16 of UNRPD (which commits State Parties to take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse) (Safeguarding Ireland 2018) .

**3.2 Lack of Access to Support to Live Independently in the Community**

Supporting older people to live at home is the ostensible Irish public policy position. However, social care in the community is ‘patchy and fragmented’ (Connolly, 2015: 28). Supports available traditionally took the form of provision of home helps and, more recently, home care packages, which are intended to provide for more flexibility. A key weakness is absence of statutory underpinning for homecare (O'Shea, Cahill, & Pierce, 2015), although as mentioned already the establishment of a statutory scheme is currently being considered (since 2017).

Significant decreases in Ireland’s health spending occurred over the austerity years (following 2008) at the same time as demands on health services increased. The evidence shows a significant decrease in the provision of Home Help Hours since 2008 and especially following 2010, at a time of population ageing (see Table 7.4 from Healy et al. 2019). Following 2008, the number of people in receipt of Home Care Packages (HCPs) grew but the funding for this scheme was largely static from 2009 and the average value of each package fell (Department of Health 2015).

A report from the Irish Longitudinal Study on Ageing (TILDA Wave 1), based on then current data, reported a 26% level of unmet need for home care amongst those aged 50 and over (Murphy et al. 2012). More than 6,000 older people were on waiting lists for home support services in October 2018, an increase of more than 200 since May (2018) (Burns 2019; see also Care Alliance Ireland 2018). A recent report that based its findings on Freedom of Information requests found that the average waiting time for home care was approximately 3.3 months, with the range going from no wait time to over two years (Care Alliance Ireland 2018). That report also suggested that there is regional variation in approaches to assessment, management and provision of home care and it highlights difficulties with access to this kind of information – a lack of transparency that potentially militates against accountability and equality of access across groups and regions.

Looking to the future, the Economic and Social Research Institute projected that demand for health and social care will increase across all sectors in the years to 2030 (Wren *et al.* 2017). Home care packages are projected to show the greatest increase in demand - of 66%, reflecting a high level of unmet demand. Significant percentage increases in demand (40 to 54%), are also projected for long-term and intermediate care places. All of this means that Ireland needs to place a particular focus on homecare (say using the AAQ framework) including investment in step-down, rehabilitation and other facilities that will support Ireland’s rapidly ageing population to live in their homes and communities.

**3.3 Access to free or affordable healthcare**

Though addressing all issues in the provision of healthcare is beyond the scope of this submission, it may be worth noting that International experts highlight that Ireland is the only EU health system that does not offer universal coverage of primary care and that, despite increased investment during the previous decade, when the financial crisis occurred in 2008 Ireland still had poorly developed primary and community care services (WHO & European Observatory on Health Systems and Policies, 2014).

The 2017 publication of ‘Sláintecare’ by a Parliamentary committee (Oireachtas Committee on the Future of Healthcare) included proposals for a ten-year strategy for health care and health policy in Ireland and proposed a universal approach based more on primary care and social care. However, the required capital allocation of €500 million per year for the first six years to support the infrastructure to implement Sláintecare has not been made available in any Budget since the programme received cross-party support (Healy et al 2019). Thus, implementation of Sláintecare has progressed little since 2017.

Older people are the biggest users of healthcare services so they are disproportionally affected by difficulties of access and deficits in provision. Accessing the complex system involved depends on whether one has a medical card, a GP visit card, private health insurance, private resources to spend on health services, where one lives and what type of services one is trying to access; it is also those who are poorest, sickest and those with disabilities who find it hardest to pay charges, to negotiate access, and who must wait longer for care (Burke 2016).

The Economic and Social Research Institute report already mentioned, concludes that two decades of rapid population growth, a decade of cutbacks in public provision of care and a consequent build-up of unmet need and demand for care, will require additional expenditure, capital investment and expanded staffing and will have major implications for capacity planning, workforce planning and training (Wren *et al.*, 2017).

(More information on these issues can also be found in Healy et al 2019, available online)

**3.4 Access to Palliative Care for Older People**

Finally, I wish to refer briefly to the issue of palliative care, which represents an area which requires a focus and investment in Ireland. While most people in contemporary western society die of the chronic diseases of old age and while palliative care is appropriate for older patients with chronic, non-malignant disease, few of these patients access such care compared with cancer patients (Coventry et al 2005). Thus, even though older people are likely to die in an acute hospital setting, numerous barriers were found to exist to the provision of high-quality palliative care for older people within acute hospital settings (in the UK) (Gardiner et al 2011) and it is recognised internationally that a key challenge, is obtaining access to palliative care for older people (see for example Van den Block 2016).

In this context, I wish to note that Ireland has a particular challenge because, as Kane and colleagues (2015) found:

* Ireland would appear to have the most rapidly rising need for palliative care in Europe.
* future palliative care policy decisions in Ireland must consider the rapidly aging Irish population with the accompanying increase in deaths from cancer, dementia, and neurodegenerative disease, with associated palliative care need (this study looked at period 2007-2011).
1. Please provide information on the existence of long-term care services in your country and describe to what extent they promote the autonomy and independence of older persons with disabilities.

**4. Residential care**

Turning to the issue of residential care, access to institutional care is facilitated through a statutory scheme involving co-payment between the state and the service-user and in some cases a charge over assets called the NHSS or ‘Fair Deal’. Over 60% of the budget for the provision of services for older people goes towards support for the approximately 4% of the over 65 population who are supported by the state to live in long-term residential (Department of Health, 2015).

However, that scheme is subject to budgetary ceilings and there have sometimes been long waiting times – although the Health Service Executive is currently supposed to keep waiting times to four weeks. The current national service plan refers to making ‘Every effort … to maintain the waiting list at the current four week level’ (Health Service Executive 2018).

A recent independent review suggests that the NHSS/Fair Deal process can be complex and daunting and many families face significant challenges completing the processes involved, which may involve legal or financial complexities (Independent Expert Review of Delayed Discharges 2018). Amongst the issues highlighted in submissions and interviews associated with this review were inadequate supports to live at home, lack of access to palliative care for older people, time required to progress through the NHSS/Fair Deal process, decisions about accessing to long-term care often happening in an acute hospital setting where that setting is recognised as the least appropriate place to assess a patient’s care needs. It is also not an appropriate setting for the patient and their family to make the life changing decision as to which nursing home their relative will move to on discharge.

I finish this section by briefly referring to the issue of inspection and standards in residential care and how they promote autonomy. The Health Information and Quality Authority (HIQA) reviews the quality of residential care. HIQA’s chief role is to develop standards, inspect and review health and social care and support services. They articulate a rights-based approach in the development of guidance for residential facilities summarised as values of fairness, respect, equality, dignity and autonomy (Health Information and Quality Authority 2016a). Thus, HIQA’s standards for Residential Care Settings for Older people and for Adults with Disabilities are said to be underpinned by values that include:

Provide care and support to promote autonomy and an excellent quality of life for people living in the service.

HIQA believes that the area of safeguarding needs to be further strengthened by introducing legislation which would enshrine adult safeguarding in law and acknowledge the State’s responsibility to protect those who may be at risk (Health Information and Quality Authority 2016b). In the absence of adult safeguarding legislation in Ireland, HIQA currently relies on national safeguarding protocols.

1. Please describe how is access to justice guaranteed for older persons with disabilities. Please provide information on jurisprudence, complaints or investigations in relation to violence, abuse and neglect against older persons with disabilities.
2. Please describe to what extent and how are older persons with disabilities involved in the design, planning, implementation and evaluation of policies related to ageing and/or disability.

See comments at 1, above relative to the greater commitment to involve disabled people generally in service planning and delivery than older people.

1. Please provide information on any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the rights of older persons with disabilities and identify lessons learned from these.

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1. Although through engagement with the policy process, advocacy organisations appear to have ascertained that the home care review is not focusing exclusively on home care for those over age 65 – in other words it may seek to apply to disabled people of all ages, something that those advocacy groups welcome (see Care Alliance Ireland 2018). [↑](#footnote-ref-1)
2. Miller *et al*. 2004:9: **Disablism** is ‘discriminatory, oppressive or exclusionary behaviour arising from the belief that disabled people are inferior to others.’ [↑](#footnote-ref-2)